NARRATIVE POWER:
SOCIAL CONTROL IN ISLs & GROUP HOMES

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by

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NARRATIVE POWER:

SOCIAL CONTROL IN ISLs & GROUP HOMES

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Dedications

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Table of Contents

Acknowledgments…………………………………………………………………….….……...… ii

Abstract………………………………………………………………………………………. iv

Chapter 1: Introduction, Literature Review, Research Objectives and Methods…...…... 1

Chapter 2: The Social World of ISLs and Group Homes for Adults with IDD……..… 39

Chapter 3: Framing Narratives………….…………………………...……...…... 78

Chapter 4: Identity Narratives……………………………….………...……... 150

Chapter 5: Summation, Findings and Recommendations ……………………...… 186

Appendix A: Semi-Structured Interview Questions …………………………………. 205

Appendix B: Respondent Demographic Information ……………………….…………. 207

Appendix C: Narrative Coding Grid………………. ……………………….………….. 209

References ………………………………………………………………….………… 210

Vita……………………………………………………………………….…….….222

Abstract

Narrative power is used in residential settings providing care for adults with intellectual and developmental disabilities as a tool of social control. Framing narratives, stories and accounts influencing the accepted version of events, are used by clients, staff people, supervisors and professionals to influence and control the behavior of people in this social world. Identity narratives, stories and accounts influencing the accepted identity of different social actors, are also used to influence and control the behavior of people in these settings. Individualized Supported Living arrangements (ISLs) and group homes are settings where the social role of a client, a person with intellectual and developmental disabilities receiving support in this setting, is a clearly marked social role with almost no ability to exert narrative power independently, making the framing narratives and identity narratives of other actors the dominant narratives in their lives. Staff people, supervisors, case managers, behavior analysts and other professionals in this social world are able to effectively use narratives as tools of social control over clients, staff and other social actors within this milieu.

These decentralized settings typically have one to three clients living in homes and apartments in the community with direct care staff support to assist them with their individualized needs, including activities of daily living, medication administration, behavioral support and community integration. Staff people routinely work for extended periods of time with no effective supervision, setting up a significant power disparity between staff and clients. Framing narratives and identity narratives are routinely deployed by staff in these settings to control the behavior of clients. Attempts by others to

use these same tactics to control the behavior of staff people and other non-clients in this social world are routinely met with alternative narratives, or counter-narratives, that blunt the effectiveness of these tactics. Clients were unable to effectively deploy counter-narratives, with the exception of making allegations of abuse or neglect against staff people or others. This tactic sometimes led to outside agencies conducting inquiries.

Lengthy ethnographic interviews of eighteen people with insider experience in the social world of ISLs & Group Homes were conducted in an active interviewing style designed to elicit narratives detailing the ways in which power is used as a tool of social control. These narratives were transcribed and analyzed to assess how the respondents used narratives to depict the use of power in this social setting.

This analysis produced a number of significant findings. The most significant behavioral changes reported by respondents occurred when the framing narrative or identity narrative was internalized, effectively making the person their own agent of social control. Respondents all depicted themselves in positive terms, while framing others in negative terms and were supportive of increased accountability for other social actors in this setting, but not for themselves. Client advocates are necessary for meaningful client choices to be implemented in this social world, due to the lack of client narrative power in these settings. Institutional methodologies of social control can and do occur in decentralized community placements, making oversight to prevent the abuse and neglect of vulnerable clients a critical need in these settings. The reluctance of caregivers and others to report abuse and neglect of clients, despite being mandatory reporters, appears to be due to fear of reprisals and lack of faith that reporting abuse and neglect will make a difference. Agencies providing ISL & Group Home services receive

significantly different levels of oversight based on political and social connections, with large and well-connected agencies getting differential treatment not afforded to smaller agencies with less political pull.

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Chapter 1:

Introduction, Literature Review, Research Objectives and Methods

Introduction

This study explores the ways in which caregivers in a specific setting account for the way in which they use their power over others, and how they have observed it being used by others. The social world being explored, that of ISLs (Individualized Supported Living arrangements) and Group Homes for adults diagnosed with Intellectual and Developmental Disabilities (IDD), is not one that outsiders are generally privy to, but it is a setting in which power over others is often more visible and overt than other settings. Community residential placements for adults diagnosed with developmental disabilities are a decentralized social world in which some people are tasked with controlling the behavior of other people, both with and without diagnosed disabilities. How these agents of social control use narratives to exert power over others provides useful insight into this social phenomenon. The combination of significant power disparities between the social roles, the tensions inherent in this setting and the decentralized nature of this setting make it a compelling site for analysis.

While many readers may not be familiar with the social setting of ISLs and Group Homes for adults with IDD, the analysis of how the agents of social control in this milieu use narratives to control the behavior of others may apply to other more common settings with significant power disparities. Social settings with similar power disparities between roles include family homes (parents/young children), law enforcement encounters (police officers/suspects) and the homes of Alzheimer patients (caregivers/patients diagnosed

with dementia). How staff and professionals in ISLs and Group Homes use narratives to influence others in this social world can potentially provide analytic insight into how power is used to exert power over others in similar settings.

This project explores how social control agents use narratives to influence both the current and future behavior of others. These narratives influence many of the critical decisions people's lives, including what people eat, how or if they have sex, and where they live, worship, and work. Narratives are deployed in this social world not only to control the behavior of clients, but also to control behavior of the caregivers and supervisors in this social world. This world is incredibly complex and decentralized, with clients and staff living and working without meaningful outside intervention or supervision for weeks at a time. The wide array of relationships between clients and their staff, as well as between staff and their peers and supervisors, make this an impossibly complicated setting to explore comprehensively. Focusing on some common narrative themes is an attempt to gain meaningful insight into a chaotic and varied social world.

Literature Review

The relevant literature presented for review is focused on the ISL and Group Home setting for adults with intellectual and developmental disabilities, the Social Construction of Reality, Narratives and Identity. The sources cited here are not an exhaustive list of relevant sociological literature but provide a good theoretical base from which to analyze the intersection of narratives, the social construction of reality, and identity in this social setting.

Literature Review: The Social Setting of ISLs & Group Homes

Literature examining the social setting of ISLs and Group Homes that provide residential care for adults with intellectual and developmental disabilities (IDD) can generally be grouped into three broad categories: macro-level studies, site-based ethnographies and professional guidance for staff and supervisors in these settings.

There are a number of studies involving the social world of ISLs and Group Homes for adults with intellectual and developmental disabilities that deal with the world in the aggregate, or at a macro-level, of analysis. Some examples include studies like Petra Björne's article, which examines the general state of group homes in Sweden through a philosophical lens, noting that while the stated aim for adults with IDD is to "live like others", while the idealization is that they live "*as if* they live like others" because their lived lives and circumstances are only similar to those of people without IDD through such an idealized lens. (Björne 2020) The systematic shortcomings of group homes with adult IDD residents in dealing with issues related to healthy adult sexuality are examined in Natalie Chin's article, "Group Homes as Sex Police and the Role of the Olmstead Integration Mandate" (Chin 2018). Nationwide issues related to poor quality of care are addressed in a government-based study which found that seven of the twenty-five states in the USA that were reviewed did not have systems in place to ensure adequate quality of care in residential placements for adults with intellectual and developmental disabilities and made recommendations of how to correct this issue. (Department of Health and Human Services, 2012). These examples each contribute to the discussion of care for intellectuals with disabilities at a macro-level, but the use of such a broad lens of analysis of group homes does not account for the significant

variation in interactions between the different staff members, different clients, and different conditions found in group homes. With a scope of analysis this wide, it is impossible to effectively account for the significant differences in interactions of clients and staff within the same group home, for example. While these studies are quite useful in dealing with broad issues of importance related to how people work and live within these settings, they are unable to provide much insight into how social control is accounted for within these settings.

A number of excellent site-based ethnographic studies of ISLs and Group Homes for adults with intellectual disabilities have been done, which provide much more detail about how social control works within these settings. Examples include Levinson's 2010 ethnography of a group home in New York City (Levinson 2010), Croft's work with a group home in Texas where she focused on "creating locales through storytelling" (Croft 1999) and the interaction of power, subject positions, and narrative performance (Croft 2005). A study following the transition, or "launching" of two young adults in Western Australia from their family homes into ISL placements is also well done and informative (Isaacson et al 2014). These ethnographic, site-based studies provide a great deal of relevant qualitative data and provide a great deal of insight into the specific environments and people being studied. These studies usually provide a great deal of detail regarding the behavior of clients, staff and supervisors in these specific settings, but it is unclear if the social interactions represent broader social patterns, or if they are idiosyncratic to that specific site. It is difficult to examine a number of sites effectively in studies such as these, leaving a gap in the literature concerning how social control operates in these settings. Questions such as, "How do staff get clients to do things that they don't want to

do?" or "Who should decide if a client should be sexually active, and with whom?" are typically addressed within these site-based ethnographies in ways that make generalization to other ISLs or Group Homes difficult.

A significant portion of the literature on ISLs and Group Homes for adults with intellectual disabilities are generalized professional guidance for staff and supervisors in these settings. Some examples include guides on developing problem solving methodology in group homes (Ailey et al 2018), how to effectively improve nutrition for clients (Humphries et al 2009), measuring group home culture as an indicator of quality of life for clients in group homes (Humphreys et al 2020) and how to provide quality group home care by addressing clients' competing and simultaneous desires for security, freedom and understanding (Shipton and Lashewicz 2017). The general goal of these studies was to enhance the ability of staff and supervisors to effectively perform their jobs in ways that would benefit clients in some way. These studies generally assumed the relative power relationships between clients, staff and their supervisors as given, with supervisors telling staff what to do, staff telling clients what to do, and clients doing what they were told. This type of article was typically focused on helping staff and supervisors to construct or modify systems to address some potential or perceived problem for caregivers in this social setting. While these studies providing professional guidance for caregivers and supervisors in group homes and ISLs may help these professionals solve specific problems, they do not address the ways in which power is used to shape the behavior of clients or staff in these settings.

Some studies focused on life in ISLs and Group Homes do not fit neatly into these three categories. One such article is "Governing Freedom Through Risk- Group Homes

Within the Archipelago of Confinement and Control" (Spivakovsky 2017). This article interrogates the role that group homes play in the broader carceral framework to control and constrain some individuals with intellectual disabilities in settings that share characteristics with prisons or asylums while simultaneously providing more supportive assistance to clients; simultaneously being sites of constraint of freedom while also serving as sites of potential learning and growth toward independence. Spivakovsky grounds this theoretical discussion within the framework of interviews with twelve stakeholders in group homes in the Australian state of Victoria.

The literature on ISLs and Group Homes provides a great deal of information about this social world and the people that operate within it. The vast majority of this literature does not provide enough insight into just how power operates within this setting. The scope of the literature is typically either too broad, too narrowly focused on a single setting, or is meant to provide techniques for caregivers and professionals in this field to accomplish specific tasks. These ISLs and Group Homes are treated as a monolithic entity of basically interchangeable residential placements in the macro-level studies or in such a fine-grained, individualized way in site-based ethnographies that a great deal of meaningful social phenomenon are not captured in these studies.

Literature Review: Social Construction of Reality and Narratives

The ways in which staff, clients and others use narratives to socially construct reality within this social world is a key component of understanding this setting. Social actors work in interactive and dynamic ways to socially construct reality. Definitions of situations are socially constructed in complex and socially significant ways. When a nursing home resident needed help to make a phone call at Murray Manor and he kept

trying to get staff to assist him for over an hour, he was "making trouble" for the staff, rather than the staff refusing to assist in granting a reasonable request (Gubrium 1975:46). The ways in which specific behavior or patterns of behavior are designated as important or significant (or socially "marked") can have significant impact on the lives of those involved (McWhorter 2005, Holstein 2013, Emerson and Messinger 1977, Buckholdt and Gubrium 1979). Whether an IDD client is biting themselves due to stomach pain, to try to communicate something, being "triggered" by something in the environment that reminds them of past trauma, or due to caregiver responses to self-injury can lead to drastically different responses to this situation, based on the dominant definition of the situation. The interpretive search for meaning within these "webs of significance" we spin for ourselves highlights the importance of narratives within the social construction of reality (Geertz 1973:5). The social construction of important issues is bound up in accounts of those issues. Discursive resources enable speakers and writers to construct their experiences as meaningful (Chase 1995; Holstein and Gubrium 2000; Foley and Faircloth 2003). Diagnosis is dynamically linked to the active work of meaning making, and the dynamic interplay between what is perceived and what is written are all significant aspects of the social construction of reality in these settings (Garfinkel 1967:71,79). In the case of the IDD client who bites themselves, interpretations of the same event can vary significantly, leading to vastly different responses from others. Just as perceived social problems don't exist for a society unless it is recognized to exist by that society (Blumer 1971:301, Blumer 1986), whether a particular behavior is treated as problematic or not is determined by the people involved (Fuller and Myers 1971:320; Holstein 2013: 192) -or at least by those with the power to select and enforce their

definition of the situation. Whether direct care staff, clients, or administrators are accurate in their interpretation of social phenomena is irrelevant, at least in the sense that the consequences of their definitions of reality, their social constructions of the social events, lead to real consequences even if they are not "accurate" or "true" (Thomas [1928] 2003: 81). Mental "lumping" and "splitting" allows certain people and their attendant problems to be separated by a "mental gap" from those not possessing those problems (Zerubavel 1991); this plays a significant role in how inaccurate definitions of situations may be applied to others seen as significantly different.

The incompetent status of clients in residential settings is socially constructed. The needs of the organization and caregivers often influenced this labeling process significantly. The fundamental injustices of the widespread institutionalization of IDD clients was challenged by critiques of the very category of "mental retardation" (Braginsky and Braginsky 1971; Mercer 1973). Many of the identifying behavioral features of people living in institutions for IDD clients have since been attributed not to individual characteristics, but to the specific contingencies in those institutional environments (Levinson 2010: 31). The "organizational embeddedness" (Gubrium 1987) of caregivers and organizational and the contextual contingencies (Holstein 2013:195-6) also play a significant role in decisions made in these environments. Institutional needs played a significant role in the social construction of incompetence for clients and potential clients, with simultaneous social constructions of productive labor (within the institution) and the need to protect society from the incurable, dangerous people within the walls of the institution (Carlson 2005:142). When children were studied in both an institution and in the community, contrasting clinical and social systems to demonstrated

that "mental retardation" was an "achieved status" and behavioral differences were described as features of each system to demonstrate that the constitution of normal "depends on system specific role performance, conformity and expectations." (Mercer 1973:22). The "Looping Effect" occurs when a patient reacts to an environmental event (such as mandatory room inspections or rigid bedtimes or mealtimes) with anything other than acceptance of the rules, this "difficult" behavior then justifies the imposition of the rules and the patient's status of incompetence (Goffman 1961:35). This process observed by Goffman in a hospital's psychiatric ward are replicated routinely in ISLs and Group Homes today. "Counselors [in the group home] sometimes focused on observable conduct to make accountable and confirm what they already knew about a resident's 'deeper' or 'inner' problems." (Levinson 2010:148). The management of risk to both clients and the organizations tasked with keeping them safe is often a significant factor in determinations of incompetence of IDD clients (Levinson 2010:231). Moving most IDD clients out of large institutions has been seen as an overall improvement in terms of the quality of life of these clients, yet the techniques used within those institutions to socially construct the role of IDD clients as incompetent has followed clients from institutions straight into ISLs and Group Homes.

Documentation and other bureaucratic technology play a significant role in the social construction this social world. Residents and counselors are "made up" in and through their ongoing work in the group home (Hacking 1986, Hacking 1999). Technologies like written plan goals and the use of "psy" technology can shape the "conditions of personhood" (Hacking 1986: 225). Never ending, yet never achieved progress is achieved in Group Homes and ISLs through the careful arrangement of

measured behavior and the constant shifting of goals, effectively constructing the "progress" that caregivers need to demonstrate on paper (Levinson 2010: 187). Daily Progress Notes, or the "Log" (Levinson 2010:103-105), is the basic format in which the staff document the behavior of the IDD client on a routine basis. These daily logs are sometimes used as the "proof" that the client is "really" who the staff say they are. The individual support plans for each IDD client in placement are another technology of control of client behavior. The goals are determined not by the client, but by their "team", which is dominated by professionals, supervisors and staff. The goals are almost never achieved, as the practical goal of the team is almost never to actually help most clients achieve true independence; perpetual progress toward a vaguely defined and ever retreating goal such as "being more independent" provides the justification for never-ending habilitation services and can be measured as "success" on the part of the staff and supervisors without ever achieving true independence (Levinson 2010:103, 187). Client preference may not even be reflected in these goals, and these goals allow for the professional intervention in every aspect of a client's life, making the most unremarkable or unproblematic issues potential sites of intervention by staff (Bannerman et al 1990:79; Levinson 2010:192). It is impossible to separate the treatment functions of residential care for IDD clients from the social control that is exerted (Trent 1994).

Staff exercise physical control over IDD clients in this social world in a number of ways. The monitoring and control of the bodies of clients with IDD in residential placement takes up a great deal of time and effort of staff in these settings and often include unlimited and unquestioned staff input and interference in issues involving personal hygiene, grooming, diet and sexual behavior (Drinkwater 2005:235-6). While

clients are only officially supposed to be physically restrained by staff for brief periods of crisis, more coercive physical restraint is always available in the form of police restraints coupled with either a jail stay or short-term hospitalization where the full complement of institutional physical coercion is available. While many of the overt physical controls of institutional living are notably absent in community placements like ISLs and Group Homes, many of the behavioral technologies are replicated in community placements. From the perspective of clients living in them, some ISLs and Group Homes can share many characteristics with being incarcerated. For incarcerated populations, many of the basic ways to exert control and self-determination are very limited, and numerous scholars have documented keeping access to the few areas of control that are available to prisoners are very important to them (Bosworth 1999, Crewe 2007, Crewe 2009, Jewkes 2002, Ugelvik 2011). For clients, the ability to refuse to exercise when prompted by staff or to choose when to eat junk food may become crucial proof of autonomy just like the small pockets of self-determination in prison are protected and, "…in the process, small acts of everyday resistance are legitimized" (Ugelvik 2011).

