The Situated and Dialogical ‘Nature’ of (In)Competence:

A Socio-Cultural Approach to Informed Consent Treatment Decision-Making Competence in Adults Diagnosed with Intellectual Disability

By

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Abstract

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Assessment of treatment decision-making competence emerges in situations where incompetence is suspected, for example in situations involving adults diagnosed with intellectual disability. Competence judgments have traditionally been considered a matter of individual intellect. Alternatively, a developmental perspective based within a socio-cultural framework considers competence an interactional process and a matter of dialogical self-other encounters. The concept of dialogical concerned in this study involves interpersonal interactions where information is exchanged and perspective taking where the point of view of the ‘other’ is legitimized as being worthy of consideration.

This qualitative study examined reports of self-other encounters by adults diagnosed with intellectual disability placed in residential agencies and the employees of those agencies. Encompassing a variety of perspectives 44 individuals across three non-profit agencies within New York State participated. Interviews were used to elicit accounts of self-other encounters from 29 adults diagnosed with intellectual disability and 19 employees across a range of positions from direct-care to upper administration.

Findings revealed that accountability issues were particularly salient for employees with and across agencies tailoring policies, practices and type of encounters with the adults placed. Employee encounters with placed adults were characterized by monological relations; constraining access to necessary social knowledge and information required to demonstrate competence. Autonomy relating to treatment decisions hinged on employee and professional's judgment of placed adults as 'kinds of persons'—competent or incompetent. Incompetence frequently emerged based on their 'placed status' positioning them 'recipients of' rather than 'agents for' services and treatments.

Accordingly, many placed adults perceived medical and mental health services and treatments as devoid of choice. Responses to a standardized capacity assessment instrument employing vignettes evidenced their knowledge of the distance between their actual experiences and 'ideal forms' hypothetically constructed. Shifts in judgments allowing them greater autonomy occurred when they articulated legitimate forms of social knowledge in self-other encounters; often not predicted by IQ scores or assessment outcomes. Accessing these legitimate forms came from sources primarily outside of the agencies—through self-other encounters involving dialogical relations (e.g. with pharmacists) or accessing 'tools' self-appropriated through available technology (e.g. Television commercials, computers).

Including the perspectives and knowledge of adults diagnosed with intellectual disability these findings demonstrate that from an agency point of view, in the context of accountability, incompetence is the default and 'safe' position. Shifting this view rests on increasing inclusive practices—encouraging dialogical relations in self-other encounters between adults diagnosed with intellectual disability and the professionals providing services to them, through which knowledge and information is made accessible. Implications of these findings impact law and policy regarding competency evaluations, guardianship, and rights as these pertain to adults diagnosed with intellectual disability.

Acknowledgements

My journey through the complexities involved in the life of people diagnosed with intellectual disability began at a very early age, prior to the public attention focused on Willowbrook, and for this experience I acknowledge those high school students who asked me, then a freshman, to join them in volunteering at a ‘special school’ located in New York. Although unaware of this at the time, the ‘special school’ was an institution for the developmentally disabled. My volunteer work, due to my age, solely involved working with the children placed there.

This early experience was to have profound implications for the eventual path my life would take. Across the thirty years I have spent working in the non-profit service provider industry the treatment, and subsequent fate, of those children has never left my thoughts; influencing the relationships I have developed and the type of ‘clinical’ work I do with the many people diagnosed with intellectual and developmental disability I have met along the way. Thus, I thank those children. This dissertation marks an achievement which is as much theirs as it is mine. I am also grateful to those individuals, diagnosed with intellectual or developmental disability, who participated in this current work as well as to those others who have influenced my thinking over all these years.

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I dedicate this work to my father, Luke (Luca). He taught me to always see the world from the perspective of the other and that respect and compassion were infallible guides in this pursuit. The love and vision he shared with me during his life continue to be undying forces in my own. I was privileged to have him as my father; his companionship and love were, and will always be, my life's greatest gifts.

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Introduction

People diagnosed with intellectual disability are often perceived as unlikely to develop the higher mental processes or intellectual ability necessary for making important decisions concerning their lives. This stems in large part due to the perceived nature of the disability, held as originating from a neurologically based disorder impervious to change and limiting whatever they may possibly learn throughout their lives. In the forty years since New York State shifted mental health services for people diagnosed with intellectual disability—from exclusionary models in institutional settings to inclusionary models in community settings, more opportunities have become available for improving the quality of their lives, expanding their experiences and integration in society. Along with this shift constructs have emerged such as self-determination, self-advocacy, and person-centered-planning, providing guides for service delivery systems within the community as well as platforms on which human and civil rights are enacted. Despite different locations of services and new constructs in the discourse concerning people diagnosed with this disability, conceptions of the disability as involving limited and unchanging mental capacity have not been greatly affected. This conception of the disability underlines an assumption of need for protection, treatment, and certain types of care thus resulting in the situation where "mentally capable" others decide the level of protection, types of treatment and care individuals so diagnosed require. This leaves little room for participation and 'voice' in areas where important decisions must be made. Making medical and mental health care treatment decisions is one such area.

The 'Informed Consent Doctrine' evolved through United States case law regarding health care treatment. Its emergence articulates the antinomy between protection (need for treatment) and autonomy (an individual’s right to be self-determined) inherent in American society and definitions of citizenship in that society. However this antinomy also describes the relationship between adults diagnosed with intellectual disability and American society in general and between these adults and the service provider settings in which they are placed in particular. Although the construct of ‘informed consent’ emerged through case law, judgments of individual competence to render an informed consent are not derived through law; rather they are clinically and socially based. In cases where individual competence is questioned, manifest for example with adults diagnosed with intellectual disability, judgment outcomes have consequences on how self-determined one is likely to be concerning matters of importance in their lives; for example, treatment decision-making. The extent to which individuals are recognized as capable profoundly influences the ability to enact rights and to experience inclusive citizenship.

Traditionally and currently assessments for competence where incompetence is suspected pertaining to medical and mental health treatment decision-making are considered a matter of individual intellect. The depth of one’s intellect is sounded to discern the landscape in which competence is expected to be found. Assessments are focused on ‘either-or’ outcomes; either an individual articulates expected forms of competent behavior within the assessment encounter or they do not. The antinomy between protection and autonomy and evidenced in either-or outcomes concerning judgments of competence confines thinking to zero-sum terms. Little room is available for movement away from this polemic with the result that this situation becomes ‘naturalized’ and hence remains unapproachable, unresolvable, and unchanging.

Rather than continue in this vein by devising assessments which can best assure the validity of ‘either-or’ questions and outcomes relating to competence and guiding current policy, practice, and law concerning individuals diagnosed with intellectual disability this work challenges the viability of that approach by considering different questions. This study concerns questions such as: How competent treatment decision-making behavior develops? What factors influence its development? And, how this development can be supported in individuals diagnosed with intellectual disability?

Notwithstanding the constraints on learning that such a disability imposes, from the developmental perspective taken here, processes involved in the development of higher level cognitive processes are contingent upon certain types of interactions with others. Learning from this perspective involves tools and signs for thinking, or ‘knowing how to know’ facilitated through interactions with others. Thus type of self-other interactions, affects the type of learning that ensues. The type of learning that is transformative enables the emergence of higher mental processes to develop. Transformative learning is aimed at teaching how to appropriate and use cultural tools, such as language, which are accessible in the culture through day to day interactions supporting an individual’s thinking. Thus within this view, the source of higher intellectual functioning is considered a matter of social interaction which influences the development of neurological structure, rather than neurological structure providing the blueprint on which the development of intellectual functioning emerges.

Giving an informed consent provides an example of the above. The ‘Informed Consent Doctrine’ in law is based on an individual’s right to make treatment decisions concerning their own lives and bodies—to be self-determined. However this right rests on one’s ability to make these kinds of decisions and, as I argue, this ability is of recent historical origin, requiring new mental processes on the part of both patients and doctors. Judgments of this ability have evolved to the point currently where assessments are heavily weighted on cognitive processes inherently considered a matter of individual intellect.

Rather than being an individual intellectual endeavor, informed consent as a legal construct conceptualizes a relational, dialogical process dependent on certain types of relations within self-other encounters. The genesis and history of human's ability to give informed consent regarding medical or mental health treatment decision encapsulates in microcosm the processes involved in the development of characteristically human higher mental processes. This is because informed consent itself is a recent form of socio-cultural knowledge; it did not exist nor was it recognized prior to the early 1950s in American history. As such it required new mental processes or new ways of thinking.

This research examines how self-other encounters and types of relations between adults diagnosed with intellectual disability and the professionals providing services to them, impacts the development and perception of decision-making competence, or incompetence, within the context of medical and mental health decision-making. My aim is to understand what may be needed in order to support such individual's development of decision-making capacity, thereby leading to decision-making competence and greater self-determination and agency in their lives. Strikingly there are no studies which look at these competency issues from the perspective of people diagnosed with intellectual disability. This one-sided emphasis, namely the professional one, gives a distorted picture of the reality as experienced and perceived by the individuals involved. As has been noted by multiple scholars, professionals shape and reshape notions of competence and difference. Addressing this distortion, the current inquiry examines how 'situatedness' in specific settings characterized by professional relationships affects the dialogical and relational nature of competence in treatment decision-making and hence, its development. This is accomplished, in this research, by speaking to and gaining accounts from adults diagnosed with intellectual disability, placed in residential facilities offered by different agencies and from those professionals associated and employed within those agencies. These accounts concern reports of self-other encounters and types of relations each experiences as these relate to situations involving medical and mental health treatment decision-making.

This research documents how the type of relations in self-other encounters might impact upon competent treatment decision-making among adults diagnosed with intellectual disability who have been placed in the 'community' of non-profit services providers. My approach to this research assumes that competence for treatment decision-making emerges through self-other encounters characterized by dialogical (inclusive of shared information, knowledge, and perspective taking) rather than monological (exclusive of information sharing, knowledge, and perspective taking) relations. Perspective taking in the dialogical approach offered here entails consideration of the perspective or point of view of the 'other', where 'other' in this case is an individual diagnosed with intellectual disability, as legitimate and worthy of consideration. To this end the inquiry is organized in the following manner: Chapter 1 begins with an historical overview of the 'Informed Consent Doctrine' and its evolving impact on self-other encounters in medical and mental health care. One such impact includes the shift from the construct's origin involving relational dialogical processes to a focus on competence resulting in assessments and judgments heavily weighted on individual attributes such as, most notably, intellectual functioning. Included in this chapter is the work emerging from assessments and capacity judgments known as the 'Capacity Literature.' This is reviewed focusing on work with adults diagnosed with intellectual disability. The legal ramifications of 'judgments of incompetence' for individuals so diagnosed and a comparative review of decision-making in the non-disabled, completes the chapter. Chapter 2 provides an overview of Intellectual Disability and the New York non-profit industry forming the ‘community’ service model from which the agencies involved in this study were recruited. Research pertaining to adults diagnosed with intellectual disability relative to choice and self-determination within such settings is reviewed. Evolving paradigms in research with people so diagnosed and implications of this for the current work completes the chapter. Chapter 3 presents the theoretical framework composed of developmental and social psychological theories, research questions, aims and expected outcomes; Chapter 5 presents the methodology and overview of analysis; Chapters 5, 6, and 7 present the findings; and Chapter 8 provides a summary discussion of findings, limitations, implications, and conclusions.

Chapter 1: The Legal Doctrine of Informed Consent and the Capacity Literature

Introduction

"How much of a deficit in abilities is enough to justify the restriction of individual liberties requires a moral and social judgment, not a scientific or clinical one"—Grisso, 2003

The 'Informed Consent Doctrine' evolved through United States case law regarding health care treatment. Its emergence articulates the antinomy between protection (need for treatment) and autonomy (an individual's right to be self-determining). Judgments of individual competence to render an informed consent are not derived through law; rather they are clinically and socially based. In cases where individual competence is questioned, manifest for example in adults diagnosed with intellectual disability, judgment outcomes have consequences on how self-determined one is likely to be.

Competence not only permeates the law, it permeates our ability to be seen as legitimate social actors living in a social world. As Trent (1995) maintains, the social representation of what it means to be intellectually disabled has led to the pathologicalization and medicalization of individuals so labeled and has impacted their participation and interactions with mainstream society throughout American history. Longmore (1995) taking a similar stance, points out "…individual and institutional behavior toward people with disabilities are shaped by historically deep-seated, cultural presumptions about disability and about what sort of persons Americans ought to be." A diagnosis of intellectual disability impacts the individual's ability to be seen as a competent social actor and as what Americans ought to be: independent, autonomous, self-determined and intelligent. These cultural assumptions concerning the definitions of what a competent and incompetent individual should be can be found in our legal system. Representative of this institutional belief concerning people diagnosed with intellectual disability is Supreme Court Justice O’Connor’s dissenting decision in the case Roper v. Simmons (2005) which concerned the use of capital punishment with minors.

> The Court observed that mentally retarded persons [1] suffer from major cognitive and behavioral deficits, i.e. sub-average intellectual functioning and significant limitations in adaptive skills such as communication, self-care, and self-direction that become manifest before age 18. Because of their impairments, [such persons] by definition…have diminished capacities to understand and process information, to communicate, to abstract from mistakes and learn from experience, to engage in logical reasoning, to control impulses, and to understand the reactions of others.—Justice O’Connor (Roper v. Simmons, 2005).

Justice O’Connor’s opinion reflects how societal institutions, such as law, are based on ‘deep seated presumptions about disability,’ which in this example presumes that impairments of people so diagnosed might be impervious to change, and moreover, limit their opportunity to participate in active, learning. Consequentially people so diagnosed are often perceived as dependent, child-like, and in short, not capable of making sound decisions or to some extent not capable of making important life decisions at all.

According to Perlin’s idea of ‘Sanism’ (2000) such cultural presumptions about the type of persons Americans ought to be are perpetuated by societal institutions, such as legal and health care systems, which historically position competency as a property within individuals, necessitating practices such as guardianship and substituted judgments. Scholars such as Perlin (2000), Grisso (2003), Tor and Sales (1996) have examined the interface between: presumptive

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[1] Throughout this work I use the term Intellectual Disability however when quoting literature I use the ‘term(s)’ applied therein.

models, assessments, practices such as guardianship and our legal institutions and have uncovered evidence for ‘inertia’ inherent in the courts where problems and issues ‘outside of the individual’ are in need of being addressed but often are left unexamined. Within the past forty years some advances have been made in law pertaining to individuals diagnosed with intellectual disability—mostly based on the right of protection from harm and right to receive services within the community as well as in areas of education and employment. (see: Youngberg v. Romeo, 1982; ADA, 1990; Olmstead v. L.C., 1999; IDEA, 1975, 2004). Rights of people diagnosed with disability have recently become an international concern. The United Nations adopted the Convention on the Rights of Persons with Disabilities in 2006 (CRPD, 2006). Most notably for the concerns of this dissertation, article 12 of this convention involves ‘equal recognition before the law.’ These legal protections however, do not necessarily indicate a change in thinking concerning the nature of the diagnosis—intellectual disability—or, the potentials possible in individuals so diagnosed, because emphasis placed on ‘professional staff’ beliefs and input.

For Grisso (2003), this lack of movement in law, or inertia as he puts it, exists because such historically embedded practices become conventional, part of the institutional structure, and remain intact impervious to change because they go unchallenged. Accordingly, when dealing with intellectual disability, it is the narrative of the disability—as exemplified by Justice O’Connor’s quote above—that becomes ingrained in the institutional structure and remains intact impervious to change because it goes unchallenged. Grisso claims the tendency in law with regard to forensic assessment, including assessment for competency, is to conform to conventional practice even if it is not optimal practice. As a leader in forensic assessment, Grisso (2003) implores practitioners to strive for the optimal.

Legal scholars such as Turnbull (1977), Herr (2009), Ellis (1992), Sundram (1994, 2006) and Dinerstein (1999, 2012) have championed this striving for the optimal as this relates to individuals diagnosed with intellectual disability in relation to rights, justice, and equality before the law. One of the early pioneers, Turnbull (1977) gave recognition to the fact that individuals diagnosed with intellectual disability have legal rights, one of which is the right to make their own decisions. Shifts in societal treatment practices toward those diagnosed with intellectual disability, from segregation in institutions to community inclusion models, have opened many domains where their decision-making applies.

Current Issues of Competency and Intellectual Disability

Emphases and movements are today underway relating to positive psychological models of research focused on individuals diagnosed with intellectual disability rather than on deficit models (see for example Shogren, Wehmeyer, Buchanan & Lopez, 2006). Such shifts include an emphasis on rights, supports, managed care, self-advocacy, functional assessments and self-determination (AAMR, 2004; Wehmeyer & Metzler, 1995). Having power to direct their own service delivery systems is the newest movement on the horizon and emphasizes giving the person with disability or intellectual impairment control over their finances, education, living and work opportunities (Dowse, 2007; Neely-Barnes, Marcenko & Weber, 2008). Choosing options of long term health care to alleviate dependence on Medicaid is another promise of the future.

Exploring how assessments of competence to make certain decisions fits into this landscape is especially timely as it seats itself at the center of this sea change in the role of non-profit service provider systems in the lives of those on whom such services are rendered. The relationship between service-provider systems and people diagnosed with intellectual disabilities' involvement in such systems plays a pivotal part in who is seen or not seen as competent to wield control over these domains; reflecting the direction of the current research. Traditionally and presently assessments for competence are considered a matter of individual intellect. This dissertation offers an alternative view.

The United States has a long history of paternalistic thought and practices in regard to people diagnosed with intellectual disability, where decisions concerning their life, mental abilities, and choices have for the most part been at the discretion of others. A statement by Appiah seems apt here as I embark on a review of the literature on informed consent including its emergence, dialogical nature, turn toward intellectual attributes of individuals, resultant assessments, research and the relation of this to individuals diagnosed with intellectual disability placed in specific settings. According to Appiah:

> issues of value and rationality always arise within a form of life and that it is only within the practices of a certain community—against a background in which these practices are taken as given—that we can ask the questions "Is this so?" and "Is this reasonable?" (2005).

Informed Consent: A legal construct and dialogical process

Many scholars situate the emergence of the 'Informed Consent Doctrine,' the ruling of law which recognizes a patient's autonomy in decision-making related to health care treatment, to the 1957 case of Salgo v. Leland Stanford Jr. University Board of Trustees (Faden & Beauchamp, 1986; Arabian, 1994; Katz, 1995, Cea, 1999). Issues surrounding the principle involved with informed consent however, have been documented as early as the eighteenth century (Meisel, Roth & Lidz, 1977). Arising as a case of malpractice, Mr. Salgo brought suit against the California hospital where he underwent a commonly used investigative procedure to determine the cause of severe leg cramping. Wakening after the procedure, Mr. Salgo found he was paralyzed in the lower extremities; a situation he later learned was permanent. The malpractice suit was decided in Mr. Salgo's favor. The defendants brought the case to the higher court on appeal. It is in the language of the Appellant Court's decision where the adjective "informed" first appears. The Appellant Court reversed the decision of the lower court and remanded the case for re-trial because it recognized no malpractice was evident. The problem as the Appellant Court succinctly surmised, was that although paralysis was a possible side effect, a risk of the procedure well known to the medical community, it was not made known to the patient. In the language of the court under 'duty to disclose' it states: "although the doctors informed Mr. Salgo of the procedure, implying his consent was given, the doctors admitted that the details of the procedure and the possible dangers (paralysis being one) therefrom were not explained" (Salgo v. Leland, 1957).

As the issue came to be framed in the court the 'Therapeutic Privilege Doctrine' involving recognition within law for a doctor to withhold information from a patient if it was felt such knowledge could harm or impact a patient's decision-making, was in conflict with a patient's right to self-determination—having all the information in order to make their own decision. As it is framed here and by other scholars, the issue involves antinomic thinking expressed as Autonomy versus Protection. According to scholars the Salgo case reflects the unrest which had been brewing since the early 20th century characterized by a series of court cases dating from 1905 through 1914 where the Therapeutic Privilege Doctrine was contested on the grounds that this legalized paternalism on the part of doctors; they could give treatments without full disclosure and in some cases without consent of the patient (Katz, 1995, Cea, 1999).

Katz (1995) points out regarding the legal framework involved in the 'Informed Consent Doctrine' that "…questions arose in many areas of law about the capacity of human beings to make their own decision and the need to protect them from their own folly. The tug-of-war between advocates of thoroughgoing self-determination and those of paternalism has continued unabated" (p. 1257). Further, Katz (1995) states the new doctrine added "the proposition that physicians are now under an affirmative duty to acquaint patients with risks and alternatives and opened the door for individualism as a challenge to traditional medical practice which for millennia has treated patients paternally as children" (p. 1258). As Katz (1995) maintains, the right at issue is the right of individual choice, "which might precisely be the right to be an 'unreasonable' person" (p. 1260).

Shifts: A Focus on Intellect and women's experience with the doctrine

The advent of the 'Informed Consent Doctrine' took time to be assimilated. Doctors needed to shift their thinking in giving patient's autonomy in decision-making just as patients needed time to shift their thinking to include their own voice in the decision-making process. Lerner (2004) documents this shift in thinking. His work examined medical decision-making prior to and approximately twenty years after the doctrine was initiated. His focus was on the extent to which patients gave consent and actively participated in their treatments between the years of 1945 until 1970. The decision-making that was involved in the study concerned cancer treatment and involved review of medical records.

Lerner's findings revealed that patients who challenged doctors or asked questions were given more information and were then giving actual 'informed consent' as opposed to other patients who acquiesced to doctor' s recommendations. Further, patients were not given information regarding alternative treatments unless they questioned doctors or in cases where doctors felt unsure of which direction to take. Lerner states that within his study "examples of patients being included in or excluded from decision-making occurred throughout the twenty-five years under study" (2004). Moreover his study documents that inclusion or exclusion from the decision-making process was evident across patients despite differences in ethnic, racial, gender, and socio-economic status. Although paternalism on the part of medical practitioners was resistant to change patient's actions, such as asking questions or challenging doctor's recommendations, was a significant factor in shifting paternalistic practices to more autonomous ones where patients were included in the decision-making process and truly 'informed' (Lerner, 2004).

Activity, on the part of patients, was a primary incentive for doctors to provide information in the early years surrounding the birth of the 'Informed Consent Doctrine.' However another shift was also emerging, this entailed how patients were viewed by the medical community. This shift involved views of patients—intelligent or not intelligent enough, to warrant receiving relevant information required to make an informed decision. Views of patients became a factor in how the 'Informed Consent Doctrine' was applied and who it applied to.

Shifts in how the 'Informed Consent Doctrine' was applied and who it applied to emphasizing the role of a patient's intelligence, impacted a patient's involvement and inclusion in the decision-making process. This is exemplified by the history of women's experience under the doctrine. Seminal works by feminist scholars illustrate how women, based on their socio-cultural and situated experiences, held different perspectives relative to the male dominated view which were often left unexamined by the social sciences, law, and medical community (see Gilligan, 1982; MacKinnion, 1979). Failure to examine women's perspectives and a prevailing view based on assumptions relating to their intelligence limited women’s autonomy and activity in their health care decision-making. This was especially evident in relation to abortion and contraceptive issues.

Morrow (1978) documents how the women’s movement increased women’s involvement in their health care, and inclusion in the doctrine, an area that took root in contraception and abortion litigation. Change was initiated by health care activists through use of the ‘Informed Consent Doctrine,’ which, by implication, required information be disclosed. According to Morrow (1978) doctors viewed women as having “inferior intelligence and an inability to dispassionately evaluate what is ‘best’ for them.” Using an excerpt from the Senate hearing concerning contraceptive use during the 1970s Morrow emphasizes this point:

> …many doctors implied that most women were either not bright enough to understand information on the pill’s adverse effects, or too emotionally unstable to handle this information (Corea, 1978 at 78-79 as quoted in Morrow 1978).

The medical community’s failure to provide information was sanctioned by a perceived view of the kind of intelligence characteristic of women. Morrow (1978) contends that challenging this, women’s groups began to emerge with the specific goal to provide women with needed information. The initiation of women’s groups served to inform women of their own health and how their bodies worked as a means to ensure their rights to self-determination in health care practices and decisions were protected.

While the sanctioned exclusion from information was offset by women’s groups providing information for and by women, this was not the case for women who also happened to have a disability. The prospect of advocating rights for self-determination and autonomy in health care decision-making for this group was especially bleak. Fine and Asch (1988a) were perhaps the first feminist scholars to explore the nuanced experiences of women with disabilities and the extent of their exclusion. These scholars used the term ‘rolelessness’ to describe the effect of these women’s position in society; a position they term “social nomads” (p. 307). Exclusionary practices exist because disabled women’s unique perspectives are often not included in policies and rights. Including intellectual and physical disability perspectives in women’s accounts, Fine and Asch (1988) found “discrimination based on sex or gender to be a societal injustice, disability is assumed a biological injustice and the injustices that lie in its social treatment are ignored.” Weinberg (1988) maintains that conceptions such as the ‘need for protection’ and ‘dependence’ evident from the medical and legal standpoint in regard to women with physical and intellectual disability results in a “fairly singular view of normality” echoing Perlin’s (2000) concept of ‘Sanism’. She maintains that the legal and psychological definition of ‘autonomy’ based on a narrow and ‘singular’ view of normality leaves little room for the interactional elements involved in real world situations and, as with other feminist and disability scholars, promotes expanding notions of autonomy.

Despite this early work advancing advocacy on the part of women (disabled women as well) in the United States, their ability to be seen as capable and ‘intelligent’ by law and the medical community continues to be an issue. Manian’s (2009) work demonstrates how women’s capacity in certain domains is still negated. Through abortion litigation, Manian argues that abortion law treats pregnant women unequally and is driven by a gender stereotype. Manian’s argument is that restrictions on abortion are manifestations of sex discrimination (2009) echoing MacKinnion’s (1979) earlier argument which framed sexual harassment as sexual discrimination in the workplace. While feminist scholars continue to work for advocacy movements in

America, scholars from other less economically advantaged countries are only just beginning to shed light on the oppression which exists as a day to day practice where women's health issues and their ability to be self-determined are concerned.

Luna's (2006) work in bioethics is a case in point as she demonstrates that it is women's marginalized status which mediates their health care decision-making opportunity and activity. The plight of women who are poor, uneducated and non-literate in Latin American countries equates with what she calls the 'Literacy Argument'. This argument justifies an *a priori* attitude on the part of legal and medical communities. Exemplifying this she uses accounts given by medical practitioners who argue: "it is difficult to communicate with the illiterate because they are uneducated, lack information, and lack the ability to understand information they are given; the physician decides what treatment the illiterate patient is to follow" (p. 31). Luna contends that stemming from this *a priori* view of women, bioethical practices and theory are "invariably contextually-situated, that history, culture and societal considerations are important factors in such deliberations…and echo some of the concerns of all populations marked by vulnerability, intolerance, authoritarianism, and corruption" (p. 10).

One such population to which her statement can be applied involves those diagnosed with mental impairments. Historical shifts in medical community practice since the emergence of the 'Informed Consent Doctrine' in law highlight how the construct has shifted. Shifts involved the original evolution from concerns with patient autonomy and co-productions of competent decision-making through self-other encounters between doctors and patients in dialogical relations, to doctors relinquishing of control to and with patients, and finally to judgments based on individual attributes of intellectual 'fitness' as a precursor to relinquishing such control. These shifts were examined from women's experience and involvement in the informed consent doctrine. People diagnosed with mental difference were neither included nor recognized by the doctrine, in the state of New York, until the late 1980s and it is to this group that the following sections pertain.

Doctrine's Impact on Mental Health

Over the years since the Salgo case, Holder (1995) documents how the doctrine expanded to include more situations and more groups of individuals. "Evidence during the last decade is litigation in various states involving the rights of minors, individuals with psychiatric or mental disability, pregnant women and the incompetent" (Holder, 1995). Prior to these group's inclusion in the doctrine, people diagnosed with mental disability were automatically assumed to be incompetent (Morris, Niederuhl & Mahr, 1993; Cea, 1999). As Meisel, Roth, & Lidz (1977) wrote in the early stages of this inclusion, "Although the applicability of informed consent to psychiatric practice is still in its incipient stages it is clear that the doctrine does apply…. The trends are unmistakably clear: the emphasis is on more information, and the consequence may well be an increase in patient participation in decision-making."

Relating to the doctrine's applicability to and eventual impact on the mentally impaired community Brown (1995) states there are three overlapping doctrines relevant to mental health care because of the historically differential treatment of involuntarily hospitalized mental patients (p. 1265). These overlapping doctrines involve an ethical doctrine: respecting the right of autonomy to refuse a treatment considered necessary; a legal doctrine guaranteeing rights and privileges of patients, establishing that they have a role in their treatment; and an evolving ideal, centered on the relationship between doctors and patients. Brown maintains, in regard to mental health, "the critical ethical issue continues to involve the extent to which patient rights should be overridden by physician’s paternalistic effort to treat ‘sickness’ despite academic debates about the meaning and definition of competence” (p. 1265). Brown’s position on this tension between autonomy and protection highlights the antinomic thinking guiding practices where the doctrine is applied in mental health. Wertsch (1998) recommends ‘an analytic position in the middle’ when antinomies are involved (to be explored more fully in chapter 3) and Brown’s suggestion for greater emphasis on the patient-doctor relationship locates this middle position (Brown, 1995, p. 1269). Arabian (1994) furthers an examination of the patient-doctor relationship in issues of competency. Arabian states that “it has been asserted that a patient’s competence is generally only called into question either when the patient is entirely incapable of cognition or the patent’s treatment decision differs from what the physician recommends” (1994). This middle position focusing on relationships rather than on the antinomy between autonomy-protection as argued by both Brown and Arabian are articulated in the case which brought members of the mentally ill community into the doctrine within New York State.

Rivers v. Katz (1986) involved the right of a woman diagnosed with mental illness, involuntarily admitted to a psychiatric hospital, to refuse psychotropic medication as a ‘treatment for her condition’. The specifics of the case were that Ms. Rivers was taken against her will to the nearest psychiatric facility because it was alleged by the police, who were called to the scene, that she was ‘agitated’ and difficult to control (she was reported to be a very large woman). She was admitted and treated with psychotropic medications despite the fact that she did not agree with the treatment and refused it. Due to her status as involuntarily committed, the hospital followed through with its recommended treatment reliant upon the ‘Therapeutic Privilege Doctrine.’ Upon her release Ms. Rivers brought suit against the hospital. The court ruled in favor of Ms. Rivers concluding that such treatment as psychotropic medication could not be administered to an involuntarily committed individual, against their will, as this constituted a violation of patient rights to self-determination. The status of her diagnosis, mental illness, did not preclude her capacity to make such a choice.

The case of Rivers v. Katz (1986) pushed overlapping doctrines outlined by Brown (1995) to one focused on self-determination by recognizing that individuals, while involuntarily committed, had a right to choose treatment decisions and determine what would or would not happen to their bodies despite a diagnosis of mental disability. Although the case involved an individual diagnosed with mental illness, the State law included people with intellectual disability because their status of being placed, whether in state run institutions or in private not-for-profit facilities located in the community, equated with involuntary commitment. As state law the decision took hold in those government offices overseeing the care of individuals with mental disabilities.

Specific to New York, mental hygiene law is divided across three offices: the office of mental health, the office of alcoholism and substance abuse, and the office of developmental disabilities (NY State Law, 2011). The latter office made its appearance on the heels of the de-institutionalization movement which began in the early 1970s, and emerged through parent and advocate efforts (Rothman & Rothman, 2009). This office oversees the management and treatment services offered to individuals diagnosed with intellectual and developmental disabilities and is formally known as the Office for Mental Retardation and Developmental Disabilities[2]. Post institutionalization, medical treatments for such individuals were now obtained within the community using medical practitioners available to the non-disabled

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[2] While writing this dissertation The Office of Mental Retardation and Developmental Disabilities (OMRDD) formally changed its name (on July 13, 2010) to The Office of People with Developmental Disabilities (OPWDD) at the urging of many self-advocacy groups. This change in name has been mandated by law and marks a great achievement. However, throughout this dissertation the former name, OMRDD, will be used to prevent confusion.

populace. One area characterizing the difference between the offices reflects the chronic versus transient nature of disability. Thus individuals with mental illness or substance abuse are depicted as demonstrating incompetence episodic in nature as opposed to individuals diagnosed with intellectual disability who are depicted as demonstrating incompetence of a chronic and unchanging nature (see Rothman & Rothman, 2009; Castellani, 2005, for the emergence and role of OMRDD within the mental hygiene system). Following Rivers v. Katz, the office overseeing developmental disabilities revised their regulations in regard to treatment. This revision mandated that any proposed treatment of an intrusive nature required informed consent from that individual, or if said individual was unable to make an informed consent, consent must be obtained from a legal guardian prior to implementation of the proposed treatment (OMRDD, 2008).

Questions of who was competent and who was not competent to make informed consent decisions, given a diagnosis of intellectual disability, ushered in the need for assessment—to prove competence rather than the reverse. Due to the history of thought surrounding the phenomenon of intellectual disability and the emphasis on the ‘fitness’ of the patient to receive information with which the construct of informed consent became involved, new challenges emerged. One such challenge was that medical practitioners, no longer protected under the ‘Therapeutic Privilege Doctrine,’ faced liability under the ‘Informed Consent Doctrine.’ Thus medical practitioners would not treat patients diagnosed with intellectual disability in absence of what they thought encompassed intelligent decision-making on the part of the patient. A requirement of informed consent by someone who was deemed competent and with authority to give such consent for the patient was required. Discerning who was deemed able to give informed consent for such individuals became a primary focus as without such consent needed treatment could not proceed in a timely manner, or in some cases, at all.

For those individuals diagnosed with intellectual disability who were deemed unable to give informed consent and for whom no family relations existed who could sign for the person, medical treatment especially in the event of immediate treatment being needed, could take an inordinate amount of time (Sundram, 1988), with dire consequences for the individual. This prompted Sundram to implement the Surrogate Consent Committee in New York State (1988). The idea behind this committee was to have a group of professionals as well as advocates voluntarily and jointly decide about issues concerning the individual's ability to consent for the treatment and in absence of this, the committee could give consent. The committee served to evaluate an individual's capacity to give informed consent or to provide informed consent in the absence of such capacity on the individual's behalf for medically related treatment. This committee is recognized under New York State law and its decisions must be accepted by all medical practitioners. Although the committee ensures that needed medical treatments are carried out without undue delay, they do not include mental health treatments such as the use of psychotropic medications, electroconvulsive treatment or ECT, and other treatments for behavioral control or mental health treatment (Sundram, 1988).

With the Rivers v. Katz (1986) case decision, individuals diagnosed with intellectual and other mental disabilities were recognized in law as having the right to consent to treatment as 'autonomous beings' despite diagnosis. However, due to the nature of the disability which involves intellectual or mental impairments, patient's competence to participate in their treatment decision-making required proof. The nature of the disability and the liability issues for medical practitioners who treat in the absence of informed consent by a 'competent individual' highlight the conflicts involved. Faced by a patient whose competence was questionable a medical practitioner, mindful of liability issues ushered in by the doctrine, required either that their competence was proven or that someone else who's competence was not questioned, make the treatment decisions for them. Antinomies of autonomy/protection as well as those between the individual and social are evident as these relate to adults diagnosed with intellectual disability and their right to make treatment decisions under the doctrine. Proving competence to engage in treatment decision-making requires definitions of competence and tests to measure it. How competency is defined and assessed concerns the following sections.

Emergences: Definitions of and tests for Informed Consent Competence

Roth, Meisel, and Lidz (1977) raised the issue that tests for competency are inherently tied to definitions of competence and that the "concept of competence itself is social and legal and not merely psychiatric or medical." These authors then list tests for competency to consent to treatment which include: evidencing a choice, 'reasonable' outcome of choice, choice based on 'rational' reasons, ability to understand, and actual understanding. Their point is that although competence is sought through all of these tests, emphasis on some tests as opposed to others is dependent upon other variables. Roth and colleagues (1977) caution that the "circumstances in which competency becomes an issue determine which tests are stressed and which are underplayed" (1977). In practice when the competency of a patient is "not absolutely clear-cut, a test of competency that will achieve the desired medical or social end despite the actual condition of the patient may be selected (1977)." Professional judgments, such as which test to stress, "…reflect social considerations and societal biases as much as they reflect matters of law and medicine" (1977).

Clinical judgment by professionals continues to be the primary means by which competence is assessed (Moye, Gurrera, Karel, Edelstein & O'Connell 2006) despite the fact that it has been found to be inconsistent with statutory characteristics. An example of this inconsistency related to the nature of clinical assessments and evidencing the claim made by Roth and colleagues (1977) can be drawn from work investigating competence to consent to sexual activity. Kennedy and Niederbuhl (2001) conducted a survey for consensus among doctoral level members of the APA with specializations in assessment, mental illness, forensic psychology, mental retardation, neuropsychology, psychology and law. Their findings revealed that for most professional participants queried, a hierarchy of varied elements deemed most important in sexual consent capacity emerged. Some of these included the ability to say "no" as a choice and knowledge of consequences such as pregnancy resulting from intercourse. Interestingly, this hierarchy of elements and the different elements emphasized did not always conform to or include the legal criterion used in many state statutes such as appreciating the moral dimensions involved in engaging in sexual activity. Their findings demonstrate inconsistencies exist between legal definitions of competence and professional participant's opinions of what such competence entails.

Zapf and Roesch (2000) write that "a major change that has occurred within the past few decades has been the development of a number of instruments specifically designed for assessing competence." These authors cite Grisso as coining the term "forensic assessment instrument" or FAI in 1986 referring to the movement to devise instruments that provide a framework for conducting forensic assessments in law. This new framework provided an alternative to an existing standard, namely the clinical assessment or interview. Objective instruments to measure consent competence used the conceptual model of consent capacity emergent from United States case law which includes four core abilities (Moye & Marson, 2007). These abilities include: expressing a choice, understanding which includes the risk/benefit calculation, appreciation of the treatment information to one's own situation, and lastly reasoning which entails rational evaluation and comparison of treatment alternatives (Moye & Marson, 2007). Sturman (2005) reviewed a number of instruments developed for the purpose of assessing competence in marginal groups such as the mentally ill and juveniles. He found that many of the tools have not been tested in large samples but measures devised have repeatedly proven to be useful in detecting specific areas of incapacity. Sturman concludes:

> Ultimately, whether or not a person is deemed to be capable of consent will depend on the legal customs and or laws in a particular state, province or country that relate to competence. Insofar as a standardized instrument separately assesses each component of capacity it will remain useful under these circumstances (2005).

Many of the instruments reviewed by Sturman (2005) are heavily reliant on cognitive domains of functioning as underlining consent capacity. The move toward the standardization of consent capacity assessment instruments became reliant upon sub components, or core abilities, inherently tied to intellectual functioning as a single indicator of competence. Prophetically, Roth, Meisel, and Lidz (1977) warned that the search for a single competency test would be likened to the search for the Holy Grail.

Instruments designed to provide a single test for competency were reliant upon a hierarchical ordering of functional cognitive abilities. These cognitive abilities assumed to be possessed by persons in order to demonstrate competence, were first set forth in the literature by

Appelbaum & Roth (1982) and later expanded by others (Appelbaum & Grisso, 1995; Grisso & Applebaum, 1995, 1998; Grisso, Appelbaum, Mulvey & Fletcher, 1995). The MacArthur Treatment Competence Study (Appelbaum & Grisso, 1995) lists psycho-legal components deemed necessary to establish consent to treatment competence. These components are legally sanctioned and hierarchically arranged from least to most cognitively challenging and include: ability to state a choice, understand relevant information, appreciate the nature of the situation including consequences, and lastly to rationally manipulate all of this information and make an informed decision (Grisso & Appelbaum, 1998). The stress on level of cognitive challenge posed by each sub-component rather than on the holistic nature of all the 'tests' combined in consent competence (Roth et al., 1977) underlines the 'heavy cognitive emphasis' some authors have been critical of (see Charland, 1998, 2006; Sabat, 2005). Turnbull (1977) an early promoter of expanding consent opportunities for people diagnosed with intellectual disability specified criteria such as: having appropriate and sufficient information, possessing the capacity to understand consequences of decisions and giving consent freely and voluntarily without coercion as being particularly important. Definition of consent capacity and assessment as this applies to individuals diagnosed with intellectual disability has its own history since its emergence in the early 1990s. The concept of capacity in decision-making and its assessment, as applied to law and civil rights, has elicited an area of research and scholarly activity. Known as the 'Capacity Literature' this body of work, as it relates to individuals diagnosed with intellectual disability is reviewed in the following section.

Capacity Research and Intellectual Disability

Decision-making on the part of individuals diagnosed with intellectual disability although recognized as a civil right based on self-determination (Turnbull, 1977) also was characterized by tensions involving the ‘fitness’ of the person as a precursor to be involved in the decision-making process. Recognizing these tensions, Lindsey and Luckasson (1991) were among the first to connect involvement in the process of decision-making activity and consent competence. Based on Turnbull’s (1977) criteria Lindsey and Luckasson (1991) investigated the extent to which adults diagnosed with intellectual disability actually exercised this right in the context of consenting to community residential placement. Their study concerned first: how such consent was obtained; their findings revealed that assessment for consent ability was primarily based on informal methods. Such methods included the “eye-ball” technique—assessing competence by observation, and unsanctioned substitute consent—the practice of allowing the parents or family members to act as legal guardians. Secondly, stemming from a sense of urgency to rectify these methods their study devised a Consent Screening Interview to assess competence in this context. Findings from use of the assessment demonstrated a difference between individuals deemed able to give consent and those not. Importantly for the present study, Lindsey and Luckasson’s (1991) hope was that their assessment tool would provide a framework to increase opportunity for involvement in placement decisions on behalf of those diagnosed.

Lindsey (1994) later argued that opportunity to engage in the decision-making process is essential to the development of self-determination. Applying the assessment interview tool devised in the earlier study (Lindsey & Luckasson, 1991) Lindsey’s findings revealed a significant difference in opportunity for involvement in decision-making activity between groups of individuals assigned a guardian (legally appointed or not) and those without. Higher assessment outcome scores were obtained for those individuals for who no such guardian was assigned. Lindsey’s study demonstrated that many adults with a diagnosis of intellectual disability were denied the right to consent and participate in the processes involved in decision-making activity based on the legal or quasi-legal appointment of a guardian. Exclusion from this activity resulted in lower scores for this group. Guardianship status affected participation on behalf of those diagnosed but did not accurately predict ability to consent (1994).

The fact that diagnosis may exclude people from participation in processes involved in decision-making and moreover, that a person's extent of participation is linked with consent competence was further explored by a study conducted in Australia. Australian laws pertaining to people diagnosed with intellectual disability differ from those prevailing in America. Australian law reflects the principle of 'noninterference'. "Neither parents nor caregivers have any clear authority to consent to treatment on behalf of an adult intellectually handicapped person" (Tustin & Bond, 1991, quoting Bright, 1981). The legal definition and assessment of valid consent in Australia entails such factors as: voluntariness, being over the age of 16, demonstration of a significantly independent life style (Tustin & Bond, 1991). Despite these laws and definitions however, people so diagnosed experienced problems when they sought to exercise their right to make medical treatment decisions.

This being the context of their study, Tustin and Bond (1991) investigated this disconnect between the legal definition of competence and what was actually happening when the topic of consent ability is raised in interactions between individuals diagnosed with intellectual disability and their physicians. These authors devised a measure of consent competence, based on legal definitions and principles, and assessed ability to consent for medical and dental procedures by adults diagnosed with intellectual disability living in differently structured residential settings (smaller versus larger congregate care models; less versus more intervention provided by staff). They then compared these outcomes to both a Guardianship board's estimates of such ability and medical practitioners. Across 194 individuals diagnosed, the authors found discrepancies in estimates of consent ability from the Guardianship board and medical practitioners, where the board found 108 of the individuals could be considered consenting (26 of the 108 requiring some support) while the medical practitioners considered only 38 as consenting.

These findings, the authors suggest, arise because consent procedures on behalf of many hospitals "were written to protect the hospital rather than to describe a contract between the hospital and patient" (1991). Accountability was directed more to the organization's concerns rather than to patient's concerns. The problem providing the context of Tustin and Bond's study implied that many medical practitioners simply assumed a person with intellectual disability would be unable to make such decisions, because of their diagnosis. Against the backdrop of Australia's legal position on the rights of adults with intellectual disability, a widely accepted belief is that people with intellectual disability are able to learn to make decisions if appropriate education is provided. This stance is in contrast to prevalent legal views held in the United States as exemplified by the quote from Justice O'Connor provided in the introduction to this chapter. According to these authors, a great deal of this appropriate education is inherent in the procedures of obtaining consent where all the information is discussed between the patent and medical practitioner: specific knowledge of the condition to be treated, alternatives to treatment, consequences of treatment, and that the recommended treatment can be refused. Being seen as lacking consent capacity based on conflicting criteria, thwarts this educational process because the individual (as patient) is not discussing this information with the practitioner, someone else is.

Not only is the 'fitness' of the person in terms of intellectual ability a factor in participating in the decision-making process, but the process itself can be different for people so diagnosed. Morris, Niederbuhl, and Mahr (1993) investigated this point as a 'different standard' for people diagnosed with intellectual disability. These authors addressed whether a double standard existed by three means: the experience of people diagnosed and place in residential settings in regard to types of treatments offered, severity of intellectual impairment based on IQ scores, and significant for the present inquiry, incorporating a group of non-intellectually impaired adults to provide a comparison of assessment outcomes. Morris and colleagues (1993) based their assessment tool, which made use of vignettes, on three criteria necessitating the legal requirement for consent: knowing or information of the treatment, intelligence, and voluntariness. The vignettes composed treatments involving: a restrictive behavioral intervention, psychotropic medications, and surgery.

Morris and colleagues (1993) found that experience of treatment impacted the knowing or information criteria, elevating scores in this area. The authors caution however that having knowledge or information could substitute for “less than adequate reasoning skills”. Further findings involved IQ scores where competence as assessed diminished with lower IQ scores for individuals diagnosed; a confirmation of their original hypothesis. Of interest for the present study was the finding, present across both groups of subjects, that there was difficulty in understanding legal rights and options (or alternatives) and separating hypothetical examples of vignettes from their own personal anxieties and experiences.

Cea (1999) expanded on the work of Morris and colleagues (1993) and the double standard critique regarding people diagnosed with intellectual disability. Cea devised an assessment instrument, Assessment for Consent Capacity Interview (ACC-I) which incorporated vignettes tailored to the experience of people diagnosed with intellectual disability. Her study explored severity of impairment indicated by IQ scores (within the ranges of Mild and Moderate), use of a comparison group composed of non-disabled adults and added a repeated question format for each of the psycho-legal areas involved (1999). The inclusion of this format was to address cognitive limitations such as memory impairments in order that consent capacity could more readily be elicited. Cea also expanded on the legal criteria, in line with that of Grisso and Applebaum (1998) to include: making a choice, factual knowledge, appreciation of the disorder requiring treatment, and rational manipulation of information. She further investigated the role of experience in consent competence by including a vignette dealing with a dental treatment involving braces, a treatment unlikely to have been experienced by disabled individuals whose primary medical insurance, Medicaid, does not usually cover such ‘cosmetic’ treatments. The other two vignettes dealt with allergies where treatment was allergy shots and psychiatry where the problem was behavior (yelling) and treatment was psychotropic medication. Cea recruited her adult ‘disabled’ subjects from day program facilities whereas her adult ‘non-disabled’ subjects were students recruited from a community college; both groups were residents of New York State.

Cea’s findings lend support to the role of experience in consent competence. For example, due to their exposure to real world experiences with behavior and treatments participants who were ‘disabled,’ many of whom reported experience taking medications as part of behavioral interventions, were better able to respond to questions regarding ‘appreciation of the disorder’ for this vignette as opposed to the dental vignette. Further, adult ‘disabled’ subjects had abilities comparable to or better than adult ‘non-disabled’ subjects when they were familiar with the treatment. This was evident for the vignette dealing with psychiatry and use of psychotropic medications. Adult ‘non-disabled’ subjects could not reach a decision on ‘communicating a choice’ for this vignette because, as Cea states, “their dissonance with what they perceived to be the use of medication as a control issue” (1999). A high percentage of partial credit scores emerged across the adult ‘non-disabled’ subject’s responses, demonstrating lapses in ‘reasoning’, ‘appreciation’, ‘factual information’, and ‘choice’ questions; the psycho-legal domains necessitating consent competence. Thus she cautions “the notion that people with ‘mental retardation’ are held to a higher standard than individuals in the general population regarding their capacity to consent for treatment becomes more evident in light of this finding” (1991).

Work related to adults diagnosed with intellectual disability and their consent to participate in research was investigated by Fisher, Cea, Davison, and Fried (2006). Utilizing a similar assessment format as in the previous study by Cea (1999) this study was geared toward consent to participate in a randomized clinical trial involving medication treatment for aggressive disorders. These authors found that individuals across a range of severity (Mild and Moderate functioning as assessed via IQ scores) showed summary scores reflective of understanding research procedures, human subject protections, appreciation, and reasoning processes; domains said to underlie aspects of consent competence. Demonstrating the statistical correlation between the domains within their assessment instrument, these authors suggest that common intellectual processes are inherently involved across different consent ‘tasks’. For example higher scores were obtained for communicating a choice versus providing reasons for that choice. This finding prompted the authors to suggest that a diagnosis of ‘mental retardation’ is: “characterized by an impaired capacity to make adaptive decisions in daily life thus adults with ‘mental retardation’ are more vulnerable than others to acquiescing to requests to please the investigator…” (Fisher et al., 2006). However an ‘unexpected’ finding in this study was the proportion of adults with ‘mental retardation’ whose performance on certain consent categories was comparable to that of the non-disabled adults composing the comparison group (2006).

This unexpected finding suggests that if ‘common intellectual processes’ underlie different consent tasks, lapses in such processes are not specific to individuals diagnosed with intellectual disability but rather are found in the general populace as well. The emphasis on cognition and autonomy—attributes internal to individuals as competence has come to be defined, may need expansion in light of these findings. Fisher (2003) earlier raised questions concerning the global taxonomy of consent as developed by Appelbaum and colleagues (1999) and Grisso and colleagues (1995) as it was validated on populations other than those diagnosed with intellectual disabilities. For Fisher (2003) focusing attention on the different life experiences of those so diagnosed questions the applicability these global assessments of consent have for this population. Fisher points out, echoing Lindsey (1994) that:

> Individuals with ‘mental retardation’ and their care providers often assume permission from a non-disabled guardian is required for a consent decision, regardless of whether the guardian consent is legally mandated, thus institutional authority or the influence of legal guardians may increase their vulnerability to undue persuasion and involuntary participation (2003).

For this reason Fisher promotes a ‘goodness of fit’ ethic where decision-making is relational and includes both individuals with disability to the extent they are able and people without disability to collaborate on making decisions where competence to consent is not obtained.

Jenkins (1998) following Katz (1995) maintains the use of inverted commas around words of ‘competence’ and ‘incompetence’ to indicate their contested and problematic character. For Jenkins, competence is the “capacity for adequate functioning-in-context as a socialized human being” (1998, p. 1). Jenkins adequately places current views and practices of assessment as well as definitions in perspective as these relate to individuals diagnosed with intellectual disability when he states:

> In all local settings there are, however, those to whom the presumption of competence is not extended or from whom it has been withdrawn. That they must strive to be competent—is among the most telling indicators of their exclusion from the fellowship of competence. Humanness is socially defined and culturally variable—doubt about the full humanity of some individuals or collectivities appears to be common and there are many instances in which individuals and collectives have been, or are denied their full humanity by others (1998, p. 2).

Expanding Notions of "Individual" Autonomy

Authors such as Walker (1996) and McKenzie (2002) on the other hand pose a critique to how 'relational' is defined. Although Fisher promotes a 'relational ethic' where decision-making is shared, according to Walker "autonomy is still posed as a property of individuals" (1996). Walker states that "people with intellectual disability, like all of us, are connected to others in relations of reciprocity and dependency" (1996). Walker points out those connections to others and the life experiences of individuals diagnosed with intellectual disability, in which these connections occur, differ significantly from the regular populace. For Walker, since the Belmont Report was issued, philosophical ethics places more attention "to the nature of whole human lives, the importance of attending to the particular person in the specific situation and that dependency and interdependency are at the core of human life (1996). McKenzie states that "we fail in responsibility if we stress autonomy, as indicated in the ability to give consent and do not scrutinize the ends and means and the ideologies that drive medicine" (2002). McKenzie's point is that we must analyze the ways in which society constructs illness and also, spend time to know the individual because “no one forfeits human dignity” (2002).

Appelbaum (2007) offers a caution where investigations of competence and assessments are concerned. Appelbaum makes the distinction between terms of competence and capacity as marking the difference between legal and clinical judgments but which are interchangeable because “they are not consistently reflected in either legal or medical usage” (2007). Recognizing that there are few professional societies for the assessment of patient’s capacity to consent to treatment, Appelbaum’s work has found that assignment of diagnostic categories may be confused with determinations of capacity. For Appelbaum “no diagnosis in which consciousness is retained is invariably predictive of capacity” (2007). Appelbaum proposes prior to assessing for competence clinicians should ensure that necessary information, required for consent competence, has been divulged—stressing dialogical relations in doctor-patient encounters.

Narrative Approaches

Narrative approaches have expanded competence and its assessment from an orientation on the individual to one oriented towards embedded relationships. Work in the area of the ‘formerly competent’ encompasses concepts of personhood, citizenship, value, and legitimacy using narrative approaches to ‘reconstruct competence.’ ‘Formerly competent’ is a designation for people who had formerly been considered competent but who through physical insult or disease have been rendered no longer competent, for example: traumatic brain injury and Alzheimer’s disease. Nelson (1997) points out that the turn to narrative approaches in ethics, in both England and the United States, occurred in the early 1980s. According to Nelson narrative approaches to ethics provides a personal turn, “challenging orthodox assumptions that ethics has primarily to do with right conduct among strangers, is universalizable, and favors no one” (1997, p. viii). “Doing ethics” as Nelson writes is more about “reflection on the moral aspects of particular encounters with powerful social institutions where what is said and done reveals a great deal about who we are and what matters in our lives” (1997, p. xii). Narrative approaches within this body of work are ethically and humanistically focused and based on dialogues within relationships. These approaches adhere to Jenkins (1998) argument outlined above dealing with the socially defined aspects of humanness.

One example of work in this area is by Sabat (2005). Working to ‘re-construct’ competence in Alzheimer’s patients, Sabat contends that a completely different framework is needed. Sabat, borrowing from Shwerder and Sullivan’s (1989) concept of ‘conceptual scheme’ suggests that humans are ‘semiotic subjects’ whose behavior is driven by meaning. He proposes that meaning be understood as “acting out of intention, interpretive of events and situations, and evaluative of events, situations and actions” (Shwerder & Sullivan, 1989). In this view “specific situations are understood in light of some overarching interpretive way of thinking” (1989). Sabat adds a social dynamic dimension to decision-making competence taking it beyond factors ‘internal to the individual’. In this capacity, “people with Alzheimer’s disease can be affected by how they are treated by others...” (Sabat, 2005). Sabat maintains that actions of people with Alzheimer’s are affected by more than neuropathology affecting their brains because they can be affected by psychosocial circumstances as well.

Evaluating competencies as meaning-driven behavior where competencies can be assessed through the person’s discourse provides the new framework. This framework of consent decision-making capacity aligns itself with the current inquiry in its assertion that having a valued social identity involves the cooperation of others and if this is not forthcoming, a person is restricted to the identity of, as Sabat coins the term, “dysfunctional patient” (2005). Connecting social identity and value with consequences, such as loss or gains for the ‘social self’ and development is compatible with Wolfensberger’s (2002) concept of ‘social role valorization’ in relation to people diagnosed with intellectual disability. Social role valorization necessitates that the perception of the ‘disabled individual’ is legitimized by others in social interactions, a stance developed in the current study. For Sabat “any loss of social self, as this relates to Alzheimer’s patients [as well as those with other differences in mental functioning] has its root in the social world, rather than in the brain of the person in question” (2005).

Further work in this area involving re-constructing competence through narrative is evidenced by McCormack (2002). McCormack’s work takes a narrative identity approach with people diagnosed with dementia. She argues that dominant approaches to informed consent, favoring proxy decision-making, occludes the voice of the person with dementia and disavows their autonomy and their identity (2002). Narrative based approaches necessitate the active participation of the patient in the decision-making process, an element she states is “important for personhood” (2002).

Although narrative approaches have been used in cases where competence is presumed to have existed, the ‘formerly competent’, such approaches have not been applied to those diagnosed with intellectual disability, deemed in law as ‘the never before competent’. Clinical judgments by licensed professionals continues to remain the ‘golden standard’ (Moye et al., 2006) in competency assessments across a wide array of circumstances. The following sections investigate the work that has been done pertaining to clinical judgments in the context of proxy decision-making, substituted judgment, and best interest standards as these relate to people diagnosed with intellectual disability.

Clinical Judgments and Law: Substituted Judgments, Best Interest Standards, and Proxy Decision-Making

Empirical work in law, especially relevant to surrogate law, constitutes areas of: substituted judgments, best interest standards and proxy decision-making as these pertain to people diagnosed with intellectual disability. This work is not extensive. Work with intellectual disability in law has specifically focused on criminal law and court procedures (Peacock, 2005; Grisso, 1988, 1998). The ‘Social Science in Law’ approach (see Melton, Monahan & Saks, 1987 and Monahan & Walker, 2010 for a review of this approach) works to bring social science research into the law and to court personnel, in order to widen the base of information and knowledge so as to lessen the tendency towards bluntness and either-or questions and outcomes. Thus legal scholars as well as social science researchers can add to this knowledge base of the courts and law.

In relation to substituted judgments, a recent area has emerged touching upon best interest standards as this relates not to individuals diagnosed with intellectual disability making consent decisions concerning their own treatment, but as decisions concerning the welfare of others (Harmon, 1990). An example of this is drawn from the area of organ donation or organ harvesting. Schenberg (2007) questions the substituted judgment doctrine in law as this applies to those deemed ‘never before competent’—the legal term referring to: adults diagnosed with intellectual disability, infants and young children—relating to harvesting of their organs or donating their organs for use by others. In her critique of substituted judgments and best interest standards in this regard, she states: “if the decision-maker is affected by his own values, judgments, involvement, emotions, and interests, he will not be detached and neutral, and hence will be less able to ‘don the mental mantel of the incompetent’ as the doctrine of substituted judgment calls on him to do” (2007). Further, Schenberg (2007) indicates that the best interest standard as a test is elusive and contains no model for determining what constitutes a benefit, especially relating to minors and ‘the never before competent’. Freedman (2001) in taking an ethical stance in the case of research with this population critiqued the use of substituted judgments by others for people diagnosed with intellectual disability. In such instances Freedman found evidence that substituted decision-makers decided more by their own standard rather than from the stance of the ‘disabled’ (2001).