In addition to overt physical domination of clients to control them, clients are conditioned to control their own behavior in particular ways by staff, supervisors and professionals in this social world. The ideas of independence and freedom are in constant tension with the ideas of safety and responsibility in ISLs and Group Homes. While clients nominally have the freedom to eat too many doughnuts and take a nap, they are typically pressured to make more appropriate choices as determined by what the staff people on duty decide is appropriate (Bannerman et. al. 1990: 86). Clients are free to make some choices within structured, well-regulated ways, so long as they are making

choices determined to be "appropriate" and "safe" as determined by staff and supervisors (Rose 1999:72; Levinson 2010:39). Staff and supervisors often use narratives stressing values like safety and skill building, but the only time that power is discussed in this context is when *clients* attempt to exert influence over staff (Drinkwater 2005: 234). This ever-present observation coupled with social control elements is reminiscent of the Panopticon, which exerts power over prisoners in an automatic, continuous application of self-monitoring and self-control, effectively training the prisoner to function as their own omni-present guard (Foucault 1977:102-3; Drinkwater 2005:236-7). Settings like institutions and group homes are, "…forcing houses for changing persons." (Goffman 1961: 12). Some scholars argue that some community placements exercise more power and control over IDD clients than institutions due to the insidious nature of the application of modern power, in effect turning clients into their own monitors. (Drinkwater 2005, Tremain 2001, Tremain 2002, Tremain 2005)

The narratives of psychiatrists, psychologists, therapists and others permeates almost every aspect of habilitative support for IDD clients. The presence of this "psy knowledge" (Donzelot 1979, Rose 1985, Rose 1998) is one of the most ubiquitous elements of the technologies of control found in ISLs and Group Homes. There is an element of ethical authority of the expertise of psychologists and psychiatrists, a level of professional power which is generally deferred to within the world of ISLs and Group Homes (Levinson 2010: 48). A sort of "proto-professionalism" gets passed down to supervisors and staff in these environments, who routinely use the orders and recommendations by psychiatric medical professionals to bolster their own authority to implement the goals and interventions for IDD clients in their care (Levinson 2010:49-

50). If clients are particularly resistant to other methods of social control, professionals schooled in clinical psychology, behavioral psychology or other related disciplines are sometimes brought in to implement more advanced tactics, which can vary significantly but which can involve fairly invasive behavioral interventions rarely seen outside of clinics or institutions (Drinkwater 2005:233; Taylor 2001:19-21). These professional interventions are difficult to resist, as the narrative supporting intervention is for the safety and well-being of the person who is the current or potential client. Even in situations when an elderly person who does not have an IDD diagnosis, social workers can intervene over the objections of the elderly person in cases of "self-neglect", even if the elderly person rejects this narrative (Band-Winterstein et al 2013:125-132). These sorts of claims are made particularly when clients resist the narratives that staff and supervisors attempt to enforce; the resistance itself can be viewed as "proof" that the intervention was justified. Symptoms of mental illness can be characterized interactionally as byproducts of situations in which individuals are unable or unwilling to accept the narratives others accord to them; persistent conflicts over the individual's treatment plan disrupt the social setting and are a significant source of conflict (Goffman 1969:192-193). Psy knowledge is not just found within mental health clinics or institutions but has expanded to encompass life in general, particularly for IDD clients (Levinson 2010:120). Whether the IDD client in a group home sees their behavior as a problem or not is often irrelevant, due to the power differential in residential habilitation between clients and everyone else. An IDD client may see no issues with "dumpster diving" or masturbating multiple times each day, since "…social problems are what people think they are and if conditions are not defined as social problems by those

involved, they are not problems to them, even while they may be problems to outsiders…" (Fuller and Myers 1971: 320). This sort of situation often sets the stage for a power struggle between staff people and clients, who are viewing the same situations through different interpretive lenses.

Narratives are integral to the way that social control can be exercised in this social world through the informal use of social power. Complex relationships between staff and clients are not always as adversarial as are typically depicted in psychiatric hospitals (Goffman 1961; Goffman 1969) or in prisons (Sykes et al 1960; Foucault 1977; Ugelvik 2011). In a government funded residential care facility in Denmark a researcher found an interesting social paradox where the staff expressed an ideal narrative of careful listening to the needs of clients, but the clients who were most successful in navigating this setting effectively listened to and empathized with *staff* needs (Kofod 2013). An informal exchange appears to have developed, where the nursing home residents were rewarded by staff with assistance and better support in exchange for consideration from the residents who respected the other demands on staff time and effort and did not make staff jobs more difficult than necessary (Kofod 2013). Staff were minimally responsive to residents who they deemed to be unnecessarily demanding or who refused to acknowledge the informal power staff had in this setting (Kofod 2013). IDD clients are responsive to the pressure from staff and supervisors to act in certain ways, to gain approval from staff. A significant portion of the control over the behavior of IDD clients by staff is accomplished informally. Clients are induced to engage in behavior valued by their staff and in exchange will often be given a valued social role (Drinkwater 2005:235). Staff discourage client behavior that they deem to be inappropriate, defined loosely as

complying with the staff person's idea of proper conduct (Levinson 2010:5). While client choice and rights are often discussed, client compliance with staff expectations and valued roles take precedence; non-compliance is often seen as a threat to the services being provided and overcoming this resistance is a major part of the work of staff members and other service providers (Drinkwater 2005:240-1). While political activism based on a disabled identity could potentially provide an effective counter-narrative to the narratives supporting the social control of disabled clients (Anspach 1979), most IDD clients are not able to access these narratives or to be able to effectively use them to assert their rights when they live in supported residential settings.

Clients are not the only social actors in this milieu whose behavior is shaped by narratives. Staff, supervisors, and professionals all have their behavior controlled to varying degrees by others in this setting. The control that employers and supervisors have over employees, the ways in which clients can impact staff behavior, accountability for misdeeds and a desire to maintain a positive reputation, are all elements that work together to control the behavior of staff, supervisors and professionals. The existence of an actionable issue worthy of outside intervention compared to a personal problem is socially constructed by different social actors in different, often contested, ways (Band-Winterstein et al 2013:133). Threats of punishing consequences in response to specific behavior certainly provide some level of control over staff, supervisors, and professionals in this setting. A great deal of the training for staff is modeled by other staff and supervisors on the job, establishing norms for the work group. The informal knowledge imparted by peers on how to "really" provide care is often at odds with the rhetoric of the formal training staff go through (Levinson 2010:115). The network of documentary

technologies that are used to control the behavior of clients are also used to make staff, supervisors and professionals accountable and this accountability extends up to the state government, at least on paper (Levinson 2010:181). Much as police reports rarely paint law enforcement officers in a poor light, this accountability is primarily based on self-reported accounts and data, and rarely reflects poorly on the staff or organization writing the report. Individual staff members are routinely reported for neglect or abuse by others; the "blue code of silence" police officers are often protected by does not appear to be as widespread among staff people.

IDD clients can influence the behavior of staff in many ways, despite the asymmetric nature of power typically found between these roles. Researchers have examined how men with intellectual disabilities use sexual provocation to challenge the authority of staff who are women (Thompson et al 1997). IDD clients can also exert some limited measure of power over staff or peers through the threat of aggression or other disruptive behavior, even though this tactic is limited in effectiveness as staff can always call for assistance, either from other staff or law enforcement, if clients attempt to overuse this tactic.

Staff discretion is the informal way in which each individual staff member is given leeway in determining how they will carry out their duties and is a key element in staff resistance to the control of supervisors or other consulting professionals (Levinson 2010: 118-9). The direct care staff person is generally deferred to in how they are going to carry out their duties, especially in the presence of clients. Staff do not always agree to use their discretion as other staff do, and disagreements on the best way to provide care is a common area of negotiation or even conflict among staff (Levinson 2010: 126-7). The

nature of the work of staff and supervisors is never-ending, because the work that they do is interactive work that is “not subject to closure”, as “people do not stay fixed” (Lipsky 1980:78). The endless nature of the work makes staff discretion a necessity, as there is no way in which to ever really completely perform all possible tasks in an ISL or Group Home. As long as a good faith effort appears to have been made, staff are generally able to pick and choose how they perform their duties beyond keeping the clients safe. The work for staff and clients in these environments is never done, yet the nature of the vague goals and perpetual nature of self-improvement make it so that the goal of independence is never fully reached, since reported progress toward the goal is what the system demands of clients and their caregivers (Levinson 2010:102-3).

Understanding the ways in which the social construction of reality is shaped and challenged within the social world of residential habilitation environments is an important element of understanding this world. How the people who occupy this milieu use narratives to interpret the very nature of the social reality in this setting has a significant impact on almost every aspect of life and work in ISLs and Group Homes.

Literature Review: Identity and Narratives

Understanding how identity is negotiated and used in the social world of ISLs and Group Homes is a critical aspect of understanding how this social world operates and the role narratives play within this process. Identity is a fluid, complex, contested, and complicated concept. (Brekhus 2003, Brekhus 2020) The relative value of identities varies in relation to other identities as well as by situation. (Brekhus 2020:123) An identity that may be celebrated at a Special Olympics event may be stigmatizing in a restaurant, for example.

The self and identity are important topics that have been explored by numerous scholars (Biddle 1979, Gecas and Burke 1995, Holstein and Gubrium 2000, Brekhus 2020). "Identity is central to human meaning, social life, and social interaction." (Brekhus 2020:1). Debates among scholars over the nature of identity (or the self) are numerous and ongoing: the core self, the malleable self, an evolving self, multiple selves, reflexive self, unknowable self (Cooley [1902] 1964; Gergen 1991; Goffman 1959; Holstein and Gubrium 2000; Linton 1998; Mead 1934; Strauss 1959; Zurcher 1977). A common, shared understanding of the meaning of the identity under consideration is necessary for this interactive process (Biddle 1979; Holstein and Gubrium 2000). Individuals have multiple identities (Biddle 1979; Gecas and Burke 1995; Holstein and Gubrium 2000; Zerubavel 1991, Brekhus 2020) and yet each person has their own unique identity. Identity is intensely personal yet is also socially constructed from available narratives within specific situational contexts (Brekhus 2020:67-8). Within the situational context of ISLs and Group Homes, identities are formed by clients, staff and others using the narratives available to these different groups. The identities available to individuals are greatly influenced by the identities available within the given social context (Gubrium and Holstein 2000:101) and cannot be chosen or discarded by the individual alone (Berger and Luckmann 1966:1-3). So a client living in an ISL may attempt to construct an identity free of the stigma of intellectual disability, but the other actors in this setting will be unlikely to accept such an identity. Additionally, if a staff person sees themselves as a person whose job is to protect the community from the clients they work with, they may react to client "noncompliance" very differently than a staff person who views themselves primarily as a supportive counselor. The authentic performance of accepted

identities can also influence who is included or excluded within specific identity groups, in essence determining who belongs and who does not (Brekhus 2020:76-77).

Individual identities are socially constructed. Narratives, particularly the "languages of the self", are the tools with which social actors make sense of their social reality (Gergen 1991: 5-6), and how they both shape their identities and are shaped by those very identities (Zerubavel 1997). Identities, or selves, are collaborative efforts that individuals craft for themselves in an interactive, dynamic and socially accomplished process (Brekhus 2020: 127; Gubrium and Holstein 2000:101; Fine 2012:167). The social construction of surprisingly complex peer group culture by relatively powerless preschool children (Adler and Adler 1998) indicates that this process can occur without structural power or sophisticated social interactions. This suggests that similarly complex peer group culture among clients or staff may also develop in similar ways. Changes in our socially constructed selves are also accomplished through interactive social stories (DeGloma and Johnston 2019: 625), with new challenges and fresh opportunities to reformulate personal or collective identities (Gubrium and Holstein 2000; Brekhus 2020:126).

Narrative work is central to understanding how identities are constructed, negotiated, and challenged. The ways language and identity are used to inform the behavior of individuals within a specific social setting can be better understood through ethnography (i.e. Anderson 1999, Goffman 2014), and how context is used in everyday life as a resource (Garfinkel 1967). Aspects of identity are contested and negotiated socially, including a person or group's role in society, who can and can't claim membership in certain identities, and in providing meaning related to identity (Biddle

1979; Gecas and Burke 1995; Goffman 1963; Zerubavel 1991, Zerubavel 1997). For example, descriptive work is needed to construct Alzheimer's Disease (Gubrium 1986), though the individuals who are assigned this diagnosis and the accompanying identity implications and their close relatives often resist this identity, at least for a time. Individuals display social cues for others to indicate identity claims, and their narratives are often a key component of these identity claims, whether they are trying to shape the audiences' perception of the identity or resist or embrace an identity the audience may attach to them (Goffman [1963] 1999; Holstein and Gubrium 2000; Scott and Lyman 1968).

The process of marking some individual identities and roles but not others can have far reaching social significance, including stigmatizing certain identities (Goffman 1963). Impairment is not the same thing as disability (Tremain 2005:9). Clients are typically marked as disabled, while staff are unmarked, and therefore, assumed to be within the default societal category of able-bodied (Drinkwater 2005:235). Not only do many staff people have some form of impairment themselves, it is difficult to specify just what makes a person able-bodied (Zerubavel 2018:9). There is a great deal of unmarked and unstudied behavior (see Brekhus 1998 and Zerubavel 2018) and identity narratives among supervisors and professionals provide some insight into this process. The intersection of power and knowledge plays a role in whose interpretation gains acceptance and dominance in a social milieu (McWhorter 2005: xv). The unmarked opposite of a disabled identity is, "…*able-bodied normativity*, that *a person is presumably able-bodied unless specifically designated otherwise.*" (Zerubavel 2018: 43). In other words, the process of marking specific people is important, as is the omission of

marking for those who are unmarked. “Normals” have constructed themselves through the exclusion of and differentiation from others, such as criminals, mad people, and disabled people (Foucault 1988:146). This social marking of some roles and behavior while leaving others unmarked results in an empowering of the unmarked social elements, making them the normal or default social status (Brekhus 1996, Brekhus 1998, Brekhus 2020).

Labeling individuals with specific diagnoses can be a significant part of the social marking process of clients in this milieu. This clinical “marking” (Brekhus 1998) has effects beyond the clinic or doctor’s office. People with diagnosed conduct or behavior disorders are typically discursively marked by non-medical and non-professional groups and are often treated differently based on this non-conforming or deviant social label (Hardwood 2006:5). These people may engage in behavior similar to that of their unmarked peers (see Zerubavel 2018) yet be treated quite differently. This non-standard treatment (possibly in the form of rights restrictions, focus on compliance with caregiver demands, etc.) can often have unintended consequences, contributing to more significant or intense problem behavior from these individuals. Issues that could have been considered “troubles” for other social actors are treated as “deviance” or “problems” by caregivers (Emerson and Messinger 1977). The socially constructed categories of “disabled” or the unmarked “able-bodied” and other socially marked and unmarked categories are specific to the “thought communities” that share narrative norms, traditions, and conventions (Zerubavel 1997:6). By marking the unmarked as “able-bodied”, “non-disabled” or “temporarily abled”, advocates and allies for the disabled

community challenge the socially dominant semiotic position of those who are typically unmarked in terms of disability. (Zerubavel 2018:66-67).

Which attributes are either marked or left unmarked can provide insight into the relative power of the groups of actors in a social setting over the dominant narratives and one another in ISLs and Group Homes. Identity attributes for clients, staff and others in this setting can be viewed as the ingredients in a recipe, with the marked attributes standing out and the unmarked attributes blending in as present, yet not worthy of comment (Brekhus 2020:110-111). While staff people do not have a lack of attributes (often including diagnoses involving both physical or mental impairment), many of these attributes are imbued with social power by their unmarked status within this social world or largely ignored if they are not empowering (Drinkwater 2005:234-5). The way in which some people in this setting are marked as disabled while others are unmarked sets up a significant power disparity, a ripe area for analysis of power relations based on the system of differentiation (Foucault 1982:223). The idea that staff are able, and clients are not, often reflecting real capabilities and challenges, but the competence of staff in ISLs and group homes is as unexamined as the incompetence of clients is assumed, based at least in part upon the socially constructed roles these individuals occupy.

Identity and behavior attributes are not weighted equally in terms of significance in identity formation in ISLs and Group Homes. Various dimensions may play unequal roles in the formation of a particular type of identity (Brekhus 1996:502) with different dimensions gaining salience based on a number of factors. Understanding the dimensions that play a role in the formation of clients will be explored through caregiver narratives, but could include the ability to communicate, level of aggression, social skills, ability to

perform activities of daily living, etc. Specific "washing over" effects of some markedness occur if a dimension is provocative enough (Brekhus 1996:507). The slightest amount of some detected behavior is enough to impact some marked identities (i.e. the "mental one-drop rule") while other quite obvious behavior is not marked as deviant unless there is overwhelming evidence (i.e. the "mental entire ocean rule") (Brekhus 1996:514). Deviance is created through the process of labeling of specific behavior, and individuals who engage in this behavior, as deviant. (Becker 1963) Secondary deviance results from the societal reaction to the individual with the deviant label, whose chances of deviance increase due to reduction of legitimate conforming alternatives (Becker 1963:35). Social control can be viewed as the power to influence the narrative of the definition of the situation that is "realized both in spirit and practice" (Conrad and Schneider [1980] 1992:8). To be able to not only determine what behavior is unacceptable and to also enforce the definition on others in meaningful ways appears to be the epitome of social control. This definition of social control resonates with my observations in residential settings. Studying the non-deviant or unmarked behavior, how people conform, how dominant groups interact and behave is just as performative and socially constructed as marked behavior. Focusing on this sort of behavior may provide a great deal of insight into these social processes and is at least as important as studying marked behavior and identity in this social setting. As "everything perceived is only evident when surrounded by a familiar and poorly known horizon" (Foucault 1977:144), examining the ways in which this social marking process operates within this unfamiliar social setting may highlight the role of narratives in constructing marked and unmarked identities. Analyzing both the marked and unmarked social phenomena in this specific

social context can help us better understand how these processes are used, what their effects might be, and how they may be used in other social worlds.

Identities are sometimes forced onto individuals by other social actors. Whether an individual is labeled with a particular diagnosis, as a sex crimes offender, or as an abusive staff person is not up to them; these identity labels are imposed by others and can have significant social ramifications. The social construction of the identities of others includes the ways in which people are labeled as clients or behavior analysts, or how an antagonist like “The System” can be created. Social constructions of a person’s ability and behavior are filtered through the narratives of those who are giving the account, and they may have significant stakes in the accounts and the resulting likely consequences. A clear example of this is in the case of a significantly intellectually disabled girl whose family constructed a social reality in which she was much more competent than objective observers could see. (Pollner and McDonald-Wikler 1985) The family responded to her when it was not clear she was communicating anything intentional. I have observed a similar phenomenon working with families who ignore clear evidence of impairment and see competence where others cannot in ISLs and Group Homes.

One significant way in which reality is constructed by others is the process of clientization in human services (Gubrium 2013, Spector & Kitsuse 1987, Prottas 1979, Gubrium & Järvinen 2013, Band-Winterstein et al 2013; Foley 2013:18; Goffman 1961:375). “Clientization is a general process of turning people into clients suitable for the application of human services… service institutions and providers construct the clients they need for their work.” (Gubrium 2013:137). A number of challenges to the process of clientization exist: individual challenges to these identities for themselves or

others; collective challenges such as peer group resistance; competing perspectives with vastly different constructions of clienthood (i.e. “mental illness” versus “life issue”); and contending clienthoods (such as sexual assault nurse examiners needing to both preserve evidence and serve patient needs) (Gubrium and Järvinen 2013). This clientization phenomenon occurs when people have issues that are socially constructed into problems by the people in the “psy-industry.” (Donzelot 1979, Rose 1998, Rose 1999) Diagnoses, particularly mental illness diagnoses, are sharply critiqued by some scholars (Hacking 1986, Rose 1985, Rose 1998, Rose 1999) and are often formed from a collection of socially constructed behavioral stories from non-professionals that are largely “issues” rather than symptoms. (Weinberg 2013). Thomas Ugelvik (2011) describes the social construction of a bureaucratic entity, “the System”, that takes the form of a social object that can be cast as an active opponent to prisoners. Just as “the System” is socially constructed as an active opponent in prison life, “the State” is the active character that makes life more difficult for staff and supervisors and is often constructed as an active opponent by actors in the social world of ISLs and Group Homes.

The intersection of multiple identities may result in a great deal of complexity. Intersectionality examines more than one variable (race, gender, class, nationality, etc.) at a time (Said 1979). While social scientists often focus on broad categories of identity in their analysis, individuals often treat a combination of identities as more salient in shaping their social views and identity (Brekhus 2020:106). The simultaneous interaction of multiple axes of marginalization is *not* the same thing as the sum of the different individual axes of marginalization, and that analysis must consider the axes together (Hill-Collins 2019, Brekhus 2020:105). Normative privilege is an important, and

understudied factor in how power and difference interact in social groups (Brekhus 1998, Brekhus 2020:106). The ways in which disabled and able-bodied identities, occupational identities, intellectual impairment, stigmatizing status and other identity characteristics often found in this social milieu will also need to be studied with intersectionality in mind in order to capture the complexity and nuance of the role of identities in ISLs and Group Homes.

Group identities often play an important role in identity formation. Within the social world of people with disabilities and those who care for them, group identity formation is influenced by a number of factors. Politically active participation in "identity politics" of people with disabilities fighting for change in both societal views of those with disabilities and the self-conceptions of the disabled focused on the rejection of stigmatizing narratives and challenging inequalities in societal structures for those labeled disabled (Anspach 1979). This identity politics can play out very differently for people with "spoiled identities", "discreditable stigma" or "discredited stigma (Goffman 1963), and members of the same nominal group may attempt to exclude those that may not serve the group's purpose. For example, advocates for acceptance of neurodiversity (such as autism spectrum disorders and attention deficit disorders) sometimes resist the inclusion of severely intellectually impaired individuals among their ranks, particularly when they are arguing for inclusive treatment. Idioculture is a useful term in assessing the intersection of groups and identity, focusing on the shared experiences and ongoing cooperative nature of their shared locally constructed reality (Fine 2012: 125). Boundaries can be exclusionary, reinforcing socioeconomic class boundaries (Bourdieu 1984) through the deployment of cultural capital (Brekhus 2020:91). Impression

management strategies (Goffman 1959) are attempts to present identity characteristics in line with the identity the actor is attempting to present, and sometimes to avoid being marked with a stigmatized, or “spoiled identity” (Goffman 1963).

Some marked identity labels are so powerfully stigmatizing that they have a social impact on others associated with the individual who has been labeled with the offending identity. Sex offenders are not only widely socially excluded and stigmatized (Quinn et al 2004:211), but the stigma of this label is so strong that a “courtesy stigma” Erving Goffman (1963) attaches to the offender’s entire social network (Tewksbury and Connor 2013:219). Within the ISL and Group Home community, large and aggressive IDD clients and those accused of child molestation are often shunned by members of the public as well as other clients and staff who are not assigned to work with them directly, and a courtesy stigma can attach to people associated with these individuals who are seen as unpredictable and dangerous.

One of the most disturbing aspects of identities imposed by others is the impact of the labeled individuals who internalize these labels. The stigma that some prisoners experience when they view themselves as they imagine society at large does is powerful (Goffman 1963; Becker 1963; Ugelvik 2011). This attack on a prisoner’s self-image is one of the pains of imprisonment (Sykes 1958). The lack of a “backstage” (Goffman 1959) free from the gaze of staff and other team members makes contesting staff narratives difficult for IDD client in an ISL or Group Home, just as it does for other groups at a significant power disadvantage.

Stigmatized or marginalized identity attributes can become assets in different groups in which the stigma is shared by a marginalized group, turning an identity

attribute which is stigmatized by outsiders into valuable identity currency in specific contexts (Brekhus 2020:167). Membership in a racial identity-based social movement can project a shared group identity for members, providing a sense of solidarity and agency referred to as “Strategic Essentialism” (Brekhus 2020: 55). However, identities are situationally bounded (Gecas and Burke 1995; Holstein and Gubrium 2000), and the decentralized nature of ISLs and Group Homes, coupled with the complicated intersection of disability and other dimensions of identity make it difficult for most IDD clients in these small residential settings to form a cohesive group identity. Additionally, different identity traits are valued by different audiences in differing, sometimes opposing, ways. Just as sexual orientation can be an individual’s master status at all times, or only in certain bars and other social situations, or it could be a more blended part of a person’s identity (Brekhus 2003), disability as an element of identity can be deployed by individuals in different ways in different contexts or at different stages of their life. Collective identities emerge from dynamic social interaction and are influenced by institutional and situational factors (Gecas and Burke 1995; Goffman [1963]1999; Holstein and Gubrium 2000; Ross and Nisbitt 1991; Scott and Lyman 1968). The narrative environments and contexts people operate in are intertwined with their identities (Gubrium 2005).

Organizations and culture play important roles in identity formation in ISLs and Group Homes in numerous ways. Identity is mediated and co-produced within an organizational context (Gubrium and Holstein 2001:104). Current options for identity formation are closely tied to past interactions and are developed through connecting the

present through the lens of a shared past within social groups; identities are anchored through shared understanding of identities (Fine 2012:161-7).

A coherent and consistent identity, a true self, is a widely valued aspect of identity for social actors within ISLs and Group Homes. An authentic self or identity is simultaneously unique to each individual yet can also occupy a standardized role within social organizations (Goffman 1963:57). An assumption that each person has a singular, true identity is often overly simplistic and can be harmful (Brekhus 2020:99). One identity is insufficient, and our identities are achieved through dynamic social interaction within our micro-communities and are mutable rather than rigid (Fine 2012: 164). The fluid nature of identity does not mean that it is based on the individual's whim or that a stable identity is not desirable: identity is still a socially constructed phenomenon, despite the complicated, complex and changing nature of social reality (Brekhus 2020: 155). Identity authenticity can be deployed in very different ways, even when it is the "same" identity being deployed (Brekhus 2003; Brekhus 2020:80-1). There may be tension between the way in which a staff person presents their nurturing identity in different contexts (at home with their children versus when they are working with clients) or for different audiences (when they are alone with clients or when a case manager is doing service monitoring at the ISL).

Exploring how multiple selves and social roles interact to create identities in ISLs and Group Homes will be useful in understanding the impact identity has on the individuals in this social world. The fluid and multifaceted nature of identities can complicate the study of categories of identity (Brekhus 2020:165). For example, a behavior analyst may want to present a professional, controlled appearance when dealing

with an aggressive client, but may be struggling with her own traumatic history as an abuse victim when a client begins verbally threatening her. Some occupations have a certain level of “role murkiness”, such as forensic nurses who have to balance dueling occupational responsibilities of providing comfort and care for rape victims as simultaneously have a legal responsibility to preserve evidence of their sexual assault (Foley 2013). This “role murkiness” occurs routinely for staff people who are expected to simultaneously support and care for IDD clients while they are also required to physically restrain them to prevent these clients from causing physical harm to themselves or others.

The vast array of individuals navigating the social world of residential care share a common set of problems and circumstances. Some important insights may be discernable by noting instances in interviews of “Narrative Slippage”, when people apply recognizable storylines to their experiences in ways that do not exactly match the “real” story (Holstein and Gubrium 2000:110).

Identity mobility, identity currencies and identity duration are all considerations when analyzing identity; different selves can be intentionally highlighted or intentionally muted by the same person within different social contexts by the use of different identity claims for varying periods of time (Brekhus 2020:130-33). The way an individual pronounces certain words, the types of food they order, the words they use and their mannerisms are all combined with content so that other social actors may determine who someone is. (Biddle 1979; Bourdieu 1984, Holstein and Gubrium 2000). Duration is a factor that can play a significant role in identity construction. Whether an identity is permanent or temporary, when a person can gain access to the identity or when it is no longer available, and if the person can make an authentic claim to the identity can all be

determined by the duration of specific socially marked behavior or attributes (Mullaney 2006:84-5; Brekhus 2020:150-1).

Identity plays a complex, yet integral part of the analysis of this social world. Based on my experience in the field, identity is very likely to play a significant role in determining what staff, supervisors and professionals will and will not do. There are a large number of rules, regulations, laws and guidelines that proscribe what these workers can and cannot do; yet in practical terms these are basically unenforceable by outsiders. Most staff people and supervisors follow the rules most of the time, however, even though there is almost no chance someone would catch them if they broke the rules. At least part of the answer lies in the way in which these workers incorporate specific narratives in the way they construct their identities.

Literature Review Conclusion

The aim of this research is to gain insight into how narratives influence attempts to control behavior in ISLs and Group Homes. The selected literature focused on the intersection of narratives with the social construction of reality and the sociology of identity and covers significant theoretical ground. This is in part due to the exploratory nature of this project, informed by the author's decades of experience in this field working in multiple occupational roles in ISLs and Group Homes. While the selected literature touches upon a great deal of sociological theory, they all contribute to the analysis of how narratives are used to exert power over others in this social world by influencing key aspects of their working definitions of what is happening and who it is happening to.

Research Objectives

The main focus of this dissertation is to analyze how narratives are used as tools of social control in the social world of ISLs and Group Homes. Analysis of how caregivers use these narratives provide insight into how the social control of others is achieved by social actors in these settings. Narratives are used within this social world to attempt to shape the definition of the situation and to influence identities within ISLs and Group Homes. A goal of this research is to explore how caregivers account for imposing these social control strategies over others in this milieu. The social setting of ISLs and Group Homes for adults with IDD diagnoses, with its power disparities and dual missions to keep clients safe while simultaneously promoting independence is a setting well suited for analyzing the intersection of narratives, identity and social control.

Within the social world of ISLs and Group Homes, people are routinely exerting power over other social actors for a variety of reasons. Power over others and the exercise of social control are intertwined with narratives and discourse, and essential to understanding relationships and behavior within ISLs and Group Homes. "Power is a type of relation in which one person or group of people *acts upon the existing or possible future actions of another person or group of people*." (Foucault 1982: 220, emphasis in original) There are numerous ways in which social control is attempted in beyond narratives. Examples of non-verbal social control attempts may include the physical control of people through restraint, chemical control of people using medication, and financial control of people. While these aspects of social control are certainly significant, they do not occur within a narrative vacuum. In other words, these non-verbal tactics

employed to socially control others will almost always correlate with narratives about the tactics.

The use of framing narratives is one of the most common tactics to exert control over others in this social world. Framing narratives are using narratives to define situations in particular ways in order to influence outcomes, or to make a claim that helps shape the dominant definition of the situation. For example, if a client bites their arm while in a grocery store, the staff person working with them may frame that as "Attention Seeking Behavior" that should be ignored, while an onlooker may be horrified at the apparently callous ignoring of the client engaged in self-injury in public. The use of narratives to frame or define the social situation is a continuous project. Clients, staff, supervisors and professionals all have various goals and interests which may or may not align. Clients and staff may present different accounts of the same behavior, such as getting recycling materials out of dumpsters or flipping off passing motorists, as either exciting activities to pass the time or as potentially dangerous activities to be discouraged. The narratives which are accepted and rejected often shape future encounters between these actors, as well as what interpretation of reality is the dominant and accepted narrative moving forward.

Identity Narratives are narratives that are employed to make claims that may impact the identity of a social actor in some way. Identity construction through the shaping of specific narratives is another method of social control in this social world. Narratives are used to sort and order clients and staff into various categories, such as high and low functioning individuals, medically fragile or aggressive clients, good staff or lazy staff, etc. The socially interactive nature of identity places identity construction in a key

position in this social world. If a client is labeled as a sexual offender in their official documents, this can have a significant impact over the interactions they have with every staff person trained to work with them, even if the client hadn't engaged in any behavior that would support this label for twenty years. Staff who are physically assaulted by clients sometimes use client identity narratives that excuse or dismiss physically aggressive behavior from clients, even if the staff person is injured or put in significant danger. At other times, past episodes of aggression or other "behaviors" from clients may justify significant rights restrictions or other interventions to control client behavior. Clients who report improper behavior of staff people often have to have significant support for their narrative to be accepted (such as a video or other staff person as a witness), while the narratives shaping the identity of clients presented by staff and others are routinely unchallenged and accepted as true.

Methods

The research design for this research was to conduct semi-structured interviews of staff people, supervisors and other professionals in the social world of ISLs and Group Homes in order to record the narratives that they use to explain how power is accounted for in this social world. The University of Missouri Institutional Review Board approved the research and all related research policies were followed. In-depth interviews with eighteen respondents were conducted, with verbatim transcripts produced from recordings made of the interviews. The author's long-term familiarity with this field in a variety of roles since December 1998 shaped the selection of the interview questions, (see Appendix A below), played a role in recruiting informants as a knowledgeable insider, helped with the conduct of the interviews, assisted understanding of the jargon and

context presented in the narratives, and informed the analysis of the data. The interviews were conducted in an active, probing way designed to elicit responses focused on research questions, and active guidance back onto this topic served to increase the number of narratives dealing with power, social control and identity in this social world.

The interviews produced a significant amount of qualitative data. The interview recording were a cumulative 2,423 minutes, or 40 hours and 24 minutes, long. The resulting transcripts were a cumulative total length of 593 single spaced pages, averaging 33 pages per interview. The interviews lasted between 90-243 minutes, with an average interview time of 135 minutes, or 2 hours and 15 minutes per interview. The transcripts were stripped of identifying information of individuals, agencies and locations to protect the anonymity and confidentiality of the respondents. Protecting the identity of the respondents increased the likelihood of truthful interview responses and reduced the chances of possible negative outcomes for participants if they shared sensitive information about themselves or others. These transcripts were shared with the dissertation advisor, Wayne Brekhus, PhD, and narratives were highlighted and analyzed. As a qualitative study, the thick description of the interview transcripts provided a wealth of data to compare with the author's experiences in this social world and the relevant literature for analysis. The semi-structured interview questions were designed to attempt to draw out relevant narratives from respondents, with focus on how they use narratives to influence behavior, the role of identities in ISLs and Group Homes, and what they and others say about the use of power within this social world.

The interviews were manually coded in order to determine patterns and themes relevant to how respondents account for their use of power over others in this social

world (Spradley 1979). Analysis of the interview transcripts focused on the accounts of power being used within this social world to attempt to influence the behavior of all of the different social actors there, including clients, staff people, supervisors and professionals. The caregiver interviews provided a number of examples of how the respondents account for their use of power within this social world. The semi-structured interviews were conducted to elicit narratives that demonstrate how social control over others operates in ISLs and Group Homes. The data being coded was reviewed by the dissertation advisor, who spot checked analysis and provided inter-observer agreement on analysis of the narratives provided in the interviews as needed.

A significant number of respondent narratives dealing with aspects of social control, 971, were coded and analyzed into 3,244 narrative codes. More than one narrative code applied to most narratives. The various narratives provided by the respondents were assessed, with the focus being on narratives related to the social control of people within this social milieu, whether the subjects of the social control attempts were clients, staff, supervisors or others. Other narratives, such as Entertaining Narratives were present, but not deemed to play a significant role in the focus of this research project. Interesting and amusing stories about what goes on in ISLs or Group Homes were not included in this analysis if they did not appear to play a role in attempts of one person or group to exert control over others, or to resist such attempts at controlling their behavior. The narratives of respondents related to the social control of others fell into two primary categories: Framing Narratives and Identity Narratives. Framing Narratives are narratives which are used to attempt to influence the definition of the situation which is accepted. Framing Narratives made up 65.5% (2,125 of 3,125) of the social control

narratives coded. Identity Narratives are narratives which play a role in how people see themselves or how they see others. Identity Narratives made up 34.5% (1,119 of 3,244) of the social control narratives coded. Other categories of narratives did not appear to play a role in social control or the exercise of power within the social milieu of ISLs and Group Homes. Some narratives fit better than others within categories, and others appeared to overlap. For instance, a narrative in which a respondent made identity claims of being an ethical person who was bothered by clients having their food stolen by other staff people, but who defined the situation as one in which they were powerless to intervene effectively, is an example of a narrative that could be classified as both a Framing Narrative and an Identity Narrative.

The analysis focuses on the specific ways in which the respondents account for the use power over others in this social world. The ways the situational definition is shifted through various narrative techniques are a key analytical focus; another is the role identities play in the use of power in this social world. The basic theoretical approach pursued is ethnographic and qualitative in nature to gain insight into the narratives people in this world use to influence the behavior of others in ISLs and Group Homes. Interviews of clients living in ISLs and Group Homes were not conducted in this study, due to the high risk of potential harm that could result from their participation, and the difficulty in obtaining full and knowing waiver of the risk participation could pose. While the narratives of clients are important aspects of this social world, the focus of this study is on those imposing social control over others, not on the stories of those they attempt to control. The inclusion of client narratives would not add substantively to the analysis of how those with power over others use narratives to influence outcomes, due to the

relative lack of power that most clients have in these settings. The narratives of clients are a very important part of this social world, but their inclusion here would not contribute enough to the research topic to justify the potential risks that participation in this study would pose to the clients.

The world of ISLs and Group Homes for adult clients with intellectual and developmental disabilities is a dynamic and challenging setting to analyze. To my knowledge this study is the first to attempt to study this social world in precisely this way. The lived experiences of those living and working in this social world will likely be quite surprising to outsiders. There are also meaningful similarities in the ways narratives and power over others intersect in this social world to other social settings, particularly settings where power is decentralized and inequitably distributed.