Other emergent areas where consent issues, law, and individuals diagnosed with intellectual disability arise involve electroconvulsive therapy, pharmacotherapy, life sustaining medical treatment and end of life care (see: Lyden & Peters, 2004; Diekema, 2003; Plotkin, 1979; Matson et al., 2000; Matson & Neal, 2009; Elliot, 2003). End of life-care is one recent area of concern especially in light of evolving changes in our systems of health care and New York State Law (NY State Law, 2011). OMRDD impacted by changes in New York State Law issued an end-of-life regulation for people diagnosed with intellectual disability. Under this regulation, decisions to withdraw or withhold life-sustaining treatment can now be made by an Article 17-A guardian (OMRDD, 2008; see also In re Chantel, 2004, where the inclusion of end-of-life-care decisions under guardian responsibility was contested on constitutional grounds by the Mental Hygiene Legal Service, MHLS; Radigan & Gobes, 2006). OMRDD’s new regulations were further amended, as was state law, to allow for the designation of a guardian without a court appointment for the purpose of making end-of-life decisions for a patient diagnosed with an intellectual disability who meets clinical criteria (see Miller, 2006; Lyden, 2006)

The need to have plans for end-of-life-care for those diagnosed with intellectual disability emerged with the changes mandated by New York state law under the Family Health Care Decisions Act (FHCDA) (NY PHL, Article 29-CC, 2010). Planning in the event of withdrawing or withholding life-sustaining treatments as this relates to individuals with intellectual disability means that these decisions are now included in consent assessments or are made by others. Although such legal reasoning stems from the priority of protecting the rights of those deemed 'never before competent' in this tension between autonomy and protection, often the wishes of those deemed disabled are examined based on their status of incompetence (Miller, 2006). One preplanning vehicle offered through the current law provides for the assignment of a proxy decision-maker, which in most cases does not require a formal assessment procedure (OMRDD, 2008).

Regarding proxy decision-making, recent research has investigated this type of decision-making as it relates to adults diagnosed with intellectual disability (Fisher, Orkin, Green, Chinchili & Bhattacharya, 2009). In light of increasing health concerns as this population ages, these authors explored how surrogates make decisions on behalf of individuals diagnosed with intellectual disability. The surrogate decision-makers in their study were composed of directors of agencies providing residential services for adults diagnosed with intellectual disability. Their findings revealed that of the 158 agencies recruited to participate, the most prominent source of input in the directors decision-making, as reported, relied upon physician recommendations as well as input from the individual (2009). However input from the individual was often interpreted. According to Fisher and colleagues respondents claimed they placed greater emphasis on ‘their perceptions’ of the client’s wishes, what they perceived to be the client’s best interests (2009). Fisher and colleagues (2009) contend, ‘best interests’ of people diagnosed with intellectual disability may be difficult to fathom.

Dependence on proxy decision-makers and the variability of the decisions such decision-makers make present the conflicts which arise in legal and clinical domains where people diagnosed with intellectual disability are concerned. Variability of decisions, made on behalf of individuals diagnosed with intellectual disability by others, was investigated by Nunes-Wallace, Gill, Harrison, Taylor and Charles (2010). These authors examined discordance rates in informed consent responses made by proxy decision-makers for people diagnosed with intellectual disability. Disparities in proxy decision-making were dependent upon relationships (family or non-family member as proxy) and race of proxy (Caucasian or African American). Relationally, these authors found that non-family proxy decision-makers were more likely to give consent overall and to consent to less invasive treatments then proxies who were family members. Disparities based on race of proxy evidenced that Caucasian proxies were more likely to give consent than those who were African American.

This particular finding of variability in decision-making based on race has been substantiated in studies investigating assigning of health care proxies, drawing up living wills, and end of life care (see for example: Crawely, Payne, Bolden, et al., 2000; Blackhall, Frank, Murphy, et al., 1999; Caralis, Davis, Wright & Marcial, 1993, and Moye et al., 2006). As Nunes-Wallace and colleagues contend the ‘best interest’ standard is often not the ‘interest’ guiding proxy decision-making as it concerns individuals diagnosed with intellectual disability (2010).

Comparative Review: Capacity Research and the Non-Disabled

Borrowing terminology from the legal arena, in this section I explore the literature involving how the ‘reasonable person’ or person who is non-disabled approaches and makes health care and other informed consent decisions. Areas of ethics, bioethics, rights and justice provide perspectives highlighting the relational and emotional factors evident in such decision making. The work to follow highlights that in our attempts to ground competence in individual intellectual processes we fail to note the many components of which such decision-making is infused. Recalling Katz (1995), the ‘Informed Consent Doctrine’ protects the right of individual choice, including the right to make an ‘unreasonable choice’.

Informative to the present study, Moye, Karel, Azar and Gurrera (2004) investigated use of forensic assessment instruments in older adults. Their findings demonstrated that forensic assessments failed to probe factors such as: “quality of life, experience, cohort, race, culture, desire for input from others, locus of control, religion, and consideration for others”, all important considerations in decision-making for this population who “tend to focus more on interpersonal and experiential elements of problems” (2006). Of interest, these authors found that cohort figured prominently in decision-making processes. Older cohorts were more likely to assume family or physicians make medical decisions and therefore took a less active role in seeking relevant information. Race was also a factor affecting decisions to the extent whether life-sustaining treatments were chosen or not. Moye and colleagues found that elder African Americans were more likely to choose life-sustaining treatments while elder Caucasian Americans were more likely to choose quality of life issues (2004). Factors such as shared decision-making and culture have also been noted to be prominent outside of the geriatric population. Studies of non-Western cultures have found as well that "greater emphasis is placed upon family, interdependence and connectedness (Kapp, 1991).

Investigating the impact of cultural context, Adams, Miller, Craig, Nyima, Phuoc, and Varner (2007) maintain that "efforts to cultivate a deeper sense of the cultural context within which research is being done should begin with the assumption that 'informed' is a concept that should travel in two directions." Their study investigated the processes involved in making an informed consent to participate in research applicable to Tibetan women's lives given these women were uneducated, non-literate and lived in an economically depressed rural area. Their complex study involved Tibetan women's responses relating to consent to engage in a research protocol involving blind trials of a medical drug thought to reduce post-partum hemorrhage—a pressing problem for that region. Findings were significant for the present study as although the patients seemed to grasp the basic 'risks' concepts clearly, their comprehension according to the authors led them to ask questions based on their life experiences. Benefits were conceptualized as benefits for a 'future group' and often expressed as part of a collective. Level of comprehension required for consent seemed to mirror number of years of formal schooling and perceptions and meanings of consent were often quite different than the experimenter's due to the 'situatedness' of the women's lives. For example given their economic constraints, the question "Who pays?" was particularly salient for these women. Based on their findings, the authors concluded that "while researchers want to ensure their subjects are 'informed' about the nature, responsibilities, rights, and effects of research, so too should researchers make sure they are 'informed' about the cultural context of the places where they conduct their work and make efforts to adapt to these contexts where appropriate" (Adams, et al., 2007). Their findings, relevant for the current study, highlight that assessments for competence should have, as

Bronfenbrenner (1978) and Cole, Hood and McDermott (2001) claimed, ‘ecological validity’ so that the activity of ‘being informed’ whether for treatment decisions or to partake in research ‘travels in two directions’ (2007).

The work of Adams and colleagues (2007) highlighted that decision-making was influenced by salient features situating people’s lives. Charland on the other hand stresses that emotional elements play a prominent role. Arguing against an exclusive cognitivist theory and assessment of competence, Charland (1998, 2006) stresses considerations of the emotional components involved in consent for treatment decision-making. These “influences of the heart” are a fundamental aspect of our humanness (Charland, 2006). Pointing out there is an important issue about competency assessment at stake, namely its lack of an emotive component included in the capacities required for it, Charland argues that emotions allow us to understand ‘why’ people choose as they do (1998). He uses the example of a woman who agrees to partake in a clinical drug trial because she *hopes* that the drug might help her. As he argues, this hope cannot be captured by rationality as hope is an emotion motivating her behavior. Emotions for Charland (1998) are an essential component in ‘human’ practical decision-making (he makes no differences in mental functioning—basing emotions as an inherently human characteristic) and he advances that this ‘fact’ needs to be reflected in development of theory and standards for determining and assessing competence.

To the inclusion of situational and emotional components involved in decision-making can be added features of societal relationships. Dixon-Woods, Williams, Jackson, Akkad, Kenyon and Habba (2006) investigated one feature of societal relationships—power relations embodied by gender. These authors sought to understand women’s consent decision-making in the context of gynecological surgery. Their findings revealed that real world implications and practices of informed consent as an "'ideal' outcome of rational choices exercised by autonomous agents was far from achieved particularly in emergency situations" (2006). Women involved in their study signed consent forms even when reluctant or opposed to surgery and further "these women's choices were, in large part, circumscribed if not pre-determined by the rules of the game in this particular field and the power relations contained therein" (2006).

Percy (2005), speaking from the perspective of race and disability, uses a platform of rights and justice to view oppression in terms of societal relationships. His views are pertinent here in understanding our attempt to compartmentalize beings on the basis of differences negates their humanness, their personhood. This is due to narrow intuitions of what humanness entails. For Percy, we need to "discover that differences are features of relationships rather than traits residing in the different person" (1995, p. 427). His emphasis on relationships impacts directly on 'how' and 'why' health care decisions can be made, widening the scope from the sole view on rationality to include room for the role of social dynamics in decision-making.

One area where social dynamics has been found to play a prominent role in informed consent decision making, either treatment decisions or participation in research, involves work with children. Children are considered incompetent in law as they are under the legal age required for legal consent (either 18 or 21 depending on each State's law). Weithron and Cambell (1982) are credited with bringing the argument for children's ability to make health care decisions into the legal arena. According to these authors' argument, the law presumes children to be incapable of making rational decisions thus requiring adults to do so for them. This presumption limits children from being seen as legitimate social actors. Weithorn and Cambell's study involved minors from eight to eighteen years-of-age as well as adults (college students) and used hypothetical stories designed to elicit consent. However, and relevant for the present study, these authors provided that minor subjects were ‘asked directly about certain types of experiences in order to supplement the demographic and experiential information obtained from parental responses’. Findings revealed that children aged 14 demonstrated “a level of competence equivalent to that of adults” and further, children aged 9 appeared capable of comprehending the basics involved in stating a preference regarding a treatment dilemma, and expressing clear and sensible treatment preferences similar to that of adults. Noting that the subjects were not currently experiencing any physical ailments, the authors suggest that increased motivation for competent decision-making ‘in vivo’ may result in greater attention and concentration and lead to enhanced decision-making.” Weithorn and Campbell conclude that their findings “do not lend support to policies which deny adolescents the right of self-determination in treatment situations on the basis of a presumption of incapacity, due to age, to provide informed consent” (1982).

While the law excludes minors from making informed consent decisions on the one hand, it does allow for their assent to such decisions, in the context of research, on the other hand. Abramovitch, Freedman, Thoden and Nikolich (1991) investigated children’s capacity to understand the meaning of assent in the context of participating in a research study. Involving children between the ages of 5 and 12, their findings revealed that these children understood most or all of what they were being asked to do and further, most knew they could end their participation in the study. Abramovitch and colleagues concluded: “in general children of these ages do have the capacity to meaningfully assent to participate in research, but that substantial problems exist in their being able to do so” (1991). These substantial problems existed in the dynamics of the children’s status in societal relationships. One example of this dynamic involved the children’s knowing they could stop participating at any time but associating this with negative consequences. These authors state that because so much of the children's experience is transparent they had a difficult time articulating standard definitions of confidentiality, 'parents and adults know everything.' This brings forward the notion that consent and assent assessments should require standards to ensure ecological validity.

These works involving children and consent raise questions such as how the constant control exerted by others and the fostering of dependence affects the emergence, the expression, and the development of the components involved in competent decision-making. In the final analysis this body of work reveals that although children as young as nine years old were capable of making 'competent decisions' these children could not conceive of any reality where they would actually be allowed to make them.

In a different venue, Bearison (1991), a clinical and developmental psychologist, explored children's experience of having cancer through a narrative approach. The significance of this work for the present study is that it legitimized children's perspectives. Focusing on the children's thinking and the knowledge they held, Bearison used this as an integral component of psycho-therapeutic treatment and support for adjustment problems they faced throughout, and beyond, their medical treatments for cancer. Bearison states he "was struck that there had been no studies of how these children thought about having cancer and how their thinking affected their adjustment reactions…how children are able to understand and make sense of their cancer experience is a critical component in determining how they emotionally cope" (1991, p. xiii). Bearison's study revealed that children had information about their illness, despite the fact that often they were shielded from this information, and actively sought it. Bearison's findings also revealed that these children desired to express and share their feelings and thoughts with others. Adult's fears and discomforts about the topic necessitated 'shielding' of information. Perhaps due to these fears and discomforts and because it was safer and less threatening, dialogical encounters between these children and the adults in their lives concerning their illness, were rare. Thus these children were deprived of having this opportunity which had significant impact on their psychological well-being, recovery, and developmental trajectory.

Chapter Summary

The empirical work carried out with individuals diagnosed with intellectual disability in the area of consent has not been extensive, but what can be summarized here is the move toward assessments for competence dependent upon views of what such competence entails. Apparently, echoing Roth and colleagues (1977), standards for competence remain controversial and change dependent upon who seeks such competence, and the reasons why such competence is sought. Although the construct of informed consent first appeared in law as a relational construct, emergent through dialogical encounters between doctors and patients, in the aftermath of its birth heavy emphasis on individual intellect has taken hold. This is especially evident when decisions, or more importantly decision-makers, are deemed unsound. As the 'Informed Consent Doctrine' emerged amidst the antinomy between Protection (need for treatment) and Autonomy (being self-determined), judgments based on decisional competence affect the extent to which an individual will actually be able to enact self-determined behavior. An adjudication of incompetence denies an individual's legitimacy and authority to make decisions. Despite factors revealed by scholars taking a different approach to consent capacity assessment, current assessments for decisional competence continue to place heavy emphasis on an individual attribute, namely one's intellectual ability, as a precursor to decisional competence.

Evidence from studies of consent decision-making among non-disabled groups where perspectives are emphasized demonstrates that such decision-making often is not of the rational-cost-benefit-analysis kind. Other factors found to be involved include: cultural context, ethnicity, emotions and other domains beside the cognitive such as social dynamics. Kapp articulates that in relation to informed-consent decision-making among the elderly, autonomy and self-direction are articulated through a web of relationships which stands in contrast to legal, and clinical, frameworks with their “bluntness as an instrument that tends to dissect the world in terms of adversarial disputes, with zero sum, either/or, winner/loser resolutions” (1991). It is this web of relationships in the real world of people’s lives, situated in cultural settings that defines not only our understanding of such concepts as choice, autonomy, and self-determination, but further, provides a base upon which we enact such concepts. Individual motivation as a result of circumstances situating lives provides such a base. As revealed in the comparative section, individual motivation guided consent activity evident in questions such as: ‘who pays?’ and the acquiescing of women to agree to gynecological surgery even when not wanted, due to the power differentials evident in a male dominated domain.

Work with children revealed that although children demonstrate the capacity for competent decision-making, they could not conceive of being allowed to do so. This nuanced perception arose because of the social dynamics involved in their lives, specifically adult control. The lives of children and adults diagnosed with intellectual disability share social and contextual similarities—namely the extent of control over their lives exerted by others and the de-legitimatization of their point of view, knowledge and possible capabilities in ‘important matters’. In the following chapter I examine the literature concerning people diagnosed with intellectual disability; specifically research dealing with the specific contexts and social dynamics situating the lives of people so diagnosed and the ramifications of these contexts and social dynamics on their level of self-determination and choice.

Chapter 2: Intellectual Disability in Socio-Cultural and Relational Context

Introduction

"The setting that may seem appropriate today may be too restrictive tomorrow. If we continue to establish permanent solutions for the retarded, we will be as wrong today as were our predecessors who stated that the only answer for the retarded was permanent institutionalization."—David Rosen, President's Address, American Association on Mental Deficiency, 1974.

Intellectual disability is the most recent term used to define this population (Schalock, Luckasson, Shogren, Borthwick-Duffy, et al., 2007) whose ancestry of terms includes: feeble minded, idiot, moron, and mentally retarded. Diagnostically, intellectual disability is classified in terms of an IQ score, obtained from standardized tests of intelligence, falling two or more standard deviations below the mean; in most cases this mean equals a score of 100. The American Association on Mental Retardation (AAMR) which recently changed its name to the American Association on Intellectual and Developmental Disabilities (AAIDD) characterizes 'intellectual disability' as "significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social and practical adaptive skills, originating prior to age 18" (AAMR, 2002). The newer AAIDD definition although focusing more on adaptive functioning includes the IQ classification in their definition as follows: "Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18" (AAIDD, 2010).

According to the Diagnostic and Statistical Manual of Mental Disorders, fourth edition, (hereafter DSM-IV) severity of intellectual capacity can be measurably indicated by IQ scores such that mild intellectual disability equates with IQ scores between the range of 55-70, moderate between the range of 40-55, severe between the range of 25-40, and profound to a score of less than 25 (American Psychiatric Association, 1994, p. 40). Further the DSM-IV states "Problems in adaptation are more likely to improve with remedial efforts than is the cognitive IQ, which tends to remain a more stable attribute" (p.40).

Prevalence of intellectual disability has been calculated as less than 1% of U.S. born children (NCHS, 2004). 85% of individuals diagnosed with intellectual disability fall within the mild range and this category makes up the largest segment of those diagnosed with the disorder (DSM-IV, 2002, p. 41). Individuals diagnosed in the moderate, severe and profound ranges account for 10, 3-4, and 1-2% of the population respectively (2002, p. 41). In the state of New York 42,737 individuals with a diagnosis of intellectual disability live in state and federally funded residential facilities, provided by non-profit and state run agencies sanctioned to provide services for this population (AAMR, 2004). This has become known in health care services as the service provider industry.

Braddock and Parish (2003) note that "people with intellectual disabilities have shared a history that has often been oppressive and included abuse, neglect, sterilization, stigma, euthanasia, segregation, and institutionalization." Chronicling such a history is beyond the scope of this research. However, to understand life within community residential facilities an understanding of the emergence of the service-provider industry, which made such residential facilities possible, is in order. Thus with a mind to the findings revealed about informed consent, its emergence, history, and eventual cognitive turn, as well as research generated indicating the performance failure of those diagnosed with intellectual disability I explore in this chapter, in similar fashion, life within the service provider industry which provides the context for the present study. The focus is on the relational quality of the self-other encounters available to adults diagnosed with intellectual disability and the specific cultural settings constructed for them which serve as the context in which these relations and encounters occur. In this dissertation I am concerned with the level of active participation or ‘voice’ that individuals diagnosed with intellectual disabilities have in such settings and the effect this level (both actual and perceived) has on their decision-making activity. In the following sections I explore the empirical literature which focuses on the quality and nature of relationships available within such settings.

According to Wolfensberger, “organizations can only be understood if one understands the ‘contingencies’ that prevailed when they were founded….Thus, any organization is deeply influenced, and even controlled, by past contingencies of which its present members may have zero awareness or understanding” (1989, p. 25). Wolfensberger’s insight serves as a guide to any inquiry seeking to understand institutional settings and their effect on our human development (see also Rivlin & Wolfe, 1985). His words serve as guides not only to this chapter but to the analysis involved in this study which explores the emergence of the service provider industry, its genesis of ‘organizations’ situating the lives of adults with intellectual disability and the empirical work that has been generated on the effects of this ‘organizational’ living on the individuals whose lives it contains. Wolfensberger’s (e.g., 1972, 1975, 1989, 2002) work has had significant impact in promoting improvements in the lives of those diagnosed with intellectual disability by scrutinizing organizations which have evolved directed toward providing services for their ‘care’. His words, especially relevant to this inquiry, follow:

> In the human service field, we are confronted by a great deal of rhetoric, and by an avalanche of documents, that proclaim that services are beneficent, charitable,

> benign, curative, habilitative, etc. These then are manifest functions of human service organizations. But while services may be some of those things some of the time, they also commonly perform latent functions very different from these proclaimed ones, including ones that are competency-impairing, destructive of independence, that are actually dependency-making and dependency-keeping, health debilitating, and outright death-accelerating, and thus killing. Unfortunately, people in human services have done extremely poorly in learning to distinguish between such manifest and latent function, even when they have learned to be otherwise very sophisticated about organizational dynamics (1989, pp. 26-27).

From Willowbrook to Community Inclusion: A brief history

Any historical understanding of the birth and ensuing growth into an industry, of the human service field in New York State devoted to individuals diagnosed with intellectual disability hinges on Willowbrook. Willowbrook State School was a remote institution located within New York City in the borough of Staten Island. Located on several hundred acres its various cottages offered an official capacity to 2,950 residents. By 1963, as the Rothmans (2009) note 6,000 residents were crammed into its space with predictable results of neglect and abuse (p. 23). But it wasn’t until 1972 that Willowbrook “became the site for a nationwide movement for human rights” (Rothman & Rothman, 2005, p. 36). A confluence of events marked the years between 1972 and the eventual settlement of the class action suit which characterize New York State’s unique service-provider industry and aided its birth.

The case, New York State Association for Retarded Children Inc. (NYSARC) v. Rockefeller (1973), adopted a legal strategy that had wide ranging implications for the growth of the service provider community care model in New York. This legal strategy emanated from a young lawyer, Bruce Ennis, who took up the case. Ennis, a public interest lawyer, had a history of advocacy work related to end institutionalization of adults and children diagnosed with disabilities (Rothman & Rothman, 2005). Ennis' legal strategy was to marshal parent groups, who chose not to institutionalize their disabled children seeking and advocating for services located in the community instead, to become involved in the class action suit.

It was this group of parents that composed the National Association of Retarded Children (NARC) which he eventually persuaded to take on the case. NARC was a parent led organization which emerged in New York during the 1940s and steadily grew to become a national organization fighting for services needed by their disabled children within the community, including the right to receive an education (Castles, 2004). Ennis's aim was to close Willowbrook and end such types of custodial care (Ennis was an avid reader of Szaz and credited as one of the founders establishing first principles in mental health law specifically with his focus on patients' right to treatment, according to the Rothman's account pp. 50-54). Because the parents of the actual Willowbrook residents sought only to improve conditions within it, he petitioned NARC to take on the class action suit because it was a strong parent movement and would aid in his aims to close Willowbrook. The case was eventually settled as a consent decree in 1975 and by 1987 Willowbrook closed "officially and forever" as an institution, its grounds eventually taken over by the City University of New York, known as the College of Staten Island (Rothman & Rothman 2005).

Emergence and growth of the Non-Profit Industry: Life in the Community

The “Willowbrook Consent Decree,” as it came to be known, stemming from the class action case, was finally signed in 1975 (NYSARC v. Carey, 1975). The ‘Decree’ mandated the closure of Willowbrook and the relocation of all residents by 1981 (Rothman & Rothman, 2005, p. 314). Willowbrook’s closure provided the niche in which the service provider industry would take hold and expand. For some, the ‘Decree’ was driven by reasons other than solely humanitarian ones (Castellani, 2005, p. 134). One such reason involved economic incentives. The ‘Decree’ would lead to the State’s loss of federal reimbursement because it would translate to non-compliance with Medicaid regulations. To avoid this, the rapid depopulation of the residents into other Medicaid reimbursable environments had to be undertaken and undertaken quickly as the law suit mandated a time frame of closure. As there were few community options available at that time, more needed to be created and quickly. Thus, fledgling community agencies, mostly initiated by parent groups, were encouraged to expand while the formation of new agencies, given federal and state financial support, became not only a reasonable business opportunity but a much needed reality.

Growth of the non-profit sector was also attributed to the fact that the state put no limit on the size or operation of both day and residential programs. Due to the ‘special’ nature of Willowbrook’s “severely disabled” population, many social welfare agencies already in existence were reluctant to provide services for them. Therefore those non-profit agencies who would guarantee placement were supported and their expansion welcomed. Non-profit agencies were used exclusively, as Castellani (2005) points out, due to Willowbrook’s need for rapid depopulation and the problems with fraud which at that time was rampant in the for-profit sector, for example nursing homes (p. 136).

Willowbrook was influential in creating the platform on which the service provider industry was eventually created and its hegemony over services for those diagnosed with intellectual disability or developmental disability made absolute. With their growth and ability to offer multiple services, the non-profit sector became a voice within the 'mental retardation' constituency advocating for services within the community rather than in institutional settings, a position formerly occupied solely by parent-advocacy groups of which NARC was one. Castellani (2005) documents that ensuing from the class action suit involving Willowbrook, an agreement was made between the state and the non-profit agencies giving them control over who had access to their facilities. In light of the 'Decree' and the Willowbrook class members need for rapid placement within the community, now sanctioned by New York State Law, New York State agreed to fund agencies expansion if 50 percent of their occupancy was taken by Willowbrook class members.

Although the state of New York has shifted its emphasis on type of care for individuals diagnosed with intellectual disability from institutionalized and segregated models to models based on 'community care' in the community emphasizing principles of 'normalization'(see Neire, 1979; Wolfensburger, 1972) some institutions still exist and are functional despite the Rothman's optimistic proposals (2009). There are said to be 125,000 individuals with diagnosed developmental disabilities which OMRDD lists as receiving services in the state of New York (Ritter, 2010) 42,737 of whom live in residential facilities sponsored by state and federally funded non-profit service provider agencies regulated by OMRDD and responsible for providing them with needed services (AAMR, 2002). In the aftermath of the shift to community placement and service, service provider agencies have evolved and expanded.

Definitions of 'Community'

Agencies offer community residential living, in different facilities: group homes or individualized apartment settings, and an array of services within community including day and supported work programs, recreational services as well as medical, habilitative, and mental health services. This is an enormous achievement. However at stake can be the meaning of 'community' characterizing such facilities. Bogdan and Taylor (1987) differentiate between being 'in' the community as opposed to being 'of' the community. For these authors, settings constructed for individuals diagnosed with intellectual disability seem to be of the 'in' rather than 'of' variety. "'In' the community points only to physical presence, while being 'of' the community means having opportunity to interact and form relationships with other community members, freely chosen" (Bogdan &Taylor, 1987 p. 210). Walker (1996) extends this view of community and rests her definition on connective bonds such as those involving geographic location, kinship, friendship, and common interest. While for Markova (Markova, 2003) community entails relationships which are interdependent encompassing differences. Echoing the opening quote by Rosen (1974), service provider agencies have become a permanent solution and in many cases the sole answer to institutionalization. Offering a wide array of services across the life span of individuals diagnosed with intellectual and developmental disabilities, the service provider industry composes a type of community within the larger social community.

Positioning service agencies as a type of community offering specific types of relationships and existing within the larger social community is one way to conceptualize their relationship to the sense of community described above. In this sense they are composed of members, or stake holders of which individuals diagnosed, as well as staff who work for the agency, are all members 'of' while the agency itself is situated 'in' the larger social community with the attempt for integration of those placed so as to be 'of' the community at large. The importance of this distinction between 'in' and 'of' in regard to community relative to the current inquiry is that it can impact access to socio-cultural resources of knowledge and information. Alternatively there are other ways of conceptualizing the nuanced experiences and relationships offered by such settings.

Notably, Levinson (2010) relies on the concept of government and work to describe life and tensions within the service provider setting. His ethnographic study of group home life within an agency located in New York describes the setting as organized by the same tension between authority and the freedom of individuals inherent in liberal societies. Levinson summarizes this tension as: "the very notion of providing services to citizens in the community presumes that even those whose capacity for freedom is always in question are somehow able to govern themselves" (2010, p. 38). Levinson characterizes the relationship between the residents and staff as likened to the tension evident between authority and freedom found in democratic societies and how this tension affects the 'work' that must be accomplished within the 'group home.' This concept of 'work' involves becoming more independent on the part of residents and facilitating this process on the part of staff. Particularly relevant for the current study, Levinson's work elucidates the realities of such living situations which may be difficult to fathom for the uninitiated. One example of this concerns interpretations of self-determined behavior; where self-determined behavior can be interpreted as a 'clinical problem' dependent on perspectives of staff in interactions with residents. 'Clinical problems' are perceived to be located within residents. What is defined as a 'clinical problems' depends on how the behavior is interpreted by different staff and the work needing to be accomplished. Thus Levinson elucidates the arbitrary nature of what constitutes a 'clinical problem' and highlights its location dependent upon different perspectives: either within an individual or emerging within interactions between individuals.

Service provider agencies construct what may be seen as 'total communities' for the individuals placed within their settings. They can be seen as total communities because they offer housing, social and recreational activities, medical and mental health services, which because of this inclusiveness, may not be seen as segregating in its own right. Although there is no question that life in community residential placements is better than life in institutions (see for instance: Goode, 1992, 1994; Blatt, 1973; Blatt & Kaplan, 1974; Taylor, 1987) as both Castellani and the Rothman's work reminds us, to what extent are the new 'community based systems' defined and shaped by the beliefs supporting the former model of institutionalization? The following sections review work which has been conducted on life within such settings.

Choice and Self-Determination

Studies by Owen and Smoles (1993) and O'Brien (1991) embedded Wolfenberger's (1972, 1989, 2002) concepts of normalization, social role valorization and guidelines for assessing institutional settings to probe 'choice' in service provider settings. Such studies, cautious at best, revealed that choice on the part of individuals diagnosed with intellectual disabilities could be seen as a continuum concept where "partial competence in specific domains can determine the degree of staff intrusion" because staff intrusion was so widespread when choice was evaluated in such settings. Taylor (2001) brings into focus the concept of choice as a characteristically human endeavor:

> Choice means that people with disabilities, regardless of the severity of the disability, should be able to enjoy the same choices and options available to other

> people in society. A public commitment to choice means that public funds and programs should support people in making these choices and selecting these options. It does not mean that public funds and programs should support lifestyle choices and living conditions other people do not enjoy (2001).

Variability of choice dependent upon type of setting was examined by Kearney, Bergmean, and McKnight (1998). Their results, a longitudinal analysis, revealed that smaller settings had more choice availability and further that choice availability was a key ingredient of quality of life and closely related to adaptive behavior skills increasing over time. Types of choice and availability to choose involved such areas of: choice of clothes, roommates, day programs, privacy, movement about facility, meals, bedroom clean up, treatment services and television programs.

Social power is another construct explored in the literature as affecting choice and self-determination. Whitehead (2001) used social power as a framework to highlight mechanisms by which disenfranchised groups are maintained in powerless positions. Her study revealed very little control, power or autonomy among individuals placed within service-provider settings with regard to such areas as: personal choice, action taken when dissatisfied, control over individual planning meetings, and negotiations. Specifically, users of such systems reported no choice in work activity even if available, no choice in residential placement, staff or roommates. Interestingly, the participants of this study were advisors from self-advocacy groups who had first-hand knowledge of the experiences of individuals diagnosed with developmental disabilities and their interactions within the service- provider system. One particularly striking finding involved paid staff feeling that, if they put individual’s rights ahead of agency needs they could risk being fired. For these reasons, Whitehead's recommendations called for advisors and self-advocates, from outside the setting, be at the helm of the self-determination movement.

In looking at social networks and relationships, Robertson, Emerson, Gregory, Hatton, Kessissoglu, Hallam, and Lineham (2001) revealed that on the whole, service-systems echo institutional models of the past and that social networks of people with developmental disabilities tend to be very small (limited to two or less people and mostly composed of staff people paid to provide care). Further, these authors note there is little reciprocity in the type of relationships available to individuals diagnosed with intellectual disabilities placed within them: "It was extremely rare for participants providing support to others, or to be in involved in reciprocal relationships" (2001).

Specific areas of study in the literature involving individuals diagnosed with intellectual disabilities in interaction with service provider systems have focused on self-determination and medical care (Shorgren, Whemeyer, Resse & O'Hara, 2006) as well as self-determination and choice as part of selves in relationship with others. The lives of individuals diagnosed with intellectual disability placed within such settings is characterized as devoid of choice, lonely, powerless and having lower quality, comparatively, than the rest of the populace (Treece, Gregory, Ayres & Mendis, 1991; Stancliffe, 2000, 2001; Wehmeyer & Metzler, 1995; Wehmeyer & Bolding 1999; Wehmeyer et al., 2008; Finlay, Walton & Antaki, 2009). This body of work elucidates that the phenomenon of intellectual disability, rather than the individuals who embody it, may have a significant impact on enactment of choice and self-determination.

Social and Medical Models of Intellectual Disability

The social model of disability, as a movement, emerged in the United Kingdom and Australia through social psychology and sociological disciplines. In opposition to the medical model where disability is viewed as pathology within persons requiring treatment, the social model rests on the view that problems associated with disability can be located in society rather than in individuals (Oliver, 1996). Such models are useful not only in understanding social factors affecting individuals diagnosed with disability, but also how these factors constrain and affect all individuals living in the larger society; for example, in capitalist societies where emphasis is placed on corporations. Klotz (2003, 2004) maintains that social models do not deny the 'ontological reality' of the disability for the individual but rather, focus on how constructions of the disability by society 'other' the individual resulting in a form of social oppression. In line with work generated by feminist scholars using standpoint theoretical approaches, an important element of social models of disability maintains that individuals with disability are sources of legitimate forms of knowledge contributing to research rather than sites on which research is conducted. Theoretical approaches emergent from this model have led to qualitative, participatory action and emancipatory work with people diagnosed with intellectual disability bringing wider views of the phenomenon of intellectual disability to the literature (Barnes, 1990; Edgarton, 1993; Ferguson, Ferguson & Taylor, 1992; Goode,1994, 1992; Trent, 1995; Goodely, 2001; Danforth, 2002; Rapely, 2004; Levisnon, 2005; Carey, 2009).

Findings amassed by this work indicate the importance of social connectedness in the lives of people diagnosed with intellectual disability within service delivery systems and society in general. Relationships are not only an ingredient in quality of life they also locate diagnosed others in positions which can either be inclusionary or exclusionary dependent on beliefs others hold about the diagnosis. Shifts in research paradigms have brought the subjective experiences of the people on whom the diagnosis is placed to light. Stalker (1998) for example argues for emancipatory research in relation to work with those diagnosed with disability in order to transform traditional research relationships. She advocates that research with people diagnosed with disability should have them assuming control of all aspects of the process. Such emancipatory models, she argues, are based on three main beliefs: conventional research relationships are inequitable, people have the right to be consulted about and involved in research concerned with issues affecting their lives, and quality and relevance of research is increased when people are involved in the process (1998).

Research Paradigms and Intellectual Disability: Qualitative, Participatory and Emancipatory Research

Bogdan and Taylor can be credited with the start of qualitative and emancipatory research with individuals diagnosed with intellectual disability. They provide an 'insider's view' to what it may be like to be so labeled by publishing "Ed's Story" (1976). Ed's story describes his experience of being 'diagnosed' with 'mental retardation' and how his life experiences and relationships were impacted by this diagnosis. Bogdan and Taylor's emphatic claim is to 'listen' to the voices of those labeled 'retarded' to find out about ourselves, our society and the nature of the label. Emphasis is on the perspective of the labeled person, thus they maintain that people so labeled have their own understanding about themselves, their situation and their experiences which are different from those of professionals and further, that they respond to things according to how they see it not to how staff see it (1976).

In a similar vein, Stanovich and Stanovich (1979) claim that with mainstreaming and the normalization principle, a concerted effort is being made to deemphasize the difference between people labeled ‘mentally retarded’ and the rest of society; however they maintain that programs of mainstreaming and integration are subverted by an excessive emphasis on the ‘specialness’ of this group of people (1979).

Langness and Levine’s (1986) objective was to “elucidate questions about change, adaptation, conformity to societal expectations, and individual innovation” and to do so they compiled a selection of studies using life history methodology and analysis. Their anthology of studies involves people diagnosed with mild intellectual disability living outside of institutional settings (but who may have experienced institutional settings at one point in their lives). Pertinent for the current research, are those chapters which illuminate the different developmental trajectories experienced by people so diagnosed. This collection of studies demonstrate that the course and daily activities of the lives of those diagnosed with intellectual disability are impacted and determined by a number of factors: childhood experiences, the social and cultural milieu in which lives are being lived, a sense of self-worth and efficacy, crisis events and short and long term goals both realistic and unattainable. This anthology highlights that when dealing with those diagnosed with intellectual disability and the contexts constructed for them, we are dealing with human development involving different processes, an insight first formulated by Vygotsky through his early work with children diagnosed with disabilities in 1920s Russia (2004, p.166).

Other areas of study on the intersection of individuals diagnosed with intellectual disability in interaction with others and service provider settings, focused on perceptions of stigma. In an early study focused on giving ‘voice’ to those diagnosed with intellectual disability and placed in service provider settings Mest (1988) investigated stigma by talking to people diagnosed with intellectual disability. Mest’s study concerned how ‘stigmatized’ others deal with stigma. She found that on the whole, individuals diagnosed with stigmatized conditions did not define themselves around their disability. Rather, “ their disability or difference became a part of their lives only when others failed to see them as they saw themselves, at those moments, they had to deal with the narrow, preconceived ideas imposed by those not labeled different” (1988). Findings from her study revealed a need to be supported by others (peers, social groups) and that current service provider settings establish the need for placement in the most normalized setting but often overlook the importance of the social bonds that can or cannot occur due to the type of setting individuals are placed in. Mest’s work is particularly relevant because it revealed individuals diagnosed with intellectual disability were able to discern when their problems were not a concern for others. Mest points out that in a setting specifically designed to aid persons with disabilities, unanswered questions or sidestepped problems signified to the ‘clients’ that their concerns were viewed as trivial, unrealistic or not worthwhile (1988).

Jahoda, Markova and Cattermole, (1988) present an alternative view regarding stigma and people diagnosed with intellectual disability based on social-construction theory. Their findings revealed that all participants had insight into their situation as ‘stigmatized other.’ Further, individuals knew that they were treated differently from non-disabled others and that this was evident in family life as well as their day center activity placement. Using a variety of perspectives (mother of the participants involved and staff members) findings revealed that whether the mothers or staff felt that the individuals were essentially the same or different (from people without a disability diagnosis) predicted the types of interactions they had as well as the type of service or level of inclusion advocated for (1988).

Levine and Langness (1985) exemplify a situated and interactive as well as qualitative methodology concerning the everyday cognition of people diagnosed with intellectual disabilities. Investigating grocery shopping skills, these authors found that people who were less sheltered fared better in problem solving than those who had been more sheltered, despite IQ level. Their study is particularly relevant to the present investigation in that it highlights that through active participation individual's diagnosed with intellectual disability use the same strategies and available tools as non-disabled individuals providing they have access to them. Familiarity with grocery stores aided shoppers ability to problem solve and appropriately use 'tools' (such as aisle arrangement, product placement, sale signs and symbols) present in the grocery store. Familiarity with the problem space and participation within it enabled shoppers to be better problem solvers using real world, practical intelligence; in contrast with a sole reliance on static measures of cognitive performance such as those generated by IQ tests to predict problem solving potential.

Raising the argument that despite what emancipatory, participatory and qualitative approaches have revealed, obstacles still remain, Neely-Barnes, Marcenko & Weber (2008) address the concept of IQ as one such obstacle. For these authors the IQ debate has not yet been put to rest. Their study was an attempt to understand whether all people diagnosed with developmental disabilities have the same access to community based, 'consumer' or individual controlled interventions or treatments and whether some benefit more from these services than others. These authors found that the lower the IQ scores the less likely people were to engage in such services or benefits, despite the potential that could be evident or develop through participation in such activities. Further, they report that lack of choice and larger group home living arrangements were associated with limited access to the community for people who had lower IQ scores (2008). One result of this work demonstrates that a reliance and focus on IQ scores obscures sources for other possible competencies which remain hidden and untapped.

Recent research on leadership and self-advocacy emphasizes the paradigm shift in research with individuals diagnosed with disabilities; including persons diagnosed with intellectual disability, oriented towards qualitative, participatory and emancipatory criteria (Powers, Ward, Ferris, Nelis, Ward, et al., 2002; Dowse, 2007). As reported by Powers and colleagues (2002) “major obstacles remain in services and systems that prevent people with disabilities from expressing their citizenship.” These authors, following Whitehead (2001), recommend that one way to remove some of these obstacles lies in ensuring that people diagnosed with disabilities are the primary training force of educating the agencies that serve them. Another insight stemming from this body of work involves sharing knowledge and experiences across different disability groups for collective advocacy or “cross-disability solidarity” (Powers et al., 2002). In this solidarity view, cross-disability organizing fosters awareness of common issues across people with disabilities as groups—such as people with physically disabilities, people who are deaf, people who are blind and people diagnosed with mental illness—and increases opportunities for these groups to work together. Such solidarity would create a powerful, unified voice for the recognition of rights, choice, and self-determination according to these scholars.

Participatory action approaches exemplified by Dowse (2007) in her work on the ‘self-advocacy’ movement, advance the claim that definitions of quality of life must emanate from those experiencing a life as lived with intellectual disability—their self-defined interests. Such approaches privilege and legitimize the voices of those diagnosed with intellectual disability. Findings from approaches such as these demonstrate differences in perceptions exist on what quality of life entails. For people diagnosed with intellectual disability quality of life equates with deep, committed personal relationships (Dowse, 2007). Dowse maintains that the “failure of people with intellectual disability to cope in the mainstream is often attributed to their intellectual impairment when in fact it is likely to have as much to do with their self-esteem as well as systematic discrimination” (2007).

Inclusive research is part of the relatively new tradition of research with people diagnosed with intellectual disability. This approach encompasses life history, participatory action research and emancipatory approaches associated with radical disability studies (e.g., Longmore and Umansky, 2001; Meade & Serlin, 2006). This body of research speaks to the stance advocated by Sprague and Hayes (2000) as well as that advanced by Bogdan and Taylor (1989) that people without disability neither stigmatize, stereotype nor reject people with disability but rather enjoy their relationships with those diagnosed with disability. Combes, Hardy and Buchan (2004) uncovered that for their sample of adults diagnosed with intellectually disability, being with families and friends was ranked the highest valued activity. Their findings demonstrate that differences exist between what service providers currently offer and what individuals want them to provide. Further their findings suggest that what is most expedient and measurable for the service providers may take precedent over those areas less prone to objective, quantifiable measures such as establishing and maintaining close relationships as a measure of satisfaction and quality of life.

Chapter Summary

This chapter explored how the phenomenon of ‘intellectual disability’ affects self-other encounters and types of relations individuals diagnosed with the disability experience and moreover, how this impacts their choice and self-determination activity. Despite what research has exposed in term of the consequences such constraints manifest, a dominant discourse in ‘intellectual disabilities’ remains strongly focused on medical models emphasizing pathology and individual mental impairments. This has resulted in a lack of movement in law and policies related to this group; constraining opportunity for their personal agency by allowing little room for their ‘voice’ in the discourse. As Percey (1995) suggests “society inevitably perceives the disabled in terms of their disabilities, for what they cannot do, not for what they can do…society is blind to their potentialities.” Further, Percey maintains “…because of this blindness, society constructs barriers ‘tangible and intangible’ that prevent the disabled from fully participating in contemporary life, which as Stetenko and Arievitch (2004a) maintain is crucial for the social formation of mind.

Using a socio-cultural approach based on the Cultural-Historical tradition, the social processes involved in our human development, the social formation of our human mind in particular, are elucidated. Such a framework allows probing into how vulnerability and disability are created and elaborated through social practice rather than biological cause (Vianna, 2009). In the following chapter I present an overview of the theoretical frameworks used to investigate this terrain, and the research questions guiding this dissertation.

Chapter 3: Theoretical Framework

Introduction

"In any account of disability it will prove necessary to take into account contextual factors for the ascription to individuals of capacities and abilities presuppose at least the possibility of their manifestation and the possibility of their manifestation necessarily presupposes some reference to phenomena beyond the person. It will not prove possible to judge that "A" has an incapacity or disability independently of consideration of the physical and social context inhabited by "A". One cannot determine whether a person is disabled simply by scrutinizing the person"—

Edwards, 1998

The theoretical framework from which this study derives is predominantly based on developmental perspectives emanating from the Cultural-Historical tradition. However a social psychological perspective also informs this study based on Markova's dialogical theory of social knowledge, a perspective based in Moscovici's (2001) theory of social representations. In combining these two frameworks I can best explicate the unique tensions involved in investigating agent's access to and appropriation of socio-cultural tools mediating informed consent decision-making activity and the contours competence takes. Antinomic thinking articulated in such instances of protection versus autonomy is involved in the legal construct of informed consent as well as in clinical and social judgments of individual capacity for decision-making competence. Antinomic thinking characterizes a case of polemics; a zero sum game where one side takes precedence over the other dependent upon the situation. Issues involving antinomies such as that between protection and autonomy are left unresolvable, static and lacking in movement. In this inquiry my perspective lies within the middle of these antinomies. As previously mentioned, Wertsch (1998) maintains antinomic thinking is unresolvable; in debates grounded in an antinomy between the individual and society he suggests an analytic approach in the middle. Markova (2003), on the other hand, sees the conflict involved in antinomies itself as the site for an analytic approach because incorporating the dynamic of both positions creates new movement with potential for change.

In this dissertation the combination of these two theoretical frameworks serve as tools with the aim to create new movement, such as reform and change, as these relate to law, policy and competence assessment applied to adults diagnosed with intellectual disability. As argued in chapter two, giving informed consent and the type of decision-making this entails can be viewed as a form of socio-cultural knowledge of recent historical origin, necessitating new mental processes, or new ways of thinking. Competence to engage in this decision-making is often considered an attribute within individuals, based on their intellect. In this inquiry competence in such decision-making is activity; motivated and goal-directed activity organized and dependent upon access to and appropriation of the cultural tools mediating its expression through language. Framing the four psycho-legal domains deemed crucial for consent competence as cultural tools rather than ‘tests’ for competence, I investigate how this activity is influenced by self-other encounters and types of relations which affect access to and appropriation of necessary tools. Yet access to and appropriation of legitimate forms of socio-cultural knowledge can be constrained by beliefs or social representations of persons. Therefore I examine how these beliefs or representations affect the extent to which men and women diagnosed with intellectual disability are able to access and appropriate legitimate forms of social knowledge. In the sections to follow I outline these two theoretical stances forming the framework on which this inquiry is based.

Development and the Cultural-Historical tradition

The Cultural-Historical tradition arises from the original conceptions of development, formulated by Vygotsky and expanded through his collaborations with Luria and Leontiev (Luria, 1979). In brief, this tradition posits that we are not the products of our individual development; rather we are the producers of it. Yet the processes underpinning this production, throughout our life's history, are inherently relational. Rather than viewing cognitive development as a gradual unfolding of universal brain-based naturally forming structures, Vygotsky's insight centers on the appropriation of shared cultural tools and symbols. These tools and symbols become signs and shape the way the brain actually works. Therefore in this view, an organic difference or defect (Vygotsky's term for intellectual disability) does not necessarily occlude the development of thinking processes or higher mental processes such as reasoning, memory, and decision-making; failure to appropriate, acquire, or merely have access to such tools and symbols for thinking, can.

We are not born able to rationally manipulate information, rather, we are born into communities where the culture provides the tools we appropriate over the history of our development, as members of that community, in order to know how to know; how to engage in the rational manipulation of information however this is defined, and whatever this entails. Vygotsky posited two streams of development, the biological and the cultural (1978). The cultural stream inherently involves history and instrumentality or mediation based on interactions with others—adults actively seek to incorporate children into their culture and its historically accumulated store of meanings and ways of doing things" (Luria, 1979, pp. 44-45). As described by Luria "It is through this interiorization of historically determined and culturally organized ways of operating on information that the social nature of people comes to be their psychological nature as well" (1979, p. 45)

Thinking of human cognition or intelligence as composed of a ‘tripartite form’ (Scribner, 1990, pp. 107-120) consisting of cultural mediation, purposeful activity, and historical development provides strong contrast to cognitivist views which position cognition and intelligence as ‘inside the head’ or views strongly emphasizing ‘nature’ over ‘nurture’. What was formerly heralded as the interaction of nature and nurture, a focus on organism and environment interactions was expanded by introducing the ‘tripartite form’. Indeed as Luria expresses: “‘Instrumental’ referred to the basically mediated nature of all complex psychological functions…The ‘historical’ element merged into the cultural one. The tools that man uses to master his environment and his own behavior did not spring fully developed from the head of god” (Luria, 1979 p. 44). The area of cognitive psychology has also been influenced by the notion that cognition is affected by interactions between humans and their social and physical environment, rather than being an in-born characteristic of brain functioning. Scholars of cognitive psychology are placing greater emphasis on culture as a context affecting cognition and intellect. As Sternberg states “intelligence cannot be fully or even meaningfully understood outside of its cultural context” (2004). Although cognitive psychology has embraced the notion that cognition or intelligence cannot be attributed to internal attributes alone, the processes affecting intelligence and cognition remain centered on organism and environment interactions.

The Cultural-Historical tradition, as applied to human development, transcends this notion of organism-environment interaction by addressing the fact that our human adaptation and development occurs in worlds we create, using tools and symbols governed and fashioned for specific goal directed activity in collaboration with others. To understand the human higher forms of behavior and mental functioning, we must look to social-historical origins in the cultural historical development of our species, our individual societies, our individual children and our individual psychological processes (Scribner, 1985, p. 141). As a means of analysis Vygotsky used a historical lens to understand the culturally elaborated means made available to each individual child in their particular social milieus (Vygotsky, 1962 as quoted in Scribner, 1985, p. 137).

In order to understand what individuals know and how they know one must seek the historical processes by which they know; this entails analysis of “phenomena in movement” (Scribner, 1985, p. 120). History in this sense is the fund of cultural tools which have evolved for and by humans and made available for appropriation by the developing child. As Bakhurst (1990) maintains, “mind emerges in the transformations of the child’s biological being through appropriation of culture” (p. 213). Stressing the cultural world a child is born into as an ‘idealized environment’ reveals how the culture has evolved to have at the child’s disposal upon their entry into the world an array of workable or ‘ideal’ tools and symbols. These tools and symbols, such as language, have continually changed over the course of history and will continue to change in ever more complex and dynamic ways as humans interact with each other in the worlds they create. A historical stance is important because in order to understand what individuals know one must seek the historical processes involved in how they know (Brockmeier, 1996, p. 140). Accessing ideal forms of social knowledge involves an historical stance because ideal forms change as the needs of the culture changes. This is evident in the change of the ideal form of consent reasoning with the emergence of the ‘Informed Consent Doctrine’—the rational cost-benefit analysis.

Developmental Systems and Processes of Development

Vygotsky, Luria and Leontiev's original formulations have been expanded by others and this study is informed by a compilation of these expansions. Vygotsky's early death meant that the development of his ideas fell to others. Examples drawn from Luria and Leontiev help flesh out the Cultural-Historical tradition and its transformations and expansions. Luria developed research into cultural components of mental development (Luria, 1976) and later developed a research program and new discipline emphasizing mediation and neural activity (Luria, 1973; 1976; 1979). Leontiev developed concepts of goal directed activity emphasizing motivation which later became known as activity theory (Leontiev, 1978). For Leontiev "isolated activity cannot be understood apart from the social ties or from the contexts that inevitably bind those participating in work" (1978, p.18). Humans, in their relationships and consciousness, are always involved in activity. According to Leontiev:

> Human activity is not isolated from social relations, from life of society…in all its distinctiveness human individual activity represents a system included in the system of relationships of society, outside of these relationships human activity does not exist (1978, p.51). Psychological characteristics of individual consciousness can only be understood through their connections with those social relationships into which the individual is drawn (1978, p. 80).

Cultural-Historical Activity Theory or CHAT emerged from Leontiev's work and is a widely recognized theoretical approach (Stetsensko, 2012). Engestrom (1995, 1999) conceptualizes activity theory as human agency realized in the form of actions and has provided a practical way of applying this stance to empirical study of real life situations. Contexts in this view are not "containers or situationally experiential spaces, but activity systems" (1995, p. 67). Engestrom (1995) maintains that use of an activity system can serve as the unit of analysis as it is "not a static, homogeneous entity but a system composed of disparate elements, voices and viewpoints and further, this multiplicity can be understood in terms of historical layers as former layers or practices form the sediment on which new layers emerge" (p.65).

A system then, such as an organization providing a range of services for adults with intellectual disability, possesses 'systemness' it has a type of movement—even if this movement is directed to maintaining direction and organization based on its internal dynamics. Enegestrom's activity system analysis enables one to relate actual social phenomena in everyday practices to theoretical constructs such as 'cultural tools' and 'human activity' through use of the elements composing an activity system: community, objects, subjects, division of labor, rules, tools. Engestrom has applied this analysis to medical settings (1995) and it is a useful tool for the analysis of the facilities involved in this study, based on medical models of care in which adults with disability are placed and other adults without disability work.

Socio-cultural theory advances the idea that mental functioning shapes and is shaped by institutional, historical and cultural contexts (Wertsch, 1991, 1985, 1998). Developed by Wertsch, socio-cultural theory is influenced by the works of the 'troika' composed of Vygotsky, Luria, and Leontiev as well as from work by Russian semiologist and scholar Bakhtin, (1981, 1986) who introduced the notion of dialogical communication and its ramifications on meaning. Wertsch (1990) points out that the emphasis on dialogical underlines that self and other are both involved in development, cognitive development in particular. A socio-cultural framework allows "the relationship between human mental functioning, on the one hand, and the cultural, institutional, and historical situations in which this functioning occurs, on the other hand, to be explicated (Wertsch, 1995, p. 3). Wertsch (1991) proposes that development is heterogeneous and situated in many levels of socio-cultural activity; there is no linear progression to some preordained desired endpoint. Evidence for the heterogeneity characterizing our human development and its potentials has been forwarded by work in developmental psychobiological frameworks such as those developed by Gottlieb (2001) and other dynamic systems frameworks.

These frameworks advance the need for dynamic levels of analysis because "organism components involving the genetic and behavioral interact reciprocally or bidirectional with the physical, cultural, and social components of the environment" (Gottlieb, 2001). The point addressed within frameworks involving systems of development and dynamic interactions across levels exerting different influences is that in any system of development there are levels of influence interacting dynamically across time which preclude linear and predictive outcomes (Lickliter, 2000; Gottlieb, 2001; Thelen & Smith, 1996).

Different levels of behavior which express themselves at different moments characterize the "emergent nature of the complexities of many psychological phenomena" (Luria, 1979, p. 42). This position was expounded by Werner (1957, p. 39), whose views were influential in informing Vygotsky, Luria and Leontiev's own emergent thoughts (Luria, 1979, p. 42). Werner's orthogenic principle defined development as a process composed of two processes: differentiation and hierarchical integration (Werner, 1957). An example of this can be seen in infant's crying. Crying differentiates and is then used as a goal directed activity (hierarchically integrated hence coming under more 'executive' functions) for a specific purpose: to receive attention, to receive food, etc. However, higher forms are not used at the expense of lower forms. For Werner "it is one of the most important tasks of developmental psychology to show that the advanced form of thinking characteristic of Western civilization is only one form among many, and that more primitive forms are not so much lacking in logic but based on logic of a different kind" (Werner, 1957, p.15). This is helpful in understanding some of the literature presented in chapter one. As this work revealed treatment decisions made by individuals without a diagnosis of disability are not primarily characterized by ‘rational manipulation of information’ or higher forms of thought as ‘ideal forms’ privileged by the culture but may be the result of other more ‘primitive’ forms which have a logic of their own, perhaps known only to the individual.

The importance of an insistence on emergent qualities of psychological phenomena and recognition that there are different levels of behavior organized in different ways is applicable in cases specific to brain damage. Luria contributed much of this understanding through his work with brain injured service men, devising the specific area of neuropsychology mentioned earlier (Luria 1973, 1979). A result of Luria’s influence resulted in knowledge that differences in neural structure, such as in cases of ‘brain damage’ cannot alone be predictive of a determined outcome. A great bulk of Luria’s work sought to provide the ‘instrumentalism’ needed to regain cognitive functioning and to support further cognitive development in people suffering from organic insults to the brain.

Gindis (1999) maintains that Luria’s work influenced by the Cultural-Historical tradition demonstrates “connecting links between sociocultural processes taking place in society and mental processes taking place in the individual.” In this context, Kozulin and Gindis (2007) apply this framework to work with children diagnosed with mental disabilities. They point out that “remediation as well as development of higher psychological functions…depend on the quality and quantity of mediating activity personalized in a teacher, in the structure and organization of the learning environment” (p. 348). Further, these authors note that quality and quantity of tools, even if they have rich potential, cannot alone facilitate learning and development without a human mediator. However, they maintain that human mediation depends on assumptions about the ‘other’ and their perceived capacity to learn and develop. This point becomes particularly salient in regard to individuals diagnosed with intellectual disability and those connecting links between socio-cultural processes such as informed consent decision-making and the mental processes required by the individual to engage in such activity

Lastly, development as process involving dynamic systems in reciprocal engagements with different levels of behavior and influence present the creative possibilities and potentials inherent in human development. Bronfenbrenner’s (1979) bio-ecological theory, based on an ecological systems approach, posits that “the immediate situation extends beyond the dyad” and “accords developmental importance” to other interactions involving more than two individuals and even larger interpersonal structures in which the developing person is not actually situated or acting (1979, p. 5). Importantly, for this dissertation, Bronfenbrenner’s ecological framework posits that “what matters most for behavior and development is the environment as it is perceived rather than as it exists in objective reality” (Bronfenbrenner, 1979, p.4). The importance of motivation and perception of goal directed activity highlighted by Leontiev (1978) and Bronfenbrenner (1979) is also captured by Thelen and Smith’s (1998) dynamic systems theory. Thelen and Smith posit that individual motivation is directive in organizing levels of reciprocal interaction and integration among forms of thought and behavior (Thelen & Smith, 1998).

These notions of the dynamic systems involved in human development, specifically the role of motivation and goal directed activity in that development, clarifies how the Cultural-Historical tradition transcends the view that human development is a result of organism-environment interactions devoid of human goal-directed activity. I turn now to the implications of the Cultural-Historical tradition for individuals diagnosed with intellectual disability.

Implications for Intellectual Disability

The importance of this theoretical tradition for research involving people diagnosed with intellectual disability stems from the fact that major contributions to the tradition emanated from the work of scholars directly involved with individuals diagnosed with intellectually disabled. This is not only true for Vygotsky, but also for Luria and Leontiev as well as others. Werner, escaping Nazi persecution, came to America and the only work made available to him was in an institutional setting for the ‘mentally retarded’ (Valsiner, 2003, p. 14). Bronfenbrenner had the unique experience of growing up, from age eleven onward, on the grounds of an institution for the ‘mentally retarded’ located in New York State in which his father worked as a neuropathologist (Bronfenbrenner 1979, p. xi).

Vygotsky’s experience with disability came through teaching. There are some scholars who suggest that Vygotsky’s initial work with children who had disabilities (those blind, deaf, and diagnosed with intellectual disability) led not only to the expansion of his ideas concerning justice and consequences of exclusion, but to his interest in psychology and re-forming it (Luria, 1979, p. 39; Miller, 2002; Kozulin, 1990; Van Der Veer & Valsiner, 1994, Kozulin & Gindis, 2007). This early work of Vygotsky with children diagnosed with disabilities led to his founding a specific research institute, the ‘Institute of Defectology’ which had as its goal, ‘social education’. According to Vygotsky (1993) a handicapping condition is a social concept as it has social implications for the individual. One implication is exclusion from social tools and symbols for learning. Social education in this view was concerned with teaching children ‘to know how to know.’ Vygotsky (1993) raised specific questions concerning how the individual/child with disabilities acquires knowledge and social worth, a theme later taken up by Kozulin & Gindis (2007).

The social ramifications of disability, what Vygotsky himself felt was the ‘tragedy’ besetting a person with a disability, can best be understood not as a singular unidirectional process aimed at those positioned as different (a stance put forth in social models of disability—see Longmore, 1995), but a reciprocal process involving access to knowledge and social worth with resultant consequences for their development. Connecting human psychological development, cognition in particular, to social and collaborative practices and action mandates a position where learning precedes development. This position has been taken up by scholars examining education as a process leading development; where performance and involvement in activity are highlighted as a precursor to academic competence (Hedegaard, 2007; McDermott & Varenne, 1995; Mehan, 1993; Cazden, 1981). For scholars examining ‘special education’ this approach has been slow in being applied (Kozulin & Gindis, 2007; Donnellon, 1984).