Chapter 2: The Social World of ISLs & Group Homes for Adults with IDD

Social World of ISLs and Group Homes

ISLs and Group Homes are community based residential programs for individuals diagnosed with intellectual and developmental disabilities (IDD), such as Autism Spectrum Disorders (ASD), Cerebral Palsy or Down Syndrome, with a wide range of intellectual and physical challenges. While roughly 60% of the adults with IDD in the United States in 2017 either lived with family members or independently, close to 40% of adults with IDD got assistance from government funded paid staff and professionals in either state run facilities or in apartments and houses in the community. Of those not living with family members, 83% lived in settings with 6 or fewer people. These supported residential living arrangements in the community are referred to as ISLs and Group Homes and are dispersed throughout houses and apartments across the country. (Larson et al 2020: 25-28)

A significant number of studies have been done on changing the behavior of social actors in school settings, inside formal institutions such as hospitals and inpatient clinics and in family settings. The social setting of residential placements is a sort of hybrid setting. It shares elements of institutional settings (with formal rules, governmental and organizational oversight, etc.) as well as elements of other less formal settings (such as family settings or gangs). Certain similarities exist within the residential placement milieu that are similar to that of other decentralized work, such as police work and other milieus where there is little real supervision or oversight of most to the work

that is done, and there is a great deal of autonomy with which individual caregivers can do their jobs. The differences in socio-economic status, education, training and expertise among those working in this field are also significant. The diffused work environment makes it possible for entry level direct support professionals (DSPs) to work for weeks at a time unsupervised by anyone, with the only record of their behavior being their own written account. This is similar to the occupational oversight of many police officers or door-to-door salespeople, who largely do their work with little direct oversight.

The world of those who care for adults with intellectual and developmental disabilities (IDD) in Individualized Supported Living (ISL) homes and Group Homes cannot be understood without examining the nature of these disabilities and some of the salient historical events that shape this social world today. The world of residential care for adults with developmental disabilities is shaped by a complex combination of multiple, interacting factors. These factors include society struggling with caring for and controlling specific subsets of the population, the development of labels and new possible categories for people (e.g. idiots, morons, imbeciles, mentally retarded, autistic, neurodiverse, "on the spectrum", etc.), the development of systems and institutions to deal with these people, the discovery and recovery from the heinous abuses and horrendous conditions found in large institutions, and the current decentralized yet heavily regulated world of community residential care. By examining the people, places and history of this social world we may better be able to have a common understanding of some of the forces that have shaped it.

Author Experience in the World of ISLs and Group Homes

I have worked in ISLs and Group Homes off and on since December 1998. During this time, I have worked as a staff person, a life-skills coach, a supervisor, an administrator, a behavior analyst and as an agency co-owner. My experience is also shaped by my interactions growing up with my aunt, who has Down's Syndrome and is taken care of exclusively by family members to this day. I have also been involved in different volunteer positions, serving on the Due Process Committee (formerly the Human Rights Committee) as a provider representative. This committee primarily reviewed requests to restrict client rights, working with staff and case managers to include appropriate justification and a path to the restoration of the rights which were being restricted. I have also served on the Regional Behaviors Support Review Committee, on which behavior analysts review cases from across the state in an attempt to assist caregivers, staff and other behavior analysts in attempting to support IDD clients in crisis. I have worked directly for six different agencies providing ISL and Group Home services to adults with IDD and have interacted with dozens of agencies and families and hundreds of clients with IDD between my consulting work as a BCBA (Board Certified Behavior Analyst) and on the committees I have served on.

This social world is incredibly complex. It is impossible to do any of the various jobs I have done perfectly, as there are too many competing and dynamic occupational requirements to make it possible for anyone to do it all perfectly. For instance as an entry level staff person in an ISL, you are expected to: have positive social interactions with the clients; keep everyone safe at all times; give all medication at the right time to the right person in the right way; follow any Individual Support Plan (ISP) plan or behavior

tracking plans to the letter and document properly; complete all daily progress notes, Medication Administration Records (MARs), bowel movement charts, chore lists; track all client purchases and get receipts for everything, or make hand-made receipts if none are available; take all of the clients out to access the community when they want to, even if one client wants to stay home and one wants to go shopping; ensure all hygiene tasks are getting completed properly; don't drive too fast in agency vehicles; make sure you get all clients to all scheduled events, medical appointments and day placements on time; train new staff people; encourage clients to help you cook nutritious meals, preferably delicious ones from scratch; be kind and respectful to all clients at all times, even if they are calling you racist slurs, trying to break your car window out, or attempting to choke you unconscious; fill out all additional paperwork as assigned if there is some emergency that occurs; stay on shift until you are relieved, even if your relief doesn't show up on time or at all; make sure that all of your additional trainings are up to date; make sure to make the agency look good if the case managers or licensure team come by the ISL; don't eat client food-bring your own groceries or snacks from home; and other duties as assigned. Staff people are supposed to do this for wages similar to what they would earn working in fast food restaurants or in retail stores. Positions with more authority and responsibility have lengthier lists of requirements and duties.

Given the complexities of the job expectations and the low wages, it is amazing that so many staff people, supervisors and other professionals do as good of a job as they do. While a great deal of the narratives deal with staff misconduct, it is important to remember that most workers in this field do the best job that they can most of the time. It is also important to note that just because staff people have a social control component of

their jobs, this is a necessary function for some clients who need this support. Just as parents are social control agents for young children, the high level of social control these parents have over their children is not inherently good or bad. Parents usually use this power to keep their children safe and teach them the skills they need to know to be more independent. Staff people usually do use this power over clients to keep them safe and help teach them as well.

I have a great deal of empathy for the staff, supervisors and other professionals who appear in the narratives in this research project. I respectfully request that readers try to empathize with the difficult positions that these caregivers find themselves in as we explore the complicated intersection of social control, narratives and people in these difficult circumstances.

People In The World of Residential Habilitation

The people who currently make up this social world are a diverse group with a wide variety of social roles, abilities, and labels. I have divided the people who make up this world into the clients who receive services, the caregivers who provide services, the professionals with roles in shaping this world, and the community members who participate on the periphery of this social world.

Clients in ISLs & Group Homes

The broad category of disability is widespread, with a variety of definitions and ramifications. Nearly 57 million people in the United States (over 20% of the population, or 1 in 5 people) had some sort of disability in 2010, according to the United States Census Bureau. “The Americans with Disabilities Act (ADA) defines an individual with a disability as: A person who has a physical or mental impairment that substantially limits

one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment." 38 million people in America were estimated to have a severe disability in 2010. (DisabilityJustice.org) "A disability can be physical, intellectual or cognitive, emotional or psychiatric. Disabilities can range dramatically in severity and how they affect each individual's independence. Disabilities can be visible or obvious (e.g., blindness, a speech or communication challenge, cerebral palsy, Down Syndrome, or mobility-related). They also can be invisible (e.g., autism spectrum disorder, hearing loss, developmental disability, mental health or psychiatric disorder, or traumatic brain injury). (DisabilityJustice.org) The context of claiming disability is often quite significant, of course. In my experience, people who have some sort of disability are more likely to highlight the level of impairment in situations in which it would provide them a benefit (such as when gaining access to funding, medical care or treatment related to the disability, etc.) but minimize their level of impairment when it may serve as a detriment socially (such as when applying for a job, meeting potential romantic partners, or in situations when being marked as disabled could be embarrassing or socially isolating.)

Developmental disabilities are a subset of the disabilities of people in the United States. "Over 6 million individuals in the United States have developmental disabilities. The Developmental Disabilities Assistance and Bill of Rights Act defines a developmental disability as a severe, chronic disability of an individual that— is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in 3 or more of the following

areas of major life activity: Self-care, receptive and expressive language. Learning, mobility, self-direction, capacity for independent living, economic self-sufficiency; reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described [above] if the individual, without services and supports, has a high probability of meeting those criteria later in life." (DisabilityJustice.org). The comorbidity of multiple diagnoses for individuals with disabilities is a significant portion of the population of clients in residential placements. Combinations of multiple diagnoses can make categorization of individuals quite complicated and subjective. Individuals I have worked with have been labeled with some of the following impairment inducing diagnoses: genetic disorder diagnoses (such as Down Syndrome, Cerebral Palsy), intellectual disability diagnoses, traumatic brain injuries (TBIs), mental illness diagnoses (such as Depression, Conduct Disorders, PICA), sensory impairments (blindness, deafness), physical impairments (limiting mobility and movement, bowel control), Autism Spectrum Disorders (ASD), ADHD, sexual conduct disorders and many others. Most of the individuals I have worked with have had some combination of at least two of the diagnoses listed above, with several collecting a significant list of diagnoses, particularly of the psychiatric/mental illness variety.

The definition of what is now referred to as Intellectual Disability or Developmental Disability has evolved and been a complicated process. The American

Association on Intellectual and Developmental Disabilities [AAIDD] was formerly the American Association on Mental Retardation (AAMR) until it was renamed in 2007 (Levinson 2010: 33). AAIDD provides the following definition of Intellectual Disability: “Definition of Intellectual Disability: *Intellectual disability* is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 22. Intellectual Functioning: *Intellectual functioning*—also called intelligence—refers to general mental capacity, such as learning, reasoning, problem solving, and so on. One way to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning. Adaptive Behavior: *Adaptive behavior* is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives. Conceptual skills—language and literacy; money, time, and number concepts; and self-direction. Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized. Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone. Standardized tests can also determine limitations in adaptive behavior. Age of Onset This condition is one of several developmental disabilities—that is, there is evidence of the disability during the developmental period, which is defined as before the age of 22. Additional Considerations But in defining and assessing intellectual disability, the AAIDD stresses that additional factors must be taken into account, such as the community environment typical of the individual’s peers and culture. Professionals

should also consider linguistic diversity and cultural differences in the way people communicate, move, and behave. Finally, assessments must also assume that limitations in individuals often coexist with strengths, and that a person's level of life functioning will improve if appropriate personalized supports are provided over a sustained period. Only on the basis of such many-sided evaluations can professionals determine whether an individual has intellectual disability and tailor individualized support plans." ("Criteria for Intellectual Disability" American Association on Intellectual and Developmental Disabilities). Such detailed specifics of intellectual disability are only going to be useful to professionals and bureaucrats who determine who qualifies for specific legal protections and state funding due to disability, and who does not qualify for this legal protection or funding. The amount of state funded support can be quite significant. Qualified individuals with disabilities (as determined by bureaucrats) gain access to monthly financial support through the Social Security program for living costs, typically between $700-850.00 per month for each client. This is relatively insignificant when compared to the costs picked up by the state and federally funded Medicaid program, which spent an average of $539.00 per person, per day (or $196,735.00 per year) in the United States to provide care in state institutions. This per person, per day cost can be dramatically reduced in community residential placements, with daily budgets for care between $130/day-$400/day being more typical in my experience in working with these budgets.

The individuals who receive habilitation services include a wide variety of people who are generally referred to as intellectually disabled (ID), developmentally disabled (DD), or sometimes as ID/DD. This distinction can be very important, as individuals with

no intellectual impairment but with significant visual impairment (i.e. legal blindness) can qualify for services if they had the visual impairment before adulthood, for example. In 2009, according to the National Council on Disability, roughly 470,000 people with developmental disabilities received residential services in paid settings, while roughly 600,00 people with developmental disabilities lived with family members and received some DD services. Roughly 123,000 people who qualified for services were “waitlisted”, qualifying for services but not approved for funding or (less frequently) unable to find a service provider. (“Institutions: Definitions, Populations, and Trends” National Council on Disability).

Well over 1.2 million individuals in the United States access state and government services due to their disability. (Larson et al 2020: 28) The residential living arrangements among the IDD population generally live in four residential arrangements: with family members; in community living arrangements like ISLs and Group Homes; in nursing homes; and in state run institutions. Individuals with IDD without residential support from either their families or the government (almost exclusively through Medicaid programs) are not reflected in the numbers here, and they may be living independently with unpaid “natural” or “organic” supports. They may also be in the penal system, homeless, or in wealthy families able to provide needed supports without Medicaid supports. It should also be noted that the funds that support the living costs (typically referred to as “Room and Board costs”) are typically paid by Supplemental Security Income (SSI). The monthly maximum amount for 2021 is $794 per person per month. A married couple’s maximum monthly amount is $1,191 per month, making the practical cost of a couple who get married quite significant. (Social Security

Administration website) SSI funds would go to either the individual with disabilities or their guardian or family member if they live at home to use as they see fit. Most if not all of this money is typically paid to the residential provider in order to cover "Room and Board" costs, including food, rent, utilities, household supplies, etc. Any money not paid to a residential provider typically builds up in a Non-Allocated Funds (NAFs) account, which can accumulate and be used to pay for any bills or items the individual might want or need. A set amount (typically $30.00) is set aside out of the SIS money each month as an allowance for the individual, which they are entitled to every month to spend as they see fit, at least in theory.

Medicaid is the funding source used to pay contracted providers or state operated facilities to provide care for individuals. Different Medicaid waivers exist, though most individuals who are supported residentially by paid staff have a Comprehensive Medicaid Waiver. The Missouri Department of Mental Health website characterizes this waiver service. "The Comprehensive Waiver began in July 1, 1989. This is the only waiver that provides residential services: Group Home, Shared Living and Individualized Supported Living services. This waiver does not have an individual cap on the amount of service an individual may receive annually through the waiver. The participant must meet Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/ID) institutional level of care and must be at risk of needing ICF/ID institutional services if waiver services are not provided. In addition, there must be a determination that the individual's needs cannot be met in the Community Support Waiver. The Division serves over 8,000 people through the Comprehensive Waiver. The approximate average cost for persons in the Comprehensive waiver is under $80,000 annually. Although this waiver

can provide residential support services when they are necessary for a participant, not every participant accesses residential services. Some live with their families or on their own and receive support services." (Missouri Department of Mental Health website)

The Medicaid website defines HCBS as follows: "Home and Community Based Services (HCBS) first became available in 1983 when Congress added section 1915(c) to the Social Security Act, giving States the option to receive a waiver of Medicaid rules governing institutional care. In 2005, HCBS became a formal Medicaid State plan option. Several States include HCBS services in their Medicaid State plans. Forty-seven states and DC are operating at least one 1915(c) waiver." (Medicaid Website. Accessed 3/26/2021. https://www.medicaid.gov/ medicaid/home-community-based-services/home-community-based-services-authorities/index.html) "Home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. These programs serve a variety of targeted populations groups, such as people with intellectual or developmental disabilities, physical disabilities, and/or mental illnesses." (Medicaid Website. Accessed 3/26/2021. https://www.medicaid.gov/medicaid/home-community-based-services/index.html) "In 2014, 53% of all Medicaid long term care spending was on home and community-based services. Other Services: $71.2 Billion. HCBS Services: $80.6 Billion." (Medicaid Website. Accessed 3/26/2021. https://www.medicaid.gov/medicaid/home-community-based-services/index.html)

Individuals who live with their families in Missouri can access a significant amount of support through the Developmental Disability (DD) Community Support Waiver in Missouri. "The DD Community Support Waiver is targeted to individuals who

have a place to live in the community and receive substantial unpaid support from family members. The eligibility criteria and services available through this program are identical to the DD Comprehensive waiver with the exception of community transition, group home, and individualized supported living and shared living. The Department of Mental Health, Division of Developmental Disabilities administers this program through an inter-agency agreement with the MO HealthNet Division." (DMH website. Accessed 3/26/2021. https://dss.mo.gov/mhd/waivers/1915c-home-and-community-waivers/community-support-waiver.htm) These individuals and their families are not able to access Medicaid funding for residential services, though they are able to access supports that can support these individuals in the home, such as behavior analysts, job training and assistance, and other services through this waiver.

Nursing homes play a limited role in providing care for individuals with developmental disabilities. "An estimated 25,576 people with IDD lived in nursing homes on June 30, 2017…" which is roughly 2% of the IDD population. (Larson et. al. 2020: 49) These facilities have skilled nursing personnel on site, which may be necessary to provide care for individuals with significant and complicated health care support needs. I have worked with clients who have spent some time in nursing homes convalescing after major surgery or injury, and some whose health care needs increase significantly as their health declines due to chronic illness (such as cancer). Some ISLs and Group Homes are able to provide relatively complex and significant health care supports, such as supporting clients who require breathing tubes, feeding tubes, dialysis, etc., though most ISLs and Group Homes do not maintain the level of trained staff with the expertise to safely provide this level of care. Nursing homes are considered by many

to be a more restrictive and institutional environment than HCBS environments, and the social world of nursing homes is a study in and of itself. (See Gubrium 1975, Schulhoff 2017)

The population of clients with IDD labels live in different types of settings. "In 2009, 469,123 people received services and supports while living in state or nonstate institutions, nursing facilities, small congregate residential settings, and even in their own homes. Another 599,152 received some services and supports while living with their families. Historically, many stakeholders thought of community-based care as small group homes with three to six people staffed full time by providers, or small ICFs [Intermediate Care Facilities], which are similar to small group homes but more highly structured. However, states have been expanding options with six or fewer residents to respond to individual needs and allow people to live in the most homelike setting possible. … in 2009, 138,302 people lived in HCBS waiver group homes, 40,967 lived in host and foster homes, and 122,088 lived in their own homes. The deinstitutionalization movement tends to focus on the 32,380 people in large state institutions. However, more than 100,000 people are in other restrictive settings, including smaller ICF/DDs [Intermediate Care Facilities/Developmentally Disabled] with 7–15 residents and other large institutions and nursing homes." (National Council on Disability. Accessed 2/13/2021. https://ncd.gov/publications/2012/Sept192012/Institutions)

Staff and Supervisors

Many people provide care for others who need assistance due to impairment. Many of these people work in hospitals, nursing homes, rehabilitation centers, ICF-DDs, ISLs, Group Homes, Host Homes, Shared Living arrangements, as outpatient/hospice

nurses or nurses' aides, etc. These caregivers often perform similar functions but are referred to by different titles, making it difficult to determine the precise number of workers directly providing service to IDD individuals residentially. National Core Indicators give the average hourly wages for direct care workers as $11.11 in 2017 (with a range of $9.10-$13.97 per hour); with only 10% of workers offered health insurance and a 44.8% turnover rate, compared to a national average turnover rate of 3.5%. (President's Committee for People with Intellectual Disabilities 2017:21) Not only do staff face low wages and meager benefits, but they also face physically challenging work with a high rate of injury, high accountability for their actions, isolation from other workers and supervisors, lack of a career ladder, and insufficient training and professional development. (President's Committee for People with Intellectual Disabilities 2017: 30) People working as entry-level care workers in ISLs and Group Homes are referred to as: staff, direct support professional (DSP), direct care staff, direct care professionals, counselors, direct support personnel, staff members, staff people, direct care specialists, Live-In staff, Main Relief staff, Lead Staff, etc. Despite the variance in titles on official paperwork, these entry level workers are almost universally referred to as "staff" by the people they serve, their peers, and their supervisors. "Direct Support Professionals (DSPs) support individuals with an intellectual disability (ID) who need assistance to live their lives and enjoy the same benefits as people without disabilities. They support people in ways that enhance inclusion and independence. More specifically, as defined in the Congressional Direct Support Professional Recognition Resolution in 2003 (S. Con. Res. 21/H. Con. Res. 94), DSPs are individuals who are employed to 'provide a wide range of supportive services to individuals with an ID on a

day-to-day basis, including habilitation, health needs, personal care and hygiene, employment, transportation, recreation, housekeeping and other home management-related supports, so that these individuals can live and work in their communities' and 'lead self-directed, community and social lives' (Congressional Record, November 4, 2003, p. H10301). DSPs work in a range of settings, including family homes, people's own homes, intermediate care facilities, small community residential group homes, community job sites, vocational and day training programs and others. They include full-time (70 percent) and part-time (30 percent) employees (Hewitt et al., 2015). Employers assign a wide range of job titles for Direct Support Professionals, such as direct support specialist, habilitation specialist, job coach, residential counselor, family care provider, personal assistant and others. The vast majority of DSPs work in the private sector for both for-profit and nonprofit companies. In some states, large numbers of DSPs work for state agencies that still deliver services directly to people with an ID. A small percentage of the DSP workforce is represented by organized labor…. Given the difficulty of using BLS [Bureau of Labor Statistics] data to specifically identify the direct support workforce that supports people with an ID, estimates are made based on the number of people who receive services and what is known about staffing ratios. Using average staffing ratios per person served as drawn from state-specific studies, it is possible to make reasonable estimates. As indicated in Table 1, it is estimated that in 2013 there were about 880,000 full-time equivalent (FTE) Direct Support Professional positions allocated to providing assistance to the 1.4 million individuals with ID/ DD receiving services under the auspices of state ID/DD program agencies. Given that 30 percent of the DSP workforce is part-time and estimating that 2.5 part-time workers are needed to fill one full-time

equivalency, there were an estimated 1,276,000 DSPs working to support individuals with ID/DD on June 30, 2013. The estimated 880,000 FTEs in 2013 reflect an increase of about 89,000 (11.3 percent) in the decade between 2003 and 20113. Importantly, because of shifts in how services and supports are typically provided to individuals with ID/DD, the ratio of DSPs to service users decreased from an estimated 0.564 to 0.496 over the decade. Simply to sustain services as they are, and given current turnover rates, every year 574,200 new DSPs need to take new jobs in the workforce. Notably, too, it would require an additional 167,001 new DSPs to meet the needs of the more than 200,000 individuals wait-listed for services. With projected growth in demand, worsening workforce issues and a strong U.S. economy, this number is expected to grow yearly between now and 2030." (President's Committee for People with Intellectual Disabilities. 2017: 13-4)

The following quote gives a glimpse into the life of a staff person. "I have been a DSP for almost 14 years. This is a day in my life as a Direct Support Professional. I start my day at 7 a.m. The person I support is incontinent and I assist him to clean his bedding and start his laundry. Then I have to process his food because he can't eat solid food. When eating, he has to be watched at all times so he won't choke on his food and aspirate. If staff are not trained on how to support him, he could aspirate and get pneumonia and die. After he eats, I prompt him to brush his teeth. I administer his medications. Afterwards, he cleans the bathroom. Then I transport him to his daily activities in the community. He goes to the gym for a one-hour workout. Then I take him for lunch and coffee. At the restaurant, I have to process his food and thicken his drink to honey consistency so he won't aspirate and choke. I guide him through stores; he is also

blind. I have supported him for almost 14 years to adapt to his environment and to be as independent as possible. We head home and make dinner and again process food and thicken his drinks. I watch him eat so he won't choke or aspirate. After, I assist him with completing breathing exercises to help prevent aspiration pneumonia I prompt him to brush his teeth and get ready for bed. I administer his medications. When he goes to bed at 8 p.m., his day is done but mine is not. I still have to document what I have done to support him throughout the day. I have to coordinate with doctors and make sure all his consents are up-to-date and that his record is complete so that we comply with all licensing standards. I do this all for $10 per hour. My nephew works at Wal-Mart and makes $11 an hour, just to be a cashier. This does not make sense to me. Right now, I am working in two homes, traveling 50 miles a day because we don't have enough staff to cover the support hours needed for everyone. I get pulled from home to home because all of our staff are leaving for other jobs that pay more. I am worried that the person I support will end up with inexperienced staff that do not know his protocols and will give him solid food, not realizing that he could aspirate and possibly die. The staff shortage is real. In the last few months I have had to work more and see less of my family to provide the support needed. I feel if there was an increase in pay, we would be able to keep staff and provide better support for everyone we support in the state of Maine. —Randall Howard,DSP" (President's Committee for People with Intellectual Disabilities. 2017: 15) Randall's story is not unique, or even uncommon in my experience.

Supervisors in this field are almost exclusively former staff members with some combination of experience providing care as a staff person and some level of higher education, though that varies from organization to organization. Not only do supervisors

hire, train, and supervise staff, but they often fill in and work as direct care staff themselves. The extraordinarily high turnover rate of staff makes a supervisor's job particularly difficult, as they have a limited pool of potential candidates to recruit replacements from and face competition for potential staff from other entry level positions with much less responsibility, required training, potential for physical injury and less stringent background checks. A supervisor shares some of her concerns; "I support many DSPs in a supervisory role. I am regularly informed of the financial burdens they carry. Many are trying to manage a family, home and safe transportation with their very low-level wages. Many have student loans and/or medical challenges of their own they are trying to balance. Nobody does this work as a means of getting rich. These are individuals that truly care about people and want to give back in a meaningful way. More often than not people are being faced with the difficult decision of having to choose a better-paying position versus one that they have a heart for. Because they have to consider their families and their livelihood, they must move on, and this contributes dramatically to our current workforce shortage. —Michelle Paige-Buttoli" (President's Committee for People with Intellectual Disabilities. 2017:25)

Case Managers & Bureaucrats

State and local governments typically provide oversight for the care of individuals receiving services for IDD. Case managers, also referred to as Service Coordinators, perform a variety of functions for the individuals on their caseloads. "While definitions are often not precise or consistent from one setting to another, CM [case management] is often thought of as the process of assisting an individual secure and monitor the services they need, while SC [service coordination] tends to be more broadly defined as a process

of building a comprehensive system of supports that suit the needs of a person with ID/DD and their family (as applicable)…. Broadly, CM has two key features: (a) providing a point of connection between an individual with ID/DD and the publicly funded service system and (b) monitoring services to assure that they are of adequate quality and leading to attainment of important life outcomes (Cooper 2006). Though exact definitions of the roles and responsibilities subsumed under the CM service differ slightly based on state statutes, the Centers for Medicare and Medicaid Services (Centers for Medicare and Medicaid Services, 2008) identified four allowable categories of activity that qualify as targeted case management, the mechanism most often used by states to provide CM to people with ID/DD (Cooper, 2006a): (a) assessment, (b) development of a care plan, (c) referral to services, and (d) monitoring of services, all of which are meant to be done in a collaborative fashion between the case manager and the person receiving services and/or their representative." (Bogenschutz et al 2019: 501-2) Most case managers are employed by the state or county, though some companies do contract with governments to provide case management services. The position typically requires a bachelor's degree, and typically pays between $25,000-60,000 per year based on the location, experience, and other factors. There have been significant difficulties in recruiting and retention of case managers, due to a limited applicant pool and salary being viewed as low compared to qualifications and demands of the job. (Bogenschutz et. al. 2019)

Medical and "Psy" Personnel

Medical doctors, psychologists, psychiatrists, and supporting medical personnel like nurses can have a significant impact on the lives of clients labeled with intellectual

and developmental disabilities and those who support them. The act of diagnosing an individual with some diagnoses like Autism Spectrum Disorder, Conduct Disorder, or Major Depression may significantly impact that person's life. This impact could be positive, in that many clients with certain diagnoses are able to access funding that gives them additional supports that they may benefit from, protection under specific legislation (i.e. 504 Plan protections for students with disabilities). Negative aspects of diagnoses can come in the form of labeling, medications can be used to "deal with" behavior that is a reaction to oppressive conditions and become a form of chemical restraint. I have worked with male clients who have been prescribed medication (Depo Prevara) to suppress all sexual urges to treat their "hypersexuality", for example. While medical professionals have a powerful place in society at large, the impacts of "Physician's Orders" among individuals with paid staffing supports can go from suggestions from the doctors that can be ignored to enforced orders which are not deviated from by staff, who have a great deal of control over the lives of many people in residential placement. An example of a case I consulted on for a young woman diagnosed with IDD and with Prader–Willi syndrome (which causes never satiated hunger) had all of her food locked up by staff, and her doctor had written an order for a 1,000 calorie per day diet. She was at a healthy weight and had been for years; she had this 1,000 calorie per day limit strictly imposed by her staff and reinforced by locks on all food in her home. Medical professionals are even more empowered in habilitation facilities (also called Intermediate Care Facilities for the Developmentally Disabled, or ICF/DD) and of course in psychiatric hospitals and nursing home environments.

Therapists

Behavior Analysts, Occupational Therapists, Speech/Language Pathologists, Special Education teachers and other medical adjacent professionals may also exert a significant impact on the lives of individuals labelled as IDD and their caregivers. Many of these professionals specialize in working with the IDD population and their caregivers and have specialized knowledge that they often give to dramatically impact the supports provided to clients. Many of these professionals can provide specific training to caregivers and clients to modify their behavior significantly, often with remarkable positive benefits to the clients by increasing their skill sets and providing them with tools to get what they want and need through appropriate behavior. As a behavior analyst, I certainly attempt to use my skills to improve the lives of my clients by helping to reducing their use of aggression and the frequency and intensity of their self-injurious behavior. Patrick McGreevy argues that, "The Essential Eight are skills which are absolutely essential for a happy, fulfilling and productive life as a child or an adult." (McGreevy et al 2014: 2-4) These eight skills are: Making Request; Waiting; Accepting Removals, Making Transitions, Sharing and Taking Turns; Completing 10 consecutive, Brief, Previously Acquired Tasks; Accepting "No"; Following Directions Related to Health and Safety; Completing Daily Living Skills Related to Health and Safety; Tolerating Unpleasant Situations Related to Health and Safety. (McGreevy et al 2014: 2-4) Tools provided by many of these disciplines can be quite powerful, and quite invasive, and great care must be taken to make sure that they are applied in ways that are ethical and balance quality of life with skill acquisition, particularly in cases where the client is not their own legal guardian and/or may not be able to fully understand all of the

implications of treatment. While these individuals typically see clients a limited number of hours there are exceptions, such as early intervention specialists who work with children with autism spectrum disorder diagnoses who often work directly with young children between 20-40 hours per week. The outsized significance of many of these professionals comes with the powerful behavioral technologies they empower caregivers with, who can then use these tools to change the behavior of the client, ideally in positive ways. Implications regarding what behavior is appropriate, who determines this, and what the cost may be to the client are dealt with in detail in another section.

Family Homes

For many individuals diagnosed with intellectual and developmental disabilities and their families, the individual being cared for by family members in the family home is the best possible setting. Approximately 767,000 people, or 60% of individuals getting long term care supports from state funded sources in 2017, were living with family members (Larson et al 2020: 28.) With SSI money assisting with housing costs and many funded supports like special education programs in schools, various supplemental paid supports funded by Medicaid and day placements (like community integration programs, sheltered workshop employment, job coaching and placement) many families are able to provide the necessary level of care to their loved one in the home. Many families are able to support this arrangement indefinitely, or at least until the aging parents or siblings (the typical caregivers) are no longer able to provide this support. The difference in how demanding the support needs of the individual play a role, as do numerous factors such as marital status of parents, socio-economic status, number and needs of other dependents, and physical demands of providing care. This may be an especially significant factor for

those who need a great deal of physical assistance due to paralysis or other physical impairment, as well as those who engage in physical aggression. The family members that are able to provide this care can make sure that their loved one is cared for as they want them to be, and in this way they can be certain that strangers are not mistreating their family member. This may or may not be the best care available for the person getting this care, and most individuals with significant impairments get no say in whether they care they get care provided by family members or by paid staff. A study of a family providing care for a “severely retarded child” details how the family attributed much more competence to the child than anyone else could see, calling in to question the ability of these family members to meet the actual needs of the child. (Pollner and McDonald-Wikler 1985) Of course, having a family member with significant care needs can be a constant burden, and many family caregivers I have worked with have suffered not only significant physical injury in caring for their children with significant needs, but also report suffering from social isolation and “burn out” from the constant demands placed on them. Unfortunately, severe cases of neglect and abuse are a common feature in many client’s records, and many of these traumatic events were attributed to family members. There is no oversight in the care that families provide for free, making abuse and neglect of these vulnerable individuals very hard to prevent, detect or prosecute. Family caregivers were reported to have engaged in physical abuse, sexual abuse, physical restraint with chains or ropes, lack of access to nutritious food or prescribed medication and lack of appropriate supervision for safety with people I have worked with personally. A small group of individuals with significant disabilities are able to successfully live on

their own, either completely independently or with minimal assistance and no day-to-day care being provided by others.

Residential Habilitation in ISLs and Group Homes

Community living arrangements with paid staff members are typically either Group Homes, Individualized Supported Living arrangements (or ISLs), or some sort of shared living arrangement. All three categories are financially supported by a Medicaid Waiver, typically a Comprehensive waiver. Group Homes and ISLs operate essentially in the same way, though Group Homes provide residential support for four or more clients living in the same residence, while ISLs support one to four clients in the same home (typically two or three). There are some minor differences in the technical supports provided (with differences in individualized plans of care for ISL residents, for example), but they are essentially interchangeable placements with paid staff people and supervisors. A group home in New York City was described as follows: “Counselors at times portrayed Driggs House as a buzzing and chaotic place: demanding but exhilarating, thankless but satisfying. Especially when they understand their unpredictable, even failure-prone, work as clinical work, it can be enjoyed for the discretion and knowledgeable judgment it involves.” (Levinson 2010: 95) ISLs are ideally characterized by the following official characteristics: “Individuals with developmental disabilities have a right to make responsible decisions consistent with the choices afforded citizens without disabilities. These decisions include, within attainable means, living in homes and neighborhoods of their choice with persons of their choosing. These settings and lifestyles afford people the opportunity to pursue their own interests, express their individuality, and actively participate in their communities. To exercise

these rights, individuals with developmental disabilities may need uniquely individualized assistance. ISL Providers shall maintain compliance with 42 CFR 441.301. Individualized Supported Living is characterized by creativity, flexibility, responsiveness, and diversity as reflected by the following: People live and receive needed supports in the household of their choice which might include their family home, an apartment, condominium, or house in settings typical of people without disabilities. The selected housing should represent an adequate standard of living common to other citizens, allowing for reasonable protection and safety. Personal preferences and desires are respected. Personal autonomy and independence are promoted. Individuals receiving services lead the planning, operation, and evaluation of services. Self-determination is maximized through natural and paid supports. Supports are focused on assisting the individual in experiencing a full productive life as defined by the individual. Services are provided based on individual needs. Individuals are encouraged and supported to actively participate in civic activities and community organizations to become as involved as they choose in the fabric of the community. Service goals are directed toward participation in the life of one's own community." (Individualized Supported Living Manual Revised April 6, 2018 http//www.dmh.gov)

The management of risk is often a significant part of the care of individuals in ISLs and Group Homes. "For intellectual disability, which is not an illness, what constitutes treatment is not determined simply by the diagnostic classification. In their everyday work, professionals do not administer treatment so much as administer the techniques for assessing and monitoring risk. The ongoing cultivation of capacities that enable residents to govern themselves is about the shaping of conduct in ways that,

ideally, allow individuals to manage and reduce the risks they pose for themselves" (Levinson 2010:213-4). Case managers, supervisors, and family members may come through to visit clients and observe the residential supports being provided on a routine basis, but what is being presented is not always reflective of the day-to-day support of clients. When visitors come to visit, "…the pressure to please funding agencies, parents, and other consumers may compel direct care staff and teachers to 'put on a show' when visitors arrive. This is often done with little sensitivity to the clients' preferences at the time" (Bannerman et al 1990:81).

Institutions

What an institution is, or is not, is contested by many who provide care for and advocate for clients labeled as IDD. "The definition of 'institution' continues to evolve. This paper focuses on a traditional definition of an institution as a large, usually state-run, hospital-style setting, often located in a rural area. However, according to federal regulations, ICF/DDs, which include smaller community-based facilities with populations of 6–16, are also defined as institutions….These definitions focus on the number of people who live in the same house, but advocates have developed a definition that focuses on quality of life and control issues. In 2011, a coalition of self-advocates defined institutions based on their own priorities in Keeping the Promise – Self-Advocates Defining the Meaning of Community.[i] They defined institutions as places that: include only people with disabilities; include more than three people who have not chosen to live together; do not permit residents to lock the door to their bedroom or bathroom; enforce regimented meal and sleep times; limit visitors, including who may visit and when they may do so; restrict when a resident may enter or exit the home; restrict an individual's

religious practices or beliefs; limit the ability of a resident to select or remove support staff; restrict residents' sexual preferences or activity; require residents to change housing if they wish to make changes in the personnel who provide their support or the nature of the support; restrict access to the telephone or Internet; restrict access to broader community life and activities." (National Council on Disabilities website. Accessed 4/2/2021. https://ncd.gov/publications/2012/Sept192012/Institutions)

Habilitation Centers and State-Run Institutions

The large state-run facilities that have become infamous among critics and disability advocates still exist. They are called Habilitation Centers, and many individuals live a significant portion of their lives on their campuses. As of early 2021, there are eight state-run habilitation centers in the state of Missouri (Missouri Department of Mental Health website. https://dmh.mo.gov/dev-disabilities/habilitation-centers), and there are estimated to be over 130,000 individuals living in large state-run institutions or other restrictive settings of 6 or more residents in the United States. (National Council on Disability. Accessed 2/13/2021. https://ncd.gov/publications/2012/Sept192012/Institutions). These settings are also referred to as ICF/IDD, short for Intermediate Care Facility for Intellectual and Developmental Disability. The individuals who reside in these placements are theoretically taught habilitation skills with the stated goal of being able to make living in a less restrictive environment "possible." As one researcher put it, "Habilitation involves teaching the skills needed to live as independently as possible." (Favell et al 1984) Of course, demonstrating that you have the skills to be able to safely live in the community while residing within a restrictive institution is problematic. (See Goffman 1961)

Psychiatric Hospitals and Asylums

Institutional settings include psychiatric wards in hospitals and state-run hospitals, more commonly referred to as asylums or "psych wards". These institutions can vary in restrictiveness quite a bit, with some designed to blend aspects of prison-like security systems with psychiatric dominated habilitation and treatment. Individuals who are deemed by guardians, courts, mental health professionals and/or bureaucrats to be unable to live in less restrictive environments, live in restricted housing such as Habilitation Centers. These environments generally have the hallmarks of institutions, and allegations of abuse, neglect and mistreatment are commonplace. Psychiatric hospitals or wards within larger hospitals can be used for short term medication/behavioral adjustment for many people diagnosed with IDD, but Habilitation Centers and other ICF/DD facilities are typically difficult for clients to transition out of once they are in, despite a long-term push for deinstitutionalizing care for clients with IDD.