An implication for individuals diagnosed with disability is that exclusion from learning leads to disorganized development. This is in comparison to the expected development following from involvement in culturally and historically evolved learning practices, existing as ‘ideal forms’. This exclusion would have the greatest impact on development for such individuals, not necessarily the ‘defect’ (Vygotsky’s term). Vygotsky theorized ‘disontogenesis’ to describe the disorganized development that occurs when a developing organism is excluded from the ideal forms of tools and symbols available in the cultural world they are born into (Gindis, 1999). Exclusion from legitimate cultural forms impacts cognitive processes in ‘normal’ adult development (e.g., Wertsch, 1998). As stated by Vygotsky (1994) “if there is a situation in which the ideal form is not present the resulting development will have an extremely limited, reduced, and impoverished character (p. 350). Wertsch’s (1998) work on memory provides an example of this with adult, ‘non-disabled,’ development specific to memory processes (pp. 141-177).

Related to this notion of exclusion based on disability, Levine (1996) investigated early interactions between mothers and their children diagnosed with developmental delays. His findings revealed that these mothers often did not use ‘the voice of reason’ or more sophisticated abstract conceptual ‘tools’ when interacting with their children, while mothers of children who were ‘non-disabled’ often did. Levine notes that mothers’ failure to embed the particular problem and elaborate the problem solving process itself in an extended context supports the argument made by Vygotsky (Vygotsky,1993 as quoted in Levine, 1996) that mild ‘mental retardation’ may be associated with the denial or limitation of basic experiences in childhood. I build on this work of Levine’s to look at the interactional contexts that adults diagnosed with intellectual disability and their residential facilities (social and physical) create. I also attempt to explore their history of interactional contexts, past experiences, as having an influence in shaping their interactions in present contexts.

For Vygotsky, different treatment affects development for the child diagnosed with ‘defects’ and he cautioned that children with ‘mental defects’ should not be treated differently in terms of education—they need support but should not be excluded from the cultural tools available (Vygotsky, 2004, pp. 149-187; Gindis 1999). Writing in the early 1920s about the fundamentals of ‘defectology’ Vygotsky claimed:

> “pedagogical efforts have been directed at the advancement and perfection of the lower, more elementary processes…The [mentally defective] child was not taught to think, but to distinguish among smells, among nuances of color, among

> sounds, and so on. And it was not only sensorimotor training but the entire rearing process of the abnormal child that was oriented toward alignment of the elementary and lower functions" (1993, p. 208).

Studying 'defectology' or mental difference creates the space for new avenues in research as well as more in-depth understanding of the socio-cultural-historical processes involved in development in general. As Vygotsky pointed out "the history of cultural development in an abnormal child constitutes the most profound and critical problem in modern 'defectology'. It opens up a completely *new line of development* in scientific research" (Vygotksy, 2004, p. 166, italics added). For Vygotsky (2004) "Mastering a psychological tool and, by means of it, one's own natural psychological functions generates an artificial development, as it were; that is, it raises a given function to a higher level, increases and expands its activity" (p. 169).

Kozulin and Gindis (2007) stress that Vygotsky's passion was to change negative social attitudes toward individuals with disabilities a reason why the "trademark of his approach" was to search for positive capacities and the creation of quality of life through education and upbringing of children with disabilities. Robinson (2004), substantiating this, states that for Vygotsky "It is important to educate the handicapped, but it is even more important to reeducate the broader society" (p. 51). Vygotsky's emphasis on 'ideal forms' and the consequences when 'approximations' or exclusions from these ideal forms occur is exemplified in a study by Levine and Langness (1983).

Examining context, ability and performance Levine and Langness (1983) compared performances of adults diagnosed as 'mentally retarded' and adults with no disability diagnosis in a typical recreational activity involving competitive sport leagues. Centering on basketball their findings document that rules differed across these two groups, and moreover rules were not just simplified for the adults diagnosed as ‘mentally retarded’ they were active restructurings. This active restructuring, “maintained the flow of the game, kept things less confusing and made play easier for the ‘retarded players.” Thus, these authors revealed there were two qualitatively different games played leading to two qualitatively different experiences: adults with no disability diagnosis played ‘normal’ basketball while adults diagnosed as ‘mentally retarded’ played ‘normalized’ basketball. An implication stemming from this work was that the experience for adults diagnosed as ‘mentally retarded’ was to deny them opportunity for ‘normal’ play, placing their self-esteem and competence ‘center stage’ and contributing to increases in individual anxiety. These authors conclude ‘normalized’ settings demand and reinforce ‘retarded’ behavior. As their work suggests, contexts play a significant role in the types of self-other encounters and relations people diagnosed with intellectual disability experience.

Contexts of Development

Different settings provide different ‘sources of development’ of specifically human traits and attributes that have evolved over time, understood here as ideal forms. Vygotsky (1994) maintained “the only way these traits and attributes are found in each individual depends upon the strength of his being a member of a certain group” (p. 350). Thus the quality and quantity of tools and human mediators may differ in specific culturally organized settings or communities.

Scholars such as Rogoff (1990), Lave (1990), and Lave and Wenger (1991) place emphasis on communities as sites for situated learning. For Rogoff (1990) the rapid development of young children into skilled participants in society is accomplished through children’s routine and often tacitly guided participation in organized activities (p. 16). The emphasis is on guided participation and apprenticeship in the specific knowledge forms, or ideal forms privileged in each community of which the child is a member. Cultural activities as ‘ideal forms’ are actively structured in each cultural community in order to be appropriated by the children. “Community of practice” is Rogoff’s term (1990) emphasizing that specific communities become ‘arenas for learning’. These arenas are structured differently according to the specific cultural requirements, needs, and current conceptions of children and their abilities. Children’s opportunities for observation and active participation in valued activities as impacting learning and development has helped deflect prior assumptions such as those put forth by Piaget(1977) namely: development precedes learning and children actively construct new cognitive structures and learn when ready to learn (Crain, 2000).

Lave and Wenger (1991) take a situated approach to adult development. These authors expand notions of apprenticeship and more specific arenas of learning—those specific to adult activity. Learning is context dependent and involves movement through socially contrived organization. Their term describing this movement is ‘legitimate peripheral participation’ (p. 31). Placing emphasis on one’s position within this organization, their focus is on power differentials in who is legitimized to participate and move toward more socially contrived ‘ideal forms.’ From this perspective the function of cultural tools and symbols is dependent on how they are made sense of and used in these contrived yet meaningful organizations of human practice because it is within such systems that meaning is derived (Lave & Wenger, 1991, p. 102). Context within this framework refers to a relationship rather than merely a location. Stressing the ‘position’ of the person in situated activity emphasizes its negotiated nature, which influences learning. Thus, participation and movement in legitimate activity, peripheral or otherwise, is determined by others. In situated frameworks the status of the individual in self-other encounters is foregrounded: “Legitimacy is not a person’s choice; the community determines legitimate access (Davies, 2005). Situated activity paradigms challenge traditional cognitive theories of learning because such theoretical positions are “distanced from experiences and divide the learning mind from the world” (Chaiklin & Lave, 1996, p. 7).

Billet (1993) looks at the development of expertise in adult human activity. He stresses that the particular dimensions of social practice shape different forms of knowledge and further, adds communities of practice as specific sites where practice is encapsulated in physical settings. Analysis of social practice is necessary in order to reflect the relations among person, activity, and situation as they are given in social practice (Billet 1993).

These situated stances inform the present work by specifying how social knowledge is not just acquired but transformed by individuals as a result of occupying certain social positions. Stressing individual’s cognition as ‘knowing,’ this term links learning with thinking and acting to connote it as something projected out ‘beyond the skin’ (Wertsch, 1991). As Billet (2001) argues, in order not to disembody practice from cultural and personal need, or motivation, a situated level of analysis is needed at the level of enactment of practice. “Individuals acting in social practice construct domains of knowledge; the construction of these domains is mediated by their social histories (e.g. their existing knowledge) and by their access to the activities of the particular social practices” (Billet, 2001). And importantly, access to the activities or particular social practice is dependent on each individual’s status, social worth, and inclusive membership in the community—rendering their legitimacy to gain access.

Theoretical Constructs

Social mediation. These elaborations of the Cultural-Historical tradition document a central core premise in approaching cognitive development, namely that such development (across humankind as well as individual lives) can only be understood in the context of activity, culture, and history—all relational entities. Theoretical constructs conceptualizing processes involved in development concern Vygotsky's 'general genetic law of development': where 'what we know' was social prior to it becoming personal. "Higher specifically human psychological processes may originate only in the interaction of man with man, as in intrapsychologial actions, but they are 'finished' by the individual independently (Leontiev, 1978, p. 59). Further, Leontiev (1978) notes that consciousness originates in society, it is something produced by man therefore "internalization is not external action transferred into preexisting internal 'plan of consciousness'; it is the process in which the plan is formed (p.60). Mediation underscores that our human higher mental processes are instrumental; wrought through tools and symbols cultural-historically derived, and moreover, implies active instruction, motivation and goal directed activity.

Zone of Proximal Development. The zone of proximal development (hereafter ZPD) is referred to by Vygotsky as the space between what a child can presently do and what the child can do with help. An essential feature of learning is that it creates the ZPD. Learning awakens a variety of internal development processes that are able to operate only when the child is in interaction with people in his environment, more knowledgeable adults and peers. Once these processes are internalized, 'taken as ones' own', they become part of the child's independent achievement (1978, p. 90). Bruner (1986) points out that "society provides a tool kit of concepts and ideas and theories that permit one to get to higher ground mentally" (p. 73). Sharing occurs in the ZPD. Bruner conceptualizes this sharing as 'loans of consciousness' which are passed from more able to less able participants in negotiated transactions (1986 p. 76). The ZPD is the space where active instruction and goal directed activity unite. Within this study reports of self-other encounters between individuals diagnosed with intellectual disability and others are examined for their potential to form ZPDs.

***Tools, Symbols and Signs*.** Language, for Vygotsky, is an example of a cultural tool, a symbol system mediating thought. This implies in its inherently social nature, that thought is collaborative and emergent through the activity of human communication (Wertsch, 1985, 1990; Bakhtin, 1981, 1986). Tool and symbol use, according to Stetsenko (2004), are not merely vehicles for adaptation; they are appropriated by active agents for goal directed activity which entails changing themselves, the world, and others (p. 504). “His wide range of knowledge and interest in literary theory, linguistics and semiotics provide insights into why sign mediation and symbolization were important concepts in his theory” (Stetsensko, 2012). A central premise within this tradition is that language is not merely a symbol mediating mental activity but also value laden activity. This emphasis on value and worth impacts the learning that takes place within the ZPD as evident in the legitimacy stance foregrounded in situated theories. Thus, language forms can evidence value as well as historical origins given that they are derived in interaction with others in self-other encounters. Tools and symbols are made available in the culture to be appropriated by the developing person whereupon they become ‘signs’ for the self, organizing their mental processes.

***Ideal Forms*.** Glick expands on this value laden activity of language within the ZPD by directing attention to the type of activity as characterizing the type of learning that ensues. Language can be seen as a system for membership “speaking the language is a powerful social signal of membership” (Glick, 1995, p. 378). Within the ZPD, attention must be directed at where room is made for “the individual’s voice and participation in the activity of knowing” rather than focusing on what is to be known (Glick, 1995, p. 378). Glick (2011) maintains that learning within the ZPD entails that participants are seen as having a viewpoint worth considering (p. 29). A legitimizing stance to the ZPD maintains that participant’s views are worth considering; advancing that dialogue is a mediating process involving “exchanges of utterances” dependent upon the status of persons in the dialogue. However, Glick states “the status of the person in the dialogue as a legitimate voice is critical to many of life’s issues…opportunity will hinge on the degree to which the other is seen as a possible dialogical partner” (2011, p. 29). According to Glick (2011), “a cultural and historical understanding is a key element to address issues of human rights, cultural belonging and having a cultural voice.” This is especially important in terms of postulating that language as a symbol system includes ideal forms which are inherently involved in consent capacity assessments, where ‘ideal forms’ are evident in the types of responses expected.

The theoretical construct of ‘ideal forms’ elucidates how tools and symbols are social resources distributed within a developing person’s milieu. Accessing these social resources they become signs appropriated by the individual for organizing their mental processes. It is this process which expresses the fundamental instrumental or artificial quality of human cognitive development eminent in Vygotsky’s original insights, yet leading him to explicate his concerns as well that: “man is a social creature, that without social interaction he can never develop in himself any of the attributes and characteristics which have developed as a result of the historical evolution of mankind” (1994, p. 352).

Dialogical Theories of Social Knowledge

Scholars such as Moscovici (2001), Markova (2003, 2000, 1987), Markova and Farr (1995); Markova and Foppa (1991, 1990), Jodelet (1991), Jochelovitch (2007), Jovchelovitch & Campbell (2000) and Jovchelovitch and Gervais (1999) within social psychology have used social representational and dialogical approaches to understand how social knowledge changes in self-other encounters and the relevance this has for the view of others (their status, worth, value) in such encounters. Representational approaches are founded on the works of Moscovici (1984, 2001) whose theory of social representations first explored this change in social knowledge as a function of being appropriated by people in different contexts, for example from Professionals to lay people. Works by scholars influenced by dialogical approaches examine ways in which assumptions about the nature of phenomena are predetermined by already accumulated knowledge and the extent they are co-created in social practice through language.

This position is especially relevant when self-other encounters involve ‘others’ deemed ‘different’ and encounters involve medical or mental health care personnel, practices and treatments. The corpus of work, briefly represented here, considers ‘different’ others such as mental patients (Jodelet, 1991), those diagnosed with intellectual disability (Markova & Foppa, 1991; Markova & Farr, 1995), and those of different ethnic or cultural origins (Jovchelovitch & Campbell, 2000; Jovchelovitch & Gervais, 1999) in self-other relations relating to policy, practices and treatments in health care.

Markova’s (2003) theory of social knowledge rests on dialogism (Markova, 1990) itself based on Bahktin’s (1981) concept of the dialogical. Her theory unites dialogicality (process) with social representations (local social knowledge) in an attempt to examine the conflicts involved in antinomies such as that between the individual and the social; how knowledge becomes social and mediates ways of knowing in the individual. Knowledge becoming social and mediating ways of knowing underscores the connection between these two different schools of psychology: the developmental based in the Cultural-Historical tradition and the social based on dialogical self-other relations. According to Markova (2003), "constructivist theories separate the individual and society into two independent units ignoring their dynamic interdependence and propensity for mutual change." Markova maintains that although mutual change is evident in dialogical encounters participants do no forfeit their individuality (2000). This insight is especially meaningful in light of Stetensko & Arievitch's (2004a) claim that from the perspective of cultural-historical activity theory, 'the self neither dissolves in the social nor in the theory.'

Theoretical Constructs

The Dialogical. For Markova, a dialogical point of view entails two interdependent dyads of opposition leading to tension. This tension leads to movement or change between the participants in this dyad which, for Markova, is conceptualized as the 'Ego-Alter' (2000). The 'Object' becomes the sign, representation or symbol viewed from each participant's perspective (2000). Dialogical analysis involves examining the movements in the dynamics of the triad involved in Ego-Alter-Object encounters (Markova, 1990). Within this framework self-other encounters are viewed as a tripartite process composed of Ego (self), Alter (other), concerning an Object (a type of social knowledge either about a person, place, idea, activity).

Within this view, a heavy emphasis is on language and moreover because language is value laden, language forms as sources of knowledge can be hierarchically arranged from valued to valueless. Many scholars rely upon language based analytical tools such as discursive psychology (Rapley, 2004), narrative interviewing (Jovchelovitch & Bauer, 2000) and conversational analysis (Anataki, Finlay, Walton, 2007) in encounters with ‘different’ others.

Social Representations. Language is value laden because it arises out of the social representations or common thinking prevalent in a society (Markova, 2000). Social representations are useful in examining the historical shifts and changes Vygotsky felt vital to understanding developmental change—mental change in humans. Social representations can mark societal or ‘ideal forms’ of thinking exemplified in the process of Ego-Alter-Object within self-other encounters. Highlighting that language and meanings are value laden speaks to the dynamics which must be of focus when one considers spaces for development such as the ZPD. As Markova (2000) explains “Focusing on values in semiotics rather than on attributes (as in traditional cognitive psychology) forces us to consider that values are defined with respect to the individual and to others (groups, cultures)—rather than independently of them.” This is an important point when considering research involving individuals diagnosed with intellectual disability. Researchers using social representational and dialogical approaches underline a key point—often the social knowledge of marginalized groups is not examined nor considered valuable. As Jovchelovitch contends, in attempts to understand the strange, people compare it to what is known or familiar (2007).

Jovchelovitch (2007) employs the work of scholars such as Jodelet, Moscovici, and Freire (1970) to flesh out the view that “communication between self and other is the path for the development of personal, social and material resources. The task of a critical theory is to understand what helps or hinders this possibility and develop theories and methods that can contribute to advance it” (p. 152). Testimony to these processes addressing the strange by anchoring it to the familiar has been demonstrated by many researchers especially as this relates to difference such as mental illness, medical disorders, and intellectual disability as stated above. Jovchelovtich (2007) claims, in line with Glick's (1985, 2010) legitimacy stance, in interactions with difference those constructed as 'other' hold knowledge that is often de-legitimized. "Encounters between self and other can produce different outcomes, which depend on whether interlocutors can communicate and mutually recognize each other as legitimate partners in interaction" (2007, p. 132). Jovchelovitch's (2007) central argument is that knowledge must be "understood and explained in relation to representational modalities, which in turn relate to the type of public sphere and cultural traditions of a community; to explore these processes we must include all the 'stakeholders' involved" (p.3). Her words are particularly relevant to the present inquiry's probing of rational knowledge: "Defining who holds rational knowledge is both an unresolved theoretical problem and a political act. Its implication for the valuation and ranking of different peoples and ways of life is vast and can potentially lead to practices of exclusion and devaluation of specific groups and communities" (Jovchelovitch, 2007, p. 4).

Relating these views back to the ZPD, scholars contend that in Vygotsky's conception the ZPD is a place where knowledge although asymmetrical involves like or ideal forms, however this may in fact involve differences in perspective of what an 'ideal' form is. These differences must be taken into consideration in cases where "measuring of aptitudes implies knowledge of past cultural constructions" or 'ideal forms' privileged by the culture, of which the 'other' in self-other encounters may have no knowledge (del Rio & Alvarez, 1995). As del Rio & Alvarez (1995) maintain, awareness of these differences in perspective must be brought to light in any attempt where research "can cross easily to intervention."

Section Summary

I take from these theoretical perspectives the notion that a community of people in communication and practice can produce transformation in individual development by creating zones of possibility. Within such zones views of reality or social knowledge can be co-constructed through establishing a dialogue between different types of knowledge, such as that held by professionals and that held by individuals diagnosed with intellectual disability. However value, social worth and legitimacy of the ‘other’ within the encounter are key components in this transformation. This dual theoretical framework guides the formation of research questions, provides the methodology, and leads the analyses involved in order for this study to explore what is needed for individuals diagnosed with intellectual disability to ‘know how to know’ as this concerns their ability to demonstrate informed consent treatment decision-making competence.

Based on the theoretical frameworks guiding this research, informed consent decision-making is posed as a dialogical process, co-produced by self-other encounters characterized by dialogical relations. As a psycho-legal construct, informed consent decision-making is of recent historical origin requiring new ways of thinking; new mental processes or ways of knowing developed specifically to deal with this shift in medical practice, patient activity, and doctor-patient relations. Posing informed consent decision-making competence as an ‘ideal form’ of social knowledge mediated through dialogical relations in self-other encounters allows different questions to be examined.

Traditional assessments for decision-making competence sound the depths of an individual’s intellect hoping to find competence there. Failure to find it has implications for those whose competence is being assessed—restrictions in the extent of control they can actually exert over their own bodies and lives and how self-determined they are likely to be. Therefore, with an eye to transformative change, toward creating space for movement and interventions in order to promote and support the development of competent decision-making in adults diagnosed with intellectual disability, this inquiry concerns questions focused on how self-other encounters and types of relations within specific contexts mediate competent, or incompetent, decision-making.

Following from social dialogical theories, this investigation starts with an examination of the social knowledge men and women diagnosed with intellectual disability possess regarding their health care concerns and treatments—their knowing, and moreover, following from socio-cultural approaches, how this knowing shapes and is shaped by their relationship with the cultural, historical and institutional settings situating their lives. Privileging accounts of their perceptions, experiences and the meaning these have for them relating to health care issues and treatments, the social knowledge they possess is juxtaposed against the professional social knowledge characteristic of such settings. Jovchelovitch (2007) explains that "encounters and comparison between knowledge systems brings about problems related to the evaluation of 'knowledges', the legitimacy that is granted to 'knowledges' and the obstacle and possibilities comprised in the communication between 'knowledges'" (p.158). With these insights on the processes involved in 'knowledges' I explore the processes involved in assessment for competence.

Current assessments for decision-making competence can be seen as an attempt to match an individual's behavior (their verbal responses) to what is considered an 'ideal form'. This 'ideal form' (the actual process involved with giving an informed consent) is a depiction of a self-other encounter between a doctor and patient (in the vignette variety of assessment measures) based in dialogical relations. However the assessment process itself is a self-other encounter involving monological relations where ‘correct’ answers are sought to questions posed. It is presumed these questions tap into common knowledge or common knowing. Findings of incompetence create situations where dependence and vulnerability are created because others make decisions—limiting ability for enactment of self-determination and agency in the said ‘(in)competent’ individual’s life. Alternatively, conceptions of competence as a social process learned through self-other encounters involving dialogical relations allows for interventions supporting greater self-determination and agency; creating movement from either-or judgments of persons to transformations in potentials for personal agency.

Lastly based on developmental theory influenced by the Cultural-Historical tradition, higher mental processes are instrumental; mediated through social interactions where access and appropriation of cultural tools and symbols required for ‘ways of knowing’ are taught by skilled others. In light of the shift to community models of care offered in residential facilities by non-profit agencies how are spaces created within these specific settings where such learning occurs—how access to and appropriation of the social knowledge mediating competent treatment decision-making is afforded. How do self-other encounters, characterized by professional relations, impact the men and women’s access to necessary social knowledge?

Research Aims

The aim of this research is to examine ways in which the capacity for competent treatment decision-making can be supported and developed in adults diagnosed with intellectual disability. I seek to understand what is needed in order that individuals diagnosed with intellectual disability ‘know how to know’ as this applies to competent health care decision-making. Theoretically, whether emphasis is placed on the individual or the social does little to change the consequences a judgment of incompetence has for the person—an individual's lack of choice and agency in the kind of 'quality of life' she or he may personally desire. Historically whether in the research, law, or as found in health care policies and practices, assessment for treatment decision-making competence as this concerns adults diagnosed with intellectual disability has concerned intellectual ability and 'either or' outcomes—either the person is competent or they are not. An important issue raised by this research calls attention to the experiences of adults so diagnosed, placed in residential settings. What are the implications of placement for the existence, support, or creation of treatment decision making competence? By using the theoretical concepts outlined above I explore how creating potential necessary for the existence of competent medical and mental health decision-making is ineluctably linked to the life experiences and self-other encounters of these adults.

My approach to this research assumes that the nature of relations and the socio-cultural context in which these relations occur create the potential for the development of competent decision-making to emerge.

This research documents how types of relations in self-other encounters may foster the development of competent decision-making on behalf of adults diagnosed with intellectual disability. Through the lens provided by socio-cultural and dialogical frameworks I attempt to understand the life experiences of these adults and their self-other encounters from their point of view. However, looking only at their point of view provides an incomplete picture of the dynamics involved in self-other encounters therefore I include the experiences and self-other encounters as perceived from those employed by the settings in which adults so diagnosed are placed.

Research Questions

Stemming from the above there are three areas of research questions guiding this research with the aim of elucidating what is needed in order to support the development of competent health care decision-making in adults diagnosed with intellectual disability:

1) What social knowledge do men and women diagnosed with intellectual disability possess regarding health care treatment and decision-making? How is the social knowledge linked to their past and present experiences? What contextual and other factors influence this knowledge and how might this knowledge differ from the ‘ideal forms’ required demonstrating ‘competent’ decision-making?
2) What characterizes the relations of self-other encounters between the diagnosed and the ‘professionals’ employed to provide services for them. How do these relations influence accessibility of different forms of social knowledge mediating competent decision-making and the men and women’s ability to appropriate them?
3) How do men and women diagnosed with intellectual disability access and appropriate cultural tools to mediate ‘competent’ forms of informed consent decision-making and the form such tools take based on their past and present experiences?

Expected Outcomes

The aim of the study is to explore how self-other encounters, types of relations and specific settings (residential facilities offered by different non-profit agencies) influence the development of informed consent decision-making in adults diagnosed with intellectual disability. However, differences in policy and practice exist across settings specific to the extent to which individuals placed within participate and are involved in their own health care issues and treatments. These differences may affect self-other encounters and types of relations.

This study concerns self-other encounters, types of relations (monological versus dialogical), specific settings as contexts (agencies offering residential and other services) and their influence on the development of competent informed consent decision-making in adults diagnosed with intellectual disability. To this end I explore the same activity (informed consent decision-making) as an 'ideal form' (depicted in a capacity for consent assessment measure). Further I explore reports of self-other encounters by adults diagnosed with intellectual disability placed in different agencies having different policies on the extent of their participation in health care issues and treatments. Thus, if disability diagnosis is relatively constant, in terms of previously assessed IQ level and severity, it is expected that in those settings offering greater involvement and participation in medical and mental health concerns and treatment, individual responses to an informed consent assessment will more closely approximate the 'ideal forms' expected and moreover, reports of type of self-other encounters will characterize dialogical rather than monological relations.

Specifically, I expect that for those adults placed in agency settings affording them greater participation and involvement in their health care treatments and concerns; able to sign their own consents or deemed consenting: 1) they will most likely have self-other encounters where they occupy a valued or legitimized status and the type of relations they have in such encounters will be dialogical; 2) they will most likely due to these interactions and experiences have greater approximations of the 'ideal form' of informed consent decision-making as evidenced by scores obtained on a capacity for consent assessment measure and as narrated; and 3) IQ scores will not be predictive of scores on the assessment measure given the above.

Chapter 4: Methodology

Introduction

"If the structures of higher mental functions are 'a transfer into the personality of an inward relation of social order', then this social order must be comprehensively understood in order to understand psychology. One must be well versed in the history, sociology and politics of a culture in order to explain and describe a people's psychology."—Ratner (2004)

Posing informed consent decision-making as a cultural process, of recent historical origin, an activity involving specific forms of social knowledge, requires a methodology which: 1) probes access to and appropriation of cultural tools mediating the competent use of this form of social knowledge and 2) examines self-other relations as sites where such knowledge resources can be made available. Specific language use is considered in this study as a legitimate form of knowledge underpinning consent competence. It is inherent in the four psycho-legal domains considered as 'tests' for such competence by expressing: a choice, factual information, appreciation for need of treatment, and rational manipulation or applying the risk/benefits analysis of the treatments offered. In this study rather than 'tests' of competence, I conceptualize these four psycho-legal domains as cultural tools and signs mediating the processes required for competent treatment decision-making. However, language forms as specific knowledge types emerge within self-other relations between the intellectually disabled and those employed to provide services for them in specific contexts. Therefore, my approach to this research is situated and dialogical. I examine the accounts of all 'stakeholders' involved in residential service provider agencies, as part of the community of the non-profit industry, in order to examine how access to and appropriation of such tools and signs is afforded or constrained and moreover, what governs this. As this is qualitative research and exploratory my aim is not to make generalizations but rather, to elucidate how perceptions and viewpoints are understood and impact decision-making within certain settings as contexts.

Study Plan

The plan of the study was to recruit two or more non-profit agencies differing in their policies on the extent to which individuals diagnosed with intellectual disability placed within were involved and participated in their health care issues and concerns. Adopting an interview style most likely to encourage a dialogue, interviews were held across a variety of stakeholders within each agency including: men and women diagnosed with intellectual disability placed within and employees across different levels of the organizational hierarchy (direct-care workers, nurses, managers, and administrators). On site observations and artifacts of each agency were also used in order to understand self-other encounters, types of relations and specifics of the three settings, which were then compared.

While encouraging a dialogue with employees was not foreseen as being problematic, encouraging a dialogue with the men and women diagnosed with intellectual disability could present a challenge. As Barnes (1990) has noted, “through no fault of their own” people diagnosed with intellectual disability often have few experiences where their thoughts, opinions and perspectives are sought; therefore they may have difficulties freely discussing these because they lack experience in this type of discursive framework. Seligman, Budd, Spanhel, & Schoenrock’s (1981) classic work on the response style of people with intellectual disability demonstrated a tendency towards acquiescence, especially in encounters characterized by question-answer formats. Alternatively, Rapely (2004) raises critiques to this ‘response style’ as emanating because of disability. Rapely suggests that through a discursive psychology framework such a response style is motivated activity, goal directed and having more to do with communication environments and type of self-other encounters (with professionals and direct-care staff where it may be ‘wiser’ to just say ‘yes’) than individual internal attributes (2004).

Notwithstanding the contributions from the literature detailed in chapter one, this study included use of a standardized assessment for consent capacity instrument devised specifically for people diagnosed with intellectual disability. Composed of vignettes the instrument presented a concrete example, or ‘ideal form,’ of the dialogical self-other encounter between patient and doctor. This assessment instrument not only provided ‘scores’ but opportunity to discuss how this concrete example matched their own experiences.

Lastly, the study plan involved speaking with the men and women diagnosed with intellectual disability as a first step. In this way their knowledge was legitimized and informed and guided the dialogues later held with all employees.

Study Design

To meet the needs and aims of this study, a multiple case study design was chosen. This type of design allows the study to be driven by theory, utilize a variety of data collection methods and triangulates the different sources of data. The multiple case study design entails rigorous processes of theoretically driven analysis and interpretation. “The case study as a research strategy comprises an all-encompassing method—covering the logic of design, data collection techniques, and specific approaches to data analysis…a comprehensive research strategy” (Yin, 2003). It allows for the coherent collection of vast amounts of data, clarity in data organization and analysis, and allows for examination of the same activity (problem solving for medical and mental health care decision-making) by the men and women using a standardized assessment measure, across three settings having different policies in regard to participation in consent issues. A research protocol was devised to provide coherence and consistency due to the large amounts of data generated and collected across all three sites (see Appendix K).

Settings

Non-profit service provider agencies which operate to provide services to adults diagnosed with intellectual disabilities, served as the settings. Source for the settings was provided by OPWDD in a listing of service-providers in the New York area involved in this study. The settings were each located in an urban area though some were more centrally located within inner city neighborhoods while other's placement was in nearby proximity to the border marking suburban areas.

Criterion for inclusion in the study was twofold as follows. First, each agency should provide both residential and day program services minimally. The second criterion for participation was initiated at the time of an initial interview, if granted, and involved the question "who signs the consents?" This criterion differentiated the agencies by policies dealing specifically with consent issues. Difference in policy allowed me to place the agencies included in the study along a 'policy continuum' ranging from autonomous—some individuals diagnosed with intellectual disability signed their own consents, to protective—none of the individuals diagnosed with intellectual disability signed their own consents.

Study Participants

The source for participants came from the resultant three service provider agencies recruited, constituting the settings. In total there were 44 individuals who participated in this research, divided across two groups: men and women diagnosed with intellectual disability placed in residential facilities provided by the agency and staff members employed by the agency. The first group of participants were 29 men and women diagnosed with intellectual disability (hereafter referred to as the men and women) across a range of severity (indicated by IQ scores such as moderate, mild) who were capable of communicating effectively, had lived in residential facilities operated by the agency for at least one year, and who were a minimum of twenty-five years of age.

The second group of participants was composed of 15 employees currently employed by the three agencies. Employees were representative of different positions within the hierarchical organization of the agency including: an administrative or upper management position, middle management, nursing, and those whose work responsibilities involved direct day to day contact with the men and women, known in the field as direct-care workers. Employees in administrative positions are referred to as 'Administrators,' employees in all other positions are referred to as 'Staff'. Administrators had worked in the 'field' or in the specific agency for more than five years, and for some had been with the agency almost for its entire inception. Staff had worked with the men and women for a minimum of one year (all but one staff far exceeded this and most worked in the 'field' or in the specific agency for more than five years, none had been with the agency since its inception). There were four administrators and eleven staff members who participated.

Study Measures

The Assessment for Consent Capacity-Interview (ACC-I) designed by Cea (1999), was used in this study. The tool consists of three vignettes where an individual goes to a medical person for a particular problem. The three ‘medical persons and problems’ are: Allergist: problem is allergies and involves allergy shots as treatment; Dentist: problem is crooked teeth and involves braces as treatment; and Psychiatrist: problem is yelling and shouting at work and involves psychotropic medication as treatment (for the complete assessment, please refer to Cea, 1999). The design feature for use with this specific population entailed a component where information was broken down into more manageable pieces and these were then repeated before requiring an answer from the individual. Based on the current work in the field of informed consent, this tool highlighted the four psycho-legal ‘tests’ or constructs thought necessary for any individual to make an informed consent and included the following: Choice (the ability to communicate a choice), Factual Information (understand relevant information), Appreciation (appreciate the nature of the situation including consequences of treatment or no treatment) and Rational Manipulation: (the cost-benefit analysis where risks of treatment, or no treatment, are weighed against the benefits of treatment, or no treatment).

The assessment measure has a complete scoring manual and responses are scored numerically; the ranges of scores are specific to each of the above four areas. This tool was normed on a large sample of individuals diagnosed with ID across the severity ranges of Mild and Moderate intellectual disability (as designated by previously assessed IQ scores) who resided in service provider agencies within the State of New York. This measure as it was applied in this study had distinct purposes: to elicit numerical scores from each of the men and women which were then compared across the three settings, as a means to examine types of knowledge used by the men and women in their responses to the specific questions and types of choices these men and women make regarding treatment decisions, and lastly, to serve as the basis to elicit their talk about the similarity between the depicted hypothetical scenarios as an ‘ideal form’ and their own health care experiences.

My interest in the assessment tool was to examine the ways in which the men and women responded to the questions asked as a means to discover how their present and past experiences and type of interactions influenced their responses, the types of knowledge they used to answer certain questions (described more fully below) and to highlight those factors important to them concerning this type of decision-making. Therefore the scores, in the context of this study, were not indicative of capacity for consent decision-making competence per se. However, in light of past research findings where higher IQ scores are associated with higher scores on such formal assessment measures I did want to examine whether this pattern was upheld given that individuals with similar disability diagnoses pertaining to intellectual functioning (IQ scores) were placed in different settings having different policies which impacted directly their level of involvement in their medical and mental health care practices, treatments, and decision-making activity. Responses to the assessment measure were also coded according to different types of social knowledge used by the participants in their answers to the questions posed; an independent rater was recruited to provide a measure of inter-rater reliability. Permission was granted by Dr. Cea for the use of her tool in the present study.

General Procedure

Permission to conduct this study involving human subjects, some considered as belonging to ‘vulnerable populations,’ was granted through application to the Institutional Review Board (IRB) of the CUNY Graduate Center. Given that this dissertation research involved exploring ‘informed consent’ decision-making competence by people diagnosed with intellectual disability the granting of approval to conduct the study by the IRB was a lengthy process. Part of this lengthy process involved a primary concern for the IRB which centered on how I could ensure that some people so diagnosed, those who did not have 'legal guardians' appointed, would 'understand' the type of informed consent involved in the research. The IRB required, relative to these specific instances, that I not only specify the procedures used to assess these individual's understanding but that I supply them with the credentials validating my ability to undertake this assessment. I was able to meet these requirements because of my work related experience—having held a clinical position for the past twenty five years involving the assessment of individuals so diagnosed across a number of different agencies within New York State. If I was not able to meet these requirements only those individuals who had an appointed guardian or correspondent to supply permission for their participation would have been included in this research. Those men and women who had 'legal guardian' or 'correspondent' signing their consents were asked for their assent. For those individuals in this specific instance, I assessed each individual's ability to 'assent' similarly to the procedure I used for 'informed consent' understanding. All in all, four separate consents were involved in this research as follows: An employee consent (Appendix A); a Guardian/Correspondent Permission Form (Appendix B); A consent for men and women deemed able to sign their own consents (Appendix C); A consent meeting the requirements of the Health Insurance Portability and Accountability Act or HIPPA consent (Appendix D); and lastly an Assent form (Appendix E).

Recruitment. Recruitment was a two level process involving: 1.) Recruitment of settings; and 2.) Recruitment of participants within each setting. Once permission was granted from the IRB, agencies in the New York area were solicited for their participation as settings in this study.

Settings. The search for agencies to participate began in April of 2009. The first step in this solicitation involved contacting OMRDD for a list of service providers in the area specified. This list was reviewed in order to eliminate any agencies who did not meet the criterion of providing both adult residential and day programs. The resulting 42 agencies were then contacted directly by phone or letter informing them of the research and requesting a meeting. Any agency that I actually had contact with (spoke with a director or administrative staff as opposed to a secretary or operator; received a telephoned response to the letter I mailed) was sent a description of the research including: aims, goals, extent of involvement on the part of the agency and approximate time line require for the research to be conducted at each agency.

When no agencies proved willing to become involved, I contacted the OMRDD satellite offices which were local to specific areas throughout the central New York area. I contacted three such offices local to the area I hoped to conduct the research in. My contacts with each of these three offices entailed the same procedure: I informed them of the research briefly over the phone, secured a contact person, and then sent off the description of the research. Of these three offices, only one office corresponded with me and supplied me with a contact to an agency that might be willing to participate. A long deliberation with this agency ensued. A major factor affecting participation in the research, also voiced by other agencies I had contact with, involved the ‘disruption’ the research would cause. ‘Disruption’ involved not only the daily workings and routines of the agency and the people and staff within it, but also the perceived additional work involved which would fall upon staff members who already had enough to do. This additional work was related to the consents and the consent process involved in the study. When finally three agencies were recruited I informed this particular agency their participation was no longer an issue—even though a decision if it ever had been made was not made clear to me.

The three agencies were recruited as follows: one agency called me upon receiving the description of the research and set up a meeting desiring to be part of the study. The other two agencies were recruited through my contact with a third party who connected and recommended me to the agencies. Without this personal contact it is unlikely that I would have been able to conduct the research as designed. By the last week of August, approximately five months had passed before I had recruited three agencies and sent their agreement letters to the IRB office at CUNY.

Participants. With the recruitment of three agencies, a contact person was assigned to direct and support recruitment of participants within each agency. At the initial meeting with each agency administrative staff members who would participate were identified.

Each agency offered a choice of residential[3] facilities as sites where participants could be recruited according to the following requirements: employees in varied positions, men and women with varying degrees of intellectual disability as indicated by IQ scores. Within each agency a list was generated of specific residential facilities meeting these requirements. A contact person in connection with each residential facility helped coordinate the research and served as my contact for any problems, issues or concerns. There was also an administrator overseeing the research at each facility who offered guidance, instruction and help.

An initial meeting was held within each of the different residential facilities, with the men and women as well as employees in order to describe the research, the extent of their

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[3] The terms ‘residential’ and ‘residence’ used in this dissertation denote a place where an individual diagnosed with intellectual disability lives as offered by service-provider agencies. Residence is the newer term, replacing such terms as group home or ICF in this field and is also a term used by many people diagnosed with Intellectual disability when speaking of where they live. A residence may include a house, an apartment within an apartment building, an entire floor within an apartment building or a partial floor in a building zoned for mixed use—residential and commercial.

involvement, its aims and goals. Any man or woman placed or employee who showed interest in the study was informed of the consent procedure. All potential participants were informed they would receive five dollars for their participation. The final recruitment at each agency consisted of the following number of participants: Agency 1, eleven men and women, three staff, and two administrators; Agency 2: ten men and women, three staff, and one administrator; Agency 3: eight men and women, five staff, and one administrator.

The men and women were then involved in the consent process as follows: for those who did not sign their own consents, consent packages were compiled and sent to their legal guardian or correspondent. This procedure was coordinated by a staff member who either volunteered or was appointed at each of the residential facilities within each setting. For individuals who signed their own consents, and were deemed 'self-consenting' by the agencies, the consent process involving the assessment of their 'understanding' was undertaken at the time I met with them for the research and interview. The consent procedure was the same for staff and administrators—the consent process and signing of consents, though no assessment for their 'understanding,' occurred at the time of the interview.

Progression of Research

The progression of the research was as follows for each setting: I first met with the men and women and gave the ACC-I assessment followed by the interview; I next met with staff and engaged in the interview with them. At the completion of these interviews I proceeded to a review of the 'records' or 'charts' maintained on each of the men and women placed as part of agency policy and requirements. These 'records' contain historical, medical, and assessment—such as IQ assessment results—information; my review of these records mandated the need for

Health Insurance Portability and Accountability Act (HIPAA) consent. Upon completion of this, I scheduled an appointment to meet with the administrators, identified in my initial meeting with each agency, and engaged in the interview with each at a designated time. This marked the final phase of the research within the settings.

This progression was especially important to me as a researcher as I wanted to meet and interact with each man and woman without any prior knowledge of their diagnoses, intellectual functioning level or past histories. This also led to some surprises later on when it was revealed from the chart review that some of the men and women did not have a diagnosis of intellectual disability as defined. Other diagnoses included Autism, Attention Deficit Hyperactivity Disorder and some participants had intellectual functioning within the Borderline range (not considered having an intellectual disability). Also by this progression, I was able to keep the social knowledge of these men and women central and learn about them and their world through their own words and thoughts. I was then able to cross-reference their information against that which was compiled by others about them and their history, in the medical charts composed by each agency for each individual residing within it. This 'bottom-up' research strategy aided me in shaping and guiding my dialogue with staff and administrators later on.

This process of data collection began on October 23, 2009 and ended mid-April of 2010. Under the guidance of my contact for each agency, I was scheduled a day and time weekly when it was known that I would be on site. This was to limit the possible disruption in routine that my presence and time at the site might possible incur at the different residential facilities. I was scheduled early Saturday mornings and early Tuesday and Wednesday afternoons at one agency, early evenings on Mondays/Fridays at another agency and early evenings to later evenings on Thursday at the last agency. Men and women who lived in 'supported apartment residential facilities', and signed their own consents picked the place, time and day to meet with me. Most interviews were held in the residential facility where the men and women lived and where the staff worked. For two individuals, who resided in a 'supported apartment' residential facility and were self-consenting, their interviews and involvement with the ACC-I assessment occurred in a central location they visited often as part of that setting's normal routine.

Specific Procedures

The men and women. I met with each man and woman who had a signed consent (either signed by a correspondent or legal guardian) or who was deemed 'self-consenting' individually, in an area designated for the research by each setting after scheduling a time that was suitable for and agreeable to them. At this scheduled meeting an overview of the research was once again given. I then went over the assent procedure always giving a copy of the Assent (or Consent depending on the individual's circumstances) to each individual while I read the form out loud.

At this time I asked the individual for their permission to video record our time together. I used a small digital recorder which had the capacity to record one hour of video. I had two such video recorders for this research in the event an individual encounter exceeded one hour. The size of this digital recorder was small and compact approximating the dimensions of a small cell phone. The video recorder was also equipped with a small tripod allowing it to be free-standing and positioned in an area so as to be less obtrusive. The video recorder was silent and evidence of its being "on" was indicated by a small red light. When the video stopped recording this light turned off. If an individual consented to being videoed I demonstrated how it worked and informed them we would watch the video after we finished talking. If an individual did not consent to being video recorded, they were asked if I could audio record our time together. A small digital audio recorder was used for this purpose. In all, four individuals were audio recorded, two because they objected to being video recorded, both considered ‘self-consenting.’ The remaining two individuals, deemed ‘not self-consenting,’ were audio recorded because the people who signed consents for them objected to this practice and indicated this on the consent form. Of all the people video recorded only one individual watched the entire video at the end of our talk. The remainder preferred to watch the video only briefly, if at all. A similar practice was taken with anyone who was audio recorded.

The use of the digital video recording enabled me to download the digital video directly into a lap top computer, used for this research. The digital audio recording was also downloaded into this computer. This practice allowed for exceptional clarity when transcribing the audio and video recordings. Particularly effective, the video recordings allowed me to note the affect, body positioning, body movement etc. rendering their talk as I transcribed these encounters later on. Using a lap top and a personal computer, I watched the video on the lap top while concurrently transcribing their responses on a personal computer. Upon completion of the transcription, I downloaded the transcribed material to a flash drive which I then used to transfer this material back to the lap top housing all the data for this study. The rationale for use of video recording with the men and women was to capture nuances of expression and affect coordinated with pauses and silences as possible indicators of their thinking and emotions connected with certain areas of content, this proved vital in the analysis and interpretative process involved in the findings reported later on.

Immediately after the consent/assent and video/audio decisions were made I once again stated that I wanted their ideas, opinions, thoughts on this assessment (the ACC-I) designed to see if it helped people with disabilities make medical and mental health care decisions. I informed them about the assessment measure and that it entailed a question-answer format based on three examples of someone going to a doctor for a treatment. Within this research I departed from the standardized assessment procedure format in the following way: I allowed each individual to pick one of the three vignettes rather than having them complete all three. I presented the three vignettes, asking each individual to choose one. I altered the presentation randomly twice for example: “There is one about a person who goes to the Dentist-Allergy Doctor-Psychiatrist which would you like to choose, the one about the Allergy Doctor, Psychiatrist, or Dentist?” in order to avoid serial position effects in their choice. Ultimately this proved unnecessary as most readily chose a vignette to work on, some as soon as I finished informing them about the assessment measure.

After making a choice on which vignette to work on I asked the individual if they would prefer an example involving a man or a woman and depending on this answer proceeded with the male or female version which involved changing the name of the individual and pronouns used in the vignette. I then handed a copy of the vignette to each individual and gave one to myself. As in the consent/assent procedure I asked each individual if it would be OK if I read it out loud to them while they read along. There were no objections to this. I then proceeded to read the vignette and its questions as prescribed in the direction manual (Cea, 1999).

The ACC-I took approximately 15 – 30 minutes to administer depending on each individual and their particular approach to the assessment. Upon completion of the vignette, I asked each individual what they thought of it and if they had any questions. The ACC-I for each individual was scored by me, according to manual directions, at a later time. Additionally, I added to the scored protocol of the assessment an area devoted to the type of choice the men and women made specific to the treatment offered; this was termed ‘Final Choice’ and is more fully explored in the following chapter. At a later time, I transcribed their responses verbatim on a separate sheet on which I had typed the questions for each psycho-legal domain of each vignette. I numbered all of their responses consecutively. These sheets were later used in the coding procedure.

The interview began immediately upon the completion of the assessment and addressing any questions which might have been posed. The interview style chosen for this study involved those which were open ended and best suited to encourage a dialogue; referred to as ‘narrative interviewing’ (Jovechelovitch & Bauer, 2000). Although I had specific questions, these were often answered within the course of our dialogue (see Appendix F for interview guides). The narrative nature of the interviews helped maintain a certain coherence to specific aims of the study and the only time I intruded on their talk was to ask them for more information because I didn’t understand something, to probe for further comments for those who were inhibited in talking freely, or because I needed their guidance in understanding their train of thought. Beginning in the ‘grand style’ promoted by Spradley (1979) I started the interviews by asking each individual “is this like what happens when you go to the doctor?” The narrative interview opened opportunity for the men and women to inform me. Also as part of this interview I asked each man and woman if they would tell me an example ‘or a story’ about a health care experience they had. Lastly, I constructed for each individual a time line ‘history map’ of their life up to the present date. Borrowing from Billet’s (1995) idea of historical overlapping communities of practice, I drew a line from birth to the present and mapped out their past and present life experiences and the settings in which those experiences took place (see Appendix L).

This marked the end of our time together. After ensuring they had no further questions or any concerns, I thanked them and handed each a five dollar bill for their time and in appreciation of their participation. Interviews ranged in length from 30 minutes to one hour or more.

I later consulted each individual's 'medical chart' compiled by each setting for specific demographic information (see Appendix G). Any missing information or questions were later filled in by securing this information, where possible, with each individual or staff on my subsequent visits to each setting.

My aim with the interviews was to encourage a dialogue to the greatest extent possible. This at times involved bringing up my own thoughts, experiences, and ideas in response to some of their comments or as result of their direct questioning of me. And more importantly, I attempted to create an interaction in which they felt comfortable posing questions or talking about their experiences. For example, as related in my field notes, in the very first interview a woman asked me if I ever said "no" to a doctor. We then discussed this as in fact I realized I had never done it, I would simply not do what the doctor might have wanted me to do, or I might say I'd think about it. This resulted in a slight change in the interview format because I reasoned after speaking with this woman; it may be unlikely that anyone says "no" directly to a doctor. For the remaining interviews where appropriate, I discussed this as what if you didn't want to do that or take that instead of saying 'no'.

Staff and Administrators. Interviews in the same narrative style were employed with staff and administrators in order to elicit a dialogue where specific information pertaining to salient questions concerning this study could arise. (See Appendix H for interview guides relating to staff, and Appendix I for interview guides relating to administrators). Interviews ranged in length from approximately 20 to 45 minutes with staff and approximately one to one and a half hours with administrators. All procedures for consent were followed as stated above and all interviews with staff and administrators were audio recorded, none of these participants voiced any objections to this. All digital audio data was later downloaded and transcribed as described above for the video data.

Through the interviews with administrators I wished to understand what conflicts they faced in regard to consent issues, specific problem areas if any and how these impact their policies and practices; as well, each agency's approach to consent issues. I added a specific question concerning 'assent' to probe the extent to which the setting had formal practices for including the point of view of the men and women given that many individuals with a diagnosis of intellectual disability often had others signing consents for them. Lastly, in my time with administrators I asked if there was any information that the setting might give me related to issues involving their policies and practices concerning consent issues. Artifacts from each setting, where available and offered, were presented to me at this time.

Through the interviews with staff I wished to understand the extent to which each man or woman participated in the day to day or routine practices associated with their health care, and their abilities in terms of decision making from the staff member's point of view. At the end of each interview with administrators and staff, individuals were thanked for their time, allowed to ask any questions or voice any concerns, and then given the five dollars as appreciation of their time and participation. As with the men and women, all employee participants were invited to listen to the audio recording of our time together. None accepted this invitation to do so.

Data Sources and Collection

Data was collected from multiple sources and procedures. The ACC-I assessment for consent capacity generated numerical scores and verbal responses used in qualitative analysis. Other sources of data were derived from: narrative accounts elicited from interviews, demographic information, on site observations recorded as field notes written after visits to each setting, and artifacts consisted of Mission Statements, Protocols, Regulations and Guidelines obtained from each agency where possible. Mission Statements, setting history, and information pertaining to each setting were readily accessible and obtainable from the internet as public information.

All interviews were transcribed by me. In all 43 interviews were transcribed. Although there were 44 participants one individual, due to a scheduling conflict, had to leave immediately after the ACC-I assessment was completed and was not interested in engaging in the interview at another time.

Overview of Analysis

In order to more fully understand the settings and the types of relations among the different stake holders I use qualitative methods. This is consistent with situated learning theories which stress that the learning arena where knowledge is constructed is demonstrated in the shared and situated perspectives of those who have participated in those learning arenas or problem spaces (Lave, 1990).

Constructing each of the three settings as a community of practice focuses attention to the ‘actual social practices and material sites of action as important sources of development’ (Stetsenko & Arievitch, 2004a). It is within these settings that specific language use as ‘ideal forms’ of such decision-making are created, enacted, or used comparatively. These settings provide the external form in which the internal organization or emergence of meaning and sense is created. A dialogical approach focusing on personal narrated accounts and a situated approach focusing on the setting and the type of self-other encounters afforded, allows me to explore the 'reciprocally constitutive role of human subjectivity, and the self, in the emergent reality of social practice, dialogical interactions, and human life' (Stetsenko & Arievitch, 2004a). As the setting provides the 'arena for learning' (Rogoff, 1990) the experience of the setting is itself, part of the process in which knowledge is produced and practices emerge. I borrow the analytical tools of community of practice from situated learning theory (Lave & Wenger 1991) incorporating notions of power and status, the triad Ego-Alter-Object (Markova, 1990, 2003) as a tool to aid in analysis of the narrated accounts of all participants, and an activity system analysis as formulated by Leontiev (1978) and Engestrom (1999).

Within this study each setting is constructed as a community of practice, involving an activity system all subsumed under a culture of practice. Analysis of this culture, as in any culture, entails subjective and objective views (Bruner, 2002). Subjective views consider an insider's perspective and involve the accounts of the men and women. Objective views consider an outsider's perspective and involve the accounts of the employees. The activity system construct allows for a multiplicity of views and has been used specifically to investigate primary care medical practice as well as organizational learning in medical settings (Engestrom, 1995). As the settings involved in this study are based in medical models of care the activity system as a construct is especially relevant in that I am interested in the interaction of multiple views involving self-other encounters and types of relations offered in those encounters within the settings as these relate to their health care issues, concerns, treatments and decision-making.

In the sections to follow I present the analysis and its rationale for each area under investigation. The different analyses involved in this study entail: descriptive statistics of the scores obtained from the assessment measure, an activity system analysis of the setting including a dialogical analysis incorporating elements of the activity system as applied to the narrated accounts across all participants, and a pattern analysis across the three settings involved in this multiple case study design.

The Capacity Assessment Analysis

Descriptive Analysis. Descriptive statistical analysis involved use of Statistical Package for the Social Sciences (SPSS) software (SPSS, Tenth Edition (2010) with the scores obtained for the subdomains of the assessment tool (Choice, Factual, Appreciation, and Rational) across the three settings. Within the ACC-I the subdomains are weighted according to cognitive challenge with the subdomain of 'Choice' being the least challenging and 'Rational Manipulation' the most challenging.

Pattern Analysis. I examined which vignettes were chosen and the rationale for this and what choices were given to the treatment options offered. I referenced the personal information gathered for each man and woman from their files and self-report, which included medical and mental diagnoses and treatments to discover if any patterns emerged relating this information to type of vignette chosen and past as well as present experiences. The rationale behind this analysis was to investigate how their decision-making might be related to their present and past interpersonal experiences, activity and personal motivation.

Choices. I examined the verbal responses each man and woman gave to the assessment tool questions for each of the four areas of the assessment: Choice, Factual, Appreciation, and

Rational. The data in this analysis was converged across all settings. I examined the type and frequency of responses to ascertain whether any patterns were revealed specific to: vignette choice, treatment choice and setting.

Knowledge Types. Responses were also coded for different types of knowledge. Invoking Scribner (1985) and Billet (1995, 1998) I devised a coding system relating the different types of knowledge as sourced in socio-historical, socio-cultural, personal history and the specific settings or community of practices (see Appendix I for the coding manual) and recruited an independent coder from adjunct faculty staff in the social science department of a local community college. This rater not only helped in clarifying the coding but added to the validity and rigor of this analysis providing an inter-rater reliability measure. A random assortment of three vignettes from each of the three settings was used for the inter-rater coding analysis and repeated three times. The Cohen's Kappa, a statistical calculation, was used to analyze the strength of the agreement between coders beyond that expected by chance.

I used the individual's personal history map to link coded types of knowledge with personal past and present experiences to see if any patterns resulted. Specifically in this analysis I was interested in what life experiences and knowledge resources were brought to bear in 'answering' or 'responding to' the assessment questions, and moreover, how their past and present life experiences might be linked to their ability to access these different knowledge resources.

The Settings: Activity System Analysis

In this analysis I look specifically at the three settings which situate the lives of the men and women. Data used for this analysis was derived from accounts elicited in interviews with the men and women, administrators and staff, on-site observations, and artifacts given to me by the setting itself or obtained from public sources such as the internet. For this analysis I was guided by the elements of activity theory included in Engestrom's (1999) activity system analysis and Leontiev's (1978) activity theory. This aided in organizing the large quantity of data.

The elements of an activity system as used by Engestrom (1999) in his activity system analysis applicable for the setting are: Community, Division of Labor, and Subjects. Following Billet (1995), I add 'location and layout' as a subsection to the element of Community as my interest is in how the specific setting, with different residential facilities situated in different geographical locations and within different architectural structures, affords or limits access to knowledge resources. These knowledge resources can be available within and outside of the settings, thereby impacting medical and mental health care practices, involvement, general knowledge, and decision-making. This subsection allows for an analysis of how the physical setting impacts the men and women's ability to access possible knowledge resources or tools and signs.

Specifically in this inquiry the elements include: 'Community', 'Location and Layout' (the context); 'Division of Labor' (who does what in the hierarchy of the settings), and 'Subjects' (demographic information). Within each element, the analysis involved the following:

1. Community, Location and Layout (historical information from artifacts, public sources, observations on site, and interviews)

   a. Description of each agency as part of the community of service providers and its position within the history of this industry. Identifying ideologies, values, concerns, and approaches.
   b. Describing the physical setting, its geographical location and architectural structure.
2. Division of Labor: who does what and why? (Observations, interviews, artifacts, public sources of information—OMRDD regulations)
3. Subjects: Demographic and diagnostic information concerning the men and women; general demographic information of staff and administrators.

Information was converged across the three settings, or specific to each setting dependent on the nature of the element. The analysis is organized as follows: For the element of 'Community', I provide a descriptive account. This analysis is specific to each setting and crucial in order to situate each setting's emergence within the history of the service provider industry outlined in Chapter 2. Each setting had different residential 'facilities' such as individual buildings, apartment buildings, free standing homes; each situated in a different community or neighborhood—urban or more suburban-like, having implications for how individuals appropriate knowledge resources and how accessible they are. Data was obtained from observation, artifacts and publicly available information. Observations were made of the neighborhoods where each residential facility was located. I walked or drove within these neighborhoods surveying factors which would aid or limit access to knowledge sources on behalf of the men and women placed.

The element of 'Division of Labor' entails a descriptive account. Data from this analysis was converged across all three settings as each had an organizational structure and power differential that was primarily similar. The element of Subjects concerns demographic information on the participants in this study. In the analysis of Subjects pertaining to the men and women diagnosed, I used the demographic data collected both from the ‘charts’, a property of each setting, as well as the information offered by the individuals themselves. For staff and administrators descriptive accounts are given reliant on observations or self-report.

Narrative Interview Analysis

Activity theory’s emphasis on motivated, goal-directed activity includes elements of ‘Objects’, ‘Rules’, and ‘Tools’ (Leontiev, 1978; Engestrom, 1999). These elements served as an organizing structure in which to analyze accounts elicited through interviews with all participants.

1. Objects: Perspective of administration and staff concerning individuals diagnosed with ID; perspective of men and women diagnosed with ID concerning staff or other professionals
2. Rules: Implicit and explicit
3. Tools: Types of social knowledge and interactive procedures for ‘knowing how to know’

The accounts elicited in interviews were organized by these activity system elements and submitted to a qualitative analysis defined below.

Informed by Taylor and Bogdan’s (1998) approach toward qualitative analysis which expands upon Corbin and Strauss’ (2008) grounded theory; data from different settings were compared for similarities and differences to understand the factors that shaped the participants’ experiences. However as I sought to develop an 'in-depth understanding of the settings and people involved' insights were grounded in and developed from the data themselves' (Taylor & Bogdan, p. 140). In this approach the concern is less with theory development but more focused on people and settings, "on their own terms" (p. 140). As this approach uses description and theory I felt it the most appropriate technique for this analysis because theoretical concepts are used to guide understanding of people, settings, and processes involved in learning and development, namely self-other relations. This approach places heavy emphasis on the context in which data are collected, including interactions.

I read the narratives and watched the videos numerous times, frequently returning to these sources as I organized specific areas of the narrated accounts under the theoretical concepts involved in the activity analysis above, specific to: objects, rules and tools. I compare the accounts given by the men and women to their responses on the assessment measure to see if any differences arose between responses elicited in the question-answer format and those freely narrated.

The names of the three agencies were changed to protect their identity as follows: 'Autonomous', 'Protective', and 'New'. All names of participants within this research were changed to protect their identity and any information contained in their accounts which could possibly be identifying of each agency or any participant was omitted, replaced by the symbol "--".