Jail and Prison

While it is difficult to determine precise numbers of people with intellectual and developmental disabilities who are currently in jail or prison, the number is significant. According to the latest report by the Bureau of Justice Statistics (BJS), the National Crime Victimization Survey revealed that people with disabilities in the US experienced about 1.3 million violent victimizations in 2013 (Harrell, 2015). Rates of serious violent victimization—rape, sexual assault, robbery, or aggravated assault—were more than three times higher for those with disabilities than for those without. Among violent crime victims with disabilities, about a quarter believed they were targeted because of their disability, which was more than twice the rate reported in 2009. People with cognitive

limitations had the highest rate of violent victimization. When people with IDD are victimized, it is well-documented that there are lower rates of police follow-up, prosecution, and conviction of perpetrators than for victims without disabilities. "It is estimated that less than 4% of the US population has IDD, yet up to 10% of the prison and jail population have been identified as having such disabilities. People with IDD are more likely than their similarly situated non-disabled peers to be arrested, convicted, incarcerated, and serve longer sentences. In part this may be due to an increasing tendency of service providers to call in police to address disability-related behaviors that would ordinarily be addressed as a service issue rather than a crime." (AAIDD website. Accessed 4/3/2021. https://www.aaidd.org/docs/default-source/National-Goals/justice-and-people-with-idd.pdf?sfvrsn=683b7f21_0)

Historical Issues for the Disabled

The history of society's treatment of and labels for individuals who today would be considered clients with Intellectual and Developmental Disabilities (IDD) is a dark and inhumane record of mistreatment and abuse. The language referring to these people, as well as the ways in which these categories were constructed at different times is a clear example of an evolving, socially constructed category. The shifting categories and terms for this group of people and society's treatment of them are the general historical categories examined here. Institutional needs played a significant role in the social construction of incompetence for clients and potential clients, with simultaneous social constructions of productive labor (within the institution) and the need to protect society from the "incurable, dangerous people" within the walls of the institution (Carlson 2005:142).

Categories and Terms

The boundaries of who has an intellectual disability and what that actually means have long been contentious. "The institutions for the 'feebleminded,' the professional organization now known as the American Association on Mental Retardation (AAMR), and the existence of IQ tests were significant means by which to produce and gather knowledge about mental retardation. Yet from their inception through to the debates that continue today, this category has been a highly contested one. From the earliest attention given to 'idiocy' in the mid-nineteenth century to Binet's attempt to provide a solid, scientific basis upon which to detect feeblemindedness, there was never a conclusive definition of mental retardation." (Carlson 2005: 148) The discourse around intellectual disability has always crossed the boundaries of disciplines as well. "Mental retardation, as an object of knowledge, has never had a permanent residence in any one field; it has been, and continues to be, an object of medical, psychological, pedagogical, moral, humanitarian, and political discourse." (Carlson 2005: 148)

The official terminology for intellectual disability has seen significant changes. "The term or name for condition we know today as *intellectual disability* has changed over time; most recently the condition was primarily known as *mental retardation*. AAIDD is proud to have been a leader in the adoption of the term intellectual disability in the clinical, scholarly, public policy, and education arenas. Although the name has changed, for more than 50 years the three essential elements for all US-based definitions for this condition—limitations in intellectual functioning, behavioral limitations in adapting to environmental demands, and early age of onset—have not substantially changed. On this website are a number of historical documents that use the term mental

retardation. While the language of these documents need to be understood within their historical or legal contexts; the underlying concepts, arguments, findings, and recommendations are consistent with the vision and values of the Association." (AAIDD. Website. Accessed Feb. 13, 2021 https://www.aaidd.org/intellectual-disability/historical-context) "The history of terms used to refer to the recipients of social services originates in a narrow concept of rights and the effort to demedicalize disability, but it has become ever more encompassing. In the 1970s, 'client' was adopted (in place of 'patient') to express the informed and consensual nature of a professional service relationship. Although 'client' is still found in the regulations, in the 1990s OMRDD [Office of Mental Retardation and Developmental Disabilities] literature began using 'participant' to imply the importance of active involvement in services beyond mere informed consent. Soon after, 'consumer' became the favored term in policy and practice to express the ideal of the fully autonomous, choice-making individual…Residents almost always refer to themselves as clients, and staff use this term too. The only exception, for counselors, occurs during the rare visits from clinicians, auditors, or agency administrators, when, for a brief time, residents become consumers." (Levinson 2010:47)

A specific example from recent history clearly demonstrates some of the complicated issues involved with the contested nature of the way in which intellectual disability is socially constructed over time. "The focus on 'systems of supports' rather than 'services,' and on individual needs rather than stock interventions, is considered one of the innovations of the paradigm shift represented by the 1992 manual and developed further in the official definition issued in 2002. Now referring not to 'mental retardation' but to 'intellectual disability' (since the renaming of the American Association on

Intellectual and Developmental Disabilities [AAIDD], in 2007), the 2002 definition is considered current. It reflects the increasing elaboration and development of the issues established by the 1959 classification: the qualitative, context-bound, and individual character of the diagnostic process and of the diagnostic entity itself. This trend began accelerating in the late 1970s but can be illustrated just in the difference between the official definitions issued in 1992 and 2002. From 1992: Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18. (American Association of Mental Retardation 1992: 1) The 2002 definition incorporates, among other things, an emphasis on mental retardation as an interactional feature of individuals and environments: Mental retardation is a disability characterized by the significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18. A complete and accurate understanding of mental retardation involves realizing that mental retardation refers to a particular state of functioning that mental retardation refers to a particular state of functioning that begins in childhood, has many dimensions, and is affected positively by individualized supports. As a model of functioning, it includes the contexts and environment within which the person functions and interacts and requires a multidimensional and ecological approach that reflects the interaction with regards to independence, relationships, societal contributions, participation in school and

community, and personal well-being (American Association on Intellectual and Developmental Disabilities. 2002). (Levinson 2010: 33-4)

A comparative study of children in institutions and in schools argued that mental retardation was merely "a labeling process…a function of a social order.", stating that mental retardation was nothing more than a "crude metaphor" for that served the single purpose of justifying incarceration (Braginsky and Braginsky 1971:29). They continued their critique: "Given the category's few and unreliable biological features, …mental retardation was made 'objective' through the 'mythical power' of mental testing, which experts 'refuse to reject'" (Braginksy and Braginsky 1971:14).

Treatment of Intellectually Disabled People

The institutions that provided treatment and care for those considered intellectually disabled are filled with a history of horrible abuse and neglect for this vulnerable population. "Though idiocy was recognized as a condition before the nineteenth century, there were no institutions specifically for people who were defined as 'idiots.' In the first half of the nineteenth century, however, a process of differentiation took place in which idiocy was recognized as a distinct condition, worthy of separate consideration. The proliferation of these institutions for the 'feebleminded' gave rise to a new professional organization, and provided the opportunity for new forms of knowledge to emerge regarding idiocy and feeblemindedness….The birth of the institutions for the 'feebleminded' changed the scope and limits of what could be said about idiocy…In the early twentieth century, another equally significant method of gathering and organizing knowledge about feeblemindedness emerged: namely, mental testing….the advent of mental testing in the United States was simultaneous with a new 'type' of

feeblemindedness: the moron. The emergence of this new kind of individual had effects on the very definitions and practices associated with feeblemindedness. The significance of these two moments of discontinuity in the history of mental retardation—institutions and IQ testing—cannot be underestimated….The institution relied upon both static and dynamic depictions of feeblemindedness. In fact, a paradoxical relation between these two supposedly disparate kinds of mental retardation emerges, particularly when we look at the characterization of inmate labor. Outside of the institution, feeblemindedness is considered incurable, hopeless, and dangerous, a condition that requires the institution to protect both those who have it, and society at large. Within the wall of the institution, however, the same condition is seen as improvable, and disciplinary techniques are employed to make inmates productive….As the definitions of feeblemindedness shifted to reflect a close association with immorality, giving birth to more than one child outside of marriage became a 'sign' of feeblemindedness. This resulted in the incarceration of many 'feebleminded' women, who then served as caregivers for the 'low-grade' inmates in the institutions…. I have examined institutional discourse and practice in terms of a series of oppositions between the qualitative and quantitative and between the static and dynamic. Though these portrayals of mental retardation might initially appear contradictory, they actually operated simultaneously in the world of the institution. These conceptual pairs influenced the creation of categories, the nature of practices, and were continuously invoked by the superintendents who generated 'expert' knowledge about feeblemindedness. Yet, the institutional world did more than produce knowledge; it also produced a particular *kind* of human subject….to what extent did the structure of institutional life create their 'feeble minds,' rather than improve them? The institutions,

as protective and productive sites of disciplinary power, perpetuated the view of feeblemindedness as both a helplessly static fate and an improvable, dynamic condition. Both characterizations were indispensable to the survival of institutions and to the production of docile minds and docile bodies." (Carlson 2005: 137-44) Intelligence tests, specifically the "IQ test" as a determinant of mental disability posed significant problems in the treatment of people who were labelled as having inferior intellect. "The 1959 classifications on IQ scores were widely criticized by both professionals and popular groups. The stigma of being diagnosed with mental retardation seemed to have more impact on many than their intellectual functioning did. At that time, about 4 out of 5 people with a mental retardation diagnosis were borderline IQ (an IQ score of roughly 70-85) (Zetlin and Murtaugh 1990). Becker (1963[1973]) would refer to this as secondary deviance-the deviance based on the status of being labelled as deviant in the first place.

Efforts at Reform and Better Treatment for Clients

Despite a long and difficult history, advocates, allies and disability rights groups have fought for and won significant reforms that have improved the treatment and living conditions of most individuals with significant intellectual and developmental disabilities. There was a significant shift in legal protections for the disabled. A court case, Wyatt v. Stickney (1972), established the right for clients to live in the least restrictive environment necessary for individuals with disabilities. (Levinson 2010: 35) The Pennhurst State School v Halderman (1974) court decision established that confinement of the disabled is acceptable for rehabilitation or for treatment, but not for the purpose of custody. (Levinson 2010: 35) In other words, the disabled could no longer be treated as

another type of prisoner. The Americans with Disabilities Act (ADA) afforded protection against discrimination based on disability and required that reasonable accommodations be made for disabled employees while mandating accessibility to public accommodations. (Americans with Disabilities Act of 1990 (42 U.S.C. § 12101) "Though 'normalization' is a term no longer used, another early concept meant to individualize services remains central: 'continuum of care.' First advanced as a policy principle by President Kennedy's task force, it was integral to the legal strategy in *Wyatt v. Stickney*. This decision, finding a person's constitutional right to treatment in the 'least restrictive environment,' presumes the organization of services along a continuum, from the most restrictive (characterized by more intensive services) to the least restrictive (characterized by greater individual autonomy). Previously, only one form of service was on offer after a diagnosis: institutionalization. Now, the assessment of an individual's specific needs, in principle, determines where he or she is placed along the continuum of services" (Levinson 2010:42). Though current standards of care are arguably much improved over the universal institutionalization in the past, some disability advocates argue that the continuum of care concept just provides cover for the professional control of individuals with IDD posing as individualized supports, because the concept of "least restrictive environment" has never been clearly defined (Taylor 2001:19-21). "Two women living in a state hospital in the State of Georgia wanted to live in the community. They believed their lives would be better in the community and the treatment team agreed. They took their case all the way to the United States Supreme Court and the Supreme Court agreed. In June 1999 the Supreme Court issued its decision which has become known as the Olmstead decision. The Olmstead decision was primarily based on the non-

discrimination mandate under Title II of the Americans with Disabilities Act (ADA). This includes a federal regulation that requires states to administer their programs, services and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." "Most integrated setting" is a setting in the community where people with disabilities can fully participate in all aspects of community life. The Olmstead decision pertains to any person, regardless of age, who has a disability covered under the Americans with Disabilities Act, such as mental illness, physical disability, developmental disability, and substance abuse. Basically, all states must make community living options available to people with disabilities when three conditions exist. 1) When "the state's treating professionals have determined that a community placement is appropriate" for the person, 2) when "the transfer from an institution to a more integrated setting is not opposed by the affected individual", and 3) when "the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other person with disabilities". In other words, Olmstead is about choice. The goal of implementing the Olmstead ruling is that "no one should have to live in an institution or a nursing home if they can live in the community with the right support." The Missouri Department of Mental Health supports consumer choice!" https://dmh.mo.gov/mental-illness/programs/olmstead

The shift in consensus that community-based supports led to better outcomes for IDD clients, coupled with the discovery that governments could save a great deal of money with community placements, led to a shift from most IDD clients living in institutions to most living in the community. This decarceration movement led to states emptying institutions for the intellectually disabled to save money. "In 1992, 77,600

people still lived in state institutions in America, a number that was nearly halved by 2004, to 41,214. At the same time, the number living in facilities with six or fewer residents increased from 128,129 in 1992 to 336, 073 in 2004 (Braddock et al.)" (Levinson 2010:36)

This shift from large scale institutions to community-based, small scale residential supports in the community has been hailed by many to be a significant improvement in the potential quality of life of IDD clients. Critics of how residential support is provided to IDD clients argue that many problems have followed the clients outside the walls of institutions. "Community services systems have been criticized in general as inattentive to individual needs, still effectively segregated, and burdened by complex regulatory and professional requirements, many of which were intended to correct and prevent a recurrence of the excesses of institutional practice (McKnight 1980; Wolfensberger 1989; Castellani 2005)" (Levinson 2010: 41). Rather than making things better by caring for IDD clients in residential placements in the community, "…supported living arrangements are not emancipation, but rather a new dispersal of power relations" (Drinkwater 2005: 229).

Chapter 3:
Framing Narratives

This chapter explores the ways in which framing narratives are used in the social world of ISLs (Individualized Supported Living homes) and Group Homes to influence the behavior of others. Narratives, particularly the "languages of the self", are the tools with which social actors make sense of their social reality (Gergen 1991: 5-6), and how they both shape their identities and are shaped by those very identities (Zerubavel 1997). Framing Narratives are attempts to define social situations in particular ways. One example of the impact of Framing Narratives on the lives of people with intellectual and developmental disabilities (IDD) is the role that narrative framing played in reducing almost universal institutionalization for them. The fundamental injustices of the widespread institutionalization of IDD clients was successfully challenged at least in part by critiques of the very category of "mental retardation" (Braginsky and Braginsky 1971; Mercer 1973). The social construction of important issues is bound up in accounts of those issues, diagnosis is dynamically linked to the active work of meaning making, and the dynamic interplay between what is perceived and what is written are all significant aspects of the social construction of reality of this social world (Garfinkel 1967: 71,79). Social control can be viewed as the power to influence the narrative of the definition of the situation that is "realized both in spirit and practice" (Conrad and Schneider 1980:8).

Understanding the ways in which the social construction of reality is shaped and challenged within the social world of residential living environments like ISLs and Group Homes is an important element of understanding how power and influence operate in this social milieu. "Power is a type of relation in which one person or group of people *acts*

upon the existing or possible future actions of another person or group of people" (Foucault 1982:220, emphasis in original). How the people who occupy this site define their roles and the very nature of the reality of what occurs within this setting has a significant impact on almost every aspect of life and work in this setting. Discursive resources enable speakers and writers to construct their experiences as meaningful (Chase 1995; Holstein and Gubrium 2000; Foley and Faircloth 2003).

Framing Narratives

Narratives are stories. They are accounts that help us make sense of the world around us and what is important in that world. Framing Narratives are stories that are told in order to define the situation, or to frame it, in a particular way. Social reality is constructed differently by different social actors in different social contexts (Berger and Luckmann 1966). Kenneth Gergen argues that shared language between individuals is a fundamental way in which people understand everyday life. A key aspect of social constructionism is how people use narratives "describe, explain or otherwise account for the world (including themselves) in which they live." (Gergen 1985:266). Defining a situation as a social problem, or not, can give the person able to shape the narrative power since "…social problems are what people think they are and if conditions are not defined as social problems by those involved, they are not problems to them, even while they may be problems to outsiders…" (Fuller and Myers 1971:320) Staff can use framing narratives to frame a situation, such as eating out too many times a week, as a problem, or they can argue that it is not a problem to eat out as much a s person can afford to, if that is what they want to do. The diversity of socially constructed views of a problem in two different contexts indicate that what is socially constructed in one setting may be

constructed differently in another setting, adding flexibility to our understanding of the rationalization of experience. (Gubrium 1992: 219) An example of how similar issues are constructed differently in different contexts is the different approach to household chores that staff take from home to home, with some staff pushing a very clean environment at all times while other staff refuse to lift a finger to assist staff in cleaning, because the clients "choose not to do chores." These Framing narratives are not always uncontested. "At close range, we find that both service providers and service users may be expert in how the dominance of pertinent discourses affect their work and lives, responding to that in common at times by organizing alternatives, blurring their differences. Some troubles may not be problematized." (Gubrium and Järvinen 2014:8).

The Framing Narratives that are often encountered in ISLs and Group Homes are staff attempts to define the situation in such a way that they can shape desired outcomes for clients. For example, when Brandy jokes with her client, Tausha, that she is "going to beat her to the bathroom" and her client responds with "Oh no you're not!", then laughs and rushes to use the restroom first, Brandy used a Framing Narrative, the "race" to the bathroom, so that she could get Tausha to use the restroom before going on an outing. Just asking the client to go the bathroom is less effective, as Tausha seems to enjoy getting into power struggles, and would likely refuse a request like, "Please go to the bathroom before we go" and end up having an accident in the vehicle or in the store, as she has in the past. By changing the dominant narrative from that of a power struggle between a staff person and a client to a narrative of a "bathroom race", the use of the Framing Narrative allows Brandy to shift the definition of the situation to get an oppositional client to comply with a reasonable request. As this example illustrates, the

use of Framing Narratives can be a powerful tool, which can be used to benefit all involved, as in the example with Brandy and Tausha. Powerful tools can be used to accomplish both very good and very bad things; the ability to use Framing Narratives to shape the dominant definition of reality in a particular social scene is a very powerful tool.