In the following chapters I report the findings of these analyses guided by my original research questions and organize the findings through more specific questions. I have three areas of interest and investigation: 1) The assessment measure and what it can reveal concerning the men and women’s social knowledge concerning their health care treatments and practices and their actual choice-making; 2) The setting which involves physical as well as social, self-other, relationships and provides the context situating their lives and development as this relates to opportunities for ‘knowing’ and; 3) The accounts of the men and women, their social knowledge and how this shapes and is shaped by the setting and the impact of this on their knowing and decision-making—in this case their ability to access and appropriate legitimate forms of social knowledge and the types of self-other encounters they report. The order of the findings is presented in the following chapters relating to these three areas.

Chapter 5: Assessment Findings

Introduction

“I find it fascinating that the most work I’ve ever done educating consumers [individuals diagnosed with intellectual disability] about medical procedures is to prove that they are not competent to do it [give an informed consent]”—Licensed Ph.D. Psychologist

This chapter concerns the findings from the assessment instrument I used with the men and women from each setting. My aim with the assessment was twofold: as a tool in order to investigate whether knowledge assessed under this ‘ideal form’, revealed as scores, differed as a function of setting and what the men and women’s responses to the question areas within the assessment could illuminate about their knowing and the type of knowledge they brought to the assessment based on their current and past experiences and self-other encounters. Stepping away from the standard format, I offered them a choice of which of the three vignette areas they wanted to work on, and as recalled, those areas concerned: Dental, Allergy and Psychiatry. However within this chapter I also report characteristics of the individual men and women who participated in this study based on demographic information taken from each setting’s ‘medical record charts’ as well as from their self-reports.

Participants

The Men and Women. I begin with an overview of the participants involved in this study. Demographic information specific to the men and women placed within each setting are described more fully in Chapter 6 under the heading of ‘Subjects’ (in this specific sense ‘Subject’ is a term specific to activity theory and the activity theory analysis).

29 people with a diagnosis of intellectual or developmental disability participated in this study. There were 15 females and 14 males. Ages ranged from 25 to 73 years, the mean age

was 45.8 years and the number of individuals distributed throughout this range was as follows: Five individuals were between the ages of 25 and 34 years, twelve individuals were between the ages of 35 and 49 years, and twelve individuals were between the ages of 50 and 73 years. Ethnicities included Caucasian: 15, Caribbean: 2, Hispanic: 5 and African American: 7.

Intellectual functioning, assessed by standardized IQ measures, gives a measure for IQ scores and a range in which those scores fall. Most of the IQ tests, previously conducted by each setting and used in this study, where reported, were a result of either the Wechsler Adult Intelligence Scale or the Stanford-Binet Intelligence Measure. These standardized ‘tests’ are compatible and have 100 as an average score with a standard deviation of 15 points. The ranges and IQ scores used for this study were taken from the Diagnostic and Statistical Manual-IV for Clinicians (American Psychiatric Association, 1994) and are reported as: Normal range: 115 to 85, Borderline range: 84 to 72, Mild range: 71 to 52, Moderate range: 51 to 36, Severe range: 35 to 20 and Profound range: below 20. Individuals who participated in this study were previously diagnosed as having IQ scores within the ranges of Borderline, Mild, and Moderate. There were a larger proportion of individuals who had scores in the Borderline and Mild range. 21 individuals had IQ scores in this range and 8 individuals had IQ scores in the range of Moderate. For some individuals only the level (Moderate, Mild) was given with no numerical IQ score. In such situations the mid score for each range, 44 for Moderate, 60 for Mild was used. As I was not interested in the actual numerical score of the IQ tests, and would not be using them in any quantitative analysis, this practice served the research purposes.

Further information pertaining to the men and women includes educational experiences, years in placement, medical diagnoses, day activities and consent status (self-consenting or non-self-consenting and follows below.

Educational experience revealed that 13 individuals had experienced some form of regular primary education, 16 individuals experienced only special education.

The number of years each individual had been placed in residential settings ranged from 2 to 53 years. Some individuals were either placed as an adult or in their early childhood and had either experienced continuous placement or intermittent placement across their lives. 24 individuals experienced placement in their adulthood, the remaining five people experienced either intermittent residential placement in their childhood (three individuals) or continuous institutional/residential placement since early childhood (two individuals).

As the area of interest in this study involved medical and mental health care, the following section lists those demographics central to this area namely medical and psychiatric diagnoses and treatments. This information was gathered from each individual's 'chart' or where appropriate, from the individuals themselves. Almost every individual had a medical diagnosis which was either being monitored or treated. 23 people had three or less reported medical diagnoses and six had over three. 15 of 29 people were currently prescribed psychotropic medications. Of these 15, ten were prescribed one psychotropic medication, and five were prescribed two or more psychotropic medications, the maximum was four psychotropic medications (one individual).

Day activities entailed types of activity each individual participated in on a week-day basis. Three areas of activity were revealed: adult day program (in the same agency or in another agency), adult day program where activities involved payment (same agency or in another agency), and work in a setting outside the agency. Nine people attended day programs, nine attended day programs and received a stipend or pay, and 11 were actively employed in settings outside of the agency.

Lastly the ‘consent status’ of these men and women revealed that ten people (five men, five women) were considered ‘self-consenting’ or deemed able to sign for their own medical and mental health care consents for treatment, while the 19 remaining men and women were considered ‘not self-consenting’ and others such as correspondents or legal guardians signed consents for them. Table 1 presents the men and women who participated in the study across the three settings. The table includes demographic information obtained through ‘charts’ and self-reports, as well as information concerning their medical and mental health diagnoses and treatment. As revealed in the table all 29 adults were actively being treated for either a medical or mental health related concern, in some cases both.

Table 1

The Men and Women Participants

Person-Setting Code/Consent Status	Name	Age	IQ	Medical Diagnosis/ Treatment	Psychiatric Diagnosis/ Medication Prescribed	Years Placed in Current Setting	Previous Placement/ Years
A-1/Self	Andy	26	64	No/Vitamin	Bipolar D/O ADHD/Yes	3	No
A-2/Self	Alice	64	77	Yes/Yes	Agoraphobia/ Yes	28	No
A-3/Self	Carol	61	64	Yes/Yes	No/No	20+	No
A-5/Self	Nellie	37	76	Yes/Yes	No/No	2	No
A-6/Self	Nadine	53	61	Yes/Yes	No/No	11	No
A-7/Self	John	45	66	Yes/Yes	Anxiety D/O OCD/Yes	5	No
A-8/Self	Ruthy	53	56	Yes/Yes	Psychosis NOS Anxiety D/O/Yes	17	No
A-9/Other	Juan	31	58	No/Vitamin	Major Depression	5	No

					w/Psychosis/Yes		
A-10/Other	Donald	51	77	Yes/Yes	Autism/Yes	13	No
A-11/Other	Danny	41	62	Yes/Yes	No/No	11	No
A-12/Other	Alfredo	51	56	Yes/Yes	Not listed/Yes	5	No
P-1/Other	Nancy	38	48	Yes/Yes	No/No	9	No
P-2/Other	Lily	37	60	Yes/Yes	Impulse Control D/O/Yes	9	No
P-3/Other	Shelly	37	60	Yes/Yes	Personality D/O /Yes	5	No
P-4/Other	Ellie	30	49	Yes/Yes	No/No	9	No
P-5/Other	Chuck	31	50	Yes/Yes	No/No	8	No
P-6/Other	Jenny	52	60	Yes/Yes	Depression/Yes	9	Yes/2 years?
P-7/Other	Patty	49	60	Yes/Yes	Schizophrenia/ Yes	9	Yes/2 years?
P-8/Other	Richard	38	44	Yes/Yes	No/No	8	No
P-11/Other	Lorraine	50	36	Yes/Yes	Schizophrenia/ Yes	9	Yes/2 years?
P-12/Other	Howard	54	60	Yes/Yes	No/No	8	No
N-1/Self	Robert	73	46	Yes/Yes	No/No	17	No
N-2/Self	Ricky	25	67	Yes/Yes	ADHD/No	4	No
N-3/Other	Vicky	49	62	Yes/Yes	No/No	15	Yes/17 years
N-4/Self	Mark	56	60	Yes/Yes	No/No	4	Yes/49 years
N-6/Other	Larry	44	64	No/No	Autism/Yes	14	No
N-7/Other	Erica	55	40	Yes/Yes	Atypical Psychosis /Yes	10	Yes/10+years
N-8/Other	Sherry	47	44	Yes/Yes	Schizophrenia, Impulse Control D/O /Yes	2	No
N-9/Other	Jerry	45	59	Yes/Yes	No/No	3	No

Also evident in the table, IQ scores differed among the individuals by setting. Setting Autonomous represented individuals with higher reported IQ scores than those placed in settings Protective and New. Some people in setting Autonomous did not have intellectual disability as defined and many were considered ‘Self-Consenting’. Few individuals, across the three settings, experienced previous institutionalized placement.

Revisiting Previous Findings: IQ and Assessment Score Patterns

As stated previously, most assessment measures of consent capacity—such as the one utilized in this study—weight the subdomains relative to the ‘cognitive challenge’ required so that ‘Choice’ is weighted the least and ‘Rational Manipulation’ the most cognitively challenging. Research using such assessment measures with this population has reported a pattern whereby higher IQ scores are equated with higher scores on each of the subdomains (Morris et al., 1993; Cea, 1999; Cea & Fisher, 2003). Findings obtained from the assessment measure used in this study, reported as mean score values, are listed in Table 2. Raw score ranges for each domain listed in the manual were as follows: Choice = 0-2; Factual = 0-14; Appreciation = 0-8; Rational = 0-4. Under the area of Choice, the score range 0-2 equates with the following: A score of ‘0’ indicating no choice was made; a score of ‘1’ indicating a partial score which would result if the individual were unable to give a reason for their choice as validated in the scoring manual, and a score of ‘2’ indicates that a choice was made and a ‘valid’ reason given for that choice. This scoring information is important in light of the interest in ‘choice-making’ and ‘decision-making.’

Table 2

Means Scores for the ACC-I across settings

Setting/ (Number of Individuals)	**ACC-I Domains:**			
Autonomous/ (11)	**Choice**	**Factual**	**Appreciation**	**Rational**
Mean Scores:	1.2	10.0	5.4	2.7
Protective/ (10)	**Choice**	**Factual**	**Appreciation**	**Rational**

Mean Scores:	1.8	8.3	4.6	1.9
New/ (8)	**Choice**	**Factual**	**Appreciation**	**Rational**
Mean Scores:	1.6	7.8	4.6	2.8

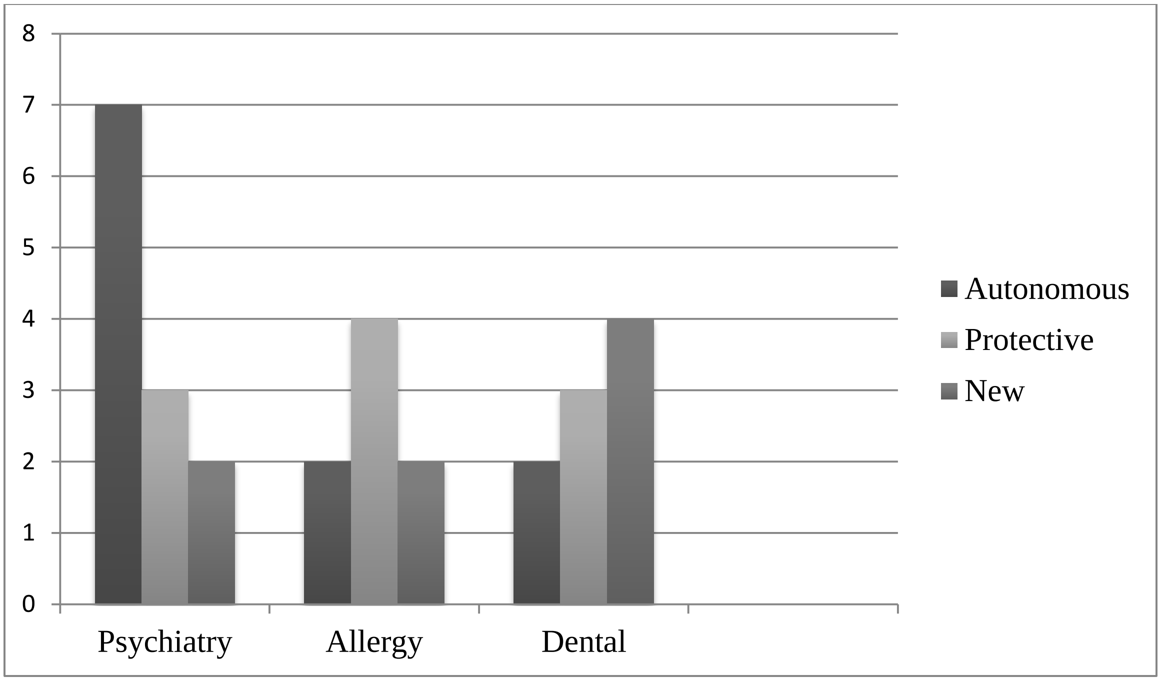
Notable in the table is the lower mean score for ‘Choice’ among participants in setting Autonomous relative to settings Protective and New. Paradoxically, for the participants in setting Autonomous who were previously assessed as having higher overall IQ scores (within the Mild and Borderline IQ ranges exclusively) their scores on the least cognitively challenging domain area of ‘Choice’ were lower than those reported for the other two settings. As recalled from Chapter 1, studies which used an assessment instrument with different groups of individuals (those having a diagnosed intellectual disability and those who did not have a disability diagnosis) reported partial scores, a score of 1, for the domain of ‘Choice’ in participants not having a diagnosis (Morris et al., 1993; Cea, 1999; Cea & Fisher, 2003). This finding was more frequently seen with vignettes associated with psychiatry than with other medically related vignettes. The lower mean scores for ‘Choice’ reported for participants in setting Autonomous were due to individuals prefacing their answers with the phrase “has to” or “have to” relating most frequently to the psychiatry vignette, resulting in the partial score of ‘1.’ However, two participants, both female and both from setting Autonomous obtained a score of ‘0’ for ‘Choice’ as they responded to this question by saying they could not answer for another person, *“it’s her decision”.*

Choices

Vignettes. Most of the men and women chose a vignette based on their personal interest or because they were currently either being treated for Dental, Allergy, or Psychiatric issues or because they had just returned from an appointment dealing with one of these areas. The reasons for choosing a certain vignette were unsolicited and given spontaneously by participants across settings and across a range of intellectual functioning as evidenced by IQ scores. The assessment tool used in this study consisted of three vignettes. These vignettes depicted a person who had a specific problem and sought help for that problem from the appropriate professional. The three vignettes consisted of: A person who had crooked teeth and went to see a dentist, the proscribed treatment being braces; A person who was yelling at work and went to see a psychiatrist, the prescribed treatment being psychotropic medicine; A person who had a runny nose and itchy eyes from allergies and went to see an allergist, the proscribed treatment being allergy shots. The frequency with which each vignette was chosen across the three settings is presented in Figure 1.

Figure 1.

Frequency of vignettes chosen by setting

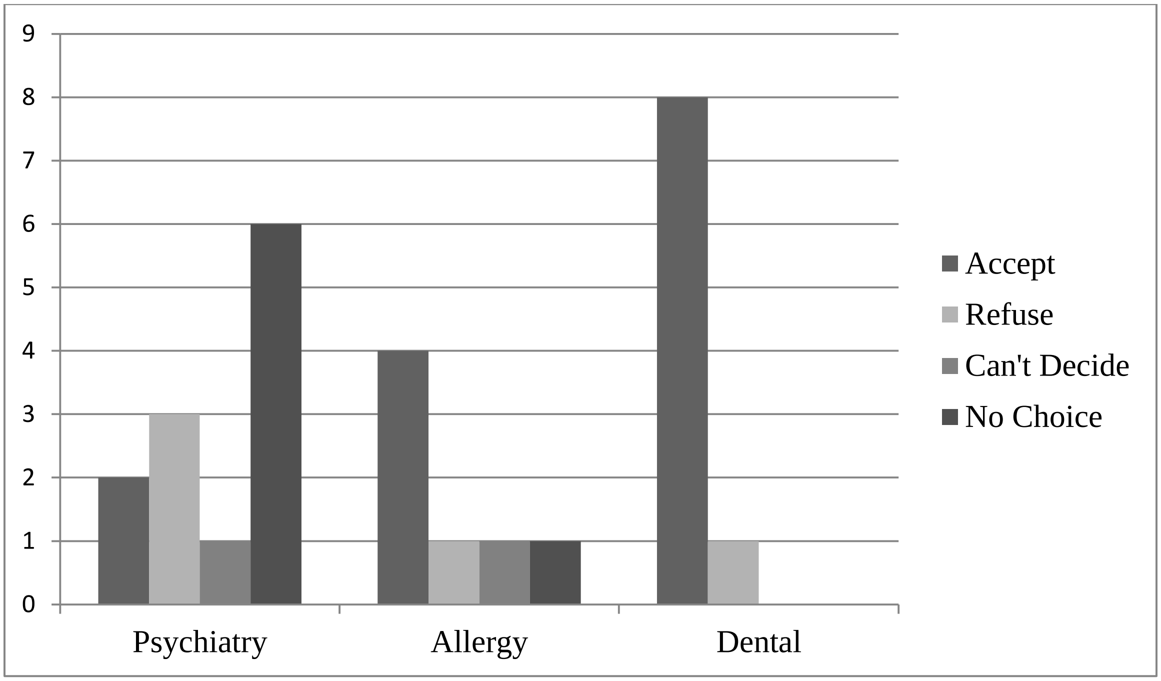


The Psychiatry vignette was the most frequently chosen of the three vignettes and was chosen most frequently by those men and women who were placed in setting Autonomous. Demographic information about the men and women, taken from self-reports as well as from each setting's 'medical record charts' revealed that of the 29 men and women involved in this study 16 were currently being treated by psychiatry. Half of these 16 individuals were from setting Autonomous. The remaining eight individuals were from setting Protective (five individuals) and setting New (three individuals).

Treatment. Responses to 'Choice' questions were of particular interest in this study. I was not necessarily concerned with scores however I was interested in the type of treatment choice responses given by the men and women and if these treatment choices would vary by type of treatment offered. In the assessment instrument used, within each vignette, questions of choice followed a scenario depicting an interaction between the practitioner and the person (patient) such as: "What choices [a yes or no are the choices] does the person have?" and "What do you think they should do? Should they tell the doctor ‘yes’ she/he wants the treatment or ‘no’ she/he doesn’t want the treatment? Why?” Findings revealed that for these men and women they responded with four types of treatment choices: ‘accept treatment’, ‘refuse treatment’, ‘can’t decide for others’, and ‘no choice’. ‘No choice’ was characterized by any statements containing the phrase ‘have to’ or ‘has to’ in answer to the “Why?” question above. As recalled from the section above these types of treatment responses were scored as a partial response, ‘1’, and responsible for the lowered mean ‘Choice’ scores in setting Autonomous. The frequency of ‘Treatment choice response’ across the three treatments (Braces for Dental; Allergy shots for Allergy; Psychotropic Medications for Psychiatry) for all of the men and women across the three settings is depicted in Figure 2.

Figure 2.

Frequency of Treatment choice response for each treatment



Type of choice varied with type of treatment. For some of these men and women accepting Allergy and Dental treatments was related to their own personal history and experiences. Therefore, having suffered from symptoms of allergies, many individuals accepted 'allergy shots' because they knew allergy medication did improve their symptoms. As for Dental most accepted 'braces' however, one man refused saying he was 'too old to worry about his smile and crooked teeth now.' Psychiatry treatment had the most variability in treatment choice types, and specifically, was associated with the highest rate of 'Refuse' responses as well as 'No Choice' responses. The lower 'Accept' and higher 'Refuse' treatment choices for this particular treatment relative to the others (Allergy and Dental) indicates that pertaining to Psychiatry and Psychotropic medications as a treatment these men and women, when given the option, are more likely to refuse than accept it. The high frequency of 'No Choice' as a response to Psychotropic treatment indicates that for these men and women, such a treatment is beyond their control.

Section Summary

The type of vignette chosen indicated that in most cases an area was chosen because the individual either had experience in the area, was currently undergoing or anticipating treatment in that area or had interest in that area. These trends were especially evident in the case of the Psychiatry vignette where of the 29 men and women, 16 or 55% were currently being seen or treated by a psychiatrist. Another trend evident was frequency of the choice response: 'refuse treatment' in the case of the psychiatry vignette. When the treatment entailed use of psychotropic medications, the 'refuse treatment' choice was more frequently applied than in dental or allergy vignettes. Of the 12 individuals who chose the psychiatry vignette only two people, one woman and one man, gave an 'accept treatment' choice. Setting Autonomous had a higher incidence of men and women prescribed psychotropic medications relative to settings

Protective and New and a higher incidence of ‘no choice’ and ‘refuse’ responses to treatment. Lastly previous findings within the capacity literature pertaining to adults diagnosed with intellectual disability report a pattern where higher IQ scores are correlated with higher scores on the assessment instrument. Within the current findings, the men and women placed in setting Autonomous were found to have overall higher IQ scores than those men and women placed in settings Protective and New. Given this difference in IQ for the men and women in setting Autonomous their overall scores from the assessment instrument specific to the domain of ‘Choice,’ the least cognitively challenging domain area, were lower not higher than for those men and women in the other two settings.

Responses: Types of Knowledge

Responses to the assessment instrument were coded for different types of knowledge used by the participants in answering the assessment questions. The different types of knowledge specific to this research were reflective of: social knowledge pertaining to medical and mental health care associated with societal shifts in time pre and post the ‘Informed Consent Doctrine,’ each woman and man’s knowledge gained from their past and present experiences, and knowledge gained from their experience in the specific settings situating their lives. Four types of knowledge were identified in the men and women’s responses to the assessment instrument. These were coded, used in the inter-rater analysis, and consisted of: ‘Personal Historical’ knowledge or knowledge gained from their present and past personal experiences. Examples of ‘Personal Historical’ knowledge were statements containing use of “I” such as “that’s what happened when I went to the dentist” or “I’m just telling you what they did to me;” ‘Socio-Historical’ knowledge or knowledge that characterized an older stance in regard to health care, existing prior to the emergence of the ‘Informed Consent Doctrine.’ Examples of ‘Socio-

Historical' knowledge were statements such as: 'the doctor knows best', psychiatry is 'lying on the couch and talking;' 'Socio-cultural' knowledge was knowledge characterized by more culturally relevant or 'timely' knowledge of health care; knowledge in touch with current societal trends and emerging after the 'Informed Consent Doctrine' was assimilated by society. Examples of 'Socio-Cultural' knowledge included statements such as: 'getting a second opinion,' knowledge of newer medications and treatments, knowledge that doctors can make mistakes, and knowledge that patients have rights and can be active in their choice and type of treatment. Lastly 'Community of Practice' knowledge was knowledge characterized by the specific setting situating their lives. Examples of this kind of knowledge included statements involving the following: talk about staff, team meetings, practices and terminology specific to the setting.

Findings revealed that these men and women drew upon different types of knowledge as resources to answer questions posed by the assessment, and further, types of knowledge used varied according to which vignette was chosen. The inter-rater analysis resulted in K = 0.333, 0.431 and 0.121 $\alpha = .95$. The Cohen's Kappa statistic is available as an on-line statistical tool (accessed from www.graphpad). Reports from this site indicate that these K values fall within ranges defining the relationship between coder agreements as: 'Fair', 'Moderate', and 'Poor' in relation to agreements expected by chance, respectively.

Discrepancies between coders occurred for specific vignettes (Psychiatry) and specific types of knowledge: those stemming from the setting (coded as 'Community of Practice') and knowledge pertaining to each individual's past and current experiences (coded as Personal-Historical). Discrepancies opened a dialogue concerning the coding and, in some cases, were resolved. For example many instances arose where the men and women used the term "acting out” to describe the behavior of the individual in the psychiatry vignette. Using an insightful tactic the rater queried many different people across different age groups concerning their understanding of the term ‘acting out.’ For most of these people ‘acting out’ was associated with “an adult tantrum.” The statement ‘acting out’ was then mutually agreed to be coded as ‘Socio-Historical’ knowledge. Where discrepancies could not be resolved these were considered a result originating in a flaw of the design, to be explored more fully in the discussion chapter. The patterns resulting from this coding are reported below.

Knowledge type characterizing the men and women’s responses across settings, in order of overall global frequency of use (from most frequent to least), was: Personal-Historical, Socio-Historical, Socio-Cultural and Community of Practice. These patterns were not related to IQ scores previously recorded for the individuals. Thus people with higher reported IQ scores were as likely to use the ‘Personal-Historical’ as a frequent type of knowledge as those whose reported IQ scores were lower. The frequency of different types of knowledge characterizing their responses did differ by setting and vignette. Patterns which emerged for this variability are as follows: One pattern revealed that ‘Community of Practice’ knowledge was used most frequently in relation to the Psychiatry Vignette across all settings. Further, Psychiatry was the only vignette where all four types of knowledge were used, also observed across each setting. Another pattern emerged concerning type of knowledge used and setting. Responses of the men and women placed in Setting Autonomous revealed that Socio-Historical, Socio-Cultural, and Personal-Historical knowledge types were used in this order of frequency for each vignette, excluding the Psychiatry vignette which in this setting had the highest frequency of ‘Community of Practice’ knowledge. However, across the vignettes the total frequency of these three types of knowledge decreased. Thus the greatest frequency of all three knowledge types was observed for Psychiatry, a decrease in frequency across all three knowledge types was observed for the Allergy vignette, and lastly a further decrease was observed for the Dental vignette. Community of Practice knowledge was used by the men and women in setting Autonomous exclusively for the Psychiatry vignette; this knowledge type did not appear for Dental or Allergy within this setting.

Responses of the men and women in setting Protective were characterized by a higher frequency of 'Socio-Historical' knowledge related to both the Allergy and Psychiatry vignette. In setting Protective the Dental vignette had a higher frequency of Socio-Cultural knowledge a finding also repeated in setting New. The higher 'Socio-Cultural' knowledge for the Dental vignette in both settings 'Protective' and 'New' related to the men and women using the names of medications and procedures/practices (e.g., Novocain, root-canal). People in settings Protective and New had responses characterized more frequently by 'Personal-Historical' knowledge while people in setting Autonomous had the highest frequency of 'Community of Practice' knowledge, due to the high frequency of the psychiatry vignette.

An interesting finding emerged relating to those individuals who had early experience with institutionalization and the type of knowledge characterizing their responses. 'Community of Practice' knowledge was most frequently used by one individual (Mark) who had spent most of his life continuously in residential facilities, beginning with his institutionalization in early childhood. Another individual (Vicky) experienced 'institutionalization' at an early age and then spent time in a variety of different life situations upon her release from the institution and prior to her current placement. This included not only living with her family but also living in her own apartment (not associated with any service provider agency) where she was attended by home health aides. For this particular woman she had no responses characterized by

'Community of Practice' knowledge. As these were the only two individuals participating in this research who had such early 'institutionalized' experiences it is a finding that could not be fully explored.

Along these lines however, it was found that for some men and women who had been placed in such settings for many years, at least ten years or more, there was a higher frequency of responses characterized by 'Community of Practice' knowledge. Thus, Alice, Ruthy, Donald, Danny, Nancy, Mark, Erica and Larry each had more responses characterized by this type of knowledge than those whose time placed in such places was less. When 'Community of Practice' knowledge responses did occur with some frequency among people who had not experienced placement in this or other like settings for a significant length of time, it was prevalent for those individuals who were prescribed and taking psychotropic medications or who revealed they had problems with medical practices such as not wanting to attend certain appointments. This was the case for John, Juan, Alfredo, Nancy, and Ellie who each had experienced placement ranging between 5 and 9 years.

Lastly, the use of 'Socio-Historical' knowledge or knowledge 'pre-dating' the Informed Consent Doctrine by the men and women was examined. Here what emerged was that Socio-Historical' as a knowledge type was used by individuals with higher previously assessed IQ scores (e.g., Alice and Donald) as well as those with lower reported IQ scores (e.g. Lorraine, Nancy, Ellie and Erica). The use of this knowledge type was not associated with an age cohort; it was used frequently by those under the age of 35 (Andy, Juan, Ellie) as it was by those over the age of 50 (Carol, Nadine, Donald, Lorraine, Howard, Erica). Interestingly, it was not used by the eldest person who participated in this study (Robert, age 73).

I link these findings with the findings of the men and women’s accounts in Chapter 7. My question to these men and women upon completion of the assessment instrument—“Is this what happens when you go to the doctor (or dentist, or psychiatrist)?” provides the bridge linking their activity, in this case assessment responses, to their ‘situated’ experiences in the settings as well as to their past experiences. In the chapter to follow I report the findings on the analysis of the settings.

Chapter 6: Settings as Activity Systems

Introduction

"But let's not jump to assume that they understand or that they will remember so a lot of times you'll ask them 'what's this medication for?' and they will answer 'I don't know' and they've been taking it for years…that's just the nature of the population"—Administrator, 2010

In my approach to the analysis of the settings I relied upon Leontiev's activity theory and Engestrom's (1990) conceptualization of an activity system to capture the dynamics of each setting situating the lives of the men and women. This approach addresses the relationships among the elements of the activity system, which not only define but distinguish the distinct nature of each setting as a community of practice. Understanding the relationships and processes within social practices requires knowledge of setting and situation, in addition to the individuals who shape the relationships into a particular activity system. This system, in turn, yields an observable product—the norms and practices referred to as the culture of practice (Billet, 1995).

Understanding social practices, in this view, involves delineating the complex of factors which are contingent upon the practices and influence them (Billet, 1995). Observations and accounts from narrative interviews combined with artifacts were used as the data to provide detailed accounts of the activity system that exists within each of the settings, each a community of practice providing an 'arena for learning'. In this way the activities, norms, and values which comprise the social practice and social knowledge of the settings situating the lives of the men and women involved in this study could be revealed. Within this analysis my aim was to understand the culture of the settings, from an 'outsider's view' namely from employees perspectives, and how this culture organized not only the physical structure of each setting but also the type of 'self-other' encounters and relations available to the men and women placed within it. In the sections to follow I report the findings of the activity system analysis for each of the three settings.

Community: The three settings as part of the service provider industry

Organization. Each of the three settings had a similar organizational structure. This structure was hierarchically arranged with influence and information flowing from top down. Thus, each agency's 'approach to consent issues' emanated from the upper hierarchy of this organizational structure emphasizing a hierarchy of power and was also a product of each settings placement on the horizon of the service provider industry. This structure from top down consisted of: A board of directors made up of an assortment of individuals such as financial supporters, parents, community volunteers, and in one case an individual who had been placed within the agency. On the next level each agency had an executive director with an executive staff. Following this an upper management level provided supervision to the various departments: residential, day programs, nursing, psychologists, clinicians. Because this research involves placement in residential services the following organization structure only concerns the residential portion. A middle management level composed of staff that managed the residential programs, each manager might be in charge of three or more residences. However, as each agency was funded through government sources, each was governed by regulations stipulated by OMRDD which were then interpreted through the policies and organization of each agency.

Within each residential facility, the actual site where the men and women resided and spent most of their time, management was composed of a residential director, assistant director, and direct care staff as well as a nurse or nurse's aide. Clinical staff such as nurses or other clinicians whose special training was a service offered such as speech, physical and occupational therapy, nutrition, etc. were supervised by upper management staff, specific to each discipline. Thus, nurses within each residence were subordinate to a nursing supervisor who was part of upper management. For each setting dependent upon the type of residential facility it was (Supported Apartment, Individualized Residential Alternative/IRA, or Group Home—meaning less or more staff and continual or intermittent supervision) the actual number of direct care staff available for any shift was dependent upon the number of people placed and their 'needs,' which were defined and assessed by the setting.

Each setting emerged at different times in the history of the service provider industry. Their emergence and development emanated from different areas of need specific to individuals diagnosed with intellectual disability. The histories of the three settings follow.

Setting 'Autonomous'. This setting was described as autonomous because of its practices: the extent to which some of the individuals placed within were deemed 'self-consenting' in that they could sign the consents for their own health care treatments, and some of the residential facilities consisted of supported apartments which had minimal staff oversight. This setting began operation as part of the parent groups fighting for inclusive community treatments for their children in the 1940s. In 1951 these parents as a group applied for and received a Corporate Charter as an organized association to advocate and become the speaker for children diagnosed as mentally retarded in New York. The primary focus of this group and others like it was education, vocational and other day services located in the community (see Castellani, 2005).

Advocacy groups that composed the historical becoming of setting Autonomous, were primarily composed of parents who wanted to keep their children at home rather than place them in the institutions such as Willowbrook. Thus setting Autonomous emerged in the atmosphere of parent narratives attempting to justify, increase and promote group-specific (exclusive to intellectual and developmental disability) services for their children based on the argument that ultimately their children could not compete on equal footing with other citizens, and supposedly, other diagnostic groups, most notably the mentally ill (Carey, 2009). Setting Autonomous' emergence from these narratives promoted parental as well as professional control over those individuals who did not—and it was believed, could not—contribute to society and little advocacy was made for 'adult' rights specific for this group dealing with important life decisions such as voting, contracting, marriage as well as health and financial issues (Carey, 2009).

Setting Autonomous' mission statement included words and phrases involving 'integrated', 'independent', and 'contributing', to describe individuals diagnosed and served, from the view of the setting. The setting's aims contained words such as: 'assistance', 'support', 'self-determination' and 'self-worth'. Setting Autonomous provided residential services for approximately 400 individuals.

Setting 'Protective'. Setting Protective was described as protective because of its practices: consent was sought solely from a correspondent: parent or family member; or a legal guardian. No individual was deemed 'self-consenting' and living arrangements were primarily in group residential facilities requiring more staff and more staff support. Setting Protective began operation in the early 1970s and emerged as a direct result of the movement toward de-institutionalization surrounding the Willowbrook class action suit. Setting Protective was founded by a small group of people, some of whom had worked at the institution. The agency began to establish services and supports within the community as a direct result of Willowbrook's closure, to provide the alternative to institutional placement that was sought and needed for the thousands of individuals who would be released. Unlike setting Autonomous, setting Protective was not characterized by strong parental input. Setting Protective can be characterized as more collaborative among clinical professionals. Input from parents was sought but parental input did not govern the setting's practices. This setting emerged from a need to provide housing given the closure of Willowbrook, to provide more 'humane care' and its first group home was entirely inhabited by people who had formerly been placed in Willowbrook. The pressing need for New York to make good on its pledge to close Willowbrook provided opportunity for the start of many service provider agencies to meet this need for housing and launched the 'group home' model of which setting Protective was one (Castellani, 2005; Rothman & Rothman, 2009).

Setting Protective's mission statement contained words such as: 'independent,' 'productive,' 'worth,' 'dignity,' 'rights,' 'feelings' and 'capabilities' to describe individuals diagnosed and served. The setting's aims were defined by words and phrases such as: 'facilitate,' 'create,' 'alternatives,' 'opportunities,' 'recognizing,' 'free of restrictions,' 'equal life style,' 'person centered,' 'offer,' 'enviable life' and 'personal choice.' Setting Protective provided residential services for approximately 80-100 individuals.

Setting 'New'. Setting New was described in this study as new because of its practices as well as it's placement in the historical landscape of the service provider industry. Setting New is 'new' from a historical perspective of the service industry as a whole. Setting New, like setting Autonomous, deemed some individuals as 'self-consenting' and able to sign their own consents. Setting New offered different types of residential facilities such as those requiring less staff support—individualized residential alternatives or IRAs.

Setting New began operation in the early 1990s and emerged in the atmosphere of individualized ‘case management’ and advocacy approaches related specifically to health care opportunities for adults and children with developmental disabilities. This agency, newer on the horizon of service delivery systems and historically more recent, is smaller in size comparative to settings Autonomous and Protective. Setting New is self-described as moving away from the ‘one size fits all’ approach characteristic of most other service delivery models and offers an array of different opportunities which due to its ‘diversified funding base’ makes such differences possible. Setting New originated with the goal to provide an array of services geared toward individual goals and needs which could be organized and effectively implemented through service coordination. Thus while setting Autonomous was characterized by parent directives and setting Protective by agency directives, setting New was characterized as directed by specialized staff—Medicaid Service Coordinators.

Setting New is also characterized by different language use in terms of consent issues in relation to setting Autonomous and Protective. Within this setting individuals are “represented.” Thus, they may either be ‘co-represented,’ signing consents themselves with a family member or parent; ‘represented,’ having another sign their consents for them—either a family member or parent and in some cases an outside government controlled source (court assigned guardian) or lastly ‘self-representing,’ signing their own consents.

Setting New’s mission statement contained words and phrases such as: ‘mentally retarded,’ ‘adults,’ ‘disabled,’ ‘need of care,’ ‘dignity,’ ‘hope,’ ‘self-reliance,’ ‘wellbeing’ and ‘productive’ to describe individuals diagnosed and served. The aims of the setting contained words and phrases such as: ‘advocacy,’ ‘one-one basis,’ ‘case management,’ ‘optimizes,’ ‘health,’ ‘accessible,’ ‘efficient’ and ‘effective’. Setting New provided residential services for approximately 50-60 individuals.

Location and Layout

The context according to the theoretical framework has influence on the activities within the setting with the settings shaped by their socially and culturally derived functions. Thus the physical setting itself is reciprocally shaped and interpreted by those individuals working and living within it. The physical setting from the perspective of those within it (in this case whether they work in the setting or live in the setting) “is viewed as an arena for social practice and is interpreted by individuals, therefore settings might not be uniformly determining of behavior” (Lave et al., 1984).

My interest in this analysis was focused on the men and women’s ability to access knowledge and cultural tools in which to mediate decision-making competence. This was specific to their medical and mental health care and how the physical location and layout of the settings affects access to and appropriation of such tools and also the nature of self-other encounters offered. This analysis was taken from data composed of: observations recorded as field notes and accounts of staff and the men and women. Results of this analysis include physical description of the location of the various residential facilities (situated in neighborhoods/communities) and their layout (interior territory). These descriptive notes were then synthesized into a table summarizing each setting in terms of the ease it afforded the men and women’s access to diversified social knowledge sources. Based on my dialogue with the men and women, ‘privacy’ was an issue in being able to access some cultural tools or just be allowed to be alone in their own rooms, and for some to keep their possessions and ‘rooms’ private. Table 3 presents the results of the analysis of the residential facilities, their location, layout, and practices as these involve accessibility of social knowledge. I include the notion of ‘privacy’ under Access TV, ‘to be alone in one’s own room’.

Table 3

Settings and facilities locations & layouts and accessibility to information (social knowledge) by the men and women

Setting & Facility	Access to people Other than employees & Professionals	Access to Neighborhood Community	Access to Entire Facility	Free to come & go with some guidelines	Free to access own room	Person/ Setting Code
A-a	Yes	Yes	Yes	Yes	Yes	A-1, 2, 3
A-b	Yes	Yes	Yes	Yes	Limited	A-5, 6, 7, 8
A-c	Yes	Yes	Yes	Limited	Limited	A-9, 10,11, 12
P-a	Limited	Limited	Limited	No	Limited	P-1, 2, 6, 7, 11
P-b	Limited	Limited	Limited	No	Limited	P-3,4,5
P-c	Limited	Limited	Limited	No	No	P-8,12
N-a	Yes	Yes	Limited	Limited	No	N-1, 2
N-b	Yes	Yes	Yes	No	Yes	N-3, 4
N-c	No	No	No	No	Limited	N-6, 7
N-d	No	No	No	No	No	N-8, 9

What follows below is a brief description of the locations and layouts involved for each residential facility across the three settings.

Setting Autonomous—Location and Layout. Setting Autonomous had three different residential facilities involved in this study, which I designated as ‘a,’ ‘b,’ and ‘c.’ These facilities were situated in urban communities characterized by residential and commercial establishments. Facilities were primarily provided in small apartment buildings, either owned or rented by the setting. All were accessible to a diverse array of public transportation and community services such as cleaners, laundries, fast food restaurants, bodegas, pharmacies, grocery stores, pet shops, clothing stores, and florists. The facilities were located in neighborhoods which were ethnically diverse and somewhat upper middle class in terms of economic makeup.

Setting Autonomous’s different residential facilities required different levels of staff support. The layout of the different facilities was dependent on this requirement. For most of these facilities a central office housed the residential management team, and the nurse. This central office also operated as a ‘medication area’ and held the ‘med book’ and a locked cabinet containing medications. Each individual’s file books, or ‘charts’ were maintained in offices attached to each facility but in two facilities were in different buildings from those where the individuals actually lived. In residential facility ‘c’ the office was situated in the same building where the individuals lived, more staff were required, and the charts were locked in a separate room of the office when the management team left their shift, usually at the end of the work day. A buzzer intercom system was used for communication to reach all individuals residing in location ‘c.’ A main living area and dining area were on the ground floor and the upper floors consisted of the central office/medication room (one floor) and rooms which were shared on the remaining floors above, approximately three. The entire building was utilized solely by setting Autonomous. This was the case for facility ‘b’ as well. Facility ‘a’ consisted of apartments scattered throughout different locations within the city. I visited only one and the building in which it was located was not completely utilized by setting Autonomous, but contained many public rentals.

Setting Protective—Location and Layout. Setting Protective had three residential facilities involved in this study: 'a,' 'b,' and 'c.' Each facility was an individual free standing home, as opposed to the apartment buildings in setting Autonomous. These houses were either owned or rented by the agency (this was not disclosed to me nor was it asked). However in one case I was informed that the parents of one of the men residing there, had 'left the house to the agency' on their death, so that their son might continue to live in his childhood home. Each facility was located in a different neighborhood, primarily suburban and residential, on the outskirts of the city limits. The ability for the men and women to come and go within each facility was dependent upon weekly scheduled activities (day program, work, and medical appointments) and scheduled outings. All such activities required staff members for supervision and transportation. There was no nearby public transportation services accessible within these locations. The facilities in setting Protective were either co-ed or gender specific. All were located in neighborhoods that were primarily homogeneous in terms of ethnic groups and primarily lower middle class in terms of economic makeup. Two facilities, 'a' and 'c' were located quite far from the nearest main street where shopping, stores, eateries, pharmacies, and other conveniences could be accessed. Facility 'b' was within walking distance to the 'main street.' Private transportation was required to access shopping, doctor appointments, recreation, and other activities within these communities or neighborhoods.

The layout of each facility involved a central dining area, kitchen, den, recreation room and each had a separate medication area where the nurse usually worked. A central office was located in the lower floor or basement of each location, in one location this office door was locked requiring a touch pad combination to gain entry. All ‘charts’ for the individual’s living there were kept in the office portion of each facility. Bedrooms, either shared or individual, were for the most part located on the upper floor. Each location had a small property consisting of front and back yard space. Each facility was nicely furnished maintaining a nice stylish décor throughout and all were immaculately clean.

Setting New—Location and Layout. Setting New consisted of four facilities: ‘a,’ ‘b,’ ‘c,’ and ‘d’ all situated in one very large building located on a short block in an urban neighborhood. This block was composed of other very large and many storied buildings that served as nursing homes and residential apartments. A commercial area was located nearby this building, at the end of the block. This commercial area, or main street, was divided by a main transportation thoroughfare on either side of which were located: diverse modes of public transportation, bodegas, Laundromats, churches, schools, small shops selling merchandise, coffee shops, delis and fast food restaurants. The neighborhood was primarily characterized by one ethnic group as evidenced by the stores and eateries and the language on the various signage. There was evidence of a small population of other ethnic groups as well. Overall the neighborhood appeared economically depressed.

The building housing setting New was vast, contained many stories, and took up a large portion of the block. At one time the building must have served the residential needs of a religious community as there were various unoccupied spaces designated as types of ‘kitchens’ located on the upper floors. The building also housed other types of residential and health facilities run by different social welfare agencies such as a nursing home for the elderly. Thus setting New and all of its facilities were housed in a building that was shared by many different 'social welfare services' and not solely utilized by setting New or its clientele. The four residential facilities were scattered among three floors while a central office space was located on one floor and a day program offering day services specifically for the individuals placed in setting New was located on another floor. I did not visit this space throughout the time I spent there but had frequented the separate office space on numerous occasions.

Entry to the building led to a large lobby, a security guard sat at a desk to the left and a waiting area furnished with couches was to the right. All visitors were requested to sign in. A bank of elevators was located to the rear of this lobby and so was a public restroom.

Spatially each facility consisted of an area of hallway on each floor with apartments located on either side of the hallway. One or two apartments occupying this area were refurbished and served as: the office for each respective facility and communal areas such as living room and dining room. A separate kitchen area was located off the dining room in most facilities. Of the four, one had a buzzer system warning staff when people came into or left their rooms, while another had entry only through a locked door which was kept locked for both entry and exits. This required a staff member to let one in or out. Individual's charts were kept in the designated office areas. Facility 'b' and IRA required the least staff, and did not have a central communal living or dining space; it did have a central office space, but no specific space appointed for nursing or medications. The individual's charts were kept in another location, actually in another facility's common space, but easily accessed.

'Subjects'

Eleven staff participated in the study. A requirement of inclusion in the study was that any staff member should have spent a minimum of one year working with the men or women placed in each setting who also participated in the study. Of the eleven staff members who participated, nine were female and two were male. Age and ethnicity were not directly asked of this group. Age was estimated to range from the late 20s to mid to late 40s and ethnicity appeared or was divulged to me, as being composed of Haitian, Hispanic, and African American. Average length of work within the current agency was six years. Some of these staff had many years in the 'field' and had worked in many different agencies over many years of their life.

Four administrators participated in this study: three females, one male. The age and ethnicity of this group was not directly asked. Age was estimated and appeared composed of 20s-30s to 60s and ethnicity composed of Caucasian (predominantly) and Hispanic. Length of time in the field ranged from 8 years to over 20 years.

Division of Labor

In relation to medical and mental health care within each setting nurses made appointments and direct care staff members if, specially trained, controlled dispensing of medications and followed directions on each 'medical consult' that was initiated for any individual who was scheduled for an appointment. This special training consisted of Approved Medication Approved Person training or AMAP. AMAP training is an approved medication administration course offered by OMRDD and is included in the regulations. Specifically this training is defined as "For purposes of medication administration, an employee who, by job description, is responsible for providing the day to day hands-on care, training, guidance, direction, assistance, support, etc. to persons in a facility" (OMRDD 14 NYCRR section 633.99, 2003).

AMAP direct care staff also ensured that individuals took their medications *"we check to make sure they are taking it and count the pills"* this practice is maintained for those individuals who reside in 'supported' apartment facilities as well as for those who are placed in residential facilities where direct care staff are present around the clock; for those deemed 'self-consenting' and those deemed not. Direct care staff also accompanied individuals on their varied medical and mental health appointments where needed, and handled the 'consult' or medical papers initiated by the nurse for any medical appointment each individual went on. For those individuals who were deemed 'independent travelers' and could travel independently to their own scheduled appointments direct care staff might not accompany them on these scheduled appointments but would in the case where a new appointment was initiated or new setting was involved. Direct care staff also oversaw shopping items for those who were able to shop on their own, to ensure that they followed their 'prescribed' diets.

Regardless of type of residential facility all AMAP staff or the nurse filled out the 'consult' for upcoming appointments and handed these once completed, to each individual scheduled for an appointment or handed them to the direct care staff member who would accompany the individual on the appointment. Medications, refills on prescriptions and follow up appointments were all conducted by the nurse or delegated through her to the appropriately trained direct care staff. Setting A given its locations afforded some men and women the opportunity to pick up their own prescriptions from the neighborhood pharmacy located nearby.

Direct care staff members, those specially trained as 'AMAPS' as well as nursing and in-house management personnel ensured that required medical activities were carried out. Namely this involved being sure that prearranged appointments were kept, medications were taken, prescriptions refilled, 'consults' from doctors recorded and filed, and recommendations carried out. I was informed that all recommendations were required to be followed: this included diets as well as recommendations from other clinicians (speech/language, physical therapy, and occupational therapy). In setting A, the individual men and women might be more involved in some of these practices, such as prescription refills or getting a follow-up appointment from the medical office.

Administrator's Accounts

Approaches to consent issues. Approaches to informed consent issues were inextricably tied to accountability under OMRDD regulations, conflicts, and the meaning of the phenomenon of intellectual disability. Following are the approaches of the three settings based on the accounts of administrators from each setting.

Setting Autonomous. Setting Autonomous's overall agency approach in terms of informed consent issues was viewed as a 'rights based stance'. Guiding their approach is concern for self-determination: "*There is no greater right than self-determination"* and that societal double standards are made transparent: *"We are concerned that these individuals are held to a higher standard than the rest of the populace."* Initiation of informed consent issues is from doctors and they take the doctor's lead: *"We don't presume to take a right away so if the doctor believes or is comfortable with competence [of the individual] we are delighted because if we disagree, we are taking away a basic right. Our presumption is that they are consenting unless there is a problem…we are not going with the presumption that they are incompetent unless shown to be, of course there are different levels [of competence]."*

Setting Protective. Setting Protective's approach was somewhat different in that consents were signed by others: *"because most of our guys have legal guardians and therefore* *they [doctors] do go to the legal guardian for informed consent, they are required to…that goes on between the doctor and the family, we maintain a copy of the informed consent because we are required to show it [to auditors] but we don't provide the information for it the doctors do."* In this way setting Protective is ready for any health related issue which might arise and there is no delay in treatment: *"because we know everybody with whom we would work with so we know right off the bat who has a legal guardian, whose actively involved to make decision on behalf of the individual [a correspondent]…so we would go right to work to handle it whenever something comes up with them."* Given setting Protective's origin to provide an alternative so that the inhumane treatment, abuse and neglect characterizing Willowbrook is not repeated, their approach was described as: *"to provide good quality care and to take care of them, the mentality is kind of still in that 'take care of them' mode."* Expanding on this more fully *"the agency wants them to live well and look perfect and if someone heard that they went out and were not dressed well, it would be a humongous thing like how can you let them present themselves like that, I mean they are dressed very well and kept very clean…you know a lot of work goes into these guys, you know they do, they [direct-care staff] take perfect care [of them] I mean cleaning under their fingernails!" I mean they are so serious about taking care of these guys!"* On one of my visits to setting Protective, staff members were in fact cleaning the fingernails of some of the individuals who lived there. This setting takes great pride in its accomplishments and their commitment is ingrained in the culture of the agency and evidenced by the fact that they have extraordinary audit and survey results: *"oh yes they are second to none here you know it's a nice safe place to have your kids, you know the State loves it, you know they always know that it's safe and that no one's going to overlook anything."*

Setting New. Setting New's approach to consent issues was described as: *"Medicaid service coordination and advocacy."* Setting New's stance of advocacy is oriented toward a rights based philosophy, however in the event that the process of 'informed consent' is "lost" on those who are "lower functioning" Medicaid service coordination staff advocate for their rights by questioning the introduction of medications, psychotropic medications, behavioral support plans, and other pertinent program services and treatments. For setting New, having consents or knowing who will sign consents, occurs at admission because it is part of the Medicaid Waiver Service: *"it's based on our paperwork at the time of enrollment, when filling out for the waiver service, which is what we provide, you have to choose an advocate…there are questions listed on the form: 'I choose to sign myself', I choose to advocate with this person', I choose this person to advocate for me'."* Here is where the language of setting New differed from settings Protective and Autonomous as choosing an advocate was related to representation and the individual could choose who to represent them or could choose to represent themselves with the choice: 'I choose to sign myself.' This also marked a difference between setting Autonomous and New as in the former this consent decision was made by the doctor in the specific case of treatment, whereas in the latter those choosing to represent themselves had to be assessed for their ability to do so by the setting. This resulted in setting New stating: *"We have very few that advocate for themselves and then we have a handful that advocate with the assistance of someone."* Thus most individuals in setting New were encouraged to seek the choice: 'I choose this person to advocate for me' where the person chosen was *"of their own choice."*

Problem areas of informed consent. Specific issues felt to be problematic concerning informed consent across the three settings was use of psychotropic mediations. For setting Autonomous, psychotropic medications were problematic because the setting, not the doctor, would involve both initiation of the treatment and the informed consent process; *"We would have to, we are the mechanism of consent for someone residing in our residences, it would be our responsibility to reach out to the family if at the time of admission the family has been the signature people for this consumer…if the consumer has signed for themselves coming in, it would be the consumer."* Setting Autonomous also stated that medical procedures were equally problematic in terms of consent issues: *"and well medical procedures, I'd say 50/50."* Medical procedures were problematic because medical practitioners became arbitrary: *"But it's tricky, every so often someone gets arbitrary, like with dental, sometimes they'll accept some consumer as self-consenting by fact that they are there in the office like the rest of the populace, and then sometimes they'll want a consent signed by someone else."* Or because medical practitioners disagree with the competence of the individual: *"…where we see the person as able to consent to medical procedures and the hospital won't take his consent that is the other side of the conflict, so you go to Surrogate,* (Surrogate Committee for Medical Decision-Making, see Sundram, 1988) *and Surrogate will do one of two things: decent or they will call the provider and tell them they must accept, the Surrogate will force the provider to accept."*

For setting Protective there weren't any problems because *"everyone follows the plan you know, following the rules is what we are paid to do and taking care of them [consumers]."* But psychotropic medications posed some problems at times: *"I would say it happens not often but on a regular basis you know we feel someone needs a psychotropic medication and the family says 'no'...parent's views sometime, or whether a medication is needed or why it's needed is different, they'll say 'give them whatever they want to, they don't have behavior problems at home' and we'll say 'no we can't just keep giving them cookies, you've got to work it through'."*

In Setting New psychotropic medications use presented conflicts especially in cases where the agency was the guardian of the person rather than a family member or parent: *"there is a mechanism in the regs that allows the EO to give consent."* This creates conflicts as expressed by the following: *"It takes a lot of responsibility off us as well [if parents/family are guardians] because once we become guardians for the individual you know it's kind of like a conflict because like…if so and so needs a psychotropic mediation and they are in our program obviously we are going to sign for it because they are disrupting our program, but is this the best checks and balances? I don't think so."* However, here as well conflicts between community practitioners and settings emerged over what constituted 'valid' consent: "*We encounter the most problems when the consumers wind up in the hospital because their guidelines are different from our guidelines and what we consider to be valid consent isn't considered valid consent for them so they usually want something from a legal guardian and nine out of ten our population doesn't have legal guardians, they have advocates or family members or next of kin that sign for them, which is ok for our guidelines but it is not ok for hospitals, then we encounter problems so we get SCMD* (Surrogate Committee for Medical Decision-Making) *involved."*

Rules and Tools. Conflicts were identified as initiation and use of psychotropic medications and medical practitioners who refused treatment without valid consent signed by others. This necessitated that consents be in place and further that these consents be signed by others because the men and women were often not seen as capable to make medical and mental health care decisions on their own, both within and outside of the settings. To ensure that health care treatment is preformed efficiently and quickly, all settings indicated that there was a 'push for guardianship' by OMRDD *"OMRDD does want parents to get guardianship."*

Legal guardianship legitimizes incompetence and emphasizes power relations; from setting Autonomous's view: *"the law has stated that this person is incompetent, many of our parents who sign are legal guardians, in fact it's been more of a move to make them legal guardians and it troubles me, because we don't know, well you know a lot of it is a power game at one point or another."* Setting Protective questioned the practices in the regulations: *"You know in all the different procedures that they [State and Federal audits] have reviewed of ours it's never come up, you know it's never proposed that we teach them how to make these types of decisions and they will never be spoken to [because others sign for them] yeah so it's definitely a mindset."* Accountability to the State regulations was repeatedly a theme that arose in the accounts underlining its importance and priority in guiding practices, as in setting New: *"You know the State does come in looking for that [consents signed by others] and it's a big deal so we try our best to expedite the informed consent process."*

Administrators used a variety of tools and rules guiding their practices. As OMRDD regulations held a significant position in this regard, as both tool and rule, the following section reviews the regulations specific to the concerns of this study.

The complete OMRDD regulations are beyond the scope of this study but can be accessed through the following web site www.omr.state.ny.us. Specific regulations pertaining to 'informed consent' for "professional medical treatment" are outlined in 14 NYCRR section 633.11 and defined as follows: "A medical, dental, surgical or diagnostic intervention or procedure in which a general anesthetic is used or which involves a significant invasion of bodily integrity requiring an incision or producing substantial pain, discomfort, debilitation or having a significant recovery period, or any professional diagnosis (such as psychiatry) or treatment to which informed consent is required by law" (OMRDD, 2008). The regulations also note when an individual can provide their own consent as follows: "If the person is 18 or older and has the capacity to understand appropriate disclosures regarding proposed medical treatment, the person's informed consent is required. We would only look to an authorized surrogate to provide informed consent on the person's behalf if it has been determined that the person lacks the requisite capacity to make an informed decision with respect to the proposed professional medical treatment" (OMRDD, 2008).

Although the regulations are in line with legal proceedings, in that how judgments are derived remains up to the professionals involved, the regulations impact the extent to which the men and women participate in their own health care. This is evident in the OMRDD regulations stipulating what an individual must demonstrate in order to participate in their own care. One example of this involves "Self-Administrating Medications." According to the regulations this involves two processes: Self-administration and self-management. Self-administration of medications involves: 'a rote task that involves the act of taking the right medication at the right time, in the right dosage and manner' while self-management involves: 'an intellectual task that involves understanding medication, its use adverse effects, etc.' (OMRDD, 14, NY CRR section 633.99, 2003). The regulations also specify staff trainings required: Approved Medication Approved Person (hereafter AMAP) NYS OMRDD medication administration course (OMRDD, 14 NY CRR section 633.17, 2003). These regulation requirements limited participation on the part of the men and women and set up a 'double standard' as setting Autonomous notes: *"We can think of elderly people in our families that take their own medication do they always take it at the right time? Do they know what color the pill is? Do they know what it's for? Do they know what the side effects are? No! Are they allowed to have their own medications (nods head* *yes). Our people have to fill out this form [self-mediation assessment] and if they can't hit all those pre-requisite points, they can't self-administer [medications]."*

Across settings it was evident that accountability issues reinforced the need to obtain consents signed by others for medical and mental health services rendered. This practice was substantiated by accountability measures such as audits where consents, signed by others, were sought. To ensure health care treatments are performed efficiently and quickly, all administrators indicated that there was a 'push for guardianship' by OMRDD.

Accountability to the State and regulations was repeatedly a theme that arose in these narratives underlining its importance and priority. Having the signed consents provides assurance that medical needs will be met but also provides some relief to the service providers*: "It takes a lot of responsibility off us."* Conflicts identified as initiation and use of psychotropic medications and medical practitioners who get *'arbitrary'* necessitated that consents be in place, because '*auditors do come in looking for that'* and further that these consents be signed by others, with the implication being that individuals with a diagnosis of Intellectual disability were not seen as capable of making important medical and mental health care decisions on their own. Either within or outside of the setting, having a consent signed by a non-disabled other expedited medical services, ensured that medical services were more quickly obtained and allowed the setting to adhere to the regulation's requirement.