By influencing the dominant definition of the situation, social actors can exercise power over others. Social actors work in interactive and dynamic ways to socially construct reality. A significant event occurred in the social world of ISLs and Group Homes in 2017, and aspects of this narrative were present in most of the interviews I conducted due to the impact it had on this social world in the state of Missouri.

The Case of Carl DeBrodie

Carl DeBrodie* (real name) was an individual with a significant intellectual disability, a slight build, and very limited verbal communication skills who it was reported ran away from his ISL in Fulton, MO. His live-in staff person and the supervisor of his ISL, Sherry Paulo* (real name), called the case manager and the Fulton police department to report him missing. This occurred on the morning of April 17, 2017, the day that the ISL was transferring from one organization, Second Chance Homes* (real agency name), to a new residential provider. Some people suggested that he was scared of the change in staffing due to the change in agency ownership. When a quick search of the nearby area did not turn up any clues to his whereabouts, a more general search was called for and a large number of local volunteers assisted in the search. There was no sign of Carl, and people continued to search and local news agencies picked up the story.

Police began interviewing staff, supervisors, case managers, and the community nurse to get some clues as to what may have happened to Carl.

After an anonymous phone tip, investigators searched a storage locker in Fulton and found Carl's body in a container filled with concrete. Analysis of the body determined that the Carl's remains had been in concrete for several months, due to the level of decomposition. The nurse and the case manager had falsified documents and had not seen Carl in person for several months. Rumors swirled around the case, with general outrage directed at everyone involved. Some reports indicated that Carl and other consumers may have been forced to fight one another, and that Carl died of significant injuries sustained in the fighting and lack of medical treatment afterward. Staff people were alleged to keep his body in the bathtub for several days, then ultimately attempted to dispose of the body by putting it in concrete and hiding it in a storage locker. Several lawsuits followed, with the community nurse pleading guilty to falsifying medical forms on face-to-face meetings (and losing her nursing license). Carl's case manager was forced to resign. The Department of Mental Health settled a wrongful death lawsuit, and a former employee filed a worker's compensation claim against Second Chance Homes and the agency replacing them. The claim was that they were a witness in a murder investigation and that the staff person had to supervise a client who "had confessed to murder".

A website covering the case and its aftermath relates additional details. "5 Second Chance employees were indicted for several offenses relating to Carl's death. A nurse plead guilty to health care fraud. Others plead guilty for providing false reports and obstructing an investigation. The Missouri Coalition for Quality Care called for a review

of the Department of Mental Health and the State of Missouri was ordered to pay more than $1M to settle a federal lawsuit. Sherry Paulo and Anthony Flores entered guilty pleas in federal court for willfully failing to provide necessary medical care….Paulo faces a maximum of 17.5 years in prison and Flores faces just over 15 years." (Hoover 2020).

The Carl DeBrodie case is a tragic case in which a young person with significant disabilities was abused, neglected and ultimately lost his life. While the circumstances surrounding his life and death are not common, many of the issues surrounding the social control of both clients and staff apply not only to his case but to all cases. Many of the problems with Carl's case are problems commonly seen with the care of people with disabilities, though the differences are more of a matter of degree than being completely unheard of. Several staff and professionals discussed this case during our interview, and multiple narratives regarding Carl and many others who were involved were used by respondents, making it a grounded site for analysis of these narratives.

Snowy Creek ISL

Examining the ways in which narratives are deployed as tools to implement social control in one setting, Snowy Creek ISL[1], provides a grounded site for analysis. After a brief introduction to Snowy Creek ISL and the people who live and work there to establish a grounded site for analysis, we will examine the ways in which narratives are used as tools of social control over clients, staff members and professionals in ISLs and Group Homes.

Contested Narratives at Snowy Creek ISL

[1] All names of organizations, places, and individuals have been changed to protect privacy and maintain confidentiality except where specifically noted.

The differing narratives presented by three respondents who work at Snowy Creek ISL provides for an interesting site to ground the discussion of how narratives are used to attempt to exercise power over others in the social world of ISLs and Group Homes for adults with developmental disabilities. Snowy Creek ISL is a one-story home with a walkout basement located in a nice, middle-class neighborhood in a mid-sized city in the Midwest. The home is divided into two distinct areas, a downstairs apartment and an upstairs apartment. In the two-bedroom, downstairs apartment, Alan and Jason live in the ISL portion of the home, where they are supported by staff people and supervisors from ANGELS. ANGELS is a non-profit organization that provides a number of services to adults and children with developmental disabilities, including residential habilitation. The supervisor for Snowy Creek ISL is Joe, a bright and energetic man in his mid-thirties. The Live-In staff person, Sheila, lives in the upstairs apartment with her adult son Andre and two large dogs. Jay and Linda are two staff people who work shifts at Snowy Creek ISL, and who have been working there for over 30 years. They are very close to Sheila, as Jay is Sheila's ex-husband and Andre's father, while Linda is a close family friend. The full-time day shift is staffed by Lisa, a young woman who has less than a year of experience in the ISL, this being her first job. Snowy Creek ISL is atypical in a few ways. Sheila owns the home and rents it out to ANGELS and it is extraordinarily rare that so many staff have so many years of experience in the field, much less at one specific ISL. This may be due, at least in part, to the relative ease of providing care to Alan and Jason. Neither man has significant behavioral problems or personal care needs; Sheila referred to them as "really easy clients." Despite the relative ease of working with Alan and Jason, there are significant issues at Snowy Creek ISL. I interviewed Lisa, Sheila and

Joe, who all present very different narratives describing the situation and people at Snowy Creek ISL.

Lisa is a young white woman in her early 20s. She really likes her job, though she had only been working in this field for about 10 months or so at the time of the interview. Lisa describes Alan and Jason as “wonderful” guys who are a lot of fun to work with and whom she cares about a great deal. She told me that the other staff at Snowy Creek ISL are very close to one another, but that they do not like her. The other staff do a really bad job, in her view, and don’t do enough to support Alan and Jason the way they should. She claims that a lot of this stems from laziness; the staff will manipulate the guys into doing what benefits staff, rather than what Alan and Jason want to do. For example, while Alan likes to stay at home and cook, the other staff will often talk him into agreeing to go out to a restaurant to eat, which makes their shift considerably easier, since they do not have to help Alan cook or clean up the kitchen if he agrees to eat out. The ISL supervisor, Joe, has had to intervene over the issue of Sheila and Andre’s large dogs being in the back yard when Lisa tries to enter or exit the walk-out basement, where the ISL is located. She has actually been bitten by one of these dogs twice, though not seriously enough to draw blood; this prompted Joe to write up a written agreement between Sheila, her son Andre and Lisa on when the dogs should be let out into the back yard and when Lisa should be notified, to prevent further incidents. Lisa and Andre have had arguments over text regarding the dogs in the back yard; Lisa said that Andre and Sheila don’t care if the dogs hurt her, and she thinks that Andre was upset about her bossing him around regarding the dogs. In addition to being an outsider compared to the other staff, Lisa indicated that since, “…the other staff people are close; they won’t rat each other out. Any reports will

obviously be from [me]…they don't like me. They are family. I will tell on them. They leave notes for me to do things and I won't do it…If I quit, they would just treat someone else like shit." While Lisa does not directly work alongside any of the other staff, she believes Alan and Jason when they tell her about questionable behavior on the part of the other staff. Lisa believes Alan when he told her that Jay called Alan and Jason fat, but she doubted that Jay was foolish enough to record it in the daily notes. She also told me that a staff person threw away a client's cheetah slap bracelet, because it was too "girly", even though the client really liked it a lot. She reported Jay for using client funds to buy soda to take to a friend's birthday party after work, as well as for replacing a new can of Pam cooking spray with an empty one from the upstairs apartment the day after Lisa had purchased it for the guys with their money for groceries and supplies. Lisa reports that "he just lied" and never got in trouble for essentially stealing from the clients.

Sheila tells quite different stories about Snowy Creek ISL and the people who live and work there. A white woman in her fifties, she is an animated storyteller who seems to enjoy sharing juicy gossip. Examples of gossip she shared with me in our interview include who has been caught watching pornographic videos on agency computers and where Principals who get caught having affairs with counselors in the school gym get sent by the local school board. She agrees that Alan and Jason are great, and that they are easy clients to work with, which has helped her avoid burn out as a long-term staff person. Sheila has been working two full time jobs for years, since being demoted from an administrative position at ANGELS several years ago. Sheila notes that Jason's guardian has sided with her in disputes with the supervisor, Joe in the past and indicated that if Sheila left ANGELS, that Jason's guardian would likely change agencies so that

Jason could stay with Sheila. When Andre's girlfriend applied to work at Snowy Creek ISL part time, Joe refused to hire her, saying it is not "best practice" to hire family members to work with clients; Sheila was openly scornful of this idea. Sheila has been reprimanded by Joe for not getting her daily documentation completed in a timely manner, or as she phrases it, the "…supervisor wants to yell at me and write me up for being a few days late on notes." Sheila admits to being lax in writing her daily notes for her shifts, but challenges aspects of this, arguing that staff have several days to complete daily documentation according to the contract between ANGELS and the state Department of Mental Health. She argues that the person who should be in charge of what happens in ISLs should be the person who knows the most about the situation. "Do you think that is a staff person of thirty-plus years, or a 19-year-old who has been working for 9 months?" Sheila thinks that Lisa has not been adequately trained in how to properly support Alan and Jason, and that she is resistant to being taught how to do the job by more seasoned staff. Sheila notes that she gets irritated when supervisors hire staff and place them in "her house" without consulting with her:

> That's what I'm interested in. Not having brand new people coming into my house, first of all, that I don't know! [Sheila chuckles] Like, I didn't even get to *meet* her and she is already working downstairs and acting like that, you know? And she is very passive-aggressive. She is like 19-years-old and she thinks she knows everything….Well, the supervisor has basically told her that she doesn't need to listen to us, because we aren't her bosses. And we are not, but…I emailed Sondra [a manager at ANGELS] and I am like, "Me, Jay and Linda are in our fifties. We have kids her age. Do you think we are really gonna gang up on some little 19-year-old girl and try to make her feel like shit? Do you really think we would do that? That would be like somebody yelling at our own kid. We wouldn't want that. But we are just trying to show her, if she wants to work here, this is how- the best way to do it….So the old supervisor left and Joe had to come in and work a shift one time. So she left him a note explaining what all to do. The 19-year-old, who has only been there a few months. She writes, 'Jason can get up and take a bath on his own.' Ugh! Since when!? [Sheila laughs] So I kind of like put a sticky note and say, 'Well, not really.' If you let him go in there on his own, he

> will go in there and rub his thighs for about 10 minutes and then get out. So you have to kind of stand there and, you don't have to go hand over hand, he can physically do it, but you have to stand there and say, 'Jason, get your armpit. Jason, get your shoulder.' You know, tell him what to do. But nobody told her that! So now why does he have body odor? Because nobody trained her on how to help Jason take his bath!

Sheila also seemed incredulous that Lisa didn't know that when a case manager is coming over for a visit, that you need to put your best foot forward and help the guys pick up the apartment and get dressed for the day rather than "letting" them greet her in their pajamas. The presence of a case manager in the ISL changes the ISL living space from a backstage setting to a frontstage one, a social space more open to scrutiny and critique (Goffman 1959). Sheila has suggested a house meeting to air differences and help Lisa get some training so that she could be on board with the other staff, but the supervisor seemed concerned that Sheila and the other staff would gang up on Lisa. When Sheila complained that Lisa was leaving passive-aggressive messages on sticky notes for the other staff members, a supervisor at ANGELS suggested that she take pictures of the notes and send them to the supervisor. Sheila refused, saying, "I'm not going to sit her and tattle on some 19-year-old kid! I am not going to tell on her to my boss; I'm a grown-ass woman! I am older than all of y'all. [Sheila laughs] …If I have an issue with her, I will talk with her about it. But I know she is just going to come running to you all!" One reaction to Lisa's insistence that Alan and Jason are adults who can eat whatever they want, including frequent trips to Starbucks, was to convince Alan's doctor that he needs to have his caffeine intake restricted to one coffee per day, due to a heart condition. Sheila also convinced Alan's physician to refer him to a dietician to "read him the riot act." Alan also hates getting his blood sugar checked, "finger sticks, so any time

he gets out there a little bit, I am like, ‘Hey, remember what the dietician said!’” Though this seems to be a clearly threatening and somewhat coercive statement, Sheila did not seem to see anything problematic about it. Sheila avoids driving agency vehicles, which have an online reporting system that reports drivers to supervisors whenever they exceed the speed limit too much, brake too hard, or engage in other risky driving behavior. She tells agency supervisors that it hurts her back to get in and out of the small agency vehicles, but she indicated that at least part of the reason she drove her own SUV instead was to avoid the digital reports on her driving. “I think over 100 MPH would be too much. But I’m just saying, 75, 80, 85 you know…on a straight stretch where you are going with the flow.” Sheila says that when it comes to supervision on the job, people should do what their supervisors tell them to do. She said her motto is, “Just do your damn job! Just do what’s asked of you!” She also noted that since she is a busy person with two full-time jobs, working at both the ISL and at a local high school, that “if people are on me more, I do better.” Sheila was discussing a person who had been reprimanded at her other job, and said, “When you get in trouble, you put your tail between your legs and go sit down somewhere!” These statements about how an employee was supposed to behave in the workplace were delivered sincerely, without a hint of sarcasm and without any indication that Sheila was aware that she does not behave as if any of these rules she is freely applying to the behavior of others should be apply to her by her.

Joe tells a different, more nuanced narrative of Snowy Creek ISL and the social actors there. He took over supervision of Snowy Creek ISL after Lisa was hired by the previous supervisor and Joe had been the supervisor for that ISL for over 6 months at the time of the interview. He feels that there are problems with some of the staff there; that

the experienced Snowy Creek staff manipulate clients for staff benefit, but he is impressed that combined that they have so many decades of experience between them. Joe noted that while he really enjoys visiting with Jay, who is very personable, that as a staff person Jay will do the bare minimum and then go home. "Survival level, you know?" He says that there is "Nothing, and I say *nothing*, will get Sheila to do anything…I can tell her when I bring up coaching or whatever, she is like, 'I have been through all of this before.' So I am like, 'Well. This thing I need to do, and it can happen at any time, to term [terminate her employment at ANGELS]. But I know that at the same time I have a lot of respect. To work at the same place for 30 years, there has to be something there. You know?" In previous situations Joe has fired employees he viewed as substandard and worked additional hours (at no additional pay, since he is a salaried employee), until he was able to get staff hired and trained to relieve him. And while he is willing to take this step if needed, he is concerned that significant change in the staffing, particularly of Sheila, Jay and Lisa, could be detrimental to Alan and Jason's care, since they have been providing care to them for so long. He wants to make sure that if there is a change in staffing that it benefits the clients at Snowy Creek ISL. Joe did note that when he relieved some staff and the rest quit at an ISL, he personally worked 157 hours in one week; but that he didn't have time to properly document during those shifts! After two to three weeks, when he got some relief staff, he started completing required documentation of shifts again. That time period was later audited by "The State", and the agency was forced to repay a significant amount of money due to Joe's failure to properly document those shifts. Joe says that he felt awful about it. While he has worked with incompetent staff people, supervisors and managers both when he was a DSP and as a supervisor, Joe

is committed to helping staff improve their performance. His main approach to changing staff performance is by making them feel valued and respected, by noting mistakes that they might make, but feigning surprise that they would make such a mistake, "…because they are such a great staff person." His overall goal is to help establish a good team in a house, so that it is no longer just about the money, but it is about doing a good job for the clients and helping your team out. He says that "a history of place" can develop, so that if something weird happens, it will be reported but not condoned, because there is "a certain way" things are supposed to be done in that place.

These narratives all focus on the same social scene, Snowy Creek ISL. The wide disparity between the narratives results from the different viewpoints and goals of the different narrators. This highlights some important aspects of this research project. The narratives are not, necessarily, "true", in the sense that different narratives are not being independently verified for accuracy. Some important insights may be discernable by noting instances in interviews of "Narrative Slippage", when people apply recognizable storylines to their experiences in ways that do not exactly match the "real" story (Holstein and Gubrium 2000:110). Attempting to discern the "Truth" underlying these narratives is beyond the scope of this research. Whether these narrators are technically accurate in their interpretation of social phenomena is in one sense irrelevant. The consequences of their definitions of reality, of their social constructions of the social events, are certainly real in their consequences, whether or not the stories are technically "true" (Thomas [1928] 2003: 81). As these three very different presentations of what goes on at Snowy Creek ISL indicate, there are numerous ways to use narratives to define a situation and make meaning of it. Lisa presented a narrative of being picked on but doing what is

ethical and right for “her guys.” Sheila shared a narrative of being exasperated by people who don’t know what they are doing and wanting (other) people to just be better employees who do what they are supposed to do. Joe’s narrative of balancing perceived shortcomings among staff at Snowy Creek with respecting the long-term relationships between staff and clients in order to try to support the best outcomes for the clients shows yet another perspective. Returning to the narratives presented by those working at Snowy Creek ISL throughout this project will provide a grounded example of how narratives can be as tools of social control, to exert power over the actions of clients, staff people, supervisors and other professionals in this social world.

Framing Narratives Used to Control Clients

Controlling the behavior of clients, the adult residents of ISLs and Group Homes for adults with intellectual and developmental disabilities, is one of the defining aspects of working in these social settings. The monitoring and control of the bodies of clients with IDD in residential placements takes up a great deal of time and effort of the staff in these settings and often include unlimited and unquestioned staff input and interference in issues involving personal hygiene, grooming, diet and sexual behavior (Drinkwater 2005:235-6). The lines of authority within an ISL or Group Home are clear. Clarissa, an agency administrator, noted: “Because I always tell my staff there is no power struggle ever between you and a client. Any more than there is a power struggle between me and a staff member. For there to be a power struggle, we have to be talking about equal levels of power. You have the power. You don’t have to exert that with a client! What is wrong with you?” Framing Narratives related to the control, or attempted control, of clients are commonplace. “Social control: the control of deviance and the promotion of conformity.

The means by which society secures adherence to social norms; specifically how it minimizes, eliminates, or normalizes deviant behavior" (Conrad & Schneider 1980 [1992]:7) These Framing Narratives demonstrate how agents of social control in these settings use narratives to impose their interpretation of reality as dominant, thereby exercising power over clients in this setting in a variety of ways.