However, guardianship and having others sign consents for individuals placed was a practice of which the men and women were often not aware. This situation arose early in the research during the consent/assent stage. Some men and women questioned why their parents or family had to be informed when they had already 'given' their consent and agreed to participate in the research study. 'Shielding' was a practice frequently reported within and across settings according to administrator's accounts. As noted by setting Protective: *"There's a lot of shielding going on."* This practice was validated because some health related information may cause them anxiety, might frighten them, may cause them psychological and emotional harm so the clinicians *"back off"* according to setting Autonomous. Shielding was also a practice relating to guardianship and involvement of correspondents. When I brought up some concerns which emerged in the consent/assent process involved in the research, where some men and women questioned why I needed to obtain consent from someone else despite the fact that they had already said yes (specific to setting Protective) the response was: *"I bet he was really insulted."*

Shielding was 'practice as usual' as an administrator in setting Protective described the process to me: *"you know things happen so quickly, they might not even realize their parents sign for these things, its [consent form] certainly not with them when they go to the doctor, they go home [to their residential facility] they heard what they heard, and the nurse might call the mom and say the doctor is going to call you, and the person may not have known…yeah according to him, he may think he does authorize it [the treatment].*

'Objects'

This drive to have consents signed by others was impacted by accounts concerning the 'nature' of intellectual disability or other developmental disability as equated with a lack of competence. Lack of competence was implied by the diagnosis itself. Themes emergent from administrator's accounts regarding the view of the men and women centered on their child-like nature, limited potential for intellectual ability as indicated by IQ scores, lack of skills in other areas—most notably academics, and fear that apparent capabilities might 'mask' the depth of the disability. This last area was especially relevant in regard to language. In this regard, capability regarding language use (vocabulary, use of specific terms) did not equate with potential ability. Therefore, the men and women's use of good language could make them 'appear normal' masking the depth and pervasiveness of the disability. Thus, a potentially harmful situation could arise. This harmful situation would arise because the men and women might "present" as normal; as if they were higher functioning than they actually were. The result of this would be opportunity for the men and women to be taken advantage of. This 'fear of them appearing normal' was a pervasive theme and seemed not only to drive assessments, but elucidate the 'depth' of the diagnosis and the resulting conflicts posed for service provider agencies. For example, within setting New, reference to an individual that participated in the study (Ricky) highlights this 'Fear of appearing normal': *"he speaks beautifully but when you get down to basic you know academics skills or anything he is clueless…he'll sit there and have a conversation with someone...people feel like he presents as much higher functioning than he actually is…people feel like he speaks beautifully and if you sat down with this guy you'd say 'there's nothing wrong with this guy, but he's a huge follower and he always follows the wrong example."*

Within setting Protective a similar view and example was given: *"I don't know how clear their understanding would be, but it's hard to tell, you know a lot of times they can seem really intelligent because they have learned good language and they know phrases and they are so up on the times that you just assume 'wow they are really with it' but then you talk about pros and cons of a surgery and they'll be like 'what?' and I guess that's why you have to get a good evaluation."*

In setting Autonomous, daily living skill abilities or lack of, drove conceptions of potential competence: *"it depends upon the capabilities of the person, historically the 'pool' was much more attractive, there was degree of competence that we don't see now, we had a choice [historically who to accept into the program]."* Capabilities of the individual were assessed globally by the clinical team in setting Autonomous according to what the individual could do upon their admission, based on daily living skills: could they cook, make a bed, clean? Being able to travel independently (where the individual became known as an 'independent traveler') was emphasized as one such skill especially relevant for capacity to consent in this setting.

These beliefs concerning the phenomenon of intellectual disability necessitate the need to seek consent from others. Therefore across all three settings, getting a consent signed by others and having this document in the file was a priority. In many cases, the person whose signature on the consent on file was the person conferring with the doctor, getting information about proscribed treatments, side effects, and alternatives. In these settings how individuals got information was either a function of the practitioner initiating the 'treatment' or staff. This practice existed not only for medical treatments but also for mental health treatments as well and the task of providing information about treatments to the men and women might rest on a medical practitioner, a variety of staff members, a parent, on in some cases, on no one.

Rules and Tools: Placement

What emerged from these accounts was that prior to the need for an actual informed consent, the question arises pertaining to 'who' authorizes the services offered by the settings where informed consent issues may originate? This was related to practices in each setting originating at the time of each individual's admission to the settings.

Thus in setting Autonomous, although this agency had a strong stance based on self-determination as no greater right, whoever brought the individual to the setting authorized the services offered: *"If they come in with a parent or guardian who really wants to or has always signed [given consent] then yeah, that games over, we don't fight to take it away from them."* Setting Autonomous's practice closely aligned itself to the history of its origin: *"The family has brought this consumer to us and presented them for screening and that is how the consumer showed up at our door in the first place with the parents steering the ship so that's how it continues."*

In setting Protective, the stance was also 'rights based' however here the authorization for services came from the setting itself and parents and guardians relinquished control once the individual was placed: *"by having them [consumers] live here they [parents] are giving up their responsibility and they are allowing us to take responsibility for all general health care and for identifying when they need medical treatment, for seeking medical attention, the parent has the right to say 'I want this doctor' and we would have to follow up with that doctor…"* but ultimately if the setting felt medical attention was necessary they would seek this attention regardless of the parent, guardian, or correspondent's wishes: *"actually within the law we are allowed to do that, we are responsible for basic treatment you do not have to authorize us and we cannot withhold it, it is up to us, all they can authorize is the intrusive [procedure] or anything that can cause great pain…anything like that, that's all they have the right to make a decision on and to help select the doctors that they are going to use but they don't have to consent, well its good practice to keep them informed of everything but we are not required to say you know 'we are going to take him to the doctor to get this sniffle checked'."*

While in setting New, the Medicaid Advocate decided: *"It's based on our paperwork at the time of enrollment, when you are filling out for the waiver service which is what we provide, you have to choose an advocate so normally, whoever brought the individual to us would be the advocate so it might be a parent or sibling. I'll be honest with you, we usually don't get that [individual signs for themselves] once they have someone signing for them and answering questions for them, they are or seem comfortable with that, it doesn't ever usually change once it has been established."* But if a conflict arose the setting advocate would step in: *"Nine out of ten there have been situations where the individual has flat out refused to have a procedure done and the guardian wanted it done because it was an important test and that's where [the Medicaid Advocate] step in because [Medicaid Advocates] are the advocate on paper and can say 'no, my individual does not want this test and he does not have to have this test' so what we do then is we call the psychologist and he documents the refusal and his capacity to refuse."* Frequently in this instance, as I was informed, the outcome of this assessment finds the men and women lacking the necessary capacity/competence and their guardians or correspondents sign for their treatments. This practice of designating a 'competent' person to sign for the individual commences upon their admission to the setting and rarely, if ever, changes throughout the person's life.

Assent. As revealed above, authorization of services offered by each setting was primarily at the discretion of others. This authorization occurred at the time the men and women were admitted to the setting and rarely changed once established. Given that others primarily authorized services rendered how this affected the men and women's participation and level of involvement was explored through the question of assent. When the subject of assent was raised, none of the settings incorporated this as a practice. Reasons for omitting each individual's assent had to do with the ‘importance’ and necessity of medical and mental health services as opposed to recreation or field trips where assent was elicited. Assent was not elicited in situations having to do with medical or mental health related treatments or procedures for those individuals who had others (correspondents, parents, guardians) authorizing services for them.

Setting Autonomous’s response to the question of assent demonstrated why obtaining assent from the individual was unnecessary: *“I mean the point of all that, we’ve decided that they can’t give consent, what is the value of forcing them to look at certain things or face certain things…it doesn’t matter whether they agree or not, if they say ‘No’ they are still going to get it [a treatment].”* This stance was justified by the harm knowledge of medical or mental health issues may cause for the person: *“I think there is a big question mark on how valuable that is for the individual, see I’m not buying automatically that that’s necessarily a good thing, I mean with some people at that level [non-consenting] we might just be adding more anxiety.”*

Setting Protective’s stance was similar except within their policy they upheld an individual’s right to say ‘No’. *“So while we don’t necessarily seek them out for their authorization, if they say ‘no’ we would never go forward, we might continue to work with them on it you know as far as desensitization or meeting with the doctor or anything we would have to do to make sure they are healthy…but yeah, there’s a real fine line that anyone on any level can say ‘No’.”*

Setting New promoted assent in other areas but not those deemed important such as in medical or mental health care decisions: *“Well when we look to get informed consent it’s primarily for medical procedures, medication, behavior plans and things of that nature, so they are things that are necessary so it’s not, it’s not like ‘oh do you want to go on this field trip?’ If* *that's the case, than that's a different story but things of a medical nature, NO!"* Like Setting Autonomous, setting New did not see a right to refuse as standard practice especially if 'more capable others' were available to 'sign', 'consent to' or 'authorize' a treatment. Setting New reported: *"nine out of ten times yes we go with the guardian or advocate if a medical intervention is recommended and the individual says no."* Whereas for setting Autonomous, only those men and women deemed to be self-consenting actually refuse*: "the only consumers who refuse their treatment plans are those that are self-consenting"* stressing that no refusals or objections are heard from those who have others authorizing services for them.

Formal assessments for capacity to consent across the settings were acknowledged by settings Autonomous and New. Assessments consisted of an assessment tool such as the one used in this study (setting New) or by 'clinical interview' (setting Autonomous). Informal assessments usually emerged in cases of compliance and were based on global 'markers' indicating competence such as being able to travel independently, and daily living skills such as being able to cook or clean (setting Autonomous), whereas formal assessments emerged in cases of refusals (setting New).

Thus across the three settings, the priority was to obtain 'valid' consent on behalf of the individuals placed, from someone else. But the validity of this practice and its possible negative effect on the men and women placed was questioned as the interviews with administrators progressed. For example: *"I think people on the whole urge to get people assessed so they have it on paper that they are consenting or not is a fear, people are protecting themselves, it might not be worth the paper it's written on but we've got it"* (setting Autonomous), and *"Is it the absolute power of guardians to affirm everything? We were taking the request of a parent much more,"* (setting Autonomous). Other views questioning this practice were as follows: *"so if you* *get the right psychologist, because the parent wants guardianship, they want to take care of their child, so I don't think it's looked at as 'let's give these individuals independence' it's looked at as 'let's keep them safe and make sure you [parents] can make those decisions for them.' How they're imparting information to the individual? Is this looked at by the State [auditors], it's not asked about at all, which is really an individual's right's question you know"* (setting Protective). And lastly, *"Like I explained to you about the parents, they automatically think that because the child is DD (developmentally disabled) the parent is the parent for life, which they are, but I feel, [parent's think they] need to make decisions for this person and answer questions for this person, and its jut not the case in every situation"* (setting New). As an administrator from setting Autonomous summarized, getting consents signed by someone else was historically deemed a relevant practice which, despite the passage of time and experience, continues to be an automatic, unquestioned practice, within many agencies: *"I think too many psychologists signed off on them [guardianships] at the request of parents without having a serious discussion about what this really means."*

Along these lines the practice of assessment as a possible space to provide learning rather than yielding only a yes-no, zero-sum outcome concerning competence was brought up in the interview with administrators. The example where competence assessments can be used as tools to provide education to support competence was drawn from the area of assessment for capacity to consent to sexual contact. Based on my experience in the field I was aware that in some agencies, individuals are assessed for their sexual knowledge and where areas of deficit arise, training or teaching is made available, with the goal of aiding competence in sexual decision-making behavior. A discussion concerning this aspect of capacity assessments, as providing a space for teaching and learning, could be explored only in setting Autonomous as in setting

Protective consent/authorization is supplied by others and in setting New, the outcome of the assessment for competence in medical and mental health decision-making was valued as giving the yes/no status on competence, solely. However, in setting Autonomous this aspect of assessment was met with mixed views. According to one administrator, *"Our training isn't geared to give them the capability to have consent, we are not going to give them the training to enable them to give consent."* Whereas for the other administrator, within the context of the assessment encounter: *"sometimes they are [found consenting] or it can lead to consent [capacity]."* But as the first administrator made clear: *"that is not usually the goal [in cases specific to medical or mental health care treatment decision-making]."*

Staff Accounts

The preceding section involved the view of administrators. The following section involves the views of those staff members who had day to day contact with the men and women who participated in the study. As previously stated these staff members were composed of direct-care workers, nurses, and managers. My interest was to understand the nature of the relationships within the settings and their impact on the men and women's access to knowledge concerning their health care. Within this section the analysis involved Objects, Rules, and Tools and how these impacted the men and women's ability to access and appropriate social knowledge resources. Data consisted of the narrated accounts elicited in interviews with these diverse staff and field notes.

As in the section reported above for administrators, the narrated accounts of staff members were characterized by an intertwining between conceptions of the phenomenon of intellectual disability and accountability, however with staff members accountability was aimed at job responsibility and fulfilling this responsibility for job security.

‘Objects.’ It will be recalled that ‘Objects’ as defined here is related to the Activity Theory analysis. ‘Objects’ are one of many elements involved in activity theory, and as applied within this research, concerns the perceptions of the men and women placed from the viewpoint of staff.

A strong theme emerged across settings in staff accounts, equating the phenomenon of intellectual disability with mental inability and difference. Mental inability and difference led to the need to take care of and monitor the men and women diagnosed, and moreover emphasized the primacy of the role staff members played in the lives of the men and women placed in each setting while also highlighting the differences between them. Relating to the understanding of their medical conditions, staff members saw these men and women as lacking in basic understanding, because of their diagnosis, necessitating their need for continuous oversight by staff.

In many instances mental inability was associated with something wrong with the ‘brain’ and often when referring to the men and women they worked with, staff members would gesture to their head to indicate the source of the problem. This was also in response to the request in the interview for staff to give an example or tell a story of a related experience. Relating to medical conditions and information distribution, staff members explained that medical conditions were too involved; too complex for the men and women to understand due to their mental problem. This also meant that these men and women were not seen as being able to make their own decisions as follows: *“no they can’t make decisions…it’s always going through the nurse and the* *parents that make decisions for them."* This stance was fairly consistent despite the fact that some of the men and women were 'self-consenting' or deemed able by the setting to make their own decisions.

Thus when dealing with men and women who were considered self-consenting (as in settings Autonomous and New), these individuals according to staff, still required staff supervision. Staff intervention was required so that the men and women, even those deemed self-consenting, did not get into trouble. This necessitated some use of control. Although this gesturing to the head, witnessed across all settings, was a way of expressing deficient mental functions, in some cases deficient mental functioning was linked to IQ scores as a measurement of mental inability. In other instances a more concrete example of mental inability was given based on observed behavior as described below.

In one account taken from my field notes, a staff member used an example of a woman placed in the setting (setting Protective) who has diabetes. This example was used to demonstrate the woman's inability to understand the 'complex concepts' involved with medical diagnoses and treatments, requiring need for staff oversight: *"I don't think they understand well for example, [being] a diabetic, [she] knows, 'I'm a diabetic' but the sugar part ok, 'I'm not going to eat the regular sugar [use artificial sweetener instead] but it's ok for me to have these cookies over here'."* What is noteworthy about this example is that this staff member spoke about 'complex concepts' as underlying understanding. According to this staff person, the men and women placed do not understand the concept underlying their medical or mental health disorders—presumably because of their mental inability (gestures to head). In elaborating on this she gave the preceding example. However, at the same time she was eating her lunch, a sausage sandwich. Apparently her second one because another staff entered and questioned why she would be eating another sausage sandwich when she knows she has high blood pressure and should "lay off the salt." I then reminded her about the 'complex concepts' underlying a diagnosis of high blood pressure and the example she gave about the woman, and we both laughed. However, and less humorously, this illustrates what numerous scholars have already brought to light namely how 'normal' behaviors are interpreted as deviant inside of institutional settings (Rivlin & Wolfe, 1985; Rosenhan, 1973; Foucault 1994—as this pertains to his use of the 'medical gaze'). Due to the nature of the population as perceived by staff, staff's primary role was to provide supervision and perhaps, control*: "Well, that's how it is with them, they understand but can they really make a decision on what they think is best? No, no I don't think so…well that's what I think."*

Tools/Placement. This understanding of the nature of the population and the need for oversight and control on the part of staff emerged from the fact of the men and women's placement in the setting. Statements such as *"because being that they here right?"* or, "*they here for a reason"* validated the men and women's inability and their need for supervision. However, placement in different types of residential facilities within each setting was also indicative of a person's functional level and ability. Therefore in residential facilities requiring less staff support, such as supported apartments in setting Autonomous, these men and women were deemed to be 'high functioning' (presumably this relates to mental ability) and 'independent.' Some men and women diagnosed with disability and placed in these settings were seen as being able to make their own decisions; staff members just provided follow up: "*Well all of them are considered consenting so they are allowed to make [decisions] but we [staff] follow-up."*

Placement in residential facilities requiring more staff and 24 hour supervision, as in settings Protective and New as well as one facility in setting Autonomous was indicative of mental inability, despite mental functioning as assessed by IQ scores. An individual previously assessed as having borderline intellectual functioning, indicated by an IQ score above 72 (thus not having intellectual disability as clinically defined), but who was placed in a facility requiring more staff and 24 hour supervision was considered lacking in mental ability. Thus individuals were seen as having *"mental retardation"* and mental inability because of the 'facility' they were placed in, regardless of actual diagnosis.

Tools/Inability: A lack of experience. Many staff members explained that mental inability equated with placement and a diagnosis (regardless of what the diagnosis was). Because of this, according to staff accounts, the men and women diagnosed were unable to be more involved in their medical and mental health care and make valid decisions. However there were also staff members that described lack of ability in health care decision-making as due to a lack of experience. As exclaimed by one such staff member (setting New) *"No I don't think they can make decisions because I'm not sure they have the experience about it, you know this have to be done and that have to be done."* Interestingly this stance was expressed by a staff member who had limited experience in 'the field' and had not worked in the setting an extended period of time. This notion of experience was also a factor in some staff's reasoning as to why certain men and women seemed to know more than others (setting Protective) *"well for instance, his father had some surgery going on [related to artery blockages] and he knows that if you eat too much butter or too much fat your artery [will be affected] or too much salt, causes high blood pressure yeah that's sort of like family experiences, and like they are aware of stuff like that ,* *and about gaining weight will cause high blood pressure too so they know [family experiences].”*

Discussing things with parents was a factor in why certain men and women knew more than others as indicated by staff. In discussing one particular individual, a staff member (setting Protective) reported: *“she always asks questions, knows where to go and who to go to and how to go about it if something medical was wrong.”* Her explanation for this behavior is as follows: *“she knows a lot because her mom is a nurse, yeah and she reads, she reads, and she knows a lot about medication and she knows a lot about the process, procedures and stuff, she’s very aware of the medical things.”* In another example, a staff (setting Protective) knew that an individual was better informed than the others, because he had a cell phone and was in frequent contact with his mother. Whispering she stated: *“yes, he’ll go to his mother first and his mother tells him about it.”*

Ability: Experience in relationships. Lastly, there were a few staff members who viewed the capability of the men and women differently based on their own experiences of interacting with them and developing relationships with them. This was also impacted by the staff’s experience of the specific setting’s policies and procedures. Mental abilities, where identified, were anomalous because the individual expressing them was different than others placed, “*She knows very well, when you ask her a question she give you direct answer, like I talk to you. Like Wow, she not like the others, she knows”* (setting New). Of note in this example is that the individual she refers to had legal guardianship appointed through the court, petitioned by the agency. This was due to lack of family contact and of a ‘valid’ person to sign her consents because she was deemed not to have the capacity to do so on her own. Mental abilities were also related to awareness on the part of the men and women placed and surfaced in instances where they questioned staff about medical related issues such as medications. In one example (setting New) a staff explained: *"She sometime she know the color of the medication and she'll say well 'what is this one?' you know is the same thing but because it is a different color, same medication but the color is different, and she will ask about it."* What is relevant here is that while one staff member viewed this woman's questioning as a sign of her intelligence, another staff member could view this questioning as 'resistance' or a 'challenge.'

Although not present in a majority of staff members, there were some who reasoned that 'inability' to make decisions or be involved in medical issues was directly related to company policy and practices. Lack of experience tied into the effects of company policy and procedures because, as some staff expressed, *"the appointments are made because of company policy"* and *"there's a regulation for the company you know that somebody is supposed to do that for them [make medical appointment]."* This resulted in some staff recognizing that the setting itself constrained the abilities that some men and women may have as evident in the following: *"well yes she is smart but she really can't say 'no I don't want to take it' because the facility policy is that consumer can refuse taking one pill but not everything"* (setting New).

Rules: Conflicts. Company policy was interpreted by staff as mandating the type of relationships they had with the men and women placed, the type of information they gave them and emphasized the conflicts between job responsibility and carrying out this responsibility. For most staff, medical and mental health appointments were a priority of their job responsibility and they were accountable to follow through on these appointments and recommendations. Following through was defined as *"taking consumers on their scheduled appointments."*

Accounts given by staff equated appointments with company policy and OMRDD regulations, not necessarily medical need. Appointments were considered a form of treatment that occurred because of placement. Medical appointments based on regulatory requirements, according to staff accounts, occurred far more frequently than appointments generated due to medical needs based on illnesses. Medical appointments were described as ‘repetitious,’ ‘frequently occurring’ and ‘not necessarily linked to any current physical concern such as illness.’ Appointments were best described as pro-active or follow-ups: *“like an annual visit, they always…its part of their treatment, it’s hardly ever anything new”*, or *“most of them have these same repetitious appointments, like every two weeks or so”* (setting New) and *“it has to be done [medical appointments] that’s the rules for OMRDD, you check everything and everything has to be on point!”* (setting Protective). Or appointments were specific to company policy: *“there’s a regulation for the company you know that somebody is supposed to do that for the consumer, the appointments or the nurse do that is like more follow-up appointments”* and *“Company policy, there’s a guideline we have to go by: every six months, every three months, there is certain things that has to be done, they have to be seen by their doctors”* (setting Autonomous).

Accountability as this related to job security resulted in ensuring compliance with frequent medical appointments, treatments and recommendations. Any refusals or cancellation of appointments or treatments, on behalf of the men and women was seen as directly affecting a staff’s job. *“We’ll notify the nurse, we’ll write it down cause if you don’t it looks like you neglecting the consumers and you don’t want to look like you’re neglecting the consumers you know what I’m saying”* (setting New). Refusals were highly relevant in staff’s view of their job security and responsibilities. Conflicts were felt to impact this security directly, thus if an individual refused a treatment or appointment: *"We'd still take them cause the fact that my job would be on the line"* (setting New). Although seen as 'repetitious', 'frequently occurring' and 'hardly anything new' the necessity of these medical appointments were often given a life or death status, emphasizing staff's need to intervene ensuring that the men and women placed went on their appointments and followed recommendations, *"I mean he could die, it's a health concern, it's not a game, I know it's against their word, and you're supposed to grant them their word, but you don't want to take no chances, and then you* ***convince*** *them!"* (setting New).

Whether refusals occurred for taking medications or going on appointments, if they were scheduled or recommended—documented with accompanying 'medical consults,' they had to be carried through. One staff explained: *"they have a right to refuse medication and we just have to go through protocol when they do that, you can't make them take it you know"* (setting Autonomous). Or in the case of refusing to go on appointments: *"they get their problems some time [refuse to go to appointments] but we explain to them that they have to, you know 'in order to make it to the job you gotta be healthy, well you got to go cause this appointment is more important than your job, you sick you taking pills for this, you need to go'"* (setting Autonomous). As one staff aptly put it, *"They know* ***they have*** *to go"* (setting Protective).

In other instances, compliance was about adherence to company policy, governed by OMRDD regulations: *"yeah they refuse, but it has to be within reason for us to cancel anything cause like I said the state do go over once we set up an appointment , if it's not completed they [state or OMRDD]will ask questions"* (setting Protective). This leads to the need and urgency to ensure appointments are completed, as perceived by staff: *"Yeah so if they come up and say they [individual placed] don't feel good about doing an appointment, you know you can't force them to do it (whispers) you have to reschedule, but they know they have to do it"* (setting

Autonomous). Ultimately staff member's perceptions that appointments equated with OMRDD regulations and the setting's responsibility in seeing that these regulations were carried out put the same emphasis on need for compliance on the individual staff level as that on the administration level. One staff member exclaimed: *"Oh yeah, you [the setting] have to be compliant or else…like she has an appointment every three months, they have to go and get checked, blood pressure, and dermatology, and things like that"*(setting Protective). This emphasis on accountability affecting how freely individuals, especially those deemed self-consenting, were involved in their own appointments or treatments; factors associated with self-determination.

Rules: "Sharing Information." In the preceding sections, specially trained staff members, 'AMAPs' and nurses, were positioned as informants of medical information to the men and women placed and how they went about actually informing the men and women differed as did the level of understanding sought. These practices placed staff in the position of being accountable to ensure compliance with appointments, recommendations, and treatments. Staff became the 'first line' if any of the men or women had issues or concerns related to medical appointments and may, because of these issues, refuse. Many staff felt that they were the 'first line' in terms of relationships as well, that the men and women would come to them first if they had an issue or concern. Families were seen as a background resource, most staff felt confident that the men and women placed would confide in them first *"Oh family, that would be second line they would speak to us first then after that yeah, family"* (setting Protective). Part of this 'first line' was that staff were there to fulfill the men and women's basic relational requirements *"Staff fill their needs*" (setting Autonomous) and *"you know you give them an attention, you know you pamper everyone*" (setting New).

Along with this idea of the ‘first line’ in terms of close relationships, the topic of sharing information was discussed with staff. Many staff members had health related issues of their own, such as the high blood pressure excerpt above, and these medical concerns were of the same type of many of the men and women placed as reported to me in our discussions. Sharing of this personal information was not something any staff did with the men and women. For many staff members, this was against policy rules. For some this was not even considered, while for others, staff shared information related more to pragmatics of the medical issue. For example, one staff reported an interaction dealing with diabetes: *“I am a diabetic so with her she gives us a little problem from time to time, how to do her blood and all that and I try to tell her how it prick her finger and sometimes she puts the injection in the wrong place so you know I tell her but like I say they grown, they have their own minds, sometimes it gets through and sometimes then it doesn’t”* (setting Autonomous).

Some staff did relate personal information if relevant to help aid the men and women’s understanding. According to one staff member: *“we did do a relations thing, we relate to diabetes, I have a grandmother who has diabetes and has been on some of the medications that she has been on, so when they lowered it, that happened to my grandmother too”* (setting Autonomous). Because of her personal experience the staff member was able to reassure the woman that the practice of lowering the medication was ‘normal.’ This practice was the exception, not the rule.

For the majority of staff sharing personal information even if highly relevant was not practiced because it wasn’t part of agency policy and training: *“No, because that’s not appropriate,” “I just think that’s not in the contract, you know that’s I mean you come here to* *work to take care of them, make sure their health is OK," "That's not in the employee handbook, that's against the rules, you don't bring your personal life in here"* (setting New).

At best, sharing of information was limited to non-medial topics such as: *"day to day stuff that goes on like cleaning wise, I give them suggestions of what I would use or how something would work"* (setting Autonomous), or it was delegated to family relationships*, "he has experience with that because his father has that condition"* (setting Protective), but other than this staff did not disclose nor share personal information pertaining to medical issues with the men and women. For other staff sharing information had to do with reinforcing what the doctor wanted the men and women to do such as in the following: *"yeah we do what the doctor told us and sometime you remind them that not too much salt and the weight and stuff like that"* (setting New).

Across settings there were strong delineations of who was allowed to say what, to the men and women. Many staff delegated this to the nurse's responsibility: *"The nurse! They would speak to the nurse if they had concerns"* (setting Autonomous). Or it was the doctor's job *"No, no unless the doctor asks questions regarding their treatment then no [it is not discussed]"* (setting New). Resistance to sharing of information, even when the information and experience was similar, was relevant in widening the differences between the men and women placed and the staff who worked there: *"No it's never related to me like with certain things and them"* (setting New). Reasons for disclosing personal information or not, related to the aim of the setting overall. In one instance this involved reinforcing doctor's recommendations: *"I think, I've never advised to the point where like you know, I think more so its reinforcing, what we are doing here like, 'maybe it's important for you to keep your appointment' you know or 'go to this* *appointment over there because you have to take care of this' just like more of directing"* (setting Autonomous).

Disclosing or sharing information and experiences when it did occur, occurred most frequently to reinforce or secure compliance with medical recommendations: *"I'll say 'I don't eat salt and things of that nature' or maybe 'you shouldn't have the fries cause they're kind of salty', things of that nature"* (setting Protective). In another instance sharing of information was relegated to in-facility 'goals' for the men and women: *"Yes some of the guys have the goal [medication goal] like they get a medication for some reason like arthritis and for pain and this is explained to them so I think they have no problem when she [they]get the medication and she [they] know the name of the pill"* (setting New).

However in certain instances and for a few staff members, disclosure or sharing of personal information opened up a space for them to reevaluate the relationships they had with the men and women placed: *"No, I've never done that, no, no I see what you say, I just never thought of them…I don't know…I just never thought of doing that"* (setting New). Lastly one staff member was able to see personal disclosure as a function of a certain type of relationship existing between certain staff and certain men and women: *"Yes he would go to [specific staff member] he'll come to those staff, he'll ask [that staff] because they're some staff over there and they have, they close, they have…a relationship"* (setting New).

Rules: Decision-Making/Chains of Command. This role of the 'first line' also equated with job responsibility as well as job security because as the first line, staff had to ensure that job requirements were fulfilled. This was specific to medical issues and appointments, treatments and recommendations *"they have to go [to medical appointments] so we have to enforce that* *verbally to them," "we have to encourage, understand, we have to"* (setting Autonomous). In the event of a refusal staff explained to me that they fall back on protocol. However, staff also explained that although they were the 'first line' in dealing with the men and women, there was a command chain. Decisions were a result of multiple people, often entailing upper management. If a problem arose, for example if someone felt ill and requested an aspirin or some other aid this would involve multiple decision makers, *"They would talk to us staff first and then we would page the nurse and then she would tell us what to do"* or *"they really can't take anything outside of their prescriptions, anything outside of that is a matter of what the manager says is ok"* and *"everything's a command chain"* (setting New). Thus, although the staff are the 'first line' they are not able to make any decisions and must go up the command chain for anything that is outside of their normal day to day interactions. This command chain was also directly related to any individual's concerns or interests in their own medical treatments. According to one staff's explanation the command chain looks something like this:

> *"They go to the doctor, the doctor reports will have a consult and we read it when they come back and anything that need to go in the medical book has to be written in there and then the coordinator looks over it, the manager looks over it, the assistant looks over and then it goes to the nurse so a lot of decisions are made on the [individual] so they [individual] wouldn't, they might give their input but we have a nurse, a facility nurse that reads all the stuff and she follow up and makes sure everything is clear"* (setting Autonomous).

Evident in the above the role the individual involved actually plays entails, solely, going to the appointment. In other situations, such as if a man or woman questions a treatment; the command chain is also enacted. Thus, in an example related to me by a staff member concerning one individual—considered self-consenting—who wanted to stop taking a prescribed medication because he felt it was not working, the chain of command had to be initiated as a first step: *"before we can really do anything we have to make an appointment because he said he didn't want to take it anymore, because he felt he didn't need it so in that case I understand that he doesn't want to take all these pills for no reason"* (setting Autonomous). In this instance, the encounter between the individual and his doctor involves input from others rather than the individual himself. The 'team' would have to be consulted, a 'consult' filled out justifying reasons for the visit and medication review, and then an appointment would be scheduled by staff.

Despite some staff's insistence that they encouraged the men and women to be agentive when they were at an appointment with their doctors, this agentive activity was undermined in the event an important matter was involved such as changes in treatments. Thus, in routine appointments staff described their own involvement as follows: "*yeah I just sit in the background and try to stay out of the way, I intervene when needed but the for the most part I try to not deal and let them do their own talking"* (setting Protective). However, when an issue arose initiated by an individual's activity—refusing to go on an appointment involving shots administered every few months—staff intervened: "*Yeah we [team] discussed it too because she's still on the [shot] and it's like ok do she really need this shot? So at the next [appointment]* ***when I discuss it with her doctor****, or when* ***we [team] discuss it with her primary,*** *because she don't even want to go for the shot she's like 'I don't even need it'"* (setting Protective).

Tools: The Calendar, 'The Consult,' Training. With the frequency and amount of appointments scheduled in each setting, individuals were informed of their medical appointment schedules weekly and monthly, by use of a calendar. This calendar was a standard procedure and present across all three settings. Usually posted in an office close to the area within each facility designated for medications or nursing work, on this calendar was posted what medical appointments were occurring for each week, who was going, and in some cases, for what. I was assured that despite mental and academic inabilities evident in the men and women's need for placement this did not prevent use of the calendar; *"They can read the calendar"* and therefore everyone '*knows*' what appointments are occurring. Each man and woman is informed in this way across each setting and well in advance, of the appointment. Based on my field notes, some men and women checked this calendar or led me to the calendar to see that their own appointments were listed there.

In some instances, depending on the nature of the facility an individual was placed in, the clinic they attended would give them their next appointment. In this situation the individual would take this information (either as a separate appointment card, or written on the 'consult') back to their residential facility and give it to the nurse or AMAP staff (Approved Medication Approved Person: NYS OMRDD medication administration course, OMRDD 14 NY CRR section 633.17, 2003). As explained to me, these AMAP then scheduled the appointments, also entering them in on the calendar, and compiled the paperwork needed for the appointment. This paper work consisted of the 'consult'.

The 'medical consult' was ubiquitous across all interviews, across all settings. While staff and administrators spoke of the 'consult' directly, the men and women either referred to it directly or as *"my medical papers"* or *"the medical or nurse's papers."* Staff members explained to me that staff were specially trained in interpreting its meaning and further, according to some staff, the 'consult' contained *"our data."* Whether these men or women went to an appointment by themselves or with a staff member as escort everyone had a 'consult.' Referring to two men involved in the study a staff member informed me: *"Those two are* *independent travelers, they go by themselves, but everybody gets a consult anyway"* (setting Autonomous).

'Consults' were initiated by the nurse prior to any appointment, but processed by specially trained staff (AMAPs) upon the individual's return from their appointment. *"The consult is filled out before they go and we read it and document it [when they get back]"* (setting Autonomous). Information transcribed in the medical book for each specific individual became the staff's responsibility as well as work related data: "*we have a medication book and this is our data that goes on every day."* 'Consults' were seen as vital and doctors *had* to fill them out because "*doctors had to tell us [staff] what's going on with them"* but in the event staff didn't understand the 'consult,' they would give it to the nurse for greater clarity: "*she'll be like 'oh this makes sense this is why they are doing it' [test, exam, medication] and then we'll have the consumer come in and speak with the nurse about it"* (setting New).

Only staff specially trained could work with the 'consults' and the medical information they contained. This special training was so valued by staff members that it separated them from staff without such training, adding importance and more responsibility to their job description. As one staff member informed me: *"until they [other staff] get that certification [AMAP] they wouldn't be able to really answer anything or know anything about the meds because they don't have the certification, they are not familiar with it, how to understand you know what the paper, this consult is all about, and how to read the information and write it up in the medical communication book, the medical book" (*setting Autonomous).

For some staff this special training was likened to a type of 'license'. Control was then needed to prevent 'mishaps' which fell under such staff's 'licensed' responsibility. Conflicts and need for control emerged in the context of over-the-counter medicines or aids such as pain relievers, sore throat lozenges, etc. Given that such treatments are frequently seen on television commercials it became a topic of discussion in my interviews with the men and women as well as with staff. Staff who were trained as 'AMAPs' took this very seriously: *"I'm very trained, very trained, I'm certified I have my certificate so he can't get no medications that's not prescribed by the doctor so I'm the AMAP and he can't have no medicine not prescribed to him from the…he can't get no medicine"* (setting New). Thus AMAP staff controlled requests and actually intervened on the purchasing of over-the-counter relief aides *"No, never, they're not supposed to, see I'm a AMAP and so that's out of the question"* (setting New). This action of AMAP staff occurred regardless of the consent status of the individuals placed i.e., whether the individuals placed were deemed self-consenting or non-self-consenting. In one instance the AMAP training was equated with a medical practice licensure: *"You can't give him anything if it's not in that medical cabinet with his name on it, saying it's for this, you can't give these consumers anything, anything, it has to have a prescription, I'm an AMAP, I would lose my license"* (setting New). This level of control was evident even for individual excursions if the men and women were 'independent travelers' and able to go out unsupervised, *"he knows not to purchase anything you understand,"* and further, *"he can't get to do things to himself unless he gets the OK from the manager, he gets an allowance you know to see if it's OK, yes it's his money and he has the right to [use it] but he still has to answer, it's still being questioned, he still has to let someone know"* (setting New).

This specific medical training also impacted the information the men and women received and who gave them information or how they received this information. Frequently, the 'consult' was documented and returned to the nurse's work area. The nurse would then direct the follow-up needed as well as initiate, if appropriate, the signing of the consent. In most cases where consent was needed, for example to start a new psychotropic medication, signed consents were obtained from the parent, family member or legal guardian, or if the individual was considered self-consenting, from the individual concerned. Thus in many cases the 'consult' carried with each individual to their appointments contained information generated by the RN: why the individual was scheduled for an appointment, their current status, and current medications if appropriate. After any appointment the 'consult' carried back contained information generated by the doctor: documented findings, progress, side effects monitoring and recommendations, which was then returned to the medical staff (RN or AMAP) at the residential facility.

Despite the calendar, in many cases the 'consult' itself heralded an appointment: *"well he'll be given the consult so he'll know he has an appointment"* (setting Autonomous) or *"We'll give her [staff accompanying an individual on an appointment] our copy of the consult, so she explains to them, 'like you got your appointment', she talks to the doctor and she'll come back and we'll put it in the med book and then we'll call the nurse and let her know"* (setting Protective). The 'consult' was a practice exclusive only to trained staff in the setting and medical personnel therefore the men and women, even though 'they could all read the calendar,' were not given opportunity to read the consult nor were they informed of its content either prior to or after the appointment. One staff explained: *"NO! They don't see the consults because that's her business [the nurse or AMAP staff]"* (setting New).

So although some staff attempted to support individual's agentic activity while at doctor's appointments by encouraging them to speak to the doctor, fill out paperwork in the doctor's office such as their name, addresses, birth date, etc.; the 'consult' contained the important information. Often this information was not divulged to the individual and further, special training was required so that staff could understand the information written in it.

Staff, provided they were AMAP trained, or in some cases the nurse had the job of explaining medical procedures and recommendations to the men and women after their appointments. How this was accomplished involved interactions between the staff and men and women placed based on staff's perceptions of the individuals and their disability, their job responsibilities and accountability, which defined the nature of these self-other encounters, described in the following section.

Self-Other Encounters

As revealed above, based on staff's accounts, the men and women's failure to understand the complexity involved in the concepts underlining medical issues and treatments was a result, primarily, of their mental inability. Conversely, if the men and women were successful in understanding certain medical information, it was due to staff's ability to successfully relay relevant information. One theme which continued to arise, first with administrators and later with staff, involved equating behavior on the part of the men and women such as agreement or the absence of refusal, with understanding. Thus, 'understanding' as interpreted by staff based on their interactions with the men and women meant that the men and women did not refuse a treatment (usually a medication, or appointment).

Information was broken down to their 'level of understanding' as well as to what was mandated by company policy. Thus, in terms of medications a staff member exclaimed: *"yeah they know the dose, they know the time, the route, what it's for, color, yeah they know the color, they know that!"* (setting Protective). Many staff felt the men and women had information concerning their medical issues because of staff's explanations and training—all based on setting policy. One example of this concerned pill color. Identifying the color of the pills taken by each man and woman was considered highly relevant information that was directly related to staff's training and their ability to ensure understanding in the men and women they worked with, "*they know the color!"* (setting New). This training relates to the OMRDD medication administration training and AMAP training (OMRDD, 2003). Staff trained as AMAPs provided follow-through in relating important information to help the men and women 'understand' their treatments. In one example this encounter was reported as follows: *"that is the staff's job, management's job, we are all AMAP certified in order to give out medications so if there is a new medication that they are given they are told how to take it and what it's for and we ask them questions: 'Do you know what this is for?' 'Do you know why you are taking it?' And most of them can give you the answer*" (setting Autonomous). Understanding was assured by the response of the individual, *"if they get a new medication the staff who administer the medication will say 'ok you have a new medication and it's for this or for that and they will say 'ok', and they will understand"* (setting New) *or "He understands, once you give him the answer he can repeat it back"* (setting Autonomous). This minimal depth of understanding is not only acceptable but valued; it is indicative of basic skills training evident in staff's interactions with the individuals. However it reinforces issues relating to mental inability, especially when such valued and acceptable standards of understanding are applied in different contexts: *"We had the doctor explain everything and we kind of said 'well that's just like having this' and she was like 'all right' but then you see her next time, she's like 'what?!"* (setting Autonomous). In another example an administrator explained: "*when you ask them 'what's this medication for?' and they will answer*

‘I don’t know’ and they’ve been taking it for years…that’s just the nature of the population” (setting New).

More in-depth explanations were offered to the men and women by staff members only in the context of refusals. In such situations staff would attempt to make the individual ‘understand’ on a deeper level, *“there is a liquid medication for the vitamin, she don’t like it, so staff try to explain it to her that it is a vitamin, and it’s good for her body and she sometimes no takes it and said ‘no!’ we say ‘you drink it, it’s good for your body’ and so she take it, we explain it to her”* (setting New). Some staff members stated, although this was not often substantiated in my interviews with the men and women, that doctors inform the individuals about their new medications, reasons for being on the medications, or need for treatment. Refusals are then due to the behavior of the individual *“I think the doctor does that, yes the doctor speaks to them [about medications and treatments]”* (setting Protective), and therefore the staff does not need to go into any deeper explanation. Other staff members stated that in the case of refusals associated with new medications, staff members need to reinforce why a new medication has been recommended in the first place. One staff described the process as follows: *“let’s say it’s my turn to give out meds that evening, all of us are AMAPs, when it’s the first evening you’ll explain ‘you have a new med’ and what it’s for and you know you try to break it down the best for their understanding as best as possible”* (setting New). For some staff, this deep explanation involving the necessity of the medication or treatment and the consequences if the medication/treatment was not taken led to better understanding and so to compliance in taking it. In speaking about one individual [deemed non-consenting] the staff member felt this person would be able to make her own medical decisions after careful explaining. This staff member based her views on an experience with this individual over an episode dealing with eye drops for glaucoma. Her example involved the following encounter: *"After explaining to her what it's for and it would help her like to maintain her vision and stuff like that she said ok and she tried it and now she takes it willingly"* (setting New). In this example the staff connected the treatment to the condition, and that no treatment or the women's continued refusal of treatment, would likely result in the loss of her vision: *"she knows that if she doesn't [take the eye drops] the condition, glaucoma, will worsen and she might end up losing her sight."*

Chapter Summary

Although the three settings had different practices ranging from autonomous to protective, the difference apparent in each was a matter of degree not kind as this relates to the level of participation each man and woman diagnosed had in their own health care. None of the men and women involved in this study came to these settings on their own, voluntarily; all were placed in the setting by others. Their 'placed status' entailed other's authorized the treatments and services provided by each agency, and began at their initial placement. This practice once set up was not known to change.

Division of labor within the settings entailed that staff: initiate appointments, follow-up on recommendations, explain information to the men and women, and enforce compliance with medical recommendations, treatments, and appointments. The men and women's actual level of activity based on staff and administrator accounts involved: compliance—going to their appointments and taking their prescribed medications and treatments. Other than the medication administration training, where staff 'teach' the men and women to recognize the color, name, dose, and function of the medications they take, there were no leading activities in the settings that were designed with the intent of building skills in 'managing' their medical and mental health knowledge and skills. There were no leading activities which could be appropriated by the men and women with this intent in mind. Rather than developing an understanding of 'concepts,' a focus of the settings was geared toward memorization and information at the sensory level: what color, time, name, etc.

This chapter reports the findings on the setting as a source of development for the men and women diagnosed with intellectual (or other) disability. Within this section my aim was to focus on the socially contrived organization of the settings as enabling or limiting types of self-other encounters between the men and women placed and the professionals (medical practitioners as well as employees) with which they interact. Types of self-other encounters involved either dialogical or monological relations as impacting the movement of the men and women toward more 'ideal forms' of social knowledge mediating competent consent decision-making. In these settings, as proclaimed by their mission statements and goals, 'ideal forms' involve a focus on independent functioning, autonomy and self-determination. Yet evident in the above findings, 'ideal forms' available in the setting relating to decision-making involved command chains and hierarchical decision-making, where the men and women did not authorized the services rendered to them and overall, had little to no participation and input in the command chain. Ideal forms of understanding, as standards within the settings applicable to the men and women placed, required minimal cognitive processes based on sensory discrimination and elementary, lower functions: saying yes, identifying the color, name and use of a medication. 'Knowing' the underlying concepts involved in medical and mental health care was often perceived as too complex for the men and women's understanding. Knowledge and information which could lead to developing this understanding was often not given. In many instance this exclusionary practice was validated as "shielding" the individuals from social knowledge and information which was felt could be harmful to them or induce unnecessary anxiety.

In exploring the settings in which these men and women were placed I attempted to ‘close the distance from the experiences of the learning mind and the world situating it’ (Chaiklin & Lave, 1996). According to a situated learning framework, learning in a community is not about merely acquiring knowledge or skills, rather it involves social participation. Encouragement offered on behalf the setting, to participate in legitimate forms of adult activity relative to health care on behalf of the men and women was absent across all settings. Tools and signs mediating this exclusion as an active decision on the part of staff and administrators involved: diagnosis, IQ scores, ‘consults’, parents, guardians, correspondents, and regulations. Seen through a historical lens policy and practice was derived from standards and beliefs set at the time each agency emerged within the industry. Although the newer setting used different language forms, the underlying practice remained the same. And these practices once put in place rarely changed across the life of the individual placed. The cultural-historical development of the industry as illustrated within these three settings characterizes expansion—each agency has become larger offering services to more individuals—but not necessarily involving change in their historically situated policies, practices and beliefs.

Because administrators and staff member’s perceptions of the men and women’s ‘mental’ diagnosis, individuals were often not trusted as valid sources of knowledge, as having valid understanding, nor seen as valid recipients of certain kinds of social knowledge. Practices which excluded their participation in important matters pertaining to their own life were evident and validated by their portrayal as being incompetent. Even when engaging in legitimate forms of activity, evidenced in certain forms of language use, this was often seen as a mask covering an underlying deficiency—faulty reasoning ability—leading to possible dangers for the individual. Thus for these men and women their adult status and their ability to access adult forms of social knowledge and information were constantly negated and rarely legitimized.

Markova (2003) elaborates Vygotsky's (1978) claim that 'all higher functions originate as actual relationships between human individuals" (p. 67) in that we can understand social knowledge and how this mediates ways of knowing by looking at language arising out of social representations or common thought held by a society. In the above accounts given by administrators and diverse staff, the social representation associated with intellectual disability affected ideologies, policies, practices, self-other encounters and the extent to which these men and women could access and appropriate cultural tools and signs. This had the effect of seriously curtailing their access to important and necessary information. Social representations of intellectual disability were explicated as unchanging and involved limited cognitive functioning due to brain damage, precluding what they could possibly learn. Stemming from this, each setting as an 'arena for learning' was structured in a way to contain and support existing skills while negating the possibility for other skills such as medical and mental health treatment decision-making to emerge and develop.

This chapter examined the culture of practice from an objective or outside view of the setting in terms of employees perceptions of the setting, its aims, goals, objects and accountability issues that appear to drive practices: accountability to State and Federal Regulations and Correspondents or legal guardians on the part of administrators; accountability to job responsibility and job security on the part of staff members. As part of the methodology I employed in this study, I met with the men and women first and so used their insights and social knowledge in guiding my discussions with administrators and staff. I present their accounts last in order to explicate how the culture of the settings impacts their development in terms of appropriating health care knowledge and information as this relates to developing competent health care decision-making activity. In the chapter to follow I present the findings of the analysis involving the men and women's accounts, completing the examination of the 'culture of practice' from an 'insider's perspective' based on their reports of their self-other encounters.

Chapter 7: ‘Knowing’

Introduction

In this chapter I report the findings of the narrated accounts given by the men and women. In presenting these findings I elucidate the relationship between the specific cultural settings as reported in the preceding chapter and the 'knowing' of the individuals placed within. Moreover, the influence of this relationship on the organization of their knowing as this relates to their health care decision-making activity can be explicated. Within this chapter I link the previous findings reported for the setting and the assessment, with their own reports, to more fully understand their ways of knowing and how this affects the development of their decision-making and choice.

In the sections to follow I report the findings concerning the men and women's 'knowing' as a result of their 'situatedness' and the opportunities they have for 'knowing how to know' as a factor shaped by their relational experiences, in as well as outside of the settings. These findings are a result of the activity system analysis and include the elements of 'Subjects,' Objects, Rules and Tools. I begin with the 'Subjects' element involved in this activity analysis relating to the men and women, specified by setting.

'Subjects'

Setting Autonomous. Eleven men and women diagnosed with a disability from setting A were recruited to participate in this study. Of these, seven individuals were deemed to be 'self-consenting' and they all were placed in the 'supported apartment' facilities of locations 'a' and 'c' described in the preceding chapter. The remaining four individuals were deemed 'non-consenting' and resided in facility 'b' a group home like facility requiring 'round the clock' staffing.

For eight of these men and women they were reported as having previously assessed IQ scores within the Mild range (IQ scores of 50-71). The remaining three were listed as having IQ scores within the borderline range (IQ scores of 72-85); these individuals did not have a diagnosis of Intellectual Disability as defined, but had primary diagnoses of: Autism, Learning Disability, and Attention Deficit Disorder. Of these three, one was considered ‘non -consenting’ while the other two were considered ‘self-consenting.’ There were five females and six males and their ethnicities were composed of: white, Caribbean, Black, and Hispanic. The age range for these men and women spanned from 26-years-of-age to 64-years-of-age. Five individuals were below fifty, six individuals were fifty-one and above.

For these men and women placed in setting Autonomous their time placed in the setting (or other previous settings prior to the current one) ranged from three to twenty-nine years. None of these men and women had ever experienced institutionalization, and all had resided with their families until placed. Many of these men and women had spent between twenty-three to forty-five years living at home with parents or extended family members, or families of their own (husbands, wives, children) prior to being placed. For a few of these men and women, due to their age, the amount of years living outside and within such settings was almost equal. For example one individual lived for thirty-six years with family and had been placed for twenty-eight years, while for another she lived for forty years with family and had been placed for twenty-one years.

Current treatment for medical disorders included nine people, eight of whom had two or more diagnosed conditions. There were two individuals who had no medical diagnosis, but were being treated with daily vitamins. Medical diagnoses, from most prevalent to least characterizing these medical disorders consisted of: Hypertension, High Cholesterol, Allergy, Epilepsy, Diabetes, Glaucoma, Asthma, Ulcer, Lupus, and Heartburn.

Psychiatric disorders and treatment, currently prescribed psychotropic medications or treatment by a psychiatrist included seven people. Psychiatric diagnoses as listed included: Bipolar Disorder (hereafter disorder will be D/O), agoraphobia, Generalized Anxiety D/O, Psychosis NOS, Obsessional Compulsive D/O, and Autism. One individual was presently prescribed a psychotropic medication (an anti-depressant) but did not have a psychiatric diagnosis listed in the files presented to me. While another individual had started ‘seeing’ a psychiatrist and he informed me he *“would start taking meds soon.”*

Eight individuals had past exposure to traditional education, including being home-schooled. The three remaining individuals had little in their personal history as ‘filed’ and their reports were not revealing as to the nuances between a ‘special education certificate’ and a ‘high school diploma.’ For example one individual when speaking of his past educational experiences claimed: *“it was a high school diploma! Like a certificate, like you know… I don’t even know where it’s at.”* Another individual spoke about a ‘star’ program: *“Yeah I went to school, I graduated, I got a regular diploma, the tests, where you get a star, I didn’t get that because I didn’t pass, I mean that’s the RCTs that’s how you get the star on the diploma, I didn’t get that because I didn’t pass, I was in ‘special ed’ but it was RCTs that you had to pass to get the gold seal on the diploma.”*

Day time activities included paid work outside of the setting for six men and women. One individual engaged in volunteer work, an activity she was already engaged in prior to her placement, two people attended a ‘sheltered workshop’ and the others attended a day habilitation program which apparently offered a stipend for attendance, for some this was considered ‘pay’. One woman had previous experience of paid employment in a large corporation as a ‘porter’ and also engaged in factory work, while another women had previously been employed as a messenger, a position she held for ten years.

Outside interests these men and women relayed to me were: taking an adult education course at a local four year college for remedial math. One woman was taking an adult education course at a local four year college for remedial math. This woman was taking this class with her boyfriend, but she said, she did most of the work for both of them. She spoke of her ability to do ‘figuring’: *“I do all the figuring myself, I don’t use no calculators.”* Other interests involved attending a dance program at a local dance hall, operating as a DJ for parties, engagement in a ‘special athlete’ organized sport group, and participation in church which included being a member in the church choir. One woman was an active member of a support group specific to her medical diagnosis. Two individuals had friends who were not part of the setting and they would often go out at night or during the day to meet with their friends whom they communicated with via cell phones. A curfew existed at some facilities in setting A. One individual leaving the facility one night while I was there explained to me that he was going to meet his friends and was in a hurry, *“I got to be back here by eleven PM.”* Another individual was very involved with his family, including his own family consisting of his three children. He often coordinated activities to do in the community with his children and family. While we were discussing the research this individual explained to me how costly things were, *“like to take the kids out to see the circus, you need money man.”*

All of the men and women placed in this setting who participated in this research were considered by the setting as ‘independent travelers’ which meant they were able (as previously assessed by the setting) to get to their community based activities such as work, recreational, medical appointments, etc., on their own using public transportation which was, in this urban area, easily available and varied (bus, taxi, subway, and even walking). One woman opted to use a medical transport system to take her to all outside activities. This entailed much planning on her part as the service was limited to one round trip per day, as she informed me, and was funded by her Medicaid Insurance. She said she opted for this mode of transportation after sustaining an injury from a fall in the subway.

In setting Autonomous depending on facility (a, b, or c) the individuals who participated in this study lived in their own apartment alone (five people in location ‘a’ and ‘c’) or shared a room or apartment with another person (six people, two who shared an apartment at facility ‘c’, the rest resided in facility ‘b’).

Setting Protective. Ten men and women participated in the research from setting Protective across the three different facilities and locations involving ‘a,’ ‘b’ and ‘c’. None were considered by the setting to be ‘self-consenting’ and none signed their own consents. Most of these individuals had legal guardians or correspondents (parents, family members) signing consents for them.

These men and women had previously assessed IQ scores within the Mild (IQ scores of 50-71) and Moderate (IQ scores of 36-49) ranges. Their ethnicity varied but was predominantly white, with Caribbean and Black characterizing the rest. The age ranges for these men and women was between 30 to 59 years. A greater majority of these men and women were under 40 (six individuals), while the remaining four were above 49.

Time placed for these men and women ranged from four to eleven years and some had experienced short stays in institutionalized settings immediately prior to their current placement. For most of these men and women, they began their placement upon the opening of the specific residence they were placed in, around eight to nine years ago. One woman informed me she experienced a short term placement in a 'juvenile home for troublesome girls' when she was about 13 or 14 years-of-age. According to her account: *"they [her parents] had to put me away cause I was coming home one o'clock in the morning…my mother was worried."* Years prior to placement, ranged between 23and 47 years and for most was spent with family in local communities and neighborhoods. Most of these men and women grew up in the suburbs or residential areas within the city limits.

Based on reports included in their 'charts' supplemented by self-reports, six of these men and women has some exposure to traditional education prior to being placed in special education. The remainder had experienced solely special educational services. Medical conditions currently diagnosed and treated in order of frequency included: Hypertension, Syndromes (of which there were three), Hyper and Hypo Thyroid, Glaucoma, COPD, Seizure D/O, Allergy, Diabetes, High Cholesterol and Leukocytosis. All of these men and women were currently being treated for one or more of these disorders.

Psychiatric disorders receiving treatment with psychotropic medications and psychiatry were diagnosed in five of these men and women. Psychiatric diagnoses included: Impulse Control D/O, Generalized Anxiety D/O, Depressive D/O, Dependent Personality D/O, and Schizophrenia.

Day time activities for these men and women included paid employment outside of the setting (one individual) a position he held prior to his placement and which continued to be on-going. Others described being in a 'sheltered workshop' run by another agency while the rest attended a day habilitation program where they received a stipend for attending, most referred to this as 'pay'. According to one woman's account of getting pay: *"oh we get paid this week, matter of fact, the 12th, and we're going to have a Valentine's party too and we still getting a paid check."* For this woman, she expressed her pleasure that even though she and others would be involved in a party they still got paid, "*for being there."*

Outside interests primarily involved family visits. One individual was part of a 'special athlete organization' and participated in organized group sport training and events. He required transportation to get there. For those men and women who had little contact with family, their time and social interactions occurred within the setting and involved offered activities organized by that setting or other settings like it such as day programs, recreational 'dances', holiday parties at one of the many other facilities within the setting. Another offered activity involved participation at self-advocacy meetings which were held at the setting's main building. In each of the facilities I visited pictures lined the walls of vacations the individuals took with staff. Some of these were cruises while others involved visits to other states.

In this setting, across all three facilities, the men and women shared a room with another person. Only two individuals, both women, had their own rooms.

None of these men and women were considered 'independent travelers' and all were dependent on the setting to provide transportation for them, either to get to recreational activities, sporting events, day programs, visits to family, or other setting locations.

Setting New. Eight men and women participated in the study from setting New across four of its facilities 'a,' 'b,' 'c' and 'd.' Three individuals were considered 'self-consenting' (co-represented in this setting's language) while the remaining individuals were not and had others (legal guardians or correspondents such as parents or family members) sign their consents for them (in setting N's language: *"represented by others"*). The three individuals who were considered self-consenting were placed in facilities 'a' and 'c.' The ethnicity of the men and women consisted of predominately Black and Hispanic with white making up the remainder. Ages for these men and women ranged from 25 to 73 years. There were five individuals under 49 and three individuals above 55. Individuals had previously assessed IQ score ranges between Mild (50-71) and Moderate (36-49).

Time placed for these men and women ranged from three years to sixteen years. Three individuals experienced previous institutionalization, two of whom experienced such institutionalization starting in their early childhood (one at three-years-of-age and the other at twelve-years). One individual had experienced institutionalization in adulthood (when she was 31).

For most of these men and women, their background experiences included living at home with their families in neighborhood settings which for most, entailed life within urban areas. Educational experiences included exposure to traditional education for three individuals, one of whom was 'home-schooled' while the other two individuals had experienced traditional education prior to placement in special education. The remaining five men and women experienced special education and for two who had experienced early institutionalization, their exposure to special education began in their adolescence upon release from the institution.

Medical conditions for which treatment was prescribed consisted of the following there was no order of frequency for the conditions listed: Diverticulitis, Glaucoma, Hypertension, High Cholesterol, Allergy, Seizure D/O, Arthritis, and Diabetes. All but one of these men and women were currently diagnosed with a medical condition for which treatment was currently rendered. For the only individual who did not have any medical health concerns, he was being treated with a Multi-Vitamin and received treatment—four psychotropic medications—for his diagnosis of Autism.

Psychiatric diagnoses requiring treatment by psychotropic medications and psychiatric services included Atypical Psychosis, Schizophrenia, Impulse Control D/O and Autism. Day time activities were limited to attending a day habilitation program run by the setting itself, which was also located in the same building, or run by other agencies within the service provider system. None of these men or women was gainfully employed in a job located within the community. One individual attended a day habilitation program ‘without walls.’ This, as it was explained to me, entailed no specific program within the building or in another agency that he physically attended. The day program ‘without walls’ was uniquely designed to meet both his and the setting’s needs due to the fact that he was resistant to attend the already existing program offered by setting New as well as day programs offered by other agencies within the industry.

Activities outside of the setting occurred only for those who had family they could visit otherwise all activities were provided by the setting and included escorts to medical and mental health appointments, escorts to board meetings, and escorts to parties and celebrations sponsored by the setting itself and held in catering halls located in the community. Only one individual spent time away from the setting. Considered an ‘independent traveler’ he often visited his old neighborhood and hung out with friends there. For some individuals the spaciousness and diversity of purpose of the large building housing setting New served as an activity in itself. At least one individual, from facility 'b' made use of the lobby and enjoyed *'hanging out'* there with the security guard. This individual utilized a medical transport system, funded through his Medicaid insurance, which gave him opportunity to interact with drivers as well as others waiting in the lobby, who were not part of setting N, for their transport services.

Five of the men and women placed in setting New shared a room with another individual, and three individuals had a studio apartment to themselves, though they did not cook their own meals there.

Only one person was considered an 'independent traveler' and he was able to make us of public transportation. Excluding the man who utilized the medical transport service, which he took solely to and from his residence to his day program, the remaining men and women were escorted by staff to all activities, medical appointments, and excursions in the community utilizing public transportation or a van provided by the setting.

Opportunities for knowing

'Knowing' implies activity; however, different forms of knowing demonstrate different forms of activity and different levels of engagement in what is to be known. 'Knowing what' and 'knowing that' or 'knowing for' are categories of knowing which provide opportunity to identify institutional agendas. As seen in the preceding chapter, one such agenda is accountability for taking care of the men and women; often accomplished through negotiating compliance. However, as Glick (1998) maintains 'knowledge that counts' is often the knowledge possessed by individuals. 'Knowing that' and 'knowing what' are different types of knowledge, both ingredients in and necessary for accomplishing some task (Glick, 1998) but ‘knowledge in action’ provides a regulative principle of the knower’s activity, where activity counts for knowledge related to the activity and not knowledge disembodied from it.

Billet (1995) on the other hand states that ‘knowing that’ is declarative, comprising facts, information, and assertions while ‘knowing how’ is procedural and enables skillful action. Procedural knowledge is connected knowing and implies collaboration. Billet stresses that problems and their solutions are set in social circumstances so such goal-directed activity is shaped by the social circumstances and this patterns types of knowledge or knowing as activity and influences its construction. In the sections to follow I report the findings on the different types of knowing, as activity, evidenced by the men and women. These types of knowing are also seen as a result of the problems and problem-solving experiences they have had through which they have gained knowledge of what problems are worth solving (Goodnow, 1990).

Findings revealed that for many of these men and women what they knew was a function of their ‘situatedness’ in the setting. Themes emergent from their narrated accounts involved types of relationships and constraints on activity. Such themes involved ‘knowing that’ and consisted of: ‘treatments are to be accepted,’ ‘there are no alternatives,’ and ‘doctor appointments are frequent occurrences possibly indicating illness.’ ‘Knowing what’ was also specific to information made available in the setting and involved: ‘what color,’ ‘what time’ and ‘what med’ (Claritin, Synthroid, Haldol, Lithium). ‘Knowing what’ knowledge also involved ‘knowing what for’ and included: ailments (allergies, thyroid, and nerves) and psychological states (unhappiness).

‘Knowing that’ involves a more hierarchically arranged knowing, it implies some connection to the individual and other events, factors, things and relationships. ‘Knowing that’ implies some level of personal engagement with what is to be known. ‘Knowing that’ involved how the individuals perceived their ‘siuatedness’ in the specific settings. Examples based on the men and women’s accounts entailed the following: You can’t say no, talking to staff can have unexpected consequences, you can ask questions but they [everyone else] has a right to answer them or not, and some information is none of your business. ‘Knowing that’ also entailed: rules change, rules are arbitrary, direct care staff members have power but other staff members higher up in the command chain have more power, direct care staff members have more information than you have, and doctors don’t listen.

‘Knowing how’ involved the tools these men and women appropriated in order to develop learning how to know as this related to health care decision making activity. In some cases these tools were not appropriated from the setting but were actively pursued from other resources available in the larger community; however, one had to have access to these socio-culturally distributed resources. Accessibility was affected by the location and layouts of the residential facilities within the three settings. While for others knowledge appropriated from their experience in the setting characterized their type of ‘knowing how’ and dealt with relationships within the setting. ‘Knowing how’ links the setting, its location and layout, its approach and its practices to the tools that, for some of these men and women, they were able to appropriate.

In the sections to follow I present the accounts of the men and women’s knowing as this relates to ‘knowing how’ as a consequence of type of self-other encounters and relations involved. Monological or exclusionary relations in self-other encounters involved limited information which constrained knowing how to know. Dialogical or inclusionary relations involved reciprocal exchanges of information and enabled development of knowing how to make a choice and a decision relating to health care. I return to their assessment responses, linking these responses to their narrated experiences, life history maps, and perceptions in order to elucidate this. I begin by sounding the distance between the men and women's reality as perceived and that depicted in the capacity for consent assessment measure.

Depictions versus reality

Asking the men and women the question 'is this like what your experience at the doctor is like?' revealed that the health care experience depicted in the vignettes of the assessment measure held little relevance to the actual lived experience of these men and women. For many individuals their actual encounters with doctors and doctor appointments did not include the elements painstakingly articulated in the vignettes; the vignettes presented an 'ideal form' of self-other (patient-doctor) encounters involving dialogical relations where information was distributed allowing decision-making to be a co-produced process.

Initiation of Appointments. One area in which the experiences of these men and women departed from that depicted in the vignettes concerned how doctor appointments were initiated and why. For some this was indicative of the setting in which they were placed *"people here [the setting] believe in doctors"* while for others it was for routine checkups to make sure they were healthy *"So I can stay healthy, so I could keep my teeth healthy"* and *"well its routine to go."* But as seen in the preceding chapter from staff accounts, appointments were repetitious, hardly anything new, and this was also communicated to the men and women, thus for many their responses to this question was based on their experiences in the setting: *"I don't know why I go, I just go"* and *"I don't know why I got to go for the doctor for…I have no idea.* One outcome of their experience with multiple appointments was to infer illness: *"Cause I go to the doctor?*

I'm allergic to cats?" Well they check up on me to see if I'm ok", "Because I'm sick?", "Because of my condition?" or "for my nerves?" Doctor appointments were often initiated by staff and not always connected with a reason that could be easily discerned by the men and women: *"The staff sent me up there, the nurse on duty too"* or *"cause they made me go to get medications [psychotropic medications]."*

In cases where the reason for the appointment was evident the men and women were able to connect the reason for going with an apparent malady: *"So I could get a checkup, I had a dental appoint last week and I had no cavities"* and *"My tooth was loose one time, he [dentist] fixed it."* For one man, obviously having a problem hearing which he found especially difficult because he enjoyed watching television, he reported his problem to a staff member who then made an appointment with an audiologist. Robert, a 73-year old man previously assessed with an IQ of 46 was considered self-consenting. He relayed the following experience: *"Yeah when I can't take it any more with my ear problem, my ear bothering me, I can't hear the TV and they made me an appointment to go to the ear doctor, because I can't hear any more, and when I watch TV its awful quiet and you know that gets me upset because I can't hear no more."* His experience of the appointment was enlightening to him *"he took, the doctor had to clean my ear and then he gave me some kind of ear drops to put in my ear and the doctor says if it doesn't do it nicely I'll have to go for a hearing test."* But the ear drops were working for him, and Robert had information on why the ear drops were prescribed: *"I think so yes, when I see the TV I could hear better…I never had that done either, but the ear drops make it so the wax not be so hard and you know when they did that [irrigated his ears to remove excess wax] a piece of hair was in my ear! You know I don't got hair on my head how did it get into my ears [laughs]."*

Robert's experience was not the norm however. For most of the men and women staff at the setting made their appointments according to schedules, follow-ups, and routine check-ups: *"My staff change the doctor, my staff chose this dentist"* and *"I'll ask staff if I got an appointment and she'll say 'yeah this week you see Dr. [--]'."* Often the men and women pointed to a calendar on which were listed appointments with their names. In some cases, the men and women were not made aware, in advance, of when the appointment would occur. This caused concern for many of the men and women ranging from simple routines needing to be altered as in Robert's example: *"she didn't let me know…I didn't get to eat breakfast because I wasn't expecting to go to the doctor that day."* Failure to be alerted to appointments also occurred as a function of the many staff members involved in these types of organizational structures. Sherry's example highlights this. Sherry a 47-year-old woman who was not considered self-consenting had a previously assessed IQ within the Moderate range (an IQ of 44). Sherry spoke about a similar situation as Robert's though not intentionally complaining as in Robert's case. According to Sherry staff inform her when appointments occur, on the day of the appointment not beforehand. Her account of how she learned she had a dental appointment indicates not only that she was not informed prior to the appointment but neither was the staff member who would escort her—despite the calendar. *"I went there about 10 [to the dentist] I ain't going back downstairs today [she attends a day program in the same building where she lives]. They say [staff in the day program] 'you want to sign in?' [Then] they said 'you don't have to sign your name in the book downstairs,' they say 'you got an appointment so go back upstairs,' we came back [from the dentist] around 2 or something."*

Based on staff and administrator's accounts, the men and women are always informed prior to appointments and informed of the nature of their appointments and why they need to go.

However as related here by the men and women, this appears to be more of an ideal rather than actual practice, echoing Wolfensberger's (1989) rhetoric versus reality argument. Not being informed, perhaps because no need to do so is apparent, speaks to the how the personhood of these men and women is perceived, and the 'value' of their social role, by professionals providing treatment or care to them.

Medical Appointments: Experiences and Relations. A majority of the men and women said their experience with doctors was not like that depicted in the vignettes. Specifically 18 men and women voiced this, while two individuals said sometimes their experience was like that and eight individuals agreed that their experience with doctors was like that depicted. However, as our dialogues progressed it became clear that ultimately only three people had experiences closely aligned with that depicted in the vignettes.

For the eight people who said their experience was 'like' that depicted in the vignettes this was strongly related to how they felt about their doctors, their doctor visits and what these visits meant to them. Thus, some men and women liked their doctors and enjoyed visiting them. This provided an opportunity to talk with someone other than staff members. They liked the opportunity appointments gave them to talk not only to doctors but other people in the doctor's office. For others, the visit to the doctor was an escape from routine, a chance to be in a different setting, a chance to travel independently as it gave them a place to travel to. Lastly, going to the doctor was not unpleasant as long as it did not interfere with work or other more socially pleasurable activities. Therefore, as stated by these men and women, medical appointments were visits that were not medically or health informing but rather allowed for diversified social experiences which they enjoyed. The experiences of the three individuals, one man and two women whose felt their experiences were similar to those depicted in the vignette is presented below.

Carol

Carol is a 61-year-old woman who has a previously assessed intellectual functioning level of Mild (IQ of 64), but there were also reports indicating intellectual functioning in the borderline range though no IQ score was listed. Carol had medical diagnoses of Diabetes, Hypertension and high Cholesterol for each of which she is prescribed medications. Considered self-consenting, Carol has been placed for approximately twenty years, all of which have been lived in the present apartment, a studio in which she lives alone. Prior to her placement Carol lived with family members, she also experienced regular education and attended a Catholic school. Carol was familiar with the city; she described herself as having *"always been a city girl."* She experienced special education in the form of a vocational school, because *"they thought I was 'slow' because my mother was an alcoholic."* She has had various employments and currently holds a 'supported work' position in the food service department for a community hospital where she is a dishwasher and cleaner. Carol chose the allergy vignette because she suffers from allergies, she is not under a psychiatrist's care, and because she could not relate to the dental vignette: *"dental I'm under* [she is being treated by a dentist] *my teeth are bad and there is nothing I'm going to do about this you know I'm 61 and I'm too old for braces."*

Most relevant here is Carol's use of the television and other knowledge resources in her community, most notably, the pharmacist at her local drug store. Carol received most of her medical services as part of a local community based clinic associated with a hospital, not connected with the service provider industry specific to the settings involved in this research.

One result of this is that she often received patient satisfaction surveys from the clinic. These surveys, she said, asked her many questions concerning her medical treatments, interactions with personnel, and how satisfied she was with her overall experience there. Carol appropriated this survey as another tool to help herself because, as she said, *"this has good questions to ask".*

Much of Carol's knowledge about her medical conditions emerged through her own experiences. For Carol in relating to the woman getting allergy shots: *"you should think about it you know, ask, but it's good for you to think about things before you go into anything like that."* Throughout our time together Carol's theme was you have to think and you have to learn to ask questions. She informed me that her nutritionist was very good because the doctor *"gave me some advice and I have to get used to her and she'll show me like boxes [from different foods] yeah so she's good though and I trust her, she tells me the facts and the combines, yeah that's how she's teaching me, you know instead of just following the diet, I just, she is teaching me things like that. They cut me down to two pills and I'm doing good right now."*

Carol also knew that doctors can make mistakes, she was apparently prescribed one medication for pain by one doctor, she had a pain in her leg, and another doctor prescribed something else for her arthritis and the two caused a reaction. Now she takes all her medications with her or a list of them, *"You know you gotta learn to ask the doctor questions too, that's what I have to do, ask questions."* Carol noted her doctors change a lot, a problem for the nurse at the setting but not for Carol who saw it as an opportunity, *"the nurse* [at the setting] *hates that because sometimes you know they have different opinion, but sometimes you find out something different from another doctor."* Having different doctors didn't bother her, rather she felt secure because of the supervisory hierarchy and modern technology available at the hospital and clinic she attended: "*I think they can consult somebody like a supervisor or somebody and then* *somebody you know the supervisors yeah they have to check all the medications on computers now."*

Carol was familiar with the 'system' of her residential setting, she knew that her appointments were scheduled with her while she was at the doctor's office but she always had her *"medical papers"* (the consult) with her. The 'consult' was a significant topic in the preceding chapter. Many of the men and women in this study referred to the consult as their "*medical papers*." 'Consults' had to be picked up prior to going on any appointment and returned to the 'office' after each appointment. The 'consults' contain the following information: the reason for the appointment (follow-up, specific problem to be evaluated, renewal of prescription for medications, including psychiatric medications); reports of progress—medical and mental health related, medical history; medications, dosages, and times; and lastly there is space for recommendations which is filled in by the practitioner being seen. Carol did not read the 'consults.' She did not say why only that *'the nurse writes my medical information down.'* But in any problem situation, she always lets the 'residence' know first and then they give her the ok *"they'll tell me to go ahead and make the appointment so I did."* Carol related to me that her doctors (at the community clinic) gave her choices and offered her alternatives, according to Carol: *"Yes they do that, yes you have choice in that, but I think you could [refuse a treatment] if that's how the tests come out, I think that's what they go by."*

Carol felt she would not take something medically prescribed if she felt there was something else that *"worked better."* As an example she told me she is prescribed a 'shampoo for dandruff' but she doesn't like the way it makes her head feel. Carol learned from her pharmacist she can get things over the counter instead of using prescription medications *"Like I got a shampoo from the skin doctor but I don't use it like he says to I only use it when I need it* *for the dry scalp but I like to use Head and Shoulders, it works better for me than that stuff. And sometimes they tell you, you get things over the counter, like the Ibufrin [sic] so I can buy over the counter some of the other stuff you can't get without a prescription like that shampoo."*

Carol uses her pharmacist to explain what medications she can take with what, because she has had experience with medication interactions having bad effects. She knows this information can be accessed by computer, whether in the doctor's office or in the pharmacy. For Carol, *"this is what you got to find out from a professional before you take something you have to ask the pharmacist but you shouldn't take something if you don't know what's going to happen."*

Carol had a way of appropriating resources, (tools) all of which were outside of the specific setting. Not only did Carol use her pharmacist and her own doctors, she learned a lot from television commercials, *"you know you see it on TV, ask your doctor."* She was also informed about allergens *"ragweed levels and such were high" by* the radio, preferring to stay indoors and keep her windows closed when levels are high.

Carol used a community health clinic for most of her medical needs. This was not a clinic run by agencies geared to providing services for the 'special needs' of men and women diagnosed with intellectual and other developmental disabilities. Carol, based on her status as a patient of this clinic, often received from her clinic a 'patient satisfaction survey.' She brought this survey out to show me during our encounter; it was fairly extensive. For her this became another tool, *"these are good questions to ask."* Carol decided that she was not going to fill it out and return it has she had done previously with the others; she would keep this one as a guide to help formulate questions to ask of her doctors. She added: *"I'm not going to show this to staff at 'the office'."*

Carol's responses to the assessment tool where characterized by frequent use of personal-historical knowledge as well as socio-cultural knowledge. Carol had newer information concerning medication interactions, side effects, and how her illnesses were influenced by other conditions and interactions with her world. However, this socio-cultural knowledge was gleaned from sources other than the setting in which she was placed. For Carol taking care of her own health entails that "*it's very important to open your mouth, you got to open your mouth."* 'Opening your mouth' for Carol entails asking questions. Carol's response on the treatment choice question from the assessment was as follows: she felt she could not answer because it was up to each person to decide. Carol felt she couldn't make a decision for someone else. For Carol it is important to speak up and to ask questions so as to get information and learn new things. Carol, based on her responses, was motivated to get information pertaining to her health and to keep herself 'healthy.'

Carol's use of sources outside the setting to gain information is to some extent based on her experience that the setting may not be a good source of information. I am able to validate her claim based on my field observations with staff. The following events highlight the interactional dynamics between staff and resident's points of view.

After meeting with Carol I went to the 'office' to review her chart, part of this review included listing her medications. While there I encountered the nurse who kindly reported Carol's medications to me. The nurse informed me: *"Don't ask her about this one, she'll never know what it is because it's the generic."* As I had already met with Carol, though this was not known by the nurse, I knew that Carol did know this. Carol had knowledge of all her medications and received this information from her pharmacist. When she picked up her prescription for the generic medication, the pharmacist informed her. Further, in her dealings with the dentist Carol reported to me that she was having *'a trouble'* with her tooth, but as she knew her appointment was soon, she waited until that appointment to inform the dentist of her tooth trouble. It turned out the tooth problem would necessitate more extensive work by a dental surgeon and an appointment would be needed. At this point Carol notified the residence that she would need an appointment with a dental surgeon. However from the point of view of the staff member who I later spoke with, this occurrence was reported as 'a problem.' The problem existed from the point of view of staff, because Carol did not tell her residence about her tooth 'trouble' and therefore they did not indicate this on the 'consult.' For staff this was viewed as a breech in procedure on Carol's part because she did not first inform staff. Staff were not pleased that Carol took care of this issue on her own in collaboration with her doctor. As the staff reported this scenario to me, Carol was instructed to always tell the staff first because otherwise: *"People will think we are not taking care of you."* This example, though not exclusive to Carol's experience, demonstrates the tendency to create dependency upon staff to 'take care of' medical and mental health issues for the individuals placed despite the fact they may be quite able to take care of these issues on their own.

Nellie

Nellie is a 37-year-old woman who was previously assessed as having borderline intellectual functioning (IQ of 76). She was considered self-consenting. Nellie currently lived in a two bedroom supported apartment which she shared with another female. She had been placed for approximately three years and prior to her placement she lived with family members. Nellie had been exposed to regular education in her native country but upon moving to America she experienced special educational practices such as *"resource rooms."* During the day she engaged in volunteer work in her community, but she said, previous to this she held a paying job in her neighborhood. She had frequent contact with her mother who was an RN however, she was adamant that her mother is a source of information *"I have been taking care of my medical concerns since I was 15-years-old and she's not been involved."* Due to the nature of her medical disorders which included: Epilepsy and Lupus, her memory was poor and her mother agreed that her placement in the setting would be a good idea, "*She was concerned about me moving into my own apartment that I would forget to take my medications and that was one of her biggest concerns, but with an agency like this if you have to record it every time you take it [your medications] she was OK with it."* Nellie's involvement in support groups led to her having a rather large group of friends which she saw often and who were an enormous knowledge resource for her.

Nellie chose the dental vignette because she had experienced braces when she was a child. Her approach to the assessment and her dealings with her medical health care issues was led by a theme of adult status and intelligence which she used to validate why she did what she did. In her first questions concerning the vignette Nellie wanted to know *"how old is Janet [the woman in the vignette], is she an adult?* When I answered yes the person in the vignette was an adult, Nellie responded: "*I had no choice, I had no choice…my mother she made the decision so that's the difference. As a child I didn't have a choice but as an adult you can say if I have no other responsibilities and can take the time to brush my teeth and the time to assess my time and if I don't have a boss that says I have to be on call all the time, for example like my mother, you are an adult so you don't think it's a decision you make at the drop of a hat*, am I making *sense?"* The decision as an adult to get braces had to do with the time she had to devote to taking care of her teeth due to having braces. As an adult considering whether or not to get braces, Nellie used adult experiences as factors affecting decision-making. She made clear that was not an option she had as a child, *"my mother just told me 'I don't care you will make the time to brush your teeth and if that means you are going to get up ten minutes earlier than that's what you do, so I had no choice as an adult you have a choice."*

The theme of intelligence punctuated much of her reported accounts concerning her encounters with doctors. Nellie felt that her interactions with her medical doctors was led by her own actions *"well I ask them…I am intelligent enough to speak to them I ask them each time I go, I ask them for the side effects of my medications, I am pretty much out there about my health care."* She expressed feelings that sometimes there were *"problems"* communicating with doctors: *"I've had problems with that before* [not getting all the information as entailed in the vignette] *for example if I have questions for my doctors, I usually, I would ask a doctor above him for example, because I usually go to clinics and I would ask another source."* Nellie expressed awareness of the medical hierarchy involved at her medical facilities and often made use of it*:* *"I would speak to the head technician or the head doctor, I could go above."* Nellie is very involved in her own health care, curious about it, wants to know everything about it, and she wants to be very active in her treatments. She relies on her own *"intelligence*" as well as on supports and resources external to the setting: *"I have the ability to question, and I can go to a second source or get a second opinion, I have the intelligence and the ability."*

Some of these resources, or tools, included her mother as well as girlfriends from her support group. *"Like for example there is some medications that I've been given that what type of medication it is or why so I'll ask about the side effects and my mother will look it up for me* *because she has a medical book [the PDR—Physician's Desk Reference]."* Her girlfriends were useful because they shared her medical disorder and had their own experiences and histories involving medication interactions and side effects *"I have quite a few girlfriends and they said, you know we talk about it, and they said 'this medication can cause you trouble' so we don't cross meds."*

Nellie's situation is unique, she was new to placement and had a long history of 'navigating her own ship' in terms of her medical care prior to her placement. This revealed itself in some conflicts with the setting: *"Most of my doctors are doctors that I choose…with this agency, I have [some] people with this agency they want me to use the doctors that they choose, yes most of their doctors. Like they want me to go to some of their doctors and I do not want to go, so right now we are kind of in a headlock, I mean I'm glad [a staff member left], we are [were] having a butting of heads and I mean I think it's their policy but I refuse, I mean I don't think their [clinic] is good enough, but they are letting me go where I choose to go right now."*

Nellie's answer to the choice question was to accept the treatment of braces because it would help her to better her smile later on. Characterizing her responses on the assessment tool was a high frequency of socio-cultural or newer knowledge. Nellie used a high frequency of personal-historical knowledge based on her past 15 years of dealing with the medical establishments in the treatment of her medical disorders. Nellie also had one of the highest overall scores on the assessment measure.

Ricky

Ricky is a 25-year-old man with a previously assessed IQ as being in the mild range (IQ of 67). Ricky was considered self-consenting. His placement in the setting occurred within the last three years and prior to that he divided his time between different family members in different states. Ricky reports that he was exposed to some regular and some special educational practices but he graduated from high school which had him in a work study program. Ricky told me that he had a *"learning problem"* because they said he was a *"blue baby something about lost [sic] of oxygen."* He had experiences at various paid employments such as working in fast food restaurants as a dishwasher and kitchen helper. Currently he was in a day habilitation program, which was offered to him at the location he resided in *"a day habilitation program without walls"* because he had difficulties adjusting to the day programs most of the other men and women attended. Ricky shared a refurbished studio apartment, all cooking facilities removed, with another man. Ricky had a diagnosed problem with allergies and borderline high blood pressure for which he was prescribed and taking medications. Ricky chose the allergy vignette because he said, he suffered from allergies.

Ricky felt his experience at the doctors was not like that depicted in the vignette because how he dealt with doctors was different. He also felt it was helpful that 'the company' (his terminology for the setting) made appointments for him to go to the doctors to check up on him "*to make sure he's feeling alright."* He did not attend medical appointments alone, but instead was escorted by a staff member who had the title of *"medical escort"* and this is how he referred to her. The 'medical escort' made sure *"she got, that he[doctor] got it right, that he's good, to make sure I don't have any broken bones, you know stuff like that."* But when it came to his actual actions with doctors he felt very much in control *"Yes I ask questions, cause I gotta know certain things to make sure that she's [the doctor] on the right track, cause sometimes doctors* *can be evil too, and sometimes you can't trust doctors like yeah I make sure that the doctor is taking care of you better than, cause like I said some doctors could be evil, they could give you a shot that could kill you, you know?"*

Ricky was glad that 'the company' made all of his appointments; he tended to see 'the company' as offering a service he could appreciate: *"The company makes the doctor's appointments like if I want to make my own doctor's appointments, yeah it's my choice but I'd rather that the company do it so I don't have to be worried about it, you know stuff like that, well since I'm high functioning."* Ricky felt confident that he could intervene on his own health care issues and could have a definite say in his treatments and the doctors he used. *"Yeah well once I see a doctor, like if I like him then I'm staying with him,"* but he was also quick to say that when he first came to 'the company' they took him to see doctors they had chosen. Ricky thought the doctor was ok so decided to stay with her, *"the doctor checked me out, I like that see, she's nice, like she's not a bad person so I keep up on her."* However if the result had been different, if he didn't like the doctor he would assert himself "*I'm leaving, I'm not coming back….that's me, that's the way I feel, I would tell him [residence manager] I'm not going back to that doctor and I don't care what you do you can't change my decision, like it's my decision and if he [residence manager] don't like it, oh well."* Ricky felt strongly about asserting himself with doctors, he was the only person in this research to state that he had rights as a patient that needed to be respected*: "Cause it's my rights, my opinion…like they can't stop my opinion."*

Interestingly, Ricky was one of the individual's alluded to in administrator's accounts relating to the use of 'good' language as a mask for underlying incompetence. Ricky's total score on the assessment was a 24, the highest score achieved in this study, and obtained by one other person, Nellie. Ricky's answer to the choice question was that the person should get the allergy shots, even though he found the use of ‘shots’ suspect in light of the fact that now medications are primarily used to treat allergies. Ricky voiced skepticism about the doctor’s use of this treatment *“why shots? Pills be much better, easier.”* Ricky’s responses on the assessment were characterized primarily by socio-cultural knowledge. Ricky had newer knowledge, he knew he could get a second opinion, that doctors can be wrong and can make mistakes, that needles can be dangerous, carry diseases and should be avoided if possible. Ricky also knew about basic health care, he had gotten himself a tongue piercing and informed me that *“they never tell you how to take care of it”*, but one of his friends told him *‘use mouthwash all the time to disinfect it.*’ Thus, although Ricky’s good use of language was felt by administrators in his agency [setting New] to be a mask covering the depth of his incompetence, (related to the theme emergent in Administrator’s accounts, “Fear of appearing normal”) he had one of the highest total scores on the assessment and a great fund of socio-cultural knowledge which included: knowledge that as a patient he had rights, such as getting information and good treatment (medical as well as social) from the doctor and his/her office personnel; knowledge that he could seek a second opinion, and question a treatment as well as seeking alternatives.

Carol, Nellie, and Ricky each had a strong tendency to see themselves as agentic in their own medical care, and to get information concerning their health care. They were motivated to ‘know’ about their medical and health concerns and demonstrated goal directed behavior associated with this motivation. Characteristic of all three, they ‘appropriated knowledge that was available to them’ however in each case, this knowledge was neither available nor appropriated from the setting. In contrast to Nellie and Ricky, Carol had been placed in the setting for a minimum of twenty years whereas Nellie and Ricky were both relatively new to ‘residential living’ having never been part of a service provider agency setting previously. Both

Nellie and Ricky had experiences which included interactions with diverse people not associated primarily with the field of intellectual disability. Carol's account was filled with 'tools' she appropriated to help her 'learn and so develop' better medical health decision-making. Carol constantly felt that she had to tell herself to ask questions, keep her eyes open, and look at things intently *"sometimes things could be right in front of you and you just don't see it, that's why I have to open my eyes and look."* Carol due to her age cohort, was dealing with an historical element in that she was raised at a time when doctors were not questioned and patients didn't really have rights as they are now known; in other words prior to the Informed Consent Doctrine. Nellie's account had a strong thread running through it concerning her intellectual ability. This emphasis on her intelligence may in part be due to her feelings that her intelligence was in question given her current placement, interactions, and relationships as well as her past experiences with doctors who apparently didn't give her the responses she wanted so she 'went above them.' Ricky on the other hand, voiced knowledge of patients having rights and his account had themes emphasizing his strong belief that his word and his opinion must be heard and valued. Returning to Chapter 5 and the assessment findings, Rick and Nellie's responses to the Assessment instrument did not include 'Socio-Historical' as a type of knowledge although Carol's responses did. Both Ricky and Nellie had diversified experiences away from residential facilities and their responses on the assessment instrument had a high frequency of responses characterized by 'Socio-Cultural' knowledge. Carol, although she did have responses characterized by 'Soico-Hisotrical' knowledge, also had a high frequency of responses characterized by 'Socio-Cultural' knowledge, which she appropriated from different sources such as the radio, television and pharmacist.

For the remaining men and women their experience with medical appointments and self-other encounters with medical personnel did not demonstrate this ‘ideal form’ depicted by these three individuals.

Individual Motivations. Medical appointments were valuable for some of the men and women in that they afforded them something of value not connected to health care. For some of these men and women, medical appointments were an opportunity to talk with someone, while for others it gave them an opportunity to be away from their normal routine, to be free of the setting. Two examples of this personal value of medical appointments follow below.

Opportunities for Interactions—Alice. Alice is a 64-year-old woman who was diagnosed with an IQ score indicating borderline intellectual functioning (IQ of 77). She was considered self-consenting. Alice had been placed for over twenty years. Prior to her placement she lived at home with her family in a quiet, upper middle class suburban neighborhood. Her years spent at home (35 years) were closely approximating her years placed (29 years). She had one sister with whom she had frequent phone contact. The death of her parents most likely prompted her placement. Alice was home schooled, she could read and write as well as read music. An account in her records stated that while living at home she played the viola as part of her family’s quartet. On a subsequent visit when I ran into her again, I asked her about this; she informed me she no longer played. When I questioned staff about this fact from her past, those staff members I spoke to were unaware she had this ability. Immediately after being home schooled she was enrolled in a sheltered workshop. Sometime after this, with her placement in a residential setting, she began her employment as a messenger in the city. She had worked as an independent messenger for ten or more years during her early placement—this fact was also unknown to staff members at her current placement. She describes her family life as warm and somewhat protective.

Alice had a boyfriend who was her constant companion for more than twenty years. He had recently died and her talk with me was accentuated with many themes concerning their relationship. Alice was living alone in a supported apartment; she did not have a roommate. Alice utilized a Medicaid funded transportation system to take her to and from appointments and other places she had to go. She currently attended a day habilitation program. She spoke about an incident on the subway which resulted in her sustaining an injury, immediately after this she began having problems taking public transportation. A note in her chart indicated that she had sustained an injury stemming from a fall in the subway which occurred in 2004. Alice had reported medical diagnoses of hypertension and high cholesterol for which she was treated with one medication. Her listed psychiatric diagnosis indicated a specific anxiety disorder which could include panic attacks and for which a variety of alternative treatments existed. Alice was currently being treated for this disorder with psychotropic medications; she was currently seeing a psychiatrist.

For Alice, some medical appointments gave her a chance for social interactions. This was specifically related to psychiatry. *"I like everything, I look forward to going there."* Alice wouldn't want to change anything about her doctors, as she describes it: *"I wouldn't want to, I really wouldn't want to because they're so nice, they are all so nice, yeah they are all so nice."* Alice described an encounter with her psychiatrist where it was revealed that her interaction differed from that depicted in the vignette, side effects were not necessarily revealed prior to or at the time a medication was prescribed, but because she enjoys talking to this doctor, this fact is overlooked: *"I wouldn't want to change them, I trust them all. Well I ask them about side effects*

I asked her, I like seeing her now, it used to be every month and now it's every two months which is good you know…there's only one side effect that I was a little bit afraid of, the dizziness, and she said 'don't worry about it because you haven't had them by now so [you're] not going to get it' and that's only for people who aren't well, you know, physically."

Alice chose the psychiatry vignette. She indicated that regarding interactions between the patient and doctor, her doctor *"writes it down on the paper, my medial papers"* ('the consult'). Alice brought up and spoke frequently about the high turn-over of her psychiatrists: "*they were recommended by staff here…but you know…they leave. You know what I mean, I had another doctor but she had a baby and so there I….they gave me another doctor up there."* According to Alice she experienced many different psychiatrists because of their tendency to leave the practice.

Alice didn't quite know why or when she started going to see a psychiatrist, but she was sure she did not initiate the appointment. Originally she felt it had to do with her problem with medicals as apparently she didn't like going to medical appointments (this mainly included GYN appointments) "*I just used to have something about going to medicals."* In the context of psychiatry and the vignette, Alice knew psychiatry was initiated by others because of her behavior *"you mean mainly my behavior. [Staff's name] sent me up there...I can't really say it cause it's been so long ago, you know what I mean, at first I denied, I don't know …you have to ask [another staff's name] about that but I wouldn't go out and I had temper…I'm not even going to tell you what I used to do."* But as our talk progressed she was able to relate more recent developments to specific behavioral events *"I had 'panic attacks' on the subway* [after her fall] *and all that…that is the main reason she [staff] sent me to a psychiatrist you know. But I can't really remember when it first came up, that I had to go to a psychiatrist, and the nurse on* *duty too, you know the nurse on call, [she recommended it too]."* Alice maintained that if staff hadn't recommended she go to see a psychiatrist she is doubtful she ever would have gone, *"oh I'm not sure."*

Alice talked a lot about her relationship with her boyfriend and how she was dealing with this death. She raised this issue up in relation to her psychiatry appointment, *"I look forward to going there…you know there's one reason because…about seven months ago my boyfriend passed away, yeah and [staff's name] wanted me to have a chance to talk to somebody about it…I don't know if you ever lost somebody or anybody? She said [her psychiatrist] 'don't, don't uhmm, cry'…see I try not to cry but sometimes, with the music we used to know, but I plan it this way, I am…I honor him with the music."* Alice ultimately speaks with her sister about her feelings related to her grief, she would speak with a staff member but realizes they are very busy and don't have time for that, *"well I could talk to [staff's name] when she's not too busy…you know she's always busy…she's always doing it [caring] for others you know."*

Those appointments which did not provide 'social' value for her were difficult. And these appointments, in contrast to more 'social based' appointments, were areas where she acted in her own interests and showed concern or questioned the treatments proposed, regardless of how nice everyone in the office was. As an example, relating to GYN appointments, she would not allow an examination to occur but she *'had'* to go on the appointment *"You know, that's another reason why they used to have to put me on [medication] to go over there…and GYN, do you like it?* I answered, I couldn't imagine many women who did. "*It's…well you know…I never, my mom never exposed me to that when I was a kid…that's the first thing they asked me…they wanted to know why I was scared…well I'm just scared, well in the residence every woman has to do it, you know."* I asked her if she could just say she chooses not to go or say no.

"NOT REALLY, but I don't like it…because when you are in the program everything's gotta be right on the line you know, they always used to ask me at GYN 'did you ever have sex' and I said No or 'did you ever or did they ever hurt you or anything?' and I said NO, see…and its very stressful, it was a very stressful situation."

Studies concerning the actions of older women (those not diagnosed with disability) in regard to GYN appointments and preventative screenings (e.g. Stable, Sabogalf & Otero-Sabogal, 1995; US Preventive Services Task Force, 2005), reveal that many of these women choose not to schedule a GYN appointment for themselves especially those over 50, who were unmarried, never had children, had limited sexual relations or were not sexually active. Alice's situation, placed in a residential facility, mandated that she had to go and her choice not to go was deemed 'problematic.' This resulted in a situation where she would arrive for a scheduled examination she would not go through with. In this situation the office personnel had to deal with the fact that a 'consenting' adult woman showed up in the office and then refused to go through with the examination. This created for Alice a situation that was not only very stressful but untenable in that she was assessed for possible sexual abuse as a reason underlying her behavior. Alice, if allowed her own way, said she would not go at all—a choice apparently popular with older women who were not diagnosed with a developmental or intellectual disability. Alice knew her situation was much different, *because* of her placement. She would have to go, as she indicates in the following statement regarding her choice in this issue: *"Well that's never going to happen as they say…as they often say that isn't gonna happen…as long as I'm in the program. See I'm getting a lot bolder as we're talking."*

Alice when considering the choice option on the vignette felt that she could not decide for someone else and did not make a choice because of that reason. Characterizing her responses on the vignette, were high frequencies of 'Personal-Historical' as well as 'Community of Practice Knowledge' knowledge types. However as found with others who chose the psychiatry vignette, her responses to the vignette questions were characterized by all four types of knowledge: socio-historical, socio-cultural and community of practice. What became most salient in Alice's account was that through our dialogue she felt she could talk freely *"see I'm getting a lot bolder as we speak*" and discuss the aspects of her life which she knew differed as a result of her placement.

Opportunities for freedom—Donald. Donald is a 51-year-old man who was previously assessed as having a diagnosis of borderline intellectual functioning (IQ of 77) and a developmental disability diagnosis of Autism. Donald was considered non-consenting and his mother signed all consents for his care. Donald had lived at home until his placement which began approximately 13 or so years ago. Historical documents in the agency's medical chart for Donald were inconclusive concerning his personal history and admission dates, but Donald supplemented this background history while talking with me. Prior to his placement he had lived at home with his 'family' which can only be guessed as involving his mother as he did not talk about siblings or a father. Donald informed me he had some exposure to regular education; he attended a high school, but also experienced special education classes as well. Donald currently attends a day habilitation program, prior to this he said he attended a *"day training program."* He was being treated for his diagnosis of Autism with a psychotropic medication, an antipsychotic, and his other medical diagnoses included high cholesterol and Glaucoma for which he was prescribed medications: a cholesterol lowering medication and eye drops for Glaucoma.

Donald chose the psychiatry vignette because he had already had braces when he was an adolescent and he did not suffer from allergies, though he acknowledged that *"well course allergies, actually I remember once, in the springtime I got a little allergic to pollen that was during the springtime but usually it's temporary."* For Donald his visits to his psychiatrist were pleasurable not only because he feels comfortable talking to his psychiatrist, because he is very nice, but mainly because of the journey there. *"Oh I look forward to it, I look forward to my appointments up at [the hospital clinic] and you know I usually look forward to it because they give me money for car fare and I go up there and I talk to the doctor and it's a nice trip up there, I take the bus up there, up the avenue and it's kind of nice going up there through the avenue or sometimes I take the train there, there is a lot of ways I could go up there."*

When I pointed out to him that it seemed he was really happy about getting there and not exactly what happened when he got there, Donald told me *that "Oh yes I like going there, yeah its real fun, Dr. [--]'s office is the only office that has a window, I look out the window, Dr. [--]'s office doesn't have a window [the psychologist's office]."* Donald felt that *"of course there is no side effects in the medication, the medication has no side effects, cause fortunately I remember my first medication, I used to take a long time ago when I first started* [at that hospital clinic- when he was already at the setting] *was [medication] and [medication], it made me kind of feel too…uncomfortable, yeah that was a long time ago, the [medication] made me feel heavy, and sort of you know uhmm…uncomfortable. Yeah they took me off the [medication] and put me on [medication] and it was much better. Yeah they said if the medications causes you discomfort they would take you off it, and put you on something else. I just want to make sure it doesn't make me feel uncomfortable. I would be nervous if it made me feel uncomfortable…well I could* *take medication as long as it doesn't have any side effects cause maybe I could talk to my psychiatrist about the side effects."*

As with Alice, Donald spoke about seeing a lot of different psychiatrists and how this made him feel *"I seen a lot of psychiatrists they came and they went, they came and they went, it's sort of sad when they go, you know its kinda sad when they go, but fortunately I have a permanent psychiatrist and psychologist now."* When asked to clarify what he meant by 'permanent' he replied *"well they don't, they are going to stay for a long time, the others came and went, and its kinda you know sad when they went, you know you had to get used to a new doctor when you got there, sometimes you get some of them are really nice, some of them you get really attached to."* Donald in describing what happens at his appointments with his doctor said "*well I talk to him, he usually writes me a prescription, the psychiatrist writes me a prescription, I like going there very much."* Donald knew that he went to the psychiatrist because the psychiatrist gives him pills. The pills are *"to sooth my nerves, sort of like to help me, you know help me be more calm yeah because one thing I don't like is complications, I want everything to be just smooth and easy, you know just, I just do it to get it over with, just to get it over with and then that's that."* Donald indicated that although doctors come and go so do staff, *"yeah there's staff I really got attached to here was, uhmm [staff's name] and of course I really got attached to [another staff's name] but they left for another job."*

For Donald, staff helping him was one way of making 'things smooth and easy,' "*they pay the cable bill for me, like see I pay my cable bill but what they do is they pay the cable bill for me all I do is just pick up the money and they pay my cable bill for me*."

Donald started a new medication on the night we were to meet. He started our encounter asking about this new medication *"it's a medication, I don't know what it's for or something, it's called [medication], yeah it's a medication, it's in the cabinet [medication cabinet in office] I don't know what it's for actually, I know the [psychotropic medication] is for soothing my nerves and the [medication] is for my cholesterol I know that because my cholesterol is high, I know that. But I'm just curious what it's for… that third medication… I don't know anything about it, that medication, that's one thing I would just like to know what that third medication is about."* In discussing this I asked him if he could speak to his doctor about that medicine and he replied *"yes I think I could do that, yeah I wonder why…I'm going this Monday, but one thing is I've been very curious about that one medication, it's a green pill, I'm just curious what's it for? I don't know what it's for?"* But, as we talked further we realized, Donald was not sure which of his doctors prescribed it.

Donald's response to the vignette, especially relevant to areas concerning questions on choice and alternatives, revealed the extent of his medical information. He was unaware of any alternatives to medications for keeping his nerves calm as offered by his psychiatrist or psychologist. Even though alternatives were mentioned in the vignette, Donald repeatedly asked *"what alternatives?"* Donald's choice on the vignette was to *"not accept the treatment of the psychotropic medication."* His reason was due to the side effects of the medication and he recommended an alternate activity for the person depicted in the vignette who had a problem with their anger and frustration, Donald recommended *"well if he doesn't want to take the medicine, if it makes him sick or dizzy maybe he should find some way to take out his frustrations like on a punching bag or something, lifting weights or something when he gets frustrated."*

Donald's responses to the vignette questions were characterized primarily by socio-cultural knowledge. Donald knew the names of his medications, both current medications and those prescribed in the past. His knowledge of side effects however consisted of how a medication made you feel, not the long term effects it had or could have on the body overall. His knowledge specific to the setting (Community of Practice knowledge) involved his experience in the setting which he used to embellish the actions of the person depicted in the vignette as well as expressing that the person would have to take the medications, indicating a lack of choice. Despite the fact that he was currently being treated by psychiatry and he had extensive experience with psychiatrists, psychiatry to Donald was *"laying on the couch sort of thing…talking to doctors"* which exemplified one example of Socio-Historical knowledge. Donald's experiences as related to me were somewhat limited and primarily involved living at home and then placement in the current setting. Although he was deemed an 'independent traveler' this basically was limited to medical appointments. Donald had a frequency of responses characterized by Socio-Historical as well as 'Community of Practice' knowledge types. As I had learned from Carol, I mentioned to Donald that he might want to consider asking the local pharmacist, since Donald picked up his own prescriptions from the pharmacy. Donald replied that he had never thought of that and maybe he could do that. The topic of the 'consult' also arose in my discussions with Donald. The 'consult,' referred to as a type of 'Community of Practice' knowledge within the assessment vignette, was mentioned by Donald as part of his visit to the psychiatrist. In light of the information Donald was missing concerning the new 'third' medication, it was most likely written on the 'consult' by the doctor who recommended it. As Donald could read and write I asked him if he read about the medication in the consult. Donald reported he never read the 'consult,' *"I never thought it was my business."* Although many men and women in this study could read and write, none said they read the ‘consults’ viewing this as ‘property’ of the nurse, staff, ‘office,’ or agency.

Men and women who said their experience was not like that depicted in the vignettes were able to give reasons why this was the case from a simple *“he doesn’t talk to me”* to a more telling *“what alternatives? What choices? They don’t tell me about alternatives.”* In expressing how their experiences differed from those depicted in the vignettes, these men and women’s accounts revealed the lack of what Bronfenbrenner (1977) as well as Cole, Hood & McDermott (2001) stressed should be a goal in situations of assessment—ecological validity. For most of these men and women when compared to their real-life experiences the assessment measure was far from their norm. Noticing this discrepancy, one individual, Chuck, after going over the vignette responded, *“I think they* [staff] *are gonna start teaching me this stuff.”*

Self-Other Encounters: ‘Objects’

Doctors. Many of the men and women expressed that doctors don’t talk to them. Although this was more frequent in the case of psychiatry it also emerged in the context of dental and other medical concerns such as allergy treatments and basic medical. For most it is assumed that the doctors want to keep them on some kind of treatment, therefore the doctors have an agenda. This was especially the case concerning psychiatry as reported by Andy who felt they psychiatrist’s would not listen to him when he said he didn’t want more or any psychotropic medications: *“I’ll say ‘NO’, I don’t want that and then afterwards they give it back to me…they [psychiatrist] say sometimes ‘yes’, sometimes ‘no’, I say ‘no’ and they say ‘let me see what I can have to give you sometimes. No, they keep on trying to give it to me.”* And because this agenda exists, one has to be careful of what one says to the doctor as evident in the following statement:

"Because he feels he needs to give you more [medication] by the way you respond to him." Andy had many responses in the vignette which were coded as 'Socio-Historical' knowledge types.

In the case of psychiatry, ultimately for many, the men and women are there because they have done something 'wrong' (a behavior which then becomes a clinical problem) or there is something wrong with them *"They could tell if you got problems or not by your face—they could tell when I'm sick or not"* and *"I went to see the psychiatrist because maybe I did something wrong."* Yet in other cases, trust was an issue where treatments were concerned. Not having full information why a treatment was ordered by a doctor led to mistrust and dislike for the doctor, as in Andy's case with psychiatry. However this distrust was evident in other areas.

Jenny's example with her dentist is illustrative of this. Jenny was previously assessed as having an IQ in the mild range (IQ of 60). Jenny was the only individual who felt the assessment was *"stupid"* because *"the same thing over and over, it asks the same questions over and over."* Jenny related to me that a former dentist was not good for her, according to her he *"was not too good, he was just…he didn't do anything, he didn't do your teeth the right way you know? And I had to take medicine, for what I had to take it for but I don't know, and I don't take it no more. I don't take it no more.* [Jenny now goes to a new dentist and she doesn't have to take a pill anymore]. *My staff did, they changed it [him]."* As it turns out Jenny, although she knew *"I have a heart problem, I don't know I just have a heart problem, a heart problem that's all,"* her heart problem was diagnosed as Mitral Valve Prolapse. With such a disorder, many dental procedures require prophylactic antibiotics prior to dental visits to protect against any bacteria which could gain entry via the mitral valve of the heart, causing endocarditis. Because Jenny was not informed of this practice and its relation to her 'heart problem' she felt the dentist's insistence that she take a pill before she went to see him was suspect. This resulted in a feeling of dislike for him. As the pill would have been administered to her at her residence, it was apparent that when given this pill, prior to each dental visit, she was not informed of the reason or its connection to her heart problem. Jenny's responses to the vignette (she picked Dental) were characterized by Socio-Historical as well as Personal-Historical knowledge types. Jenny also had a high frequency of responses coded as 'Socio-Cultural' knowledge due to her vocabulary surrounding medical terms and procedures.

For many of these men and women their treatments just happen to them with little interaction from them invited. Often their accounts revealed that they are not given information by their doctors and treatments just occur. This appeared to be the 'normal' interaction they were most familiar with. In their narrated accounts some of the men and women explained even when they say they would like something different or would like to stop a treatment this is often not granted. This was the case even for those deemed 'self-consenting.' Requests were not honored. In one case John, who is considered self-consenting, was informed that he could not stop a psychotropic medication even though he felt it was not working for him. As he reported: *" Oh he would keep, he would want to keep you on that thing [medication] even if you say that it's not working, because then he'll say that the medication is working then, if you say it's not working."*

John reported a similar stance in relation to his interactions with his psychiatrist, in terms of the psychiatrist's answering questions John posed*: "well he's got, he's got…a whatchamacallit…to answer or not to answer…he's got like a, he's got a right, I guess you could say, a right to answer it or not to answer it."*

Respect was seen as being accorded only to the doctor or others, not to oneself. The individual must respect the doctor. Nancy was previously assessed as having an IQ of 48 and was not considered self-consenting. Nancy chose the psychiatry vignette. She understood quite a lot concerning psychiatry despite the fact she was not presently being treated by one, although many of the other people she lived with were. Under the area of choice involved in the vignette Nancy replied: *"take the medicine, she'll be a good girl* [Nancy is 38 years old] *and take the medication be a nice person, respect, respect the staff and respect the doctor, nice person, yeah [a] nice person respect, respect is nice people."*

Many of the men and women reported matter-of-factly how their experiences differed from that depicted in the vignette because they are not given information, *"No, no side effects, the doctor doesn't tell me that so that's different."* While for another, even at the dentist, this failure to be informed was evident, *"He just gave it to me [a medication] he didn't tell me nothing, he didn't ask me."*

Across many of these men and women's accounts not only did doctors not talk to them about medical related issues, they did not ask them about their treatments or what they may want. Even when they attempt to talk to their doctors, for some of these men and women, they knew that they were being treated differently, *"Yeah but they don't tell me anything, they don't tell me, they'll answer you if you asked"* while for others this may be because 'doctors know best' *"Because he [doctor] knows more about you then you know yourself I guess."*

This theme of the doctor knowing best was evident in statements concerning medical personnel behavior *"he [psychiatrist] may not answer the questions, it depends on if he feels the need to answer the questions I guess."* It was also a factor in diagnosis and treatments. People could be diagnosed for something they were not aware that they had, and once diagnosed and prescribed a medication this became significant because due to the organizational procedures and policies in the settings, they could not just stop it.

John's case is one example: *"He [doctor] said 'I got allergies'…I was like what? And he said 'you got allergies', and I was wondering how I got them,* [the doctor said] *I'm allergic to everything like outside and inside. I went to him for something else and I didn't even know I had allergies, he put me on allergy medicine, it makes my nose runny I guess and I sneeze and cough.* [Here I asked for clarity as it seems he did have symptoms] *No, no, no he told me that, I didn't know what allergies were because I never knew about allergies."* John, hopes one day to be *'free of all these medications.'*

Another area that was raised had to do with who the doctor did speak to. Many of these men and women knew that the doctor spoke to others and not to them. Juan a 31-year-old man had been placed for five years and whose psychiatric treatment experience began with his placement: *"The psychiatrist talks to his brother…his father…and that's it."* This account was especially revealing in that Juan had challenges with communication but was quite clear in articulating his choice of doing the psychiatry vignette as well as making clear what the psychiatry appointment is like for him. Juan incidentally, was previously assessed as having an IQ within the mild range (IQ of 58) had no medical issues but was diagnosed with Autism. He was currently prescribed and taking four psychotropic medications, used to treat 'psychiatric conditions' associated with his autism: Major Depression and Psychosis.

Another woman, Erica, revealed that the doctors didn't speak with her, perhaps because they didn't think she would understand. Her account is particularly revealing. Erica had a previously assessed IQ within the Moderate range (an IQ of 40), she was not considered self-consenting and beside her medical issues she was treated by a psychiatrist for a psychiatric disorder of Atypical Psychosis. Erica revealed her doctor's appointments for medical care are led by staff's interactions with the doctors. At Erika's setting (setting New) all individuals are accompanied by staff when they go on their doctor's appointments, these staff members are referred to as 'medical escorts,' *"Oh [staff name] asks the doctor 'could she get, could she get pain pills? Could Erika get pain pills for her foot?' No [staff's name] she answers them [doctor's questions]. I asked the lady when she was cleaning my teeth, I asked her, I asked the lady doctor, 'is I getting my teeth?' She don't give me no answer she didn't give me no answer."* Others report similar feelings as in Lorraine's account: *"yeah I ask him [psychiatrist] if this is a change or what and then he tells [staff] about that and he'll say to her [staff] 'no changes'."*

Psychiatrists. Psychiatry was often associated with behavior and the 'wrongness' of that behavior but it was also seen as a type of interrogation as in Danny's case: "*Cause they [staff at residence] made me go, to get medications, I have to be asked questions, I have to be asked questions."* Also included here is the concept of choice. The vignettes depict a situation where doctors are informing patients that they have a choice. This aspect of choice is a key component of the construct of informed consent. For many of these men and women, they are not given a choice, they are not told of alternative treatments and more importantly, they are not told that they do not have to accept a treatment. For the men and women involved in this study, these are foreign concepts and provide the context for the 'no choice response' given in the psychiatry vignette reported in chapter 5.

The 'consult' was a frequent topic of discussion not only from the perspective of staff members as seen in the previous chapter, but also was frequently featured in the accounts given by the men and women placed. The ‘consult’ was what the doctor read, because it was previously filled out by staff or the nurse at the setting. This most likely circumvented the need to get information from the individual, perhaps as they were seen as unreliable reporters of their own conditions. The doctors, as the men and women related to me, read and then filled out the ‘consult,’ for many this is not only what the doctor did during a visit (appointment) but what a visit consisted of. Ruthy stated, for example, that her doctor *‘just filled out my medical papers and gave me a prescription* [for a refill of psychotropic medications] which she reported was prescribed because of her ‘nerves.’ Lorraine, who has a previously assessed IQ within the Moderate range (IQ of 36), reported the following experience with her psychiatrist: *“Well, [I go] for my meds* [psychotropic medications]. *Oh Dr. writes it down, he writes down my medicine* [on the consult sheet]. *I go to the doctor to see if I got medicine, get more medicine. Oh I take medications for my nerves.”* If doctors do talk with them, especially in the case of psychiatry, it is after they have read the ‘consult,’ as described by Ruthy: *“He reads the papers* [consult] *and says ‘look you nice and calm, that’s good, you nice and calm. They* [psychiatrist] *going to keep me on the same medication, they say* [psychiatrist] *‘oh you nice and calm’.”* While for another, Nancy, in an attempt to ask the doctor a question about her PPD test and the medical papers associated with it reported: *"the doctor tells me ‘you leave it alone, you’re a good girl’.”*

Staff. The preceding sections related primarily to the assessment and how the experiences of the men and women differed from that depicted in the assessment. In the following sections I report the findings of the interviews as these relate to their self-other relations within the setting. As previously stated their narratives were coded according to the elements of an activity system and involved objects, rules and tools. In the sections to follow I report on the findings from the coding element of ‘Objects’, which for this analysis involved relationships with staff members.

Staff members were often seen as ‘correcting’ the behavior or actions of the men and women placed. *“Every ten minutes staff have to come up and correct me” or “staff don’t want us to be alone in our rooms”* and *“they [staff] write me up.”* And in the case of those individuals who were considered self-consenting with regard to medication practices: *“No they come and they make sure, they watch you yes, they count the pills to make sure you are taking it.”*

Rules and the changing of rules were also related to staff. Staff made rules which could change and often the men and women were not made aware of the reasons for these changes. In one setting apparently a change occurred in self-administering medication. In my discussions with administrators I was informed that what was a priority to work on was decided by the setting *“We pick and choose, like we do that ‘self-med’ evaluation which determines how much they can participate in their own medication, but even if they can or there isn’t a real interest, or we feel that’s not really what they need to work on then they don’t do their medication, it’s not a given that they will be participating in their own medication unless that is what we choose to do with them”* (setting Protective). The individuals affected by this change in rules spoke about it: *“oh no I can’t take it myself [medication] they give it to me cause I can’t—I used to but they stopped that.” “I used to be taking it [medications],new rules from [staff’s name] so I can’t do it, I can’t do it.” “I mean I said what about me, what about me? I’ve been punching my own medicine—you know punching it out and putting it in a cup and take it—yeah but they stopped it—I said what happened to me?” “I don’t know what happened? I did it all along and then they* *[staff] just stopped, and you know what else? [Name] was doing it too, but they stopped her too, I don't know why?"*

The ability of staff to correct, monitor, and 'adjust' the behavior and actions of the men and women was seen by many as intrusive and invading of their personal privacy, as Ruthy a 53-year-old woman with a previously assessed IQ in the mild range (IQof 56), who was deemed self-consenting, explained *"Oh [staff member] she get on my nerves, she go in my closet and I don't appreciate that. Every time I go shopping [staff name] won't let me get no more [food type], yeah and that gets me upset so I'm going to tell my psychiatrist on Monday."* Ruthy was reacting to a new procedure implemented, I was told, by a manager who was really *"shaking people up in terms of being more aware of what's in their* [shopping] *carts because of their diets."* In another example, although the residence was supposed to be 'his home' certain rules made it evident this was not the case. Richard, 38-year-old man previously assessed as having an IQ in the Moderate range (IQ of 42) who was not considered self-consenting exclaimed: *"I can't leave them here, [his race cars], they don't want 'toys' here they don't want toys here, but that's my hobby."*

Staff members were reported as authoritarians related to medical appointments. Staff controlled medical appointments. For some of these men and women medical appointments meant missing work or missing other events they found enjoyable. This created conflict, *"They [staff] won't listen to me, they say 'you have to go to your appointment,' and I'll have to leave work early…you know I'm the kind of person that like to go to workshop every day, I don't want to be taking too many days off that I might get thrown out of the workshop"* and *"well if I don't get to work early every day they you know they stop me, but the appointments is holding me back you know."*

And lastly this was seen in relation to medical related 'territories.' Territories had to do with clearly demarcating staff member's responsibility and what the men and women were expected to do. *"Because they [staff] say you can't go in there [med book]—this is where we sign our names or initials in when we take our medication."* Despite age, consenting status and even IQ scores, there were clear lines demarking territories and these were palpable as seen in Nadine's account.

Nadine is a 52 year-old woman, with a previously assessed IQ in the Mild range (IQ of 61), she is considered self-consenting. Nadine was talking to me about her doctors and mentioned some small problem with one and so we discussed what she could do *"Well I'm my own advocate I make my own decisions"* however in the next breath when we talked about changing the doctor she exclaimed: *"No, no I can't change doctors I got to ask staff in my house if I could."*

Capacity assessments in their 'ideal form' conceptualize knowledge and information as held by the individuals assessed, unexamined is how this knowledge and information comes to be held. For these men and women, their participation, initiation of, inclusion in, and consideration of their point of view in their own medical and mental health care practices were constrained; limiting the knowledge and information they personally could get access to.

However, for some of these men and women there were matters which they considered not important for them to remember, they could afford to use staff to remember for them and did so. As revealed in the findings reported here, this particular finding indicates how efficiently they used their environment (in this case the social environment: the staff) as an aid to the practical activity of remembering information they may have been least motivated to do

(Scribner, 1984). Exemplifying how, as Scribner (1986) states, practical adult thinking is embedded and instrumental.

Recalled from the previous chapter, staff members described themselves as being ‘the front line’ as this relates to their relationship with the men and women placed. However in their own accounts, these men and women thought about staff members as having a different role in their lives. For some, talking to staff members may have been a practice they did early on in their placement but they ‘learned’ from their experiences that talking to staff may have consequences often leading to something they failed to anticipate. Thus they changed their behavior; no longer did they speak to staff revealing certain information. This characterized the relations in their self-other encounters with the professionals, in this case staff members employed by the agencies in which they were placed, as one lacking in trust.