Narrative Framing of Physical Restraint of Clients

Physical force is used in a variety of ways to overpower clients in ISLs and Group Homes. "Power is a type of relation in which one person or group of people *acts upon the existing or possible future actions of another person or group of people*." (Foucault 1982: 220, emphasis in original). The exercise of power over others is quite overt when physical force is used. There are numerous narratives detailing this exercise of power over clients. One of the clearest examples of this is the use of physical restraint, of staff members physically overpowering clients in ISLs or Group Homes. Narratives about this process usually use industry jargon such as "putting clients in a CPI (Crisis Prevention and Intervention®) Hold" for this physical domination, or euphemisms such as "physically managing the client for their safety and ours" if the approved CPI or MANDT physical restraint is not used. This careful use of language is often designed to make the procedure sound technical and professional when most physical restraints are violent and traumatic for clients and staff. These narratives often depict situations so dangerous to clients and others that physically restraining clients may be the best way to minimize harm to all involved. Examples of these very dangerous situations include Lewis' story about staff intervening to prevent the likely rape of an unsuspecting client by another client, or when Brandy's client scratched bloody gouges in her face when he

had pinned on the floor of an Emergency Room bathroom. In both of these stories, client and staff injuries occurred, but the physical restraint of the client was presented in each case as necessary to prevent even more significant harm to the individuals involved. These physical interventions may also be used by staff for as trivial a reason as attempting to stop an "unauthorized" midnight snack, like when Luke was a new staff person and he physically blocked access to the fridge while the large client he was working with tried to shoulder block him out of the way. This sort of physical blocking is typically frowned upon in most ISL and Group Home settings, which is probably why Luke went on to detail the steps he took not to have to do that again.

Staff people are officially restricted from using specific types of physical restraint techniques on clients. These restrictions typically include letting go of a client once they are on the ground and only using physical restraint techniques that are officially approved and theoretically less likely to result in harm to clients. These restrictions seem to generally be designed to prevent harm to clients, and to attempt to prevent serious injury and death during the physical restraint of clients. Unfortunately, many of the prohibited techniques for physical restraint, such as prone four-point restraint on the floor, in which a client is held down by their wrists and ankles by four staff people, is a much more effective restraint than approved holds, particularly if the client is large and strong. This leaves staff and their supervisors with the choice of either implementing an unauthorized restraint technique, NOT restraining the client in crisis, or calling for police intervention. When she first started in the field, Clarissa worked with a large, violent client who would often improvise stabbing weapons to attack staff. She said the sanctioned physical control procedures (CPI) were inadequate, but they had to do something to keep themselves and

the client safe, so they broke the rules and used whatever sort of physical restraint method they needed to in the moment, then covered it up or minimized details regarding it in the incident documentation. She said, “This guy is like 250, 260 pounds! If I am working with two other women, what are we supposed to do, put him in a basket hold?! It just wouldn’t work!” While staff members in community settings have restrictions on what means they can use to achieve this physical domination of a client, police officers, psychiatric institution staff, and family members do not have any such restrictions. This means that staff people are often put in positions of either breaking the rules, and risking the repercussions if someone is harmed, trying to intervene without physical restraint (like using de-escalation techniques, as needed psychotropic medication, etc.) or calling for the police to use the physical force the staff are not officially allowed to use.

Police use of force on clients does occur. Clients and caregivers may call for police intervention in a wide array of circumstances, from instances of significant client self-harm, significant property destruction and physical assaults on staff to something as trivial as a borrowed roll of toilet paper that wasn’t returned quickly enough. Police interactions are particularly dangerous situations for clients, who are accustomed to staff people attempting to use the minimum amount of force necessary to minimize harm to all involved. Police officers are legally authorized to use one level of force above that used by the person they are attempting to gain control over, and may respond to client behavior with significantly higher levels of force than a staff person would. For example, when a police officer is confronted with a punch, they are authorized to use a higher level of force, such as a tazer, OC pepper spray, or a baton to “gain control of the subject.” Staff in institutions have access to chemical restraints, such as injectable medication to

sedate combative patients as well as mechanical restraints (straps on beds restricting movement, padded or locked rooms, etc.) that community staff members do not have access to. If physical restraint of a client is against agency policy, it follows logically that staff and supervisors will go to greater lengths to prevent situations in which physical restraint is required than in settings where physical restraint of clients is routine. Jessica explains it this way, “We are a no restraint agency. I don’t want to restrain anybody…and I don’t want to be that agency…I know it is necessary sometimes. So, I get that. But I think that it should be a last resort. And I think that a lot of times when you do allow it, it’s not a last resort…It becomes a go-to response. And I think you can avoid that.” Staff in agencies that do not authorize physical restraint are still trained in it’s use; this allows for staff people or supervisors to use their discretion to intervene to physically restrain a client if they are willing to violate the agency policy. When I was a staff person working with 3 adult men with IDD many years ago, a tornado was on the ground and heading toward the ISL. One of the three clients refused to go downstairs to safety; I was put in the position of either physically overpowering the client or leaving him to risk serious injury or death if the tornado hit the house. I was able to convince him to go to safety, but I would have violated agency policy in order to keep him safe if that had been my only choice.

Narrative Framing of Physical Setting as Client Control Tool

The physical setting within an ISL or Group Home may be used as a means to control the behavior of clients. Erving Goffman referred to settings like institutions and group homes as, “…forcing houses for changing persons” (Goffman 1961: 12). There are a number of significant differences between the conditions that Goffman wrote about in a

large psychiatric hospital in Maryland over 60 years ago and modern ISLs and Group Homes, but a close look shows that there are still significant similarities between Goffman's Asylum and today's ISLs and Group Homes. Some scholars argue that community placements exercise more power and control over IDD clients than institutions due to the insidious nature of the application of modern power, in effect turning clients into their own monitors (Drinkwater 2005, Tremain 2001, Tremain 2002, Tremain 2005).The monitoring and control of the bodies of clients with IDD in residential placement takes up a great deal of time and effort of staff in these settings and often include unlimited and unquestioned staff input and interference in issues involving personal hygiene, grooming, diet and sexual behavior (Drinkwater 2005:235-6). This ever-present observation coupled with social control elements is reminiscent of Jeremy Bentham's Panopticon. The Panopticon was a prison designed so that prisoners are under potential surveillance of the guards but can never know when they are being observed and when they are not. This system exerts power over prisoners in an automatic, continuous application of self-monitoring and self-control, effectively trained the prisoner to function as their own guard (Foucault 1977:102-3; Drinkwater 2005:236-7). Lewis, who has worked extensively in both lock-down institutions and with community placements, describes how the line between institutional settings and community residential settings is blurred. "I think that the only difference [between institutions and ISLs or Group Homes] is that in most cases people are not actually locked up in their homes, but in some cases they are!...I think one of the biggest differences is actually the lack of training that most [staff] people have in the community…In the community, most agencies don't even have a physical crisis management policy, and they don't train staff

on it and so you have people engaging in honestly very similar types of behavior and staff don't have any training." The physical location of residential placements is another potential way to control client behavior. A local Group Home that often supports men who have been labeled as "sexual predators" is located in an isolated farmhouse many miles from any potential victims not living or working in the Group Home. This essentially blocks access to the broader community in order to prevent potential sexual victimization of community members. John had a dispute with a mother who moved her adult daughter from one residential placement to another when John refused to "make" her daughter break up with a boy she was dating; then new residential provider was willing to force the break-up. While conditions within most institutional settings are, according to Lewis, "universally deficient", conditions in community-based settings can also become problematic when severely understaffed. If there are insufficient staff to support the clients in a placement appropriately, there can be a significant drop-off in the level of services provided to clients during understaffed periods. "So nationally, there is currently a DSP [Direct Support Professional] turnover rate of roughly 50%....Some bigger agencies in [specific state] are having like thousands of hours over the course of a quarter that go unstaffed because they just don't have the bodies to fill shifts.", a bureaucrat noted in our interview. John shared an alarming example of what understaffed hours could look like for clients. Only two DSPs showed up to work in a large group home when six were scheduled to work with roughly 90 severely disabled clients, and they were barely able to keep them clean and fed during their shift. "And literally we took them all down to the dining room/social area and just laid them on mats from one wall to the other, with a privacy screen, and changed everybody. By the time you got to

the end of the aisle, you had to go back to the other end and start all over because everybody was incontinent. That is how we spent our eight-hour shift, just going down the line. There was no quality of care. There was no choice for individuals." When a client wanted to move in with another client, Jessica had to fight to get case managers to "allow" them to live together because they were both gay men. The client who tried to initiate the move ended up losing his guardianship. Jessica noted, "He gave up on fighting that fight. Because they took any control away from him. And I just felt like that was so…wrong. And how crippling to him. To take that power away. Because he wants to live with somebody else who happens to be gay and he is gay. When it could just be that you have that common interest…You know, that common life experience." When Don moved a new client into an apartment in a small town, the client started dating the "meth head" neighbor and started hanging out with her, doing illegal drugs and staying at her place most of the time. Don and his staff "couldn't get him out of there." Police told him they couldn't intervene if he wasn't causing any trouble. Don ended up giving notice on the client and he passed his care over to another agency; Don said he just couldn't handle the potential liability to his agency.

Alan and Jason at Snowy Creek have locks on the food in their home, purchased with their own money, as a method to control overnight snacking that "the team" determined was unsafe, justifying rights restrictions. Sheila also shared a story where a live-in staff person she knows became "so sleep deprived" that they tied a client to their bed to prevent them from wandering outside on the overnight shift they worked. This resulted in a substantiated charge of abuse for the staff person and the loss of their job. Joe recounted a time when he worked 157 hours in one week after a group of staff at his

ISL were fired and the others quit at the same time, and he didn't even have time to complete basic documentation during that understaffed period. The lack of a "backstage" (Goffman 1959) free from the gaze of staff and other team members makes contesting staff narratives difficult for IDD client in an ISL or Group Home, just as it does for other groups at a significant power disadvantage.

Social Control of Clients Using Documentation as Framing Narratives

Staff and professionals in this field use documentation as framing narratives to control the current and likely future behavior of clients. A powerful method of control of the behavior of clients in this setting is that of documentary technologies. The social construction of important issues is bound up in accounts of those issue, and Garfinkel's documentary method of interpretation which describes the dynamic interplay between what is perceived and what is documented help demonstrate the important role of documentation in the social construction of reality (Garfinkel 1967:71) Daily Progress Notes, or the "Log" (Levinson 2010:103-105), is the basic format in which the staff document the marked behavior of the IDD client on a routine basis. The work for staff and clients in these environments is never done, yet the nature of the vague goals and perpetual nature of self-improvement make it so that the goal of independence is never fully reached, since progress toward the goal is what the system demands of clients (Levinson 2010:102-3). These daily logs are sometimes used as the "proof" that the client is "really" who the staff say they are. Clients (and staff) are "made up" in and through their ongoing work in the group home (Hacking 1986, Hacking 1999). The individual support plans (ISPs) for each IDD client in placement are another technology of control of client behavior. These narratives of client problem behavior are usually included in the

Individual Support Plan (ISP) are freely available for team members to review. While the narratives included in these documents often detail events which have little to do with the client's current behavior, by documenting and sharing the most dangerous or outrageous story involving the client, various parties can use this narrative as justification for rights restrictions, additional staffing, or other means of enhanced client control. Goffman noted the "Looping Effect" that occurs when a patient reacts to an environmental event (such as mandatory room inspections or rigid bedtimes or mealtimes) with anything other than acceptance of the rules; this "difficult" behavior then justifies the imposition of the rules and the patient's status of incompetence (Goffman 1961: 35). This process observed by Goffman in a hospital's psychiatric ward are replicated routinely in group homes and ISLs today. "Counselors [in the group home] sometimes focused on observable conduct to make accountable and confirm what they already knew about a resident's 'deeper' or 'inner' problems." (Levinson 2010: 148).

Documentation can be used as a framing narrative by various organizations to define what is going on with a complex person in a way that helps them accomplish the organization's goals. "Human service organizations cannot handle the whole person; they must simplify and standardize people before they can deal with them." (Järvinen 2014:50). Don is an ISL provider who accepted placement in his ISL of a client out of a lock-down institution, even though the official documentation appeared to describe a man who could pose a threat to others. His ISP detailed several dangerous encounters with staff and police, including one story that he tried to take a cop's gun and fire it, but "the gun didn't go off." While he looked "really bad" on paper, he was a "super nice client" and the residential ISL agency has had no problems with him for over seven years. Lewis

related how documentation is used in restrictive settings differentially; sexual perpetrators who target children were more likely to encounter higher standards of behavior that the staff deemed they needed to meet than their peers who were viewed as developmentally disabled adults who staff people felt had no business being in lockdown; the team would “creatively document how they were doing so well they needed to leave”, or present higher standards of conduct for people they thought put the community at risk. Clarissa related how a huge agency in another state with over 600 clients made all the residential clients go to one of the seven different day programs the agency had in town; there was no real choice for clients or their guardians regarding day placements. If an adult lived in that area and wanted residential supports, the clients would have to participate in one of the agency’s day programs, because it was really the only agency providing services in that part of that state. Lewis noted that clients often get minimal real say in what their official goals are in their written plans, and that rather than building meaningful outcomes that the client wants, our field more often pushes outcomes that are convenient or good for caregivers and case managers. The goals of ISPs are determined not by the client, but by their “team”, which is dominated by professionals, supervisors and staff. The client goals are never fully achieved, as the practical goal of the team is almost never to achieve true independence for most clients; perpetual progress toward a vaguely defined and ever retreating goal such as “being more independent” provides the justification for never-ending habilitation services and can be measured as “success” on the part of the staff and supervisors without ever achieving true independence (Levinson 2010:103, 187). Client preference may not be reflected in these goals, and these goals allow for the professional intervention in every aspect of a client’s life, making the most

unremarkable or unproblematic issues potential sites of intervention by staff (Bannerman et al 1990:79; Levinson 2010:192). Don noted that a client of his broke into a house and dressed in women's underwear, then ran down the street before he was apprehended; this story was still prominent in his documentation and current plan, but the event had happened over 30 years ago, and nothing remotely like it had happened since. So now, when Don sees significant problem behavior in a client's official records, he thinks, "Maybe that happened, maybe not." Likewise, when people are telling "really good" stories about a client, Don thinks, "Eh, maybe he is not *that* much of a saint…"

At Snowy Creek ISL, the Alan's behavior was controlled by documentation: a written physician's order limiting caffeine intake and a rights restriction on access to food in the home to prevent late-night binge eating enforced by physical locks on some food. Joe notes that client data success does not equal successful client life; that the official goals and outcomes in ISPs are largely irrelevant in helping clients live good lives. Never ending, yet never achieved progress is achieved in Group Homes and ISLs through the careful arrangement of measured behavior and the constant shifting of goals, effectively constructing the "progress" that caregivers need to demonstrate on paper (Levinson 2010:187). Technologies like written plan goals and the use of "psy" technology can shape the "conditions of personhood" (Hacking 1986: 225) in this social world.

Financial Control of Clients and Framing Narratives

There were several framing narratives where control of client behavior was attempted through control of their finances. One of Brandy's clients would go through all of her EBT (or "food stamp") money for groceries for the month in a few days and "blow" most of it on junk food. Her guardian declared, "No more junk food with the EBT

card." Since her staff have the EBT card and keep her from accessing it, they would just refuse to use her EBT card to buy junk food when she tried, even though that money was hers. So this client would spend all of her $30.00 per month allowance in one day on eating out every meal and the rest on candy, because she was "allowed" to spend her personal monthly allowance any way she wanted, but not her grocery money." One story of financial control being exerted over a client involved child support…owed to a staff person. Clarissa said, "I mean, we had a client who impregnated a staff person there [at agency in other state]. And the poor guy ended up having to pay child support out of his social security check!" While the story did not include many details about the consequences for the staff person who seems to have engaged in sexual abuse of a client in her care, forcing an individual with developmental disabilities to pay child support out of the benefits which are supposed to pay for his living expenses seems to be unfair at best, continued abuse at worst.

At Snowy Creek ISL, both Alan and Jason make enough money from their jobs that they can go out to eat routinely, which Lisa and Joe accuse some staff of taking advantage of so that they don't have to work as hard to cook and clean up meals at the ISL. Joe tries to get Jonathan, a client who struggles with weight gain at another ISL he supervises, to go someplace expensive instead of a buffet, like CiCi's Pizza, so that his limited funds will reduce the portion sizes Jonathan is able to eat. By essentially having the amount of food restricted by the limited funds Jonathan has, Joe is able to indirectly influence how much he eats without having to convince Jonathan directly that his eighth plate of pizza is an unwise choice for a man who is trying to lose weight.

Informal Social Pressure of Clients as Framing Narrative

Framing Narratives in ISLs and Group Homes are often implemented through informal social processes, such as asking for favors or people trading off of their social relationship with clients to assist in getting their definition of the situation accepted. For example, when a staff person wants to take clients to their church with them, staff people are not supposed to force them to attend the staff person's church, because clients have rights protecting the exercise of religious freedom. But they can convince the clients that they can have snacks at the meeting in the church basement after the service, convincing the clients to go to church when they would probably rather not go. Social control is often exercised in this social world through the informal use of social power. The application of power to control behavior and narratives and social control can be consciously applied or be reproductions of societal privilege (Brekhus 2020:168). Complex relationships between staff and clients are not always as adversarial as found in a psychiatric hospital (Goffman 1961; Goffman 1969) or in prisons (Sykes et al 1960; Foucault 1977; Ugelvik 2013). Staff discourage client behavior that they deem to be inappropriate, defined loosely as complying with the staff person's idea of proper conduct (Levinson 2010:5). Brandy was irritated with a staff person who pressured the clients who lived with her to attend church with her on her shift on Sundays. "Neither of those ladies has ever gone to church ever since they don't live with her anymore. So obviously it wasn't *their* choice. They were just doing what she wanted to make her happy. You get a lot of that, that the individuals do what they think will make the staff happy. Just to make things more copacetic and get along. You have to really watch out for that." A similar pattern was documented by a scholar in Denmark. In a government funded residential care facility

there a researcher found an interesting social paradox. The staff expressed an ideal narrative of careful listening to the needs of clients, but the clients who were most successful in navigating this setting effectively listened to and empathized with *staff* needs. Staff were minimally responsive to residents who they deemed to be unnecessarily demanding or who refused to acknowledge the informal power staff had in this setting (Kofod 2013). An informal exchange appears to have developed, where the nursing home residents were rewarded by staff with assistance and better support in exchange for consideration from the residents who respected the other demands on staff time and effort and did not make staff jobs more difficult than necessary (Kofod 2013). IDD clients in the United States are also responsive to the pressure from staff and supervisors to act in certain ways, to gain approval from staff. A significant portion