As one example involving trust, John stated: *“I used to talk to them [staff] I don’t do that no more, talking to them is how I wound up taking these meds* [psychotropic medications]*in the first place.”* As John spoke with me he recounted how a staff member got into his head about all these things that made him very nervous, it was the staff that told him he should see a psychiatrist and that led to him being placed on psychotropic medications. Now John does not talk with staff members, *“I may have done that a long time ago, I don’t do that anymore.”* This fear of unexpected consequences of talking with staff was made explicit by Ruthy, who said *“No I won’t talk with staff cause I’m afraid they’d send me to the doctor and I don’t want to miss work—I go to work every day.”*

Staff members ‘difference’ attributed one reason why the men and women did not share information or speak with them about personal issues, as exemplified by Alfredo: *“No, they way* *different from us [staff], I have no idea why, they way different from us."* Mark stated that the reason why he liked his current placement was because the director *"treats us like staff"* which for him signified the epitome of being treated with respect. While for other men and women, staff members were like *"professors,"* they knew everything. In such cases staff members were seen as all knowing, but the information staff knew concerned the men and women: *"he knows more about me than I know about myself," "you got to ask staff about the reason I take that."* Such views of staff indicated the flow of information; staff did know more about the men and women's medical issues and treatments because staff had access to this information; staff members having access to such information, and not the men and women themselves, was viewed as a legitimate function of their job responsibility.

Others voiced that they could speak with staff but chose not to, though could not really articulate why: *"No ,no, no I never done that, I don't know why."* For many of the men and women staff were not the 'first line,' instead other sources, if available were used, *"Oh I never do that I never ask them things like that, I don't know why I just don't, well I could ask my family, my sister."* Many of the men and women offered that they spoke to their girlfriends, family, friends or their doctors. In one case the individual was quite adamant that she would discuss things with people *"only outside of the agency."* In another example Juan informed me that he would only speak to his doctor*: yeah I hear staff discussing their medical issues, no I don't have none of that, I talk to my doctor [his psychiatrist] I talk to the doctor first because she's the one giving it [psychotropic medication] to me."*

Richard informed me that he would speak with his mother because *"well sometimes, she takes them, she takes the same pill I do, she told me."* In response to my statement that he and his mother most likely discuss their experiences due to their common medication regimen

Richard replied: *"Yes well we don't talk about that too much, we talk about different things, we don't talk about pills a lot."*

For others speaking with staff involved privacy issues and underlined the professional nature of their relationships. As stated by Ricky: *"No I never talk to them about it [medical conditions or questions about it], well you know they don't talk about it, I don't know maybe privacy issues? I never talk to them about it no."* While for others this privacy had more to do with minding their own business: *"No I know, but I mind my own business"* and if something is shared, again the unexpected consequence is that it gets written down *"[staff member] will write it down on my medical papers [the consult]."*

This 'professional definition' delineating staff by job responsibility affected reciprocity on the part of the men and women sharing personal and medical issues with them: *"No cause its two different things, two different things, like whatever they got, they keep that at home, they don't bring it on the job, like if you want to sit there talking about your health, you talk that with your husband or your kids, you can't come on the job and say 'oh my health problems' NO!"* This element of the professional relationship was not connected with years placed as Ricky was recently placed while Mark, who had been placed for most of his life stated: *"Ohhh no! Because if the staff have a medical condition, I don't want to know about it, well maybe [if it was like his own medical problems] but not really, no, no, no, what happens in this room [his studio apartment] is my room, my territory!"*

Confidentiality and company policy was another factor underlining the professional nature of their relationship with staff members. As one person said *"well I don't talk a lot about it you know, it's not mentioned, I don't know if they [staff] would like me asking those questions,* *you know it's confidential."* Or *"it's privacy issues."* While for others sharing may not be allowed due to company policy*: "Sometimes I hear staff saying they have to go to the doctor because they are sick I guess or something like that but they don't really discuss the like, the medical conditions we have, or they have, I guess…and I don't think they are really supposed to or they are not allowed to I guess."*

Tools and Signs: Knowing How

For these men and women knowledge resources were appropriated from many different sources, however sources had different levels of information. Some of these knowledge resources or 'tools' were social and involved others, while others involved technology such as television, cell phones, and computers. Lastly some resources were gleaned from the setting itself, but this information was deemed the least informative (in terms of the sources of 'tools' for knowing each setting offered). Social sources of knowing consisted of family, friends, co-workers, Pharmacists, and in some cases Doctors. Of the 29 men and women, 14 specified social sources as most informative; all of these social sources were predominantly from outside of their current setting. Technological sources of knowing such as cell phones, computers, and Television, were specified as moderately informative for five individuals. The setting as a source of knowing was least informative. These 'tools' available in the setting and the number of individuals who said they used them as such consisted of: the calendar (five people); the "Med" book (five people); the "Medication Administration Training" which occurred associated with the "Med" book (four people); and the 'consult' (six people). In the following section I elaborate further on these sources and tools for knowing, beginning with the least informative to the most informative.

Information/knowledge from the setting. As reported by the men and women, least informative sources of information arose from the setting and involved resources such as the 'calendar.' The calendar listed their appointments and for most settings, who they were scheduled to see: psychiatry, dermatology, gastro, dental, etc., and often what time. The 'consult' was more frequently spoken about as an indicator that an appointment had been scheduled. As most of the men and women did not 'read' the consult, nor was it read to them, the consult was then a limited source of information indicating only that an appointment would occur. The 'Med Book' was also a limited source of information but provided a space in which an interaction took place between the staff members and the men and women, at least those who 'signed' the book. Signing the book indicated that they were asked to identify their medications and what those medications were and what they were for, in some cases. The med book contained all the medication they were prescribed however, it also contained information concerning side effects. One individual, Alfredo, got the med book *"the magic book"* he called it because he knew it listed all his medications. Careful to turn only to his section in the book, he instructed me to look at one particular medication because he wasn't sure why he was getting it. Pointing to the writing under the medication he said *"look it says what it's for right there."* However what was actually listed there were the side effects of the medication. When I pointed this out to him, he responded *"there's side effects even from those meds?"* For Alfredo, side effects were a product of psychotropic medications prescribed for behavior conditions and not a product of medications prescribed for medical conditions. In the end we couldn't find the answer to his question based on the 'magic book' but we talked about who he might ask. The 'Med Book' was tied to the Medication Administration Training and offered more information concerning their medications and why prescribed, but not everyone partook of this training; for some this ‘training’ might end for no known reason, or for others, may never be started.

Information/knowledge from technology. Moderately informative sources of information were more individually based and involved technology. Television was utilized by some of the men and women not only to gain information, but also to understand how to go about getting information, change health care status, and learn why medically indicated conditions might occur such as high cholesterol. Television also provided a source of information regarding side effects of medication. This information was relevant solely to commercials. But as I observed in the different settings, one needed to have access to the television, and be able to watch television commercials without interruption. Two individuals used the knowledge they gained from watching television commercials to guide their self-other encounters with their medical practitioners and in one case, John’s, with his psychiatrist. Specific to both these individuals they lived alone and were placed in locations which required less staff oversight.

Carol used the television as a source of information concerning side effects of medications but also as a guide to getting information how to act. Specifically, Carol related to me that she saw it on TV that there are privacy and confidentiality issues involved with health care. This prompted her to say in relation to sharing medical information with staff, *“well I don’t talk about it a lot; it’s not mentioned like I know it’s mentioned on the TV but I don’t know if they would like my asking those questions, like the doctor said—it’s confidential.”* She related this to the fact that there is little sharing of information between staff members and *“the clients.”* This information also guided her in not sharing or asking information from staff, so she would ask professionals who would be more likely to share information and not be constrained by privacy and confidentiality issues. But Carol also ‘learned’ from television commercials how to get information. In one instance she told me “*Like they say, ‘ask your doctor about…’ so I do.”*

John also reported frequent use of television commercials as a teaching tool. For John, he not only learned about side effects he also learned how to manage his health conditions. John was highly motivated and wanted, someday, to be off all his meds. John in relating to his diagnosis of ‘borderline high cholesterol’ informed me that *“I saw the thing on the TV about Cheerios and cholesterol, it changed it, it lowers cholesterol!”* John made sure he bought Cheerios and further that he paid attention to the types of foods that are cholesterol lowering and those that increase it. But more than this John related to me how by watching Television he learned that the psychotropic medication he was currently prescribed and desired to stop taking, had side effects he wasn’t happy about. *“oh it was another medication, I changed it, I saw it on TV something about the side effects…Yes I told him [psychiatrist] I saw this thing on TV about the medication, like, so then he started me on it when I was telling him about it then he started to change me to put me on [another medication] instead of the other one.”*

The computer was another source that some people used, deemed as moderately informative. Ruthy knew that all of her medications were listed on the computer and she could *“print it out for me if I wanted.”* The computer for her served as an external memory aid so she did not have to bother with remembering all of her medications. In another instance, involving John, he explained to me his use of the computer and that he had been on some searches. John used the computer as a means to social interactions and often frequented ‘chat rooms.’ John discovered that he could ‘chat’ about information and this led him to knowing that he could conduct computer based searches, using ‘Google.’ I told him he could look up medications and medical conditions on the computer as well. His response was somewhat unbelieving *"you can look up that information on the computer?!"*

Unique to both of these individuals, according to their own accounts, was that they had limited social resources. Both had little contact with family, few friends and tended to be private relying on the television for their information, and at least in John's case, relying on the computer for his social connections. For the other men and women sources of knowledge were more socially derived because they had access to others and the information they gleaned from these others was indicative of the type of relations characterizing these self-other encounters. These encounters involved dialogical relations as indicated in their accounts.

Information/Knowledge from others. Most informative sources of information came from others. These other included family, friends, co-workers, and professionals including doctors and pharmacists. Fifteen of the men and women stated they used others for information. Also included here is another form of technology, the cell phone. Cell phones were a source of connection to others and were used by those who had one as a means of accessing information sources, support, and reassurance.

Andy used his cell phone to call his mother for her opinion. When we first met to discuss the research and whether or not he wanted to participate, he decided he wanted to participate. He then he used his cell phone to contact his mother to ask not her permission but her opinion about it: *"this woman wants me to be part of this research about medical decision making and consenting, what do you think about that?"* But he also used his cell phone to call his medical practitioners. He described to me an interaction in a clinic, an agency run clinic that he was not happy about. He told me he had called the supervisor on his cell phone while still in the office to complain—apparently he was made to wait a long time only to learn eventually that the appointment had been canceled. No one had informed him and it was not the first time this had occurred. Andy also stated that he could use his phone to contact his girlfriend, *"she can help me out, she can calm me down,"* when he was upset over something.

Chucky also had access to his own cell phone and used it quite frequently to get in touch with his mother for any concerns or questions he might have. Chuck used his cell phone as well when we first met to discuss the research, because he wanted to let his mother know that he wanted to be involved. Interestingly, Chuck was one of the few individuals considered non-consenting, who did not know his mother consented to all his treatments as his legal guardian. When I went over the consent and assent procedures, Chuck questioned why I would have to ask his mother, as he already told me he wanted to be involved in the research: *"how come I can't sign, why do you have to ask my mother?"* I then had to explain his status and that I would need his mother's consent as she signed all of his consents and authorized all treatments and services. Chuck seemed surprised by this however, whenever I visited his facility, he questioned me as to why I didn't set a date to meet with him. I explained to him we couldn't do that until I received the consent signed by his mother. Chuck immediately took out his cell phone and asked his mother to complete the consent. The staff members that worked with Chuck also spoke about his frequent use of his cell phone, *"he calls his mother for everything."* But this connection with his mother was a source of information, his mother recommended the dentist he went to and he could discuss medical issues, relating to himself though he had few medical concerns, as well as medical concerns involving his family members.

Juan used a cell phone for social connections with friends, all of whom were from outside the setting. During our scheduled time together, Juan received frequent calls on his cell phone from his friends as he was going to meet up with them after we finished. Juan was aware of his curfew and let me know that his time was limited. Juan also had a community job which he said he enjoyed, he enjoyed the people there. Juan maintained that he would talk about medical issues, for him mental health issues as he reported he had no medical concerns, with his psychiatrist and was somewhat guarded in this stance: *"She's the one prescribing it so I talk to her about it."* Juan was the only individual who had insight into why he went to a psychiatrist *"I'm depressed because I'm here, I'm the youngest one here"* and he found his psychiatrist helpful. If Juan spoke to his friends about his placement, and his feelings about his placement, he did not reveal this to me in our time together.

Another form of knowledge brought to my attention was a health care clinic's 'Patient Satisfaction Survey.' This 'survey as tool' was specific only to Carol's experience which she shared with me. While we were together, Carol brought out one such survey she had recently received from her clinic. Carol received much of her health care services through a community clinic associated with a nearby hospital, having no connection with the residential setting, or the service provider industry in general. Her status as a patient in that clinic included her in receiving these surveys and previously Carol had completed them and sent them back. However, she informed me she decided to keep this one because it was something that could help her, *"I don't know if I'll show this to [staff's name] it has good questions, I think I'll keep this one and not send it back like I did the others, I'll have these questions now so that would help."* For Carol the questions asked by the survey gave her clues to how her treatments and encounters with doctors should be. The format and questions in the survey provided her a framework in which to understand how her self-other encounters with the professionals involved in her health care should be and what kind of information, encounters, and treatment she 'should' expect.

Her statement that she would not show it to staff at the residence, indicates her awareness that knowledge resources were ‘protected’ or ‘limited’ by the agency setting. Carol’s awareness of this was linked to her experience and was also demonstrated in my interactions with employees in the setting as related earlier dealing with the use of generic medications.

Pharmacists. Carol’s experience provides segue to another resource for very informative information, the pharmacist. Three individuals, two women and one man, informed me they asked their pharmacist about medications. In one case, Carol’s, this was a serendipitous discovery because the pharmacist started the interaction by *“telling me about the medication”* when she went to pick up a prescription. Asking the pharmacist implies that an individual can get to the pharmacist and have the ability to speak with them without a staff escort. The three individuals (all from setting Autonomous) who spoke about using the pharmacist were considered ‘independent travelers,’ ‘self-consenting,’ and all could access their local pharmacy easily. John said *“If you don’t know something about the medications or something you have to ask questions about the side effects and things like that, sometimes I ask the pharmacist, like maybe [I’ll] ask the pharmacist.”* For Carol as indicated previously, she knew the pharmacist was a professional who was able to give her information: *“But another thing is that you got to find out from a professional before you take something or ask the pharmacist.”* While for another woman Nadine, she said, as a matter of fact if she had questions about her medications she’d ask her pharmacist not her doctor: *“No the physician, oh wait not him…the pharmacist.”* However, she also informed me that the setting was implementing a new practice: having the medications delivered. She didn’t think she’d be seeing the pharmacist anymore: *“No well no I don’t pick it up, they send the meds to here by car or messenger or something like that now.”*

Doctors. Doctors also were a source of information. The level of information gleaned from doctors was based on how each individual viewed their relationship with the doctor and their experiences of relating to doctors. Five men and women saw doctors as a resource for information. Carol's experience is informative here. For Carol one of her doctors was actively teaching her: *"She is a diabetic doctor, she gave me some advice and she'll show me like boxes [nutritional labels on food boxes] so she's good, she tells me the facts and the 'combines' yeah that's how she's teaching me, she's teaching me things like that."* This particular doctor, Carol informed me, was part of a non-profit service provider agency clinic she used for some of her medical needs. In her interactions with this particular doctor Carol recognize that the doctor was giving her full information *"the facts and the combines"* and actively teaching her things to which Carol was very receptive. In her apartment Carol demonstrated what she had learned as a result of her interactions with this doctor by showing me some of her grocery items and identifying the information on the labels and how this related to the status of her diabetes (for which she took medicine not insulin injections).

Vicky also voiced her satisfaction with her medical groups at least those specific to her primary concerns. Vicky is a 49-year-old woman with a previously assessed IQ in the Mild range (IQ of 62). Vicky had her father sign her consents for her, even though she felt she could consent for herself. Specific to her residential setting (setting New) Vicky was 'represented by' her father. She wanted him to do this *"I am able but I let him sign."* Vicky was a healthy woman but had a physical disability that affected her hips. Prior to her placement in the present setting, she had experience with a hospital group who had helped her with a previous hip problem which eventually required surgery. Vicky informed me that she told the staff in her setting: *"I tell them where I go [for medical treatment concerning her hip issues]."* Vicky told me that she had been with this medical group for a long time, they did her first hip surgery and when she started having trouble with her other hip she wanted to return to this group. Because of how they treated her the first time, she trusted them and felt she could ask them questions and her questions would be answered. As she related to me, her questions to her doctors involved: *"I want to know what if?"* and *"I want to know will it help me?"* Vicky related to me her first experience of how she learned about her hip condition which was a result of her physical disability: *"I had pain, they gave me pills but it didn't help, it rubbed [the bones], so they gave me an X-Ray, they told me about the X-Ray, the rubbing [bone on bone] and I needed an operation."* Vicky indicated that she also saw the X-Rays and so knew the bones were rubbing, her experience with alternatives to surgery, medications, were not helpful and her decision to have the surgery she not only discussed with the doctors but with her father as well.

Patty, 49, (setting Protective) had a previously assessed IQ in the Mild range (IQ of 60). Patty chose the psychiatry vignette. In responding to this vignette, Patty voiced that maybe someone was bothering the woman depicted in the vignette and that was why she was angry *"maybe somebody is bothering her at her, at her job, if somebody's bothering her she went to the psychiatrist for no reason at all, I would have gone to another doctor and tell the doctor that somebody's bothering me at work."* Patty indicated that she could talk to her psychiatrist about her psychotropic medication *"I talk to them well for my meds…"* if she felt she didn't want a certain medication she could relate this information, *"sure I'd tell him I'm not taking it and I ask him for something else, yeah I did it once, yeah he accepted it."* Patty had experience with psychiatrists and psychotropic medications and she used this experience to speak with her psychiatrists and get information. Patty was one of the few individuals who knew she had the option of getting a second opinion.

Friends. Friends were identified as another source of information for some. Four men and women informed me that they used friends for information, as a source of support, or because of their relationships with friends they vicariously learned about medically related things. Alice and Nelly's example is most relevant of the usefulness of friends as informants. Alice in her talk with me mentioned that she learned about *"open MRIs"* through her boyfriend because he had many medical issues and therefore underwent many tests and Alice either accompanied him or discussed these with him. When an episode occurred in Alice's life necessitating that she required an MRI, Alice asserted she wanted an *"open one." "I was experienced with that through [her boyfriend] because he went through a lot of tests so I didn't want a closed MRI, I wanted an open one."* Prior to this Alice didn't know that such an option was available.

Nelly used her friends as 'resources,' *"I have resources that I can get information from. I have quite a few girlfriends they have one of my conditions and we talk about medication, we share information."* Some of Nellie's friendships were fostered due to her involvement in a support group, not part of the settings services, geared toward people with her medical condition.

Family. The most frequent source of information came from family members. Nine men and women spoke about getting information from their families or talking with their family members about their medical issues. Some examples of how family members were used as knowledge resources follow.

Alfredo, 51, had a previously assessed IQ in the Mild range (IQ of 56) and was deemed non-consenting by his setting (setting Autonomous). Alfredo learned through his brother that some psychotropic medications can have bad side effects. *"Yeah my brother, he tell me to call* *him to let him know how things turn out, he's my guardian angel, he looks out for me. First they [setting] want me to take [a psychotropic medication] but my brother said it wasn't good to take it, yeah somebody tell him it make people 'go off' or whatever 'go off' you know, so my brother said NO!"*

Nelly, 37 and Alice, 64 both deemed consenting, used family members as an information source. Nelly's was more focused because her mother was a nurse and so she could look up medications in the PDR or help her out with medical terms. Alice called her sister to ask her about emotional issues related to the death of her boyfriend: *"I called my sister, I wanted to find out why that was happening…she said it was a good thing."*

Shelly, 37, deemed non-consenting, was previously assessed with an IQ in the Mild range (IQ of 60). Shelly informed me that she asks her mom things, her mother is a nurse. Shelly also let me know that her mother recommended some of the doctors she sees and her mother was a source of information for medical related issues but not so informative for mental health related issues. Shelly who was seeing a psychiatrist was currently prescribed psychotropic medications. She referred to this medication while speaking about her encounter with the psychiatrist: *"she is the one that always gave me the angry medication like the [psychotropic medication] and stuff, she always gave me [medication]. I get out of control here, teasing everyone,"* however, she does not do this type of 'behavior' when she goes home *"when I'm home on the weekends with my mom I don't start that teasing garbage. NO!!! My mother won't appreciate that."* Shelly knew the names of her medications (medical and psychotropic), *"I used to be on [psychotropic medication] and then the [psychotropic medication]*." According to Shelly's account, she was taken off the medication *"I'm glad they took me off of this medication, they put me on this medication because I was out of control here, as a matter of fact I'm not on the [psychotropic* *medication] any more, well right now they think I don't need the [psychotropic medication] but I still get out of control here."* According to the 'medication book' I consulted after meeting with Shelly, she was still taking it.

Staff. Staff had things recorded, stored, managed, and filed therefore staff became a type of external memory tool for the men and women. Repeatedly the men and women referred me to a staff member because the staff member would know: *"you ask [staff's name] she know how long I'm living here."* Or *"[staff name] is one, when you're finished with me step outside and talk to her she knows all about that [medications she is taking]."* This reliance upon staff might have been interpreted as an indication of the 'inability' of the men and women placed to remember their own information however, it became evident—especially evident in the videos—that for these men and women this was one service in the service delivery system that they made full use of. The men and women were aware where the information was and with whom it was supposed to be—with staff—so in their reality there was no need for them to remember it.

Repeatedly the men and women readily encouraged me to speak with someone who had the information revealing they knew where the information was. *"After this do you want to speak with [staff's name] on the phone?"* [to ask about the doctors she sees], and *"I think the staff know, they know more about that this than me—yeah you got to talk with them"* and *"He knows more about me than I do—he's like a professor."* Staff members not only coordinated appointments, knew in part people's histories and medical pasts, but they also stayed abreast of all the various medications, which as expressed by some of the men and women, could be a nuisance *"You gotta ask [staff name] she knows all the medicine I take, I only know my [name of psychotropic medication] that's all I know, I take it for my nerves."* And as seen in some of the accounts above, most notably with Alice, people's histories could be recalled and 'replayed':

"You have to ask [staff's name] about that, I can't remember when it first came up that I had to go to a psychiatrist."

Across settings, functioning level, and diagnoses, these men and women primarily did not rely upon staff as their 'first line' of support. For these men and women they learned through their experiences with staff that unforeseen consequences could occur if they revealed information, thus they informed me, they found other people to 'share' with. Staff's tendency to record their discussions, to define their behaviors as 'aberrant' or as 'clinical problems' in need of care, led the men and women to seek out other resources, outside of the settings, revealing that trust and motivational concerns were primary issues across the settings.

Resources appropriated from outside of the setting involved Pharmacists, doctors, family, friends as well as technology such as the television, patient satisfaction surveys, computers and cell phones. These supports provided knowledge that was collaborative and informative in terms of 'knowing how to know' and indicative of self-other encounters that evidenced dialogical relations. Since there was great variety in choice responses, evident not only in the assessment but in how they talked about choice, this area was looked at more closely. Specifically the next section reveals the meaning of choice and how this meaning shapes and is shaped by the types of relations characterizing their reports of self-other encounters—namely, within the setting relations as reported tended to be monological rather than dialogical. This process is evident in the social languages existing within the settings as follows below.

Social Languages: The Meanings of Choice

For individuals in setting Autonomous, many choice responses given to the ACC-I assessment were characterized by the statement *'has to.'* This was especially relevant in the part of the assessment where the question of choice arose such as: He/she has a choice to accept or deny the treatment, what choices does the person have, and in given the final choice: What should he/she do and why? For the individuals in setting Autonomous, although having higher previously assessed IQ scores than those individuals in settings Protective or New, many of their responses to these questions involved partial scores because their answers implied *'having to'* say yes to the treatment and failing to express what 'choices' were available. Based on the interviews with administrators in setting Autonomous, in their approach to consent issues, some individuals were deemed self-consenting and therefore signed their own consents and authorized their own treatments. This was in line with setting Autonomous' stressed value on self-determination. However, because setting Autonomous was driven by parental desires, in the event parents desired to authorize services for their adult child diagnosed with a disability, the agency followed the parent's directives and desires, regardless of the abilities the individual might possess.

Some examples of the social language of choice in this setting were as follows: *"oh they got to call the parents," "well she would have to take her medication," "I don't know nothing about that"* (in reference to a question concerning why a person would not want to take a medication), *"what choices? Oh he would have to take the med," "she don't take it she'll be told to take it by her mother"* and *"just call his parents."* Setting Autonomous also contained more men and women prescribed and taking psychotropic medication and the psychiatry vignette was the most frequently chosen vignette in that setting compared to settings Protective and New.

In discussions with administrators concerning approaches to consent issues, setting Protective stressed that individuals were allowed to say 'no' despite the fact that none of these individuals authorized the services they received. This emphasis on each individual's ability to say no or refuse treatment was stressed as a priority. Many of the statements regarding the choice questions from the men and women in setting Protective, were characterized by this stress on saying 'no': *"She say no, I don't know why," "No! If she no want to take her medicine, she no have to!" "She can say 'no' because she doesn't want them," "no he no get the shot, because he don't want to, because he is scared."* Setting Protective had many more individuals who picked the dental and allergy vignette and overall had fewer partial scores related to choice.

In setting New, the men and women gave answers to choice questions as yes or no and final choice decisions—to accept, deny, or 'have to' accept treatment—were dependent upon what the person in the vignette wanted to do *"well that's up to him,"* or because the treatment would be helpful for the situation described *"If she says no she's going to stay sick" (in relation to allergies),* and *"he should tell him yes I need braces to help him with his teeth."* However, for one individual in Setting New, who chose the psychiatry vignette his responses were heavily characterized by knowledge from the setting (community of practice knowledge). Considered co-represented by his setting (setting New), with an IQ in the Mild range (IQ of 60) Mark's response to the vignette demonstrated a partial choice response because he claimed that the individual would have no choice. From the perspective of staff and the setting, Mark saw the person's behavior in the vignette as *"outbursting"* and 'bad-behavior.' Resulting from this the individual required medication because of their behavior: *"let me put it this way, number 1 is: if she don't take her mediation, she can't go to work, nobody's going to tolerate her behavior, she got one choice: go to the psych ward, because if you go to the man who gave you the medicine, and you tell him you don't want to take the medication, the next thing, I think, is you go to the psych ward."* Mark's approach was strongly steeped in his knowledge of the setting and his long-time placement within institutionalized settings characterized by professional relationships.

In the vignette Mark's response to questions asking what should the person consider in deciding what to do involved: *"well put it this way, no staff is gonna fight no consumer about taking a medication, they want her to take it."* Further when asked what the psychiatrist could do to help the person Mark replied: *"Call the psychologist and have a team meeting."* Mark chose the psychiatry vignette because he knows many *"clients"* that had *"behavior problems and outbursts"* which he felt needed to be addressed. Mark himself is not under psychiatric care. Mark informed me he was a very active member of the self-advocacy group directed by his day program agency. Having moved here from another facility run by a different agency about five years ago, Mark professed that he was happy in this new agency because the executive director: *" treats us like staff."*

Meaning of 'choice' in setting Autonomous meant 'not really having one.' Many of the men and women placed within this setting, when they spoke of choice, stated that they could not say no or indicated that saying yes and not refusing was inherent in their sense of 'choice.' While in setting Protective the meaning of choice was a function of consequences. Thus, for some of the men and women placed in this setting they indicated if you say no then there are consequences. These consequences involved: you don't do other things such as go out on activities or you 'lose your rights.' Lastly in setting New the meaning of 'choice' was related to 'no choice' specific to psychotropic medications but also arose for those men and women who saw themselves as having no direct part to play in their medical affairs affecting their own life.

Chapter Summary

The accounts given by these men and women indicate that their involvement and the information they have access to, within the settings, concerning their medical and mental health care practices and treatments, is limited. Many of their accounts indicated they were marginally involved in their own health care practices and treatments, required merely to attend appointments and comply with treatments. Medical related appointments were often scheduled according to organizational agendas (such as regulations), under 'professionals' control, and were often not based on any individual's initiative or connected to current health status which the men and women could relate to. Medical related treatments such as prescribing medications, procedures, and providing necessary information concerning those treatments and procedures in many cases were not disclosed directly to the men and women by medical or mental health practitioners; instead this information was written in a 'consult' and presented to staff.

On the one hand these accounts of men and women reveal that the self-other encounters they have with professionals: staff, managers, doctors, etc. are primarily characterized by monological relations; they are told when to go, what to do, what to take, what diagnoses they have, but often are not invited to present their point of view or add their own input. For the men and women whose accounts have been recorded here, the self-other encounters they revealed indicate a lack of dialogical legitimacy; their perspective and point of view is often rarely considered or valued in its own right. In some of the accounts presented here, their past and present experiences and the type of relations they have had, are linked with the types of knowledge characterizing their responses to the Assessment instrument. In the case of monological relations, knowledge is limited and this may be related to the frequent use of 'Social-Historical' as a knowledge type by these men and women characterizing their answers to the assessment questions.

On the other hand, those men and women who demonstrated a deeper knowledge of health concerns and treatments were those who had some instruction on 'how to think' about health concerns and treatments; they were instructed on ‘knowing how to know.’ This ‘instruction’ occurred primarily in self-other encounters which were dialogical—where their point of view and perspective were not only legitimized as worthwhile but considered in the context of the treatment and recommendations—and this ‘instruction’ was informal, arising in simple day to day interactions, such as with the local pharmacist, but primarily arose from sources outside of the settings. This ‘knowing’ may be related to the frequent use of Socio-Cultural’ as a knowledge type characterizing their answers to the assessment questions.

Chapter 8: Discussion

"The fact that people were attentive to his body does not compensate for their ignoring his being"—Abraham Verghese, 2009

This study investigated the extent to which self-other encounters characterized by dialogical (inclusive of information, knowledge, and perspective taking) rather than monological (exclusive of information, knowledge, and perceptive taking) relations affected the development of treatment decision-making competence in men and women diagnosed with intellectual disability. Offering an alternative view this inquiry shifted emphasis away from intellectual factors, either-or questions and outcomes usually associated with capacity for treatment decision-making competence. The approach taken here examined treatment decision-making competence as heavily dependent on interpersonal interactions and perspective-taking—where information is exchanged—with the intent of supporting informed consent decision-making competence in adults diagnosed with intellectual disability. Toward this end, I employed a situated and dialogical framework and was concerned with questions of 'how' competent decision-making develops and how this could be supported in adults so diagnosed.

Through a situated and dialogical analysis based on a theoretical framework combining developmental and social psychological perspectives I examined, across three different settings, relationships between individuals placed and employees working within those settings. Specific settings were agencies within the New York State non-profit service provider industry offering services to men and women diagnosed with intellectual disability. Individuals consisted of men and women placed in the agencies as well as professionals and staff employed by the agencies across a range of positions. This range of positions was hierarchically organized within the settings and included upper administrators, overseeing agency policy, operation, and compliance with state and federal regulations; middle administrators, nurses and direct-care workers whose work involved day to day interactions with the men and women placed.

An expectation of this study was that placement in different settings would affect decision-making behavior, regardless of range of intellectual disability. Men and women placed in settings which provided involvement in their medical and mental health care treatments, decision-making, and issues would demonstrate knowledge and information necessary for competent decision-making behavior and would report self-other encounters characterized by dialogical relations as opposed to those men and women placed in settings which did not provide this involvement. This expectation was not realized. Despite having different policies in regard to consent issues, strong mission statements concerning self-determination, promoting independence and autonomy; the settings fostered monological relations between the placed adults and the employees and professionals they interacted with. The men and women experienced little involvement, participation, or voice in their medical and mental health related treatments or concerns, across all three settings. This was the case regardless of the consent status of the individual (self-consenting or having others consent for them) and range of intellectual disability diagnosis. Information was often excluded rather than revealed or discussed. Social knowledge and information necessary to demonstrate competent behavior, such as knowledge of ‘alternatives of treatment options,’ and ‘treatment choice options,’ were often not accessible for these men and women. Assessing the depth of their ‘integration’ into the broader society by their use of socio-cultural knowledge revealed that relevant social knowledge was often used by those men and women who had spent time outside of these settings or had access to others outside of the setting.

This inaccessibility was primarily a result of employee conceptions of the phenomenon of intellectual disability validated by their ‘need’ for placement and, accountability issues on the part of agency employees to parents, regulations, and supervisors. The priority, in the context of accountability, was not directed toward the men and women, but rather toward those ‘authorizing’ placement, services, policies and practices. The settings differed in degree not in kind as a product of two factors: static notions concerning the diagnosis of intellectual disability and the context of their emergence within the service provider industry.

Thus, one setting arising with the parent movements in the 1940s promoted within their mission statement an ideology involving the importance of individual rights and the concept of self-determination for the individuals placed yet followed the lead of the parent’s wishes. Borrowing language used by an administrator in one of the settings, within this setting the parent’s steered the ship for their adult child and that is how the agency proceeded. This was regardless of intellectual level as assessed by IQ tests and day to day functioning abilities on the part of the individual diagnosed. Similar across all three settings, this ‘steering’ of the ship began upon the individual’s placement and rarely changed once established for the remainder of the individual’s placement, usually ending with their death.

Another setting arising with the Willowbrook consent decree and its eventual closure, promoted an ideological approach supporting self-advocacy for individuals placed. Emerging in the aftermath of the abuses and neglect characterizing Willowbrook and institutions like it, taking care of the individuals placed and giving them the best possible care, though objectively defined, was an agency mission and priority. Within this setting the agency ‘steered’ the ship for the individual placed. Parental and guardian involvement was encouraged but was secondary to the decisions made by the agency itself. Parents, legal guardians, and correspondents, agreed to this arrangement at the time of admission by ‘signing’ the admissions packet authorizing the agency to render ‘needed’ services.

The third agency equated a rights based ideology with the right to receive quality and efficient health care. Emerging recently on the historical landscape of the industry, this agency used different language and followed a different procedure in regard to authorization of placement and services. Terms such as “represented by” and “co-represented” indicated who authorized services but also included the individual placed, in their initial interview at time of admission. Despite use of different language terms however, in this setting, an ‘advocate’ employed by the agency was responsible for ‘steering’ the ship for the individual.

The extent to which knowledge resources were made accessible, if at all, was evaluated by the types of knowledge required to demonstrate competent treatment decision-making as manifest in making an informed consent. The types of knowledge specific for the legal construct of informed consent decision-making include: knowledge of the ‘disorder’ requiring treatment, knowledge of the risks and benefits of treatment, knowledge of alternatives including no treatment at all, and knowledge of choice to accept or refuse treatment. Findings revealed significant constraints existed in these men and women’s ability to access, or be informed of, these specific types of knowledge.

Constraints on the accessibility of knowledge and information was a result of accountability issues which were particularly salient to employees; tailoring policies, practices and types of encounters with the men and women placed. Information and knowledge, when made available, was basic, cursory at best, and dependent upon what the men and women were *“capable of understanding or hearing”* based on employee, and as reported, professional’s, subjective judgments. Most prominently, findings revealed that for those men and women who had ‘consents’ signed by others—either parents, family members, legal guardians, or others recognized in the regulations as correspondents—they were henceforth excluded from obtaining pertinent information concerning their medical or mental health care treatments and issues. This exclusion occurred because pertinent information of medical and mental health treatments and issues was divulged only to those ‘signing’ consents or authorizing treatments.

From the perspective of the men and women placed health care practices and treatments as offered within the settings were devoid of choice and in most cases perceived as a matter necessitating only their compliance. Their reported accounts comparing the ‘ideal’ doctor-patient encounter characterized in the assessment for consent capacity evidenced their awareness that their real life experiences were far from this ‘norm.’ These men and women reported that often they were not given information, and moreover, in their encounters with professionals as well as staff, no alternatives to treatment, long term side effects of medications, or basic knowledge about their conditions was divulged. Most frequently this situation arose in the context of psychiatry, psychotropic medication use, and follow-up appointments or explorative/preventative based examinations. This was not always the case with ‘in vivo’ situations where they had experience with the illness, problem, symptoms or treatments or, actually initiated, via staff, medical treatment.

Another finding concerns individual motivation and goal directed activity. Goal directed activity initiated on the part of the setting was not always compatible with the goal directed activity on the part of the men and women. Relating to medical and mental health care, the setting’s goal directed activity was described as *“everyone has got to be checked and everything has got to be on point.”* This agenda, on the part of the agency, was motivated by different concerns, priorities, and accountability issues such as those related to: job security, audits, and regulations. Thus, when these goal directed activities were at odds with the motivations or goals of the men and women, conflicts ensued. Such conflicts were often interpreted, by staff, as arising within the individual men and women, as part of their ‘disability.’

My objective in this research was to broaden current knowledge and practice concerning assessments of capacity for informed consent treatment decision-making as this applies to adults diagnosed with intellectual disability. This is an area involving matters of critical importance in the lives of adults diagnosed with intellectual disability because it centers on their right to self-determination and autonomy as citizens in American society, protected under law. An area adults, diagnosed with intellectual disability, are usually exempt from because, it is assumed, they lack the ability to do so given the ‘nature’ of their diagnosis (see Stalker & Harris, 1998).

Broadening knowledge and practice in the context of assessment for ‘competence’ involves examining the contextual and relational processes involved in capacity for such decision-making. Factors external to persons such as context and relations and their impact on the process of ‘capacity’ in decision-making have been examined with other ‘vulnerable groups’ such as the elderly and children, as recalled from chapter one. Relational, dialogical and contextual factors were revealed as inherent in treatment decision-making processes and competence. These factors emphasize the sociogenesis (see Lightfoot & Cox, 1997) of human intellectual functioning and development. Within this research I examined these factors in the lives of adults diagnosed with intellectual disability, placed in residential settings, as affecting ‘capacity’ and decision-making. Framing this as knowing *‘how to know’* as this applies to making competent treatment decisions implies an active teaching-learning, dialogical, interaction. These interactions enable transformation; the emergence of new mental processes or new ways of thinking. Interactions such as these can occur in self-other encounters between patients and doctors as well as between staff and placed adults. Findings revealed that often the diagnosis of the individual and their status as ‘placed’ was a major deterrent in allowing these types of interactions to occur. As other scholars have noted lacking a valued social identity profoundly impacts an individual’s development, treatment prognosis, and ability to advocate for themselves (Wolfensberger, 2005; Sabat, 2005; Sabat & Harré, 1999; Fine & Asch, 1988).

Movements: Toward change and reform

Accordingly, another aim though implicitly stated, resides in using this research as a platform on which to enable the perspective of men and women diagnosed with intellectual disability, placed in such settings, to be heard. Strikingly, their perceptions and voice have been absent both from the literature and in law regarding competence assessments, guardianship procedures, and rights. Vygotsky’s theory was situated in a strong social-political and socio-justice context. The Vygotskian ‘project’ then and now, can be conceived of as a new approach in psychology with “a mission, devoted not to pursuit of knowledge but to creating new forms of social life and practice….to create psychological processes that set individuals free, rather than how to observe existing processes” (Stetensko & Arievitch, 2004b). This lends a critical stance to the current research in its creation of a space for “semantically mediated negotiations to occur” (Rommetviet, 1985) between the discourse of individuals diagnosed with intellectual disability and those of the professionals and employees with whom they interact.

It is in these negotiations with the Ego-Alter concerning an ‘Object’ (Markova, 2003) that conflict, stress and through these, change occurs as each ego meets an alter perspective in the course of interactions over an object. Within this research I attempted to create a space where these semantically and semiotically mediated negotiations could occur. These negotiations allow for intersubjectivity to be achieved and through this transformation in knowing and practice created. Thus these negotiations allow for movement towards change, making a space for reform possible. Following, I present scenarios of the various movements or areas of change that occurred, or revealed, within this inquiry.

Scenario I: A woman enters a pharmacy, she wears no sign that she is diagnosed with a developmental disability as she approaches the counter to pick up her prescription. The pharmacist informs her that she is getting a generic medication instead of the known brand because the doctor indicated this was possible on her prescription. The pharmacist goes on to inform the women what the generic medication means and why it is given (cost). From this encounter the woman now knows she can ask the pharmacist questions concerning her medications and she uses the pharmacist as a knowledge resource. She has learned that some medications if combined can cause negative side effects, she has learned that the pharmacy has a computer program that lists those medications that interact negatively if combined, she has learned that she is viewed as a person like everyone else in the drugstore, and is treated in the same matter and provided meaningful and important information.

Scenario II: A man on his visit to his psychiatrist tells the psychiatrist that he no longer wishes to take the psychotropic medications the psychiatrist prescribed for him because he feels the medication is not working. He feels he does not need the medication. He is informed by the psychiatrist ‘no, he must continue to take it because it is working.’ While watching television he sees a commercial advertising a psychotropic medication that happens to be the same medication he is currently prescribed. The commercial lists the side effects possible from taking this medication. At his next appointment with the psychiatrist the man tells his psychiatrist that he no longer wants to take the prescribed medication because of the side effects which he lists. The psychiatrist agrees to change his medication, though not to discontinue its use, however if the man agrees to see a therapist for counseling, the psychiatrist will entertain discontinuing the medication.

Scenario III: A woman is informed by her residential facility that she has an appointment for an MRI. The woman based on her experience with a friend who had both a closed and open MRI, tells the residence staff member she wants an open MRI. The appointment is rescheduled so that an open MRI can be obtained.

Scenario IV: A man is approached to ask if he would like to partake in a research study investigating what is needed to support people in making their own health care treatment decisions. The man uses his cell phone to call a family member. In discussing the request with this family member he does not ask them to tell him what to do, nor for permission to participate; instead, he asks for their opinion, *"What they think about this."* Upon ending the call he poses some questions and after they are answered, he responds he would like to participate.

Shifts in thinking concerning current practices were also evident and emerged within the context of this research with administrators and staff as well.

Scenario V: A staff member relatively new to working in the setting approaches a woman, herself recently placed in the residence, with her evening medications. The woman views the medications and notices that one pill is different. She asks the staff member what the medication is and what it is for. The staff member answers her questions and views this woman as being 'smarter,' *"she knows"* despite the fact the woman had not been informed of any changes.

Scenario VI: An administrator confronts the practices of the setting in light of an altered view of competence—as a skill that can be developed and fostered. She states: *"you know following the rules is what we are paid to do, and taking care of them and even when we talk about individual rights, like their right to do this or that, at the end of the day you are still telling them when to go to sleep, what to eat, and they are still be driven to where you want to take them, or the choices you gave them, they are not allowed to break their own diet and when they do we write an incident about it, they are not allowed to make bad decisions, but we are. You know in all the different procedures that they have reviewed of ours (state and federal audits) it's never come up, you know…it's never proposed that we teach them how to make these types of decisions and they will never be spoken to [because others sign for them], so it's definitely a mindset."*

Scenario VII: A clinical psychologist confronts guardianship within the context of discussions involved in the present research. He states: *"I think too many psychologists signed off on them [capacity assessments indicating incapacity] at the request of parents without having any serious discussion about what this guardianship really means, I mean I would say early in my career, I signed off on some guardianships that I would be much more leery of doing today…you know we were taking the request of a parent much more. Can someone ever have 'guardianship' over someone else?"*

Including the perspectives and knowledge of people diagnosed with intellectual disability these findings indicate that what is usually viewed as (in)competent behavior arising from an internal attribute, on the part of individuals so diagnosed, has more to do with the type of self-other encounters and information made available in the contexts situating their lives.

Implications

These findings revealed that whether any of the men or women were deemed 'consenting' or 'non-consenting,' had little to no effect on their responses or narrated experiences as this concerns their 'knowing' of medical or mental health care. Individuals deemed 'self-consenting' were primarily among those who had no family or others to provide, or who insisted on providing, 'valid' authorization for services rendered to them. In most instances where informed consent arose for these individuals, it involved their consenting to the use of psychotropic medication. None of the individuals in this study were currently facing medical procedures or treatments of which an informed consent was required. Often, regardless of their consent status, they were not informed of knowledge and information necessary to demonstrate 'informed' consent competence; someone else was. There was also a similarity among significant caregivers, family members, and settings characterizing the contexts in which many of these men and women developed, according to their own reports, as sheltered, protected, and closed. These combined contexts and relational experiences then characterize the type of 'cognition' they evidence as seemingly similar and may lead to the conclusion that such thinking on their part is a result of the disability diagnosis rather than a consequence of embeddedness in constrained knowledge systems mediated by lesser quality tools, information, and instructors. Strikingly, what many of these men and women did know was that there was knowledge and information—concerning their lives—that they were not supposed to know. Hence, 'it was none of their business,' because it was the nurse, doctor, or staff's business.

Vygotsky (2004) stressed the development of higher mental abilities involves processes common in our shared humanness and applies to those with intellectual disabilities where this focus is especially important in order to promote optimal development. His words are especially relevant in the context of ‘knowing’ and ‘intellectual disability’ and are repeated here:

> “The inability to use natural psychological functions and to master psychological tools in the most basic sense determines the kind of cultural development a handicapped child will attain. Mastering a psychological tool and, by means of it, one’s own natural psychological functions generates an *artificial development,* as it were; that is, it raises a given function to a higher level, increases and expands its activity (p. 169).”

Vygotsky developed a theory of disontogensis—distorted development—to understand the development of children with ‘special needs’ (Kozulin & Gindis, 2007 p. 335). Applying this theory in the case of ‘defects’ development is likely to be disontogenetic or distorted as a result of exclusion from socio-cultural mediated tool use and knowledge of ‘ideal forms.’ However, the findings reported here suggest that for the men and women involved in this study, their development—concerning mental functioning relating to decision-making—was not characterized by disorganization such as Vygotsky postulated. Rather, a characteristic of their development as revealed by these findings is more accurately described as improvised rather than disorganized because they do not have all the necessary information needed. This was evident in many individuals who expressed incomplete or improvised knowledge.

For these men and women their access to tools and ability to use them was limited or constrained as their interactions with others failed to mediate ‘knowing how.’ In some cases this exclusion consisted of ‘not knowing’ others were authorizing their treatments and services. This exclusion exists, as revealed in the accounts given here, because encounters with these men and women are interpreted through representations of the cognitive (in)competence associated with the phenomenon of intellectual disability—the ingrained narrative—validated by their 'need' for placement in the settings.

Their unique and nuanced knowledge and perceptions emerged from their status—placed. These men and women were often not perceived, encouraged or expected to be agentic toward their own medical and mental health care concerns. In some cases when they did demonstrate agency, it was not welcomed by staff in the settings due to the priority of accountability issues and agendas evident in each setting's hierarchical organization. The social representations of intellectual disability, as narrated by employees, potentially colored interactions in many other of life's domains relevant to these men and women. Though I used the lens of informed consent to concentrate on medical and mental health care, in dialogue with the men and women, as well as employees, other areas of their lives were often brought into focus. Thus, occasions presented where multiple staff were interviewed concerning the same individual. While one staff member described an individual's questioning of a medication as a sign of the person's capability, another employee described this as a 'challenging behavior,' a resistance, and a result of the person's "*mental retardation.*"

The ecology of the settings revealed the extent of interplay between multiple and conflicting voices—each with their own agendas and accountability issues—in any one individual life. The effect of this multiplicity of voices, inherent in the settings, was to render information and knowledge the men and women did receive, as arbitrary. For many of these men and women, they were largely dependent upon knowledge given to them by staff. In light of these findings and the theoretical framework on which they were examined, it is the perfunctory and conflicting nature of this knowledge, which had the greatest potential in rendering them ‘vulnerable.’

Given the similarity of social interactions characterizing the settings in which these men and women were placed, it can be said that adults diagnosed with intellectual and other developmental disabilities demonstrate similar forms of ‘cognition’ and behavior due to the ‘universalizing’ tendencies characteristic of the settings which perpetuate this. A similar thought was put forward by Gal’perin (Arievitch & Stetsenko, 2000). Gal’perin surmised that perhaps children demonstrate Piaget’s stages and also Vygotsky’s ‘ideal forms’ because of the ‘universalizing tendencies’ of education. The universalizing tendencies of the current settings exposed the men and women to similar reactions from as well interactions with, others who were non-disabled. Within this study, in light of these findings, the oft quoted phrase used across the hierarchy of staff within the settings—“That’s just the nature of the population”—becomes relevant only if the word ‘population’ is exchanged for the word ‘setting.’

Specific Implications: Rights, Law and Guardianship

Implications of these findings impact law and policy regarding competency evaluations, guardianship, and rights as these pertain to adults diagnosed with intellectual disability. For the men and women involved in this study, they were not involved in dialogical encounters where processes of ‘knowing how to know’ can take place and they were often not expected to have input into ‘important’ areas such as medical and mental health care. When autonomy did arise, relating to treatment decisions, it hinged on employee and professional’s judgment of these adults as ‘kinds of persons’—competent or incompetent. Incompetence frequently emerged based on their ‘placed’ status positioning them ‘recipients of’ rather than ‘agents for’ services and treatments.

Rights. Human rights as specified in international laws pertaining to people diagnosed with mental disabilities are often interpreted differently in relation to these groups. As Sundram (2006) points out “The abuses to which people with mental disabilities have been exposed have generally not been recognize as violations of human rights even by organizations that are engaged in human rights work.” Sundram goes on to reason that the cause of this is due in part to conceptualizations of intellectual disability:

> Despite the very progressive ideas embodied in the Universal Declaration of Human Rights, one must remember that it was a product of its time. One of the problems with the Universal Declaration of Human Rights was that, like other generic human rights documents, many people and governments thought it could not possibly have meant to apply to everyone, including people with disabilities (2006).

The United Nations conceptualized the Convention on the Rights of Persons with Disabilities (hereafter CRPD) in light of these unique inequalities faced by people with disabilities. The CRPD eventually emerged and was adopted by the United Nations general assembly on December 13, 2006. According to reports from the UN, the CRPD is conceptualized as both a development and a Human Rights instrument, as it stresses equality and justice before the law. The CRPD was opened for signatures on March 30, 2007 and its entry into force occurred on May 3, 2008 (United Nations, http://www.un.org/en/index.shtml). The United States signed the CRPD on July 30, 2009 but has failed to ratify it.

For Sundram and other scholars exploring this area one key barrier to the actual enjoyment of these rights of equality by persons with mental disabilities is ‘lack of capacity,’ specifically lack of capacity to ‘act.’ This lack of capacity to act from both legal and societal perspectives addresses the antimony between Autonomy and Protection; ensuring rights are validated while concurrently ensuring protection from abuse and exploitation.

An important issue raised by the situation above as I see it, brings attention to the fact that focus continues to be on the phenomenon of intellectual disability—the ingrained narrative, the social representation—without any focus on the individuals who actually embody it and therein lays the greatest danger to individual rights. It is to that end that this dissertation has been devoted, for although generalizations can enlighten us in some ways concerning groups of people such as those with mild or moderate intellectual functioning and global capacities (or incapacities as the case seems to be) they tell us nothing of what any unique individual is capable.

Moreover, in our efforts to promote that rights and privileges are not only recognized but enacted, it would seem that such efforts should be directed at understanding what might promote optimal development so that individuals themselves can become the sites where enactment of capacity, competence, and rights occur. In this work I have brought a socio-cultural developmental ‘voice’ to the discourse concerning intellectual disability, competence, and rights in order to broaden the conversation by including their discourse and focusing on factors that may support such individuals ‘enactment’ or capacity to act in ways privileged by society. Extent of participation and having one’s viewpoint legitimately considered are important considerations to include in discussions concerning capacity for enactment of rights. Along these lines Carey (2009) has raised similar concerns regarding participation and worth from the stance of citizenship and human rights. Citizenship she maintains “is not merely a legal status but a dynamic practice in which individuals interactively claim rights in negotiation with other citizens in the pursuit of their interests” (p. 213). While in regard to human rights she points out that “rights are necessarily practiced in relationship with other people and that the practice of rights is socially mediated for all citizens…recognizing not only variation across time and place but also the impact of power on access to rights” (p. 25). As these findings suggest, rights cannot be acted upon without knowledge and information of who is included in citizenship and of what rights this citizenship entitles.

Law. All citizens’ rights are protected through law. Yet the law constructs definitions of competence and incompetence which then further defines who and what rights are protected. People diagnosed with Intellectual Disability, before the law—especially prevalent in Surrogate rather than Criminal proceedings—are often thought to be incompetent, *a priori,* due to cognitive impairments. Deficits in decision-making arise because of deficits in neurological functioning. The law then designates its own terms defining such individuals such as ‘the never before competent’ and justifies the need for paternalistic practices such as assignment of legal guardians and the need for substituted judgments made on their behalf. Adjudications of incompetence negate an individual’s ability to engage in decision-making processes which then affects the extent of their self-determination and agency in such processes. However this also excludes them from accessing necessary information and knowledge impacting the possibility and potentials for their development.

As has been the case in the United States, the strategy when dealing with difference, law and rights is to “fit” people with disabilities into preexisting standards based on socially constructed notions of intelligence, independence, and normality. This fails to highlight how people with disabilities, due to their unique experiences and interactions with others, often leaves them ill equipped to approximate these 'standards.' As I argued earlier, failure to examine contextual and relational factors perpetuates notions that 'their vulnerability' is a product, solely due to 'internal' factors.

Conceptions of the autonomous, rational, self-directed being underpinning our laws and rights are idealized social constructions. Carey (2009, p. 40) maintains, strategies developed to deal with incompetence involved more than assessment of abilities but took into account the potential harm and interests of various people, not just those with disabilities. She states: "The level of restriction experienced [by people with disabilities] typically was determined not by level of competence, but instead by the motivations and personal interests of others, as well as the disabled person's support system and resources" (p. 41).

It is from this history of advocacy, awareness of inequality and inertia in enactment of rights that provides the context for the CRPD's emergence and its emphasis. This emphasis on enactment of rights is most clearly delineated by Article 12 of the CRPD: 'Equal recognition before the law.' Legal scholars suggest Article 12 is central to dispelling tensions between 'autonomy and protection' (Dhanda, 2007) and is particularly salient to guardianship proceedings where the distinction between the legal capacity for rights and the legal capacity to act are involved (Dinerstein, 2012).

Guardianship. Within the State of New York legal guardianship related to individuals diagnosed with intellectual disability is easily obtained and the processes involved have remained relatively unchanged since its inception. In 1969 New York State Law amended the Surrogate's Court Procedure Act, in relation to appointment of guardians of the person or property or both of ‘mentally retarded persons’ in order to facilitate the process for those parents who sought guardianship for their intellectual disabled, adult children. Article 17-A outlines New York State Law in regard to guardianship and how the need for guardianship is determined (McKinney’s 1969). It was amended once in 1992 (Rubenstien, 1992) to include the provision for “Standby Guardianship” in the event that something happened to the legal guardian(s) appointed. It was amended again to address evolving New York State Health Care Law (Radigan & Gobes, 2006).

Recent changes in New York State Health Care Law requires designation of proxy decision-makers and end of life care wishes be indicated in writing for all New York State citizens. In answer to this OMRDD revised its regulations to include previously appointed legal guardians as authorized to make end-of-life decisions for the intellectually disabled (OMRDD, 2008). Those authorized to make end-of-life care decisions for diagnosed individuals is not inclusive of legal guardians, but now includes correspondents such as family members and agency directors. If the current findings exist for other individuals so diagnosed, this implies that no information, alternatives, or discussions will take place with these adults concerning end-of-life care treatments, alternatives, or proxy decision-making options. Most likely discussions concerning these issues will take place with their legal guardians or correspondents. Failure to disclose this information, based on ‘assumed’ incompetence to understand the nature of the information or ‘shielding’ them from unnecessary anxiety, poses a violation of their individual rights.

As some of the accounts reported in this study attest, guardianship is not only easily obtained but often occurs without direct participation of the individual involved. In fact, whether the person in question is even present at the proceedings is dependent on the individual judge hearing the case. Guardianship procedures are often initiated when an individual diagnosed with intellectual disability turns 21-years-of-age and ‘ages-out’ of special educational services. One administrator explained that parents are provided the tools they need to navigate the guardianship process in the ‘aging-out’ transition from special education. Understandably, parents not only want but feel they need control over the life of their ‘disabled’ child throughout their adulthood. Beliefs about intellectual disability facilitate that guardianship is almost always guaranteed. However, the individuals concerned may never know that guardianship, rendering them legally incompetent, has been obtained with the result that possibilities for their inclusion and voice in matters of importance and concern for them have been curtailed.

According to Herr (2003) a thorough review of guardianship and alternative personal supports across the United States is long overdue in order to replace paternalistic stances with authentic partnerships. Outmoded forms of guardianship, such as those existing in the state of New York, have been criticized as “an ancient institution which is in urgent need of revitalization to meet the needs of this century” (Herr, 2003, p. 449). The problem with guardianship Herr (2003) maintains is that it limits the rights of individuals with intellectual disabilities “to a level of civil rights that is even lower than that of convicted felons” (p. 448). “Self-determination” Herr (2003) argues “involves the struggle for control and a voice in the key personal decisions that affect the life of an individual with intellectual disabilities. On its face, guardianship seems antithetical to self-determination, as it shifts the locus of control from the affected individual to a legally empowered agent, the guardian” (p.429).

The need requiring that others sign for or authorize services rendered to the men and women in this study was generated by the belief that this is the only path possible and is the safest. No attempts to ‘teach’ such skills or provide them with the information, knowledge or interactions required demonstrating competent decision-making or ‘knowing how to know’ how to do so, exists.

Dinerstein (2012) argues Article 12 of the CRPD validates that a need for support does not obfuscate a need to recognize legal capacity:

> The salience of support is a concrete expression of the social, interactive model of disability that animates the entire Convention [CRPD] and sees disability as not a thing in and of itself but rather as a product of the interaction between an individual and his or her built and attitudinal environments (2012).

In this light, Article 12 of the CRPD provides a paradigm shift away from guardianship of the person where decision-making is substituted by others, to supported decision-making where the decision-making is collaborative. In this instance dealing with change in perceptions of guardianship to supported decision-making, Article 12 promotes the dialogical legitimacy of the person diagnosed with a disability.

Limitations

Basing my middle approach on self-other encounters and type of relations within a specific context, I drew upon narrated reports of these interactions, across a range of employees and the men and women placed.   I did not include medical professionals prescribing treatments therefore no medical or mental health practitioner’s accounts were included and their exclusion presents a limitation in the research. It is also noted that for these men and women, Medicaid is their sole insurance provider.

Another limitation exists in the process involving the use of an independent coder. For this research I recruited one individual. Due to the vast amount of data to be coded, this posed a challenge for one individual. Another limitation associated with the coding process occurred in the directions given to the coder; namely describing the context as a ‘nursing home-like’ setting which affected the assignment of codes and difference between my coding and the rater’s. Rectifying these design related problems might involve: use of more than one coder, a random assortment containing smaller amounts of data, and a change in the description of the context.

Future Paths: Research, policy, and practice

Findings from this study revealed that communication and access to information, is significantly constrained for people diagnosed with intellectual disability. Therefore future studies may be directed toward increasing and ensuring access to information on behalf of adults so diagnosed. Interactions with others characterized by dialogical relations, where the person diagnosed with intellectual or developmental disability is legitimized, has the potential to create Zones of Possibility for expanding and transforming cognitive or mental processes. One example of this in terms of agency practice may be in examining ‘consults’ as sites for co-authoring, so that individuals undergoing treatment are included as sites on which information can be co-produced. Another area impacting agency policy may include the addition of a formal ‘assent’ procedure to ensure discussions of treatments are legitimately dialogical.

As reported by some of the men and women in this study, media communications in the form of videos, television commercials, radio shows and the internet can become sources of information on socio-cultural knowledge as this relates to medical and mental health care. Increasing access and use of these tools will increase these men and women’s integration with relevant socio-cultural knowledge. Discussions and sharing of information and personal experiences is another avenue for expanding repertoires of social knowledge necessary for displaying ‘ideal forms’ of competence in decision-making. Support groups, outside of the settings, may be useful modalities to expedite discussions and sharing of information.

In terms of the legal arena, findings revealed that many individuals were not aware a guardian had been assigned them, nor even that others, not appointed as legal guardians, ‘authorized’ their placements, treatments and services. This significantly undermined not only their status in the settings, but their level of self-determination, agency, and ‘independence,’ all stated goals of the agencies involved in this study. This specific finding indicates that procedures currently involved in New York State law and guardianship proceedings need closer examination. Related to this, and as other scholars have recommended, a cross-disability representative, advocacy group or coalition may be necessary in order to ensure that individual civil and human rights are protected. Such ‘support’ provides opportunity for relationships which are horizontally rather than hierarchically structured. Agencies within this study functioned as ‘closed’ systems composed of hierarchal relationships where the individual diagnosed with a disability held a marginal position in the lowest realm of the hierarchy. There was very little room for their ‘voice’ to be heard and legitimized in matters of importance. As a closed system the effect, as revealed in the current findings, limited integration with the larger society and with it, access to knowledge resources available there. A cross-disability representative, advocacy group or coalition may ‘open’ these currently closed systems.

Conclusions

Over the past forty years there has been a shift in treatment practices geared toward people diagnosed with intellectual disability—from segregation in institutional settings to inclusion in community settings. While this shift has brought with it new ideas pertaining to the treatment of individuals so diagnosed—the community service provider industry—and new constructs such as self-advocacy and self-determination, little has changed in the narrative—the social representation—of the disability itself. This ‘inertia’ has undermined movement toward change, reform and equality before the law as this pertains to adults diagnosed with intellectual and developmental disabilities.

This study sought to examine how self-other encounters could promote competent treatment decision-making by adults diagnosed with intellectual disability placed in the service provider industry. Findings revealed that despite shifts in treatment practices, people diagnosed with intellectual or developmental disability remain positioned in a status of exclusion and marginality within the industry due to the unchanging view of the nature of the disability. This exclusion manifests constraints on potential to learn while creating and sustaining vulnerability and dependence because these men and women are excluded not only from resources such as necessary knowledge and information, but from knowing how best to use them. As the above implications imply, people diagnosed with intellectual disability are not accorded the same rights and protections under the law as other citizens. Their position of marginality and otherness constrains their level of integration and participation in their immediate settings as well as the larger society. Constraints on their ability to access and secure pertinent information and interactions where they can learn to ‘know how to know’ have consequences and ramifications for their development, the protection and equality of their rights, enactment of those rights, and their ability for inclusive citizenship.

I chose the specific area of ‘informed consent decision-making’ in order to make a distinction as well as connection between the dialectical, dialogical and psychological processes involved in the legal, law, and rights discourses as these involve persons diagnosed with intellectual disability. This is most clearly brought out by focusing on the legal language as it currently exists in New York State law dealing with guardianship “the person is at the very least, no worse off than she would have been had no guardianship been imposed” (Booth Glen, 2010). From the developmental psychological perspective taken in this dissertation, individuals diagnosed with intellectual disability are worse off when they are subjected to substituted decision-making in any form because important processes enabling transformation in development are profoundly curtailed. Their discourse must be included in these other discourses.

An implicit aim of this study was to include the discourse of adults diagnosed with intellectual disability placed in residential facilities operated by the non-profit industry. Rarely are such individuals the authors of their own history and experiences. Findings revealed that in many cases these individuals understood they are excluded from information and knowledge, and further, that medical and mental health treatment and concerns are devoid of both choice and alternatives. And while some may argue that this is predominantly the case in the sociological nature of medical practice—that we are all, to some extent, paternalized within standard medical practice—the point remains that there are other aspects of our lives outside of the medical domain, where we are legitimized. For the men and women involved in this study, due to the ‘medicalized’ nature of the settings situating their lives, there are no aspects of their lives in which they are, or can be, legitimized. Questions posed by this research concerned how competent decision-making develops and how this could be supported in adults diagnosed with intellectual disability. Findings suggest that legitimizing their personhood through considering their point of view, and sharing with them rather than 'shielding from them, medical or mental health information, would be a primary place to start.   For example, some of these men and women perceived certain practices within the settings as 'supportive' and these they could appreciate such as: accompanying them on appointments to unfamiliar facilities.

Including the perspectives and knowledge, the discourse, of adults diagnosed with intellectual and developmental disability, revealed that in the dialogical processes involved in giving an informed consent the men and women involved here were not informed and knew there was little room for their 'voice' to be heard. From an agency point of view, in the context of accountability, incompetence is the 'default' and 'safe' position. Shifting this view rests on increasing inclusive practices—where legitimate forms of social knowledge are made accessible and can be appropriated by the men and women. Vygotsky, writing in the 1920s, established the importance of social education for the 'handicapped.' Yet, and more importantly, he posed that in order for this to be accomplished it is mandatory to educate the broader society first' (Robinson, 2004, p. 151). Supported decision-making is one 'zone of possibility' in which this social education can occur. However, as the findings of this research revealed, 'support' is most likely to emanate from relationships in which self-other encounters foster individual's dialogical legitimacy.

Appendix A

Employee Consent Form

Staff Consent Form

My name is Lisa Greco-Joseph. I am a student in the Ph.D. program in Developmental Psychology at the City University of New York. I am doing a research study to understand how people make decisions and choices about medical treatments.

If you would like to participate in this research, I will ask you some questions concerning the program and the individuals you work with at the program. This may take one hour of your time.

I will use an audio recorder in order to record what you and I say so that I will remember it. You can listen to the audio recording when we are finished and make changes if you like. You can also have the audio recordings erased if you want to.

What you say will be strictly confidential, no names or personal information will be included in the research. Nothing that could identify you or the program will be mentioned in the research. No one will hear these recordings except me, or if my advisor, Professor Glick, requests to hear them. The recordings will be kept in my personal office, within my private home in a locked file. No one else will have access to them. They will be transcribed by me at a later time and erased three years after the research ended.

If you would like to participate in this research, you will be paid five dollars for your time. I hope to have at least four or more staff members involved in the research from this program.

If you do not want to be part of this research, you can say NO and this is fine. You can also quit or stop the interview at any time. If you decide to quit or stop at any time, none of what you have told me or what I have recorded will be used the research, and the audio recording will be erased in your presence.

There are no special risks involved in this research. I do not think that being interviewed as part of this research will upset you but if it does, you can quit or stop at any time. You can also talk to someone you trust at the program about what bothers you as people in the program have been informed about this research.

I may publish the results of this study, but no names of anyone involved or any information that could identify the agency or anyone connected with the program will be used. If you would like a copy of the study, you can contact me and I will send a copy of the results to you.

If you have any questions about this research, at any time, you can call me at (212) 227-8526 or email me at lgreco295@aol.com. You can also speak with my advisor, Professor

Joseph Glick at (212) 817-7525 or email him at jglick@gc.cuny.edu. If you have any questions about your rights as a participant in this research or the nature of the research itself, you can call the campus Institutional Review Board office at (212) 817-7525 and talk with Ms. Kay Powell; you can also email her at kpowell@gc.cuny.edu. Thank you for participating.

I agree to be part of this research; I understand that it is voluntary. I have been informed of what I will be asked.

With your permission, I would like to audio record what you say.

I agree to have this conversation audio taped. Please circle one: Yes No

Yes/Signature: ______________________________________ Date: _______________

Witness: ____ Date: _________________

Appendix B

Guardian/Correspondent Permission Form

Guardian Permission Form

My name is Lisa Greco-Joseph. I am a student in the Ph.D. program in Developmental Psychology at the City University of New York. I am doing a study to understand how people make decisions and choices about medical treatments. I want to know how people think and feel about making these choices and decisions, and how they make them.

Some people like to talk about how they think and feel, and make decisions instead of having others talk for them, this research is interested in what __________________ has to say.

If you allow _____________ to be part of this research, I will talk with him/her about three examples of people who went to different doctors and then ask him/her what type of treatments he/she thought the people should choose, based on choices given.

I will also ask _____________for his/her thoughts, opinions, and feelings about his/her own experiences in medical treatments. And I will ask _____________ about what he/she thought about the people and their choices in the three examples and why he/she thought this. This may take one hour.

I will use a video recorder to record what ________________ and I say and how we looked so that I remember it. You can view the video recording. After viewing, you can decide to have the video recording erased if you want to.

I will also talk with other people, staff members who work at the program and who know _______________well about his/her actions when on doctor appointments. And I will need to know some information contained in his/her personal file book such as medical information, developmental history and intellectual functioning level. I have attached a sheet containing the specific information that is needed for this research (Demographic Information Sheet).

What ____________says and how he/she looked will be private. No one will view the video recording of _____________ except me, and only if needed, by my advisor Professor Joseph Glick. I will keep all recordings and notes in my personal office, within my private home, in a locked cabinet. Transcribed notes from video will be kept on a separate flash drive. No one will have access to this flash drive or the materials in the locked cabinet except me. ___________ name will not be used in the completed research. No personal information or anything that could identify him/her, including identifying information of the program, will be included in the research. The video recordings will never be shown or heard in the research. The recordings will be erased by me, three years after the research has ended

If you allow ________________ to be involved in this research he/she will be paid for his/her time.

If you do not want _______________ to be in this research, you can say NO and that is OK. Twenty people will be involved in this research.

There are no special risks to being involved in this research. I do not think that being part of this research will upset_______________, but if it does, he/she can quit or stop at any time and that is OK. _____________can talk to me or someone he/she trusts at: _______________________ about what bothers him/her because most people at the program know about the research. You also are invited to ask questions about the research at any time.

If _________________ decides to quit or stop at any time this is OK. If you decide to stop his/her participation at any time this is OK and none of what he/she has told me or what I have recorded will be used in the research. All information recorded concerning _______________will be destroyed if he/she stops participating in the research. _____________ will still be paid something for participating if he/she decides to quit or stop. Whether or not _______________ participates in this research has no effect on his/her continuation in the program or the services he/she receives.

I may publish the results of this study, but no names of anyone involved or any program information that could identify anyone will be used in the publication. If you would like a copy of the study, you can contact me and I will send a copy of the results to you.

If you have any questions about this study, at any time, you can call me at (212) 227-8526 or email me at lgreco295@aol.com. You can also speak with my advisor, Professor Joseph Glick at (212) 817-8706 or email him at jglick@gc.cuny.edu. If you have questions about your rights as guardian of a participant in this research you can call the campus Institutional Review Board Office at (212) 817-7525 and talk to Ms. Kay Powell, you can e-mail her too at kpowell@gc.cuny.edu.

Thank you for considering _______________________ participation in this research.

I agree to consent to ___________________ participation in this research; I understand that it is voluntary. I have been informed of what will be asked, and information needed.

With your permission, I would like to video record what _______________and I say in the research.

I agree to have this conversation video recorded. Please circle one: Yes No

Yes/Signature: ____Date: _____

Witness/Signature: ____ Date: _____

Appendix C

Men and Women’s Consent Form

Participant Consent Form

Hi, my name is Lisa Greco Joseph, I am a student and I'm doing a study. I am asking you if you would like to be part of this study. I am trying to understand how people make decisions and choices about medical treatments. I want to know how you feel about making these decisions and choices and how you make them. Is this clear for you? Do you have any questions about this? Do you get it? Ok. Can we go on?

Maybe you don't make decisions because other people make do that for you. That's ok because I'm still interested in how you feel about that. Is this clear for you?

Some people like to talk about how they think and feel and make decisions instead of having others talk for them. This research is interested in what you have to say. OK? Any questions about this? Do you understand? Can we go on?

If you want to be in this research, there are four things that will happen:

1) I will ask you questions about some people who went to see a doctor and what the doctor said.

2) You tell me what you think and feel about doctor appointments and your visits with your own doctors.

3) I will ask staff members questions about you when you go on doctor appointments.

4) I will get personal information out of your file book about you such as: medical conditions, where you have lived, where you were born, your functioning level, your schooling, and the type of program you're involved in. Things like that. Is that clear to you? Do you get it? Is this OK with you? Do you understand? Can we go on?

If you give me your permission, I will video record our time together so that I remember what we said. You can see the video after we are done. If you really hate it I will erase it. After the research study is over and three years pass all the videos will be erased. Is this clear for you? Do you have any questions about this? Do you understand? Can we go on?

Ok so if you want to be part of the research you should know that everything you and I talk about together is private, no one except me and maybe my advisor will ever listen or see the video of you and me. Is this ok with you? Is this clear? Do you understand? Can we go on?

Also if you are in this research or not it will not affect anything to do with your program or staff. So if you don't want to participate in this no one will be angry at you or anything. Is that clear to you? Do you get it? Do you have any questions about this? Do you understand? Can we go on?

I want you to know that if you decide to be part of this research, you don't have to answer all the questions I will ask you and you can stop at any time. Is this clear for you? Do you understand? Is this Ok? Can we go on?

Our talk together can take some time, but we will be talking in your program/residence and people you know will be around. Also, for being part of this research, you will get paid for your time. Do you understand this? Can we go on?

So if you talk with me about the people who went to the doctor, answer some questions, and if you talk with me about our own visits with a doctor, you will be paid five dollars. Is this clear for you? Do you have any questions about this? Do you understand this? Ok? Can we go on?

If you don't want to be in the research you can say no and that's OK. Your program or activities will not be stopped or changed in any way. Is that clear for you? Do you understand this? Can we go on?

You can also quit or stop at any time after you start the research. So let's say you say yes and we start talking. You decide you don't like this talking. You can say "I want to quit" or "I want to stop" and that's fine, we will stop. You'll still get paid for the time you spent with me. Is that clear for you? Do you understand this? Is this Ok? Can we go on?

Being in this research is voluntary. Only you decide if you want to be in this research or not. You don't have to be in the research if you don't want to be. Is this clear for you? Do you understand this? Ok? Can we go on?

I don't think that being part of this research will bother you. But if it does, you can talk to me or to someone you trust or like a lot in the program/residence. Everyone here knows about this research study so it's ok to talk about it. Do you understand this? Ok? Can we go on?

Other people from this program/residence will be part of this research, so you won't be the only one. Twenty people from this program will be part of this research. Is that clear for you? Do you have any questions about this? Do you understand this? Can we go on?

If you have any questions about this research, you can contact me or have someone you like contact me for you, at the phone number or e-mail I have on this form, here. Do you understand this? Ok? Can we go on?

If you have questions or want to know about your rights as a participant you can also contact these people, or have someone you like contact them for you. These other people are my advisor, Joe Glick and the woman who supervises research, Ms. Kay Powell. Their names and contact numbers and e-mail are here on the form. Do you have any questions? Do you understand this? Ok? Can we go on?

My phone number and e-mail are 212-227-8526, lgreco295@aol.com. My advisor, Joe Glick's phone and e-mail are 212-817-8706; jglick@gc.cuny.edu and the woman that supervises research, Kay Powell's phone and e-mail are 212-817-7527, kpowell@gc.cuny.edu.

So if you decide you want to be in this research you can make your mark or sign your name here on this form for YES, you agree. If you feel its OK for me to video record us while we talk, you make a mark here for YES. If you don't want me to use the video recorder while we talk, you make a mark here for NO. Is this clear for you? Do you understand this? Ok? Can we go on?

There is also a place for me to sign, that's down here and a place for today's date. You'll get a copy of this form to take with you.

Do you understand everything I have read to you? Do you understand what you will be doing in this research?

Thank you for listening to me. Does this sound like something you would like to do?

I agree to participate in the research. I understand that it is voluntary. I have been told what I will be asked.

With your permission, I would like to vide record what you and I say.

I agree to have what I say videotaped. Please circle one: Yes No.

YES: ____________________________________ Date: ________________

Witness: __________________________________ Date: __________

Appendix D

Men and Women’s Assent Form

Participant Assent Form

My name is Lisa Greco Joseph. I am a student and I am doing a research study to understand how people make decisions and choices about medical treatments. I want to know how you think and feel about making these choices and decisions and how you make them. Is this clear for you? Do you get this?

Your guardian signed a consent form. If you want to be part of this research, I'll tell you what you and I will be doing. Do you understand this?

Some people like to talk about how they feel, how they think, and make decisions instead of having others talk for them. This research is interested in what you have to say.

We will talk about people who went to the doctor and what the doctor wanted them to do. I will ask you some questions about the people and their doctor visit. I will also ask you to tell me your thoughts, opinions and feelings about your own visits with doctors. This could take an hour. Is this clear for you?

I will use a video recorder so I remember what we said and how we looked. You can watch the video of us after we are done. If you don't want to be recorded, you don't have to be. Do you get this? Is this ok for you?

I will talk to staff members who know you well about you and your visits to doctor appointments. Do you have any questions about this?

I also need to know some information from your personal file book. Do you have any questions about this? Is this clear for you? Do you have any problems with this?

If you want to be in this research you will be paid for your time.

If you don’t want to be in this research that’s ok, you don’t have to. You can say NO.

If you want to quit or stop at any time that’s ok too. If you decide to quit or stop being part of this research, you’ll still be paid something for participating. Is this clear for you?

I hope to have twenty people from this program in this research.

If you want to be in this research you can make your mark or sign at YES

Thanks for listening to this. Does this sound like something you would like to do?

I want to participate in this research. I know what I will be asked to do.

YES: ______________________________ Date: _____________

Appendix E

HIPPA Consent Form

CUNY INSTITUTIONAL REVIEW BOARD

HIPAA RESEARCH AUTHORIZATION

Subject/Client/Patient Name: ____________________ **ID Number:** ____________

Study: Intellectual Disability and Informed Consent Decision-Making

IRB Protocol No. ____________ **CUNY Institution:** The Graduate Center

We understand that information about you and your health is personal. We are committed to protecting the privacy of that information. Federal regulations and our commitment to your privacy require that we obtain your written authorization before we may use or disclose your protected health information for the research purposes described below. This form provides that authorization and helps us make certain that you are properly informed of how this information will be used or disclosed. Please read the information below carefully before signing this form.

USE AND DISCLOSURE COVERED BY THIS AUTHORIZATION

Lisa Greco Joseph must answer these questions completely before providing this authorization form to you. DO NOT SIGN A BLANK FORM. You or your personal representative should read the descriptions below before signing this form.

What information will be used or disclosed for the research? The appropriate boxes should be checked below and the descriptions should be in enough detail so that you (or any organization that will use or disclose information pursuant to this authorization) can understand what information may be used or disclosed.

☐ Any medical, treatment, or research records held by [list covered entity from whom records are sought] may be used and/or disclosed.

☒ The following information:

Basic Medical Information such as: 1) Medical conditions: anemia, high blood pressure, diabetes, Gerd,

2) Functional Status: Disability Diagnosis, Date of onset, functioning level as of IQ test results, Age.

3) Living Status: Previous living environment, history of education, history of daytime activity

Who will disclose, receive, and/or use the information while it is in individually identifiable form?
This research authorization form will authorize the following person(s), class (es) of persons, and/or organization(s) to disclose, use, and/or receive the information in connection with the research:

☒ [CUNY Principal Investigator] and his or her research staff, which may include [College] students

☐ The following co-investigators and members of their research staffs: [list names and institutions]

☐ Statisticians at the following institutions: [Enter Here]

☒ The members and staff of the [CUNY-GC] Institutional Review Board and other CUNY officials and staff who oversee research

☒ Government authorities or agencies that oversee research

☐ The members and staff of the Institutional Review Boards at participating research sites [list each co-investigator's site]

☐ Others (as described below):

[Enter Text Here]

If not specifically listed above, you also authorize the following persons or institutions that maintain records about you to disclose the information described above for the purpose of this research:

[Enter Text Here]

SPECIFIC UNDERSTANDINGS

By signing this research authorization form, you authorize the use and/or disclosure of your protected health information as described above. The purpose for the uses and disclosures you are authorizing is to conduct the research project explained to you during the informed consent process and to ensure that the information relating to that research is available to all parties who may need it for research purposes.

Many of the recipients listed in this form have legal or professional obligations to protect the confidentiality of your information. If, however, your information is disclosed to persons or organizations that are not required by state or federal law to protect the privacy of the information, such persons or organizations could reuse or redisclose the information without penalty under those laws. For this reason, it is the policy of the City University of New York, The Graduate Center, IRB that investigators ask all recipients of your information to agree to treat your information as confidential.

You have a right to refuse to sign this authorization. Your health care, the payment for your health care, and your health care benefits will not be affected if you do not sign this form.

If you sign this authorization, you will have the right to revoke it at any time. However, your revocation would not apply to the extent that Lisa Greco Joseph and the investigators in this research have already taken action based upon your authorization or need the information to complete analysis and reports of data for this research. This authorization will never expire unless and until you revoke it. To revoke this authorization, please write to Lisa Greco Joseph, Doctoral Candidate, Ph.D. Program in Developmental Psychology, The Graduate Center, The City Univeristy of New York, 365 Fifth Avenue, New York, NY 10016 or Kay Powell, Institutional Review Board, The Graduate Center, address as above.

A copy of this form will be provided to you after you have signed it.

SIGNATURE

I have read this form and all of my questions about this form have been answered. I understand that, if I have questions about this form in the future, they will also be answered. By signing below, I acknowledge that I have read and accept all of the above.

____

Signature of Subject or Personal Representative

____

Print Name of Subject or Personal Representative

____

Date

____

Description of Personal Representative’s Authority

CONTACT INFORMATION

The contact information of the subject or personal representative who signed this form should be filled in below.

Address:	Telephone:
____	_____________________ (daytime)
____	_____________________ (evening)

Email Address (optional):

THE SUBJECT OR HIS OR HER PERSONAL REPRESENTATIVE MUST BE PROVIDED WITH A COPY OF THIS FORM AFTER IT HAS BEEN SIGNED.

Appendix F

Interview Guidelines for Men and Women

Guide for Narrative Interview Questions for men and women

1. What do you think about this example?

2. Is there anything you might have said, done or asked?

3. Is there anything you would like to change about visiting the doctor/dentist/psychiatrist or the treatments they give you?

4. Is this like what happens when you go to the doctor/dentist/psychiatrist?

The remaining questions are probes to be used in the event the above three questions do not elicit enough information:

Can you tell me what going to the doctor/dentist/psychiatrist is like for you?

If you had questions about your visit, and the treatment, is there someone you would talk to about it?

When you are on a visit, do you ask questions to the doctor/dentist/psychiatrist? (Probe of why or why not?)

Why do you go to the doctor/dentist/psychiatrist?

Do you make an appointment to see the doctor/dentist/psychiatrist? (Probe if negative: who does and are you told and asked if this appointment time is ok?)

Did you pick your dentist/doctor/psychiatrist? (Probe if negative: can you change your doctor/dentist/psychiatrist if you wanted to? Why or why not?)

If the doctor/dentist/psychiatrist, says she/he is going to do something, or give something to you, like in the example I read to you, do you feel you can say “No Thanks” or “Can I think about it?” (Probe: why or why not?)

Appendix G

Demographic Information

Demographic Information from men and women and/or personal charts

Identifier Code: ______________________

1. Date of Birth: ______________________

2. Current or most recent medical diagnosis, if any:

____

____

3. Functioning Level: IQ level, Score and Test used: __________________________

____

4. Approximate date of disability diagnosis? _________________________________

____

5. Where birth and/or childhood years spent? United States or other country? Specify:

____

6. Early childhood years: Lived at home? Lived in home provided by service provider community? Hospital? Institutionalized? Orphanage? Other?

____

____

7. Exposure to schooling: Special education? Home schooled? Diploma attained? GED?

____

____

8. Salaried Employment? Work Activity Setting? Day time activity if not employed?

____

____

Appendix H

Interview Guides for Staff

Guide for narrative interview questions with staff working directly with men and women

1. In your daily work with (consumer-individual with I.D.), has she/he ever requested a medication such as an aspirin, or other over the counter medications, if she/he has a medical order allowing this? Even is she/he does not?

2. Has she/he ever initiated a visit to a doctor, dentist, psychiatrist/psychologist? If not, can you tell me how they visit such medical professionals? Who makes appointments? When or how does the individual learn they have an appointment?

3. In your experience working with her/him, does she/he ever ask questions or talk with you, and/or with the doctor concerning medical or health related issues? Do you talk with her/him about these things?

4. If he/she has a medical condition, do you think that he/she understands what it is and how it affects him/her? Can you tell me what he/she does that makes you think this?

5. If she/he had a medical or psychological concern, who do you think she/he would choose to speak to about it, if anyone?

6. In your experience working with her/him, who explains medical or health concerns, treatments or issues to her/him?

7. In your experience, what type of activities does she/he engage in, relative to her/his medical health?

8. Do you think he/she can make decisions concerning his/her medical/health issues if they exist? If they don't exist, do you think he/she could make decisions if they did?

Appendix I

Interview Guides for Administrators

Guide for Narrative Interview Questions for Administrators

1. With the changes that took place in the late 1980s concerning Federal regulations mandating the need to obtain informed consent from individuals with intellectual disabilities in order to allow them to make their own decisions in treatment matters, what changes has your program made to conform with these new guidelines?

2. How does your program approach and deal with issues relating to informed consent?

3. What guides your approach?

4. How does your program evaluate the individuals you serve in terms of informed consent?

5. What specific areas do issues of informed consent arise most frequently in your program?

6. What problems or challenges, if any, do you feel result from informed consent issues in your program?

Appendix J

Coding Manual

Coding Manual

The first vignette describes a psychiatrist's recommendation for psychopharmacological treatment (with minimal side effects, such as drowsiness and dry mouth) for behavioral outbursts jeopardizing an individual's work placement. The second vignette describes a dentist's recommendation for orthodonture work to correct misalignment of teeth. The third vignette describes a physician's recommendation for a series of injections to prevent an allergic reaction to pollen and dust.

Vignette Coding: Sources of Information

The purpose of this coding is to examine the types of knowledge people used in their responses to each area. This research is looking at changes in practice and consequently changes in thinking that took place with the advent of the "Informed Consent Doctrine" which arose in the mid to late 1950s. Prior to the advent of the doctrine doctors, not patients, made the decisions for treatment. After the doctrine, this was reversed and patients, rather than doctors, were to make their own treatment decisions based upon full disclosure by the doctor of the risks and benefits of the treatment offered. This change in practice and thinking is constructed in the present research to indicate examples of socio-historical and socio-cultural types of knowledge. However, there are two other types of knowledge that people could bring to their responses. One is knowledge from the specific setting that situates their life. In the present research all the individuals reside in a nursing-home-like/institutional setting. The other source of knowledge arises from past and present personal experiences.

The vignette scenarios, their questions, and the responses given by the individuals who participated in this research, follow. There are three different vignettes: one having to do with someone going to the dentist for braces; one having to do with someone going to an allergist for allergy shots and one having to do with someone going to see a psychiatrist for psycho-tropic medicine. The responses by each participant to the questions in the vignette are numbered consecutively and the vignettes for all participants are numbered 1-29 for identification.

<u>Directions:</u>

According to the specific codes listed below I would like you to read the responses and circle those you feel capture one of the four types of knowledge. It is strongly suggested you use a pencil and these have been included in this packet. As some of the numbered responses include the same thought or response, you can circle multiple consecutive numbers if you feel they all belong to the same type of knowledge. For example, the individual's response to one question was given two lines numbered 10 and 11. Because both these numbered lines consisted of the same type of knowledge they were both circled, by me, to indicate this. You do not have to code each numbered response, only those responses you feel capture a particular type of knowledge.

If you are confused about what type of knowledge you feel a response indicates that's ok as I was confused too which is why I need your help. We can discuss these confusing responses after you complete the coding and this type of discussion is very common. You should know there is no right or wrong coding, I am only interested to see if you, according to the codes given, see responses in the same way that I do.

You do not have to complete the vignettes in any order.

Examples of the types of knowledge codes follow.

Socio-historical Knowledge: Code = SH

This includes expressions having to do with an older idea, practice, or knowledge relating to medical or mental health care. This knowledge code expresses the type of practices and thinking that was prevalent prior to the informed consent doctrine. In general, this code is for statements that imply a passive response and include knowledge about medical or mental health care and treatment that may seem 'dated' or 'old-fashioned.' Such thinking includes: "The doctor knows best," "medicine is always good for you," or "you don't say no to the doctor or medicine." Other areas consist of "you won't get better if you don't take the treatment," "braces are ugly," "eating too much candy gives you cavities," "pain is the price for beauty," and "psychiatry involves lying on a couch," or "psychiatrists talk to you."

Socio-cultural Knowledge: Code = SC

This is knowledge having to do with well-known practices which are more current. This knowledge code expresses the type of practices and thinking that became prevalent after the informed consent doctrine, or more current knowledge about medical practices, treatments, and care. In general responses in this category contain thoughts concerning agency on the part of the person in relation to medical care and treatment. Such thinking might include statements like: "not wanting help from a doctor," "use of common over-the-counter medicines such as Hall's, or medicine such as Nasonex, Claritin, Sudafed, saline spray," "use of allergy medication rather than allergy shots." Statements that indicate medicine can have harmful side effects such as: "medicines can interact and cause harm," and "medicines control behavior (psycho-tropic medicine) rather than the person." Other responses might include statements about "psychiatrists give people medications," "Dentists clean teeth," "braces fix smiles." Also included under this code is any response that might include questioning a treatment or diagnosis.

Personal-history knowledge: Code = PH

This is knowledge having to do with an individual's personal experiences. This type of knowledge usually contains "I" or "me" or "my," such as: "I'm speaking from experience," "I'm allergic," "I had braces," "I take my meds every day," "it make me feel sleepy," "I had to be operated on," "I learned from my mother." Also included here are other statements that deal with an individual's experience and which is not mentioned in the vignette: "you talk and be reasonable with the psychiatrist," "they'll give her needles and anything like that to calm her down," "the time needed to clean braces," "maybe seizures as a side effect," "teeth being rotten, getting infected."

Communities of practice: Code = CP

This is knowledge relevant to the person's current life situation in the setting they live in. This would involve statements that do not include information specifically from the vignette or, information from the vignette is embellished. Examples would be: "acting out," "behavior problem," "outbursting," "to behave," and reference to staff, team meetings, clients, and consumers.

Appendix K

Case Study Protocol

Research Protocol Questions for each case study

1. How does each setting approach the issue of informed consent for medical/mental health treatments in individuals diagnosed with intellectual disability? (i.e. Do they seek consent from individuals with intellectual disability? Do they involve individuals with intellectual disability in other ways, such as seeking assent? Do they secure 'proxy' consent from family or surrogates? If so on what criterion is this based?)

2. What is the underlying mechanism governing each type of approach? (i.e. State and Federal regulations? Regard for individual autonomy and self-determination? Need for protection and liability issues?)

3. If issues of informed consent are centered on individuals with intellectual disability, how are they currently assessed as having this ability? (i.e., Assessment tools, professional judgments, courts, other?)

4. What is the underlying philosophy concerning consent issues governing settings and how is this manifest in the culture of the setting itself? (How is this philosophy actualized in practice? Is there a conflict between practices and outcomes within the settings? Does the setting position competence as a relational activity or as solely a component of one's intellectual ability?)

5. Do the actual practices and activity of the settings provide or limit opportunities for developing skills in informed consent decision-making?

6. How do individuals with intellectual disability, residing within the setting perceive, think, and reason about informed consent decisions? What affects this?

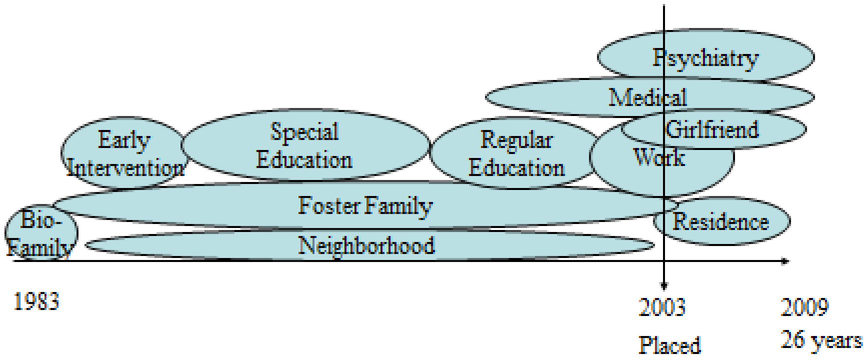
7. What knowledge do they demonstrate in making such decisions and is this knowledge elaborated or constrained?

8. Is this knowledge affected by their actual level of participation and involvement in the setting as well as by the self-other encounters in which they engage?

Appendix L

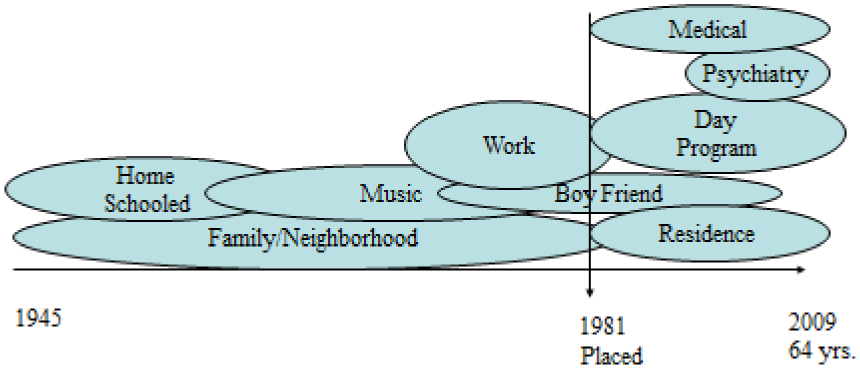
Personal History Maps of Overlapping Communities of Practice for the Men and Women

Communities of Practice



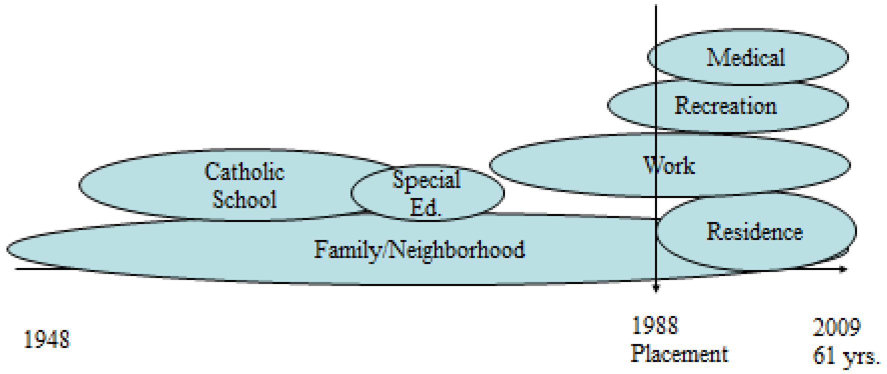
Ontological History
A-1

Communities of Practice



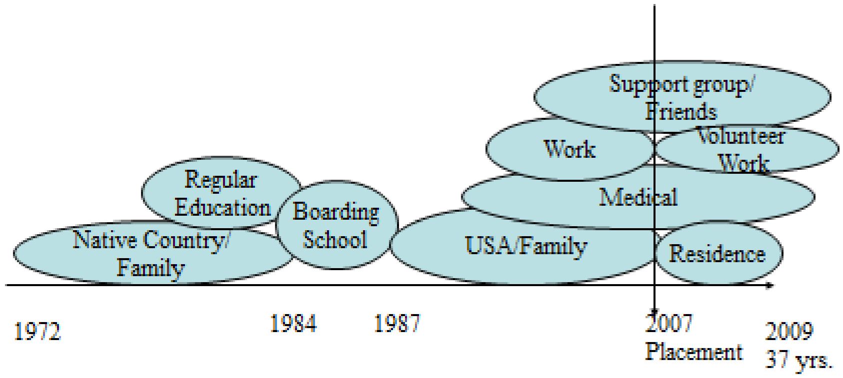
Ontological History
A-2

Communities of Practice



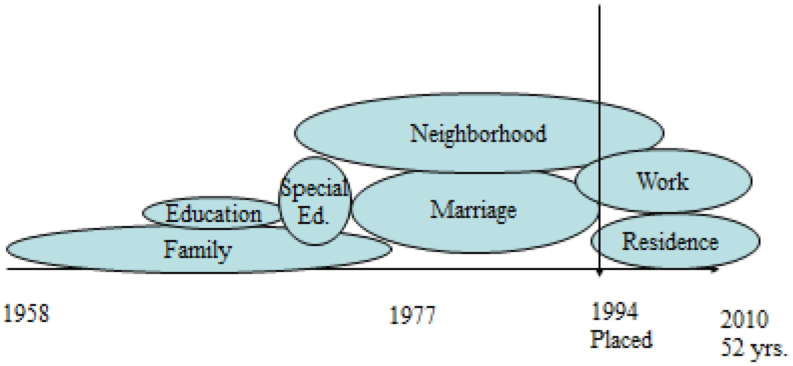
Ontological History
A-3

Communities of Practice



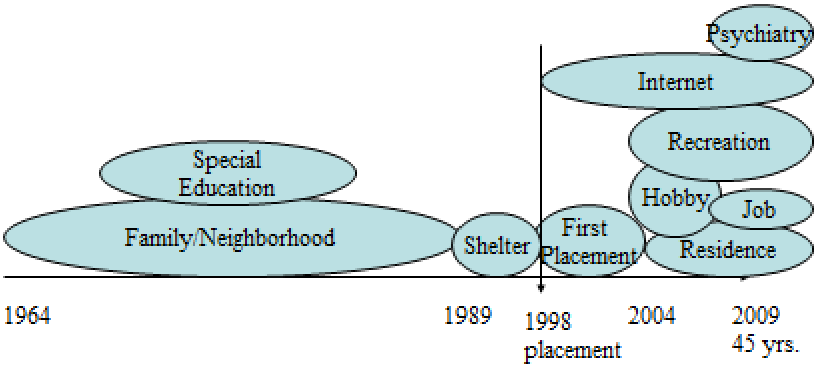
Ontological History
A-5

Communities of Practice



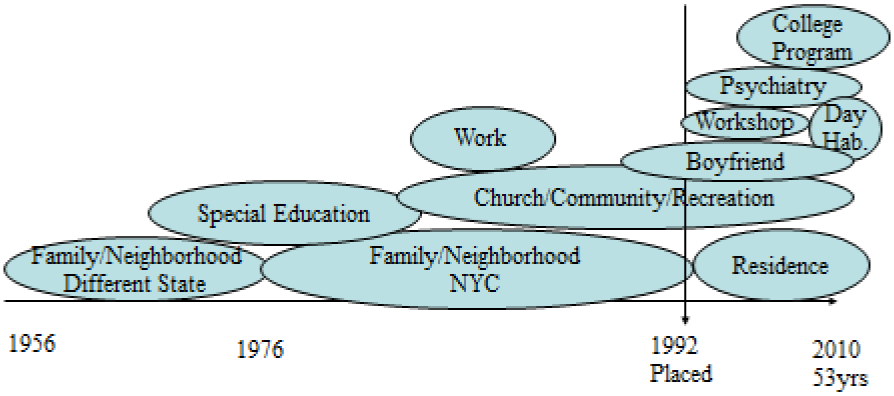
Ontological History
A-6

Communities of Practice



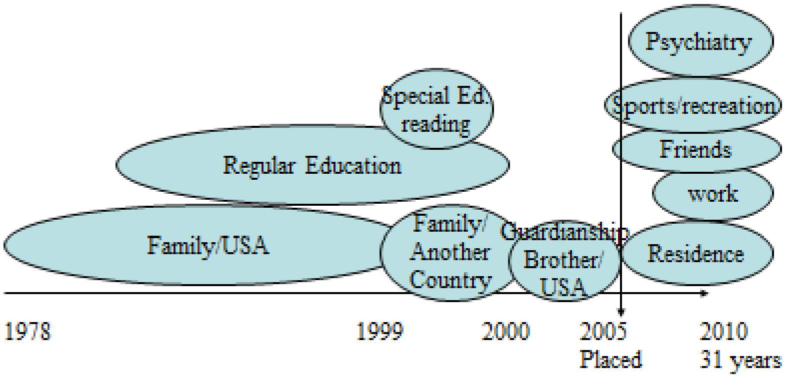
Ontological History
A-7

Communities of Practice



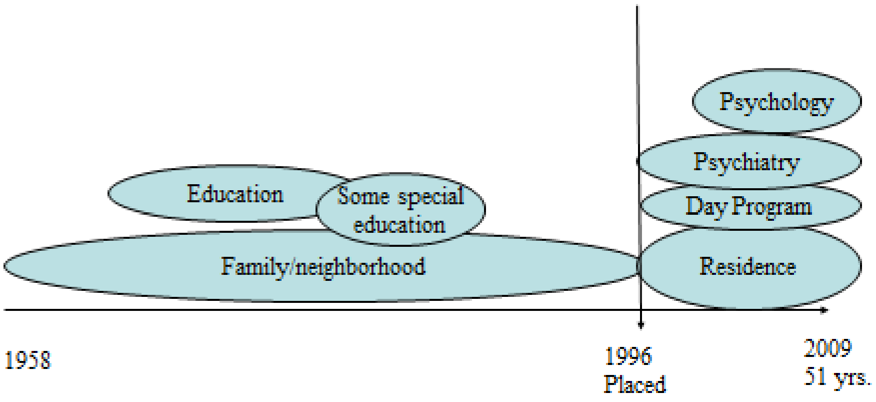
Ontological History
A-8

Communities of Practice



Ontological History
A-9

Communities of Practice



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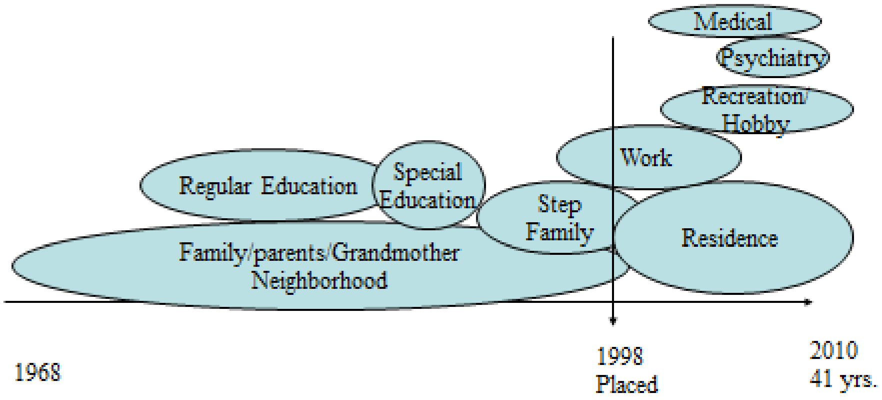

Ontological History
A-11

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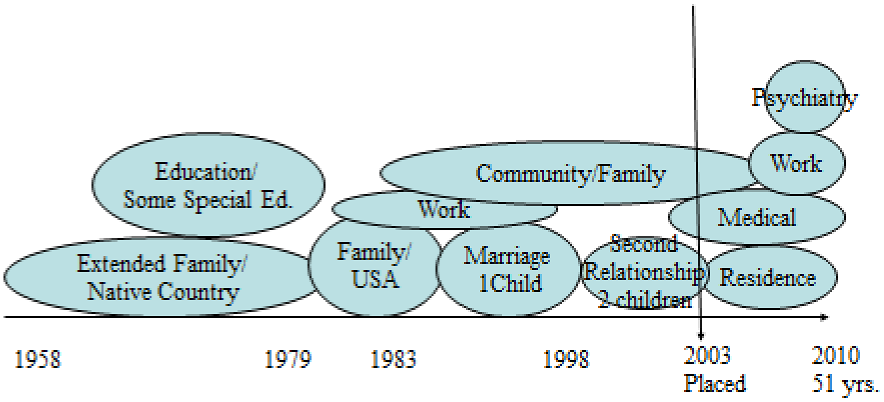

Ontological History
A-12

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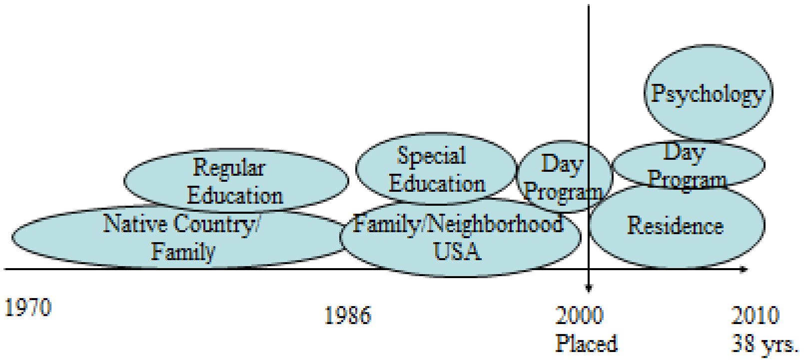
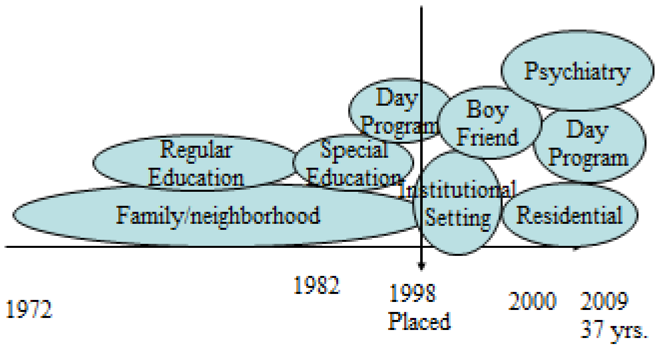


Ontological History
P-1

Communities of Practice



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P- 2

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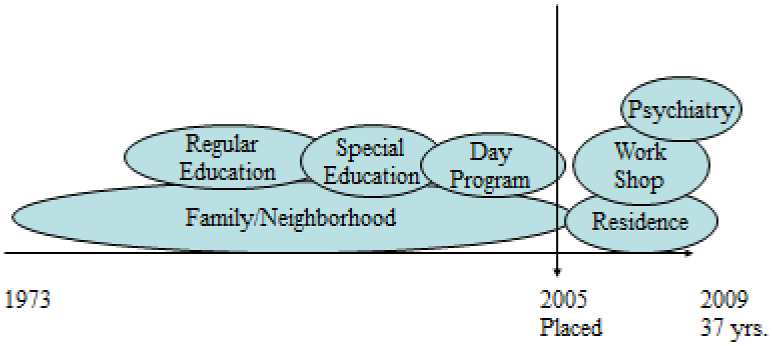

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P-3

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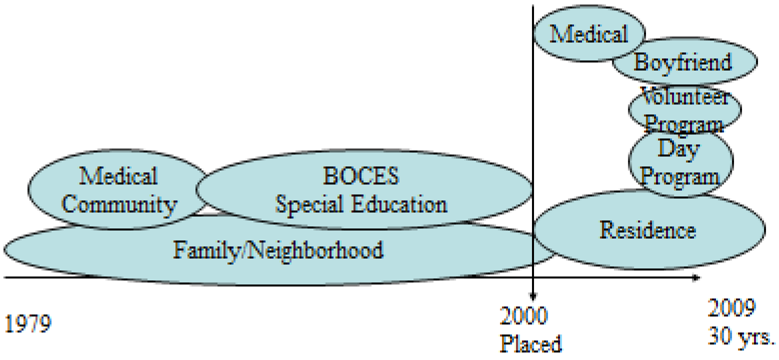

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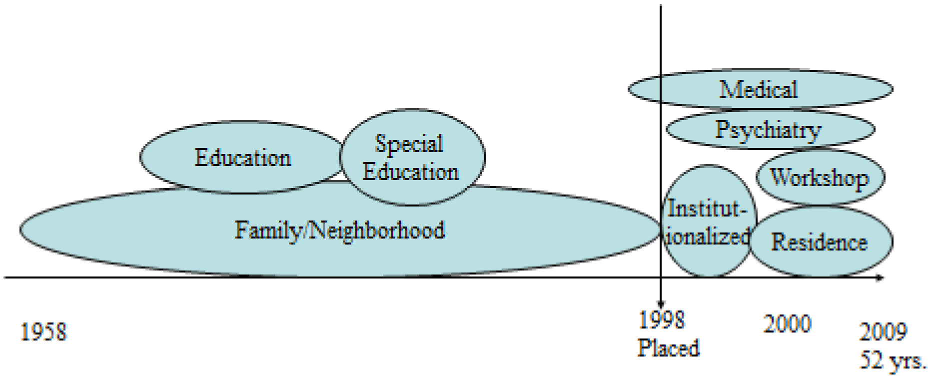
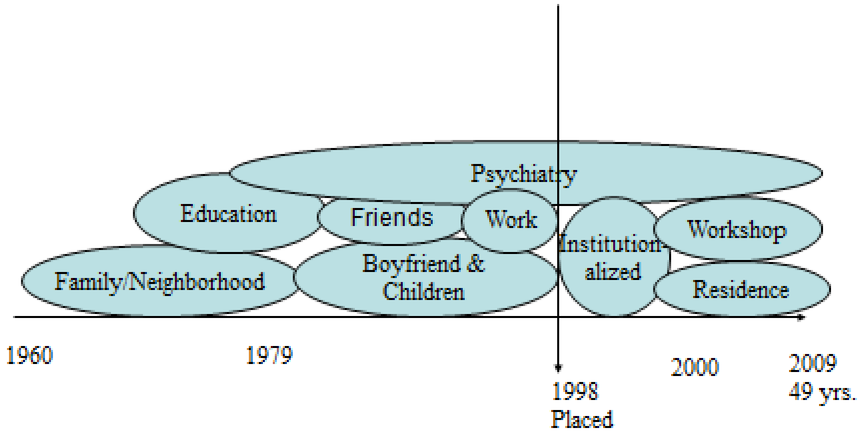
Communities of Practice



Ontological History
P-6

Community of Practices



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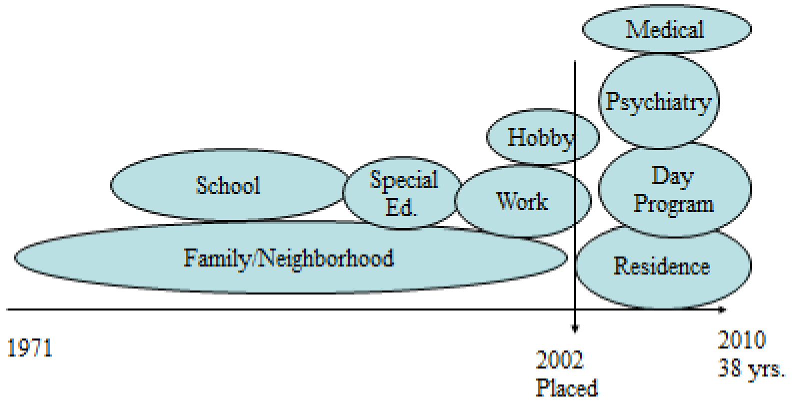
Communities of Practice



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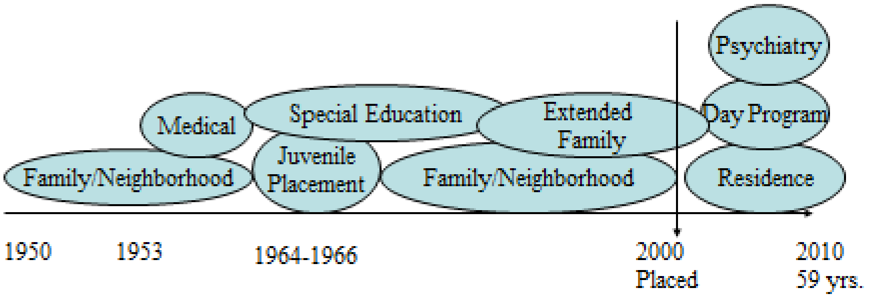
Communities of Practice



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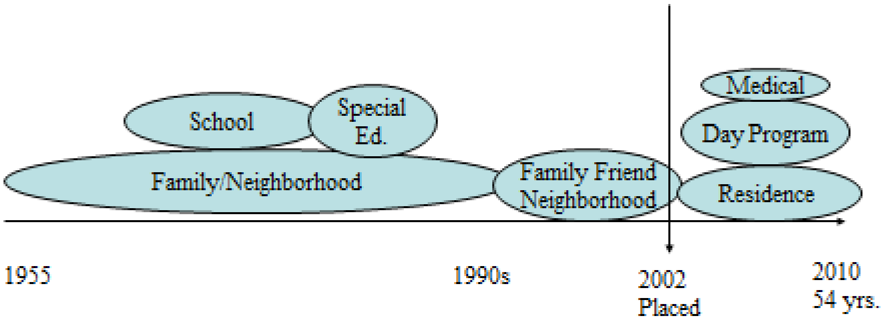

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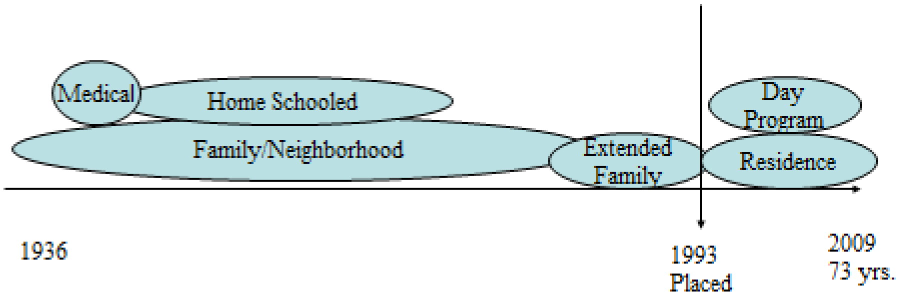
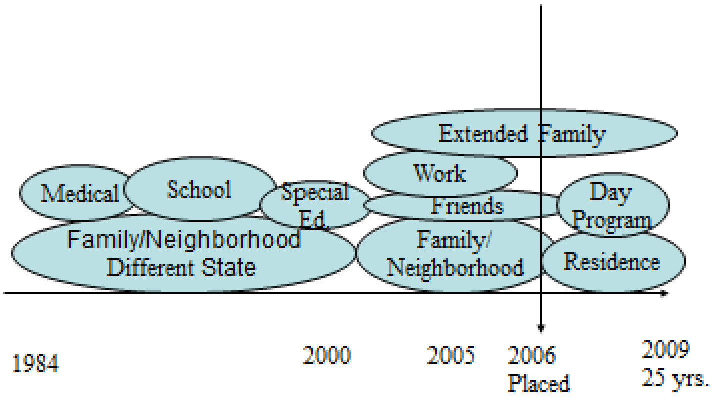


Ontological History
N-1

Communities of Practice



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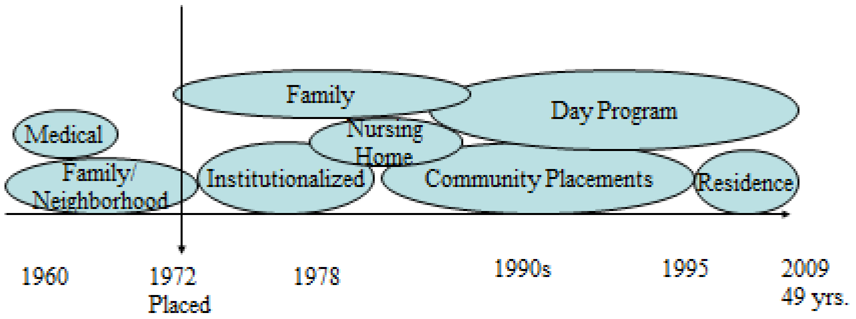
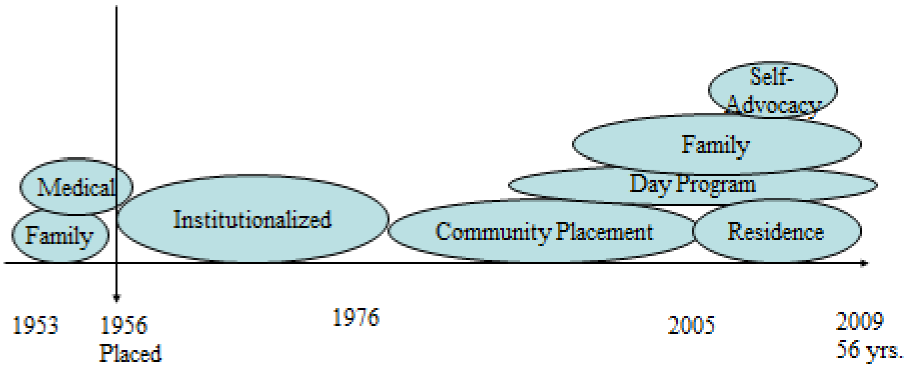
N-2

Communities of Practice



Ontological History
N-3

Overlapping Communities of Practice



Ontological History
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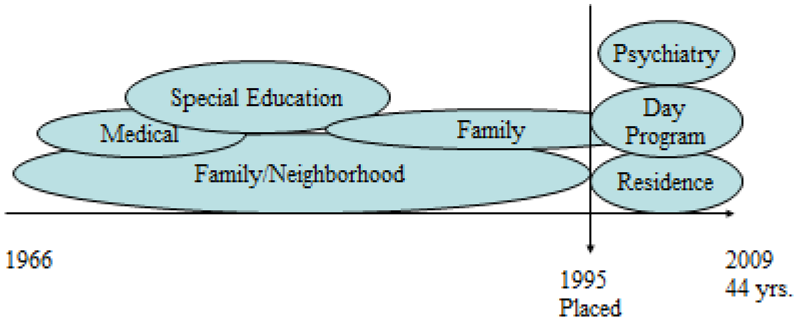
Communities of Practice



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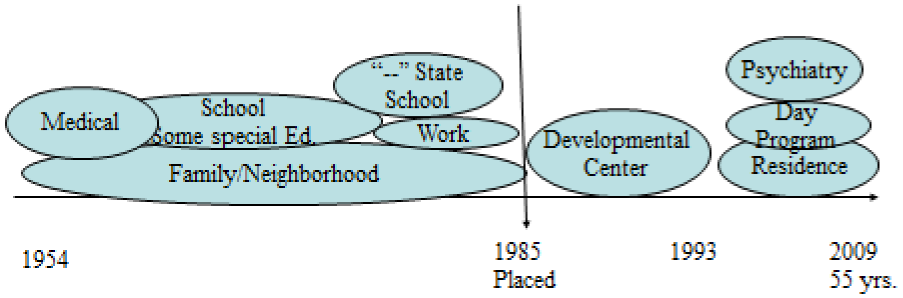
Communities of Practice



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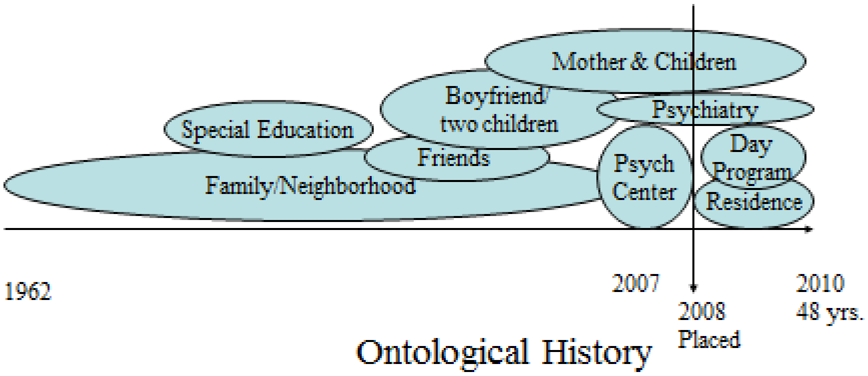
Communities of Practice



Ontological History
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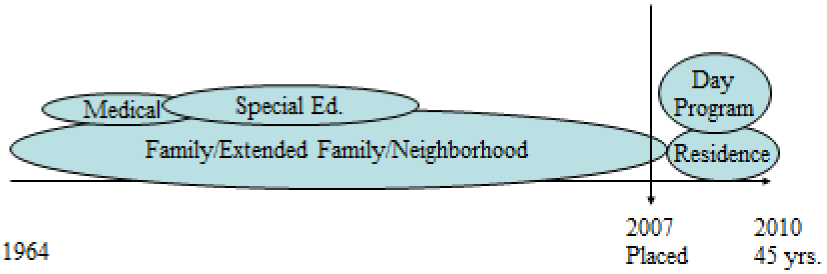
Communities of Practice



Ontological History
N-9

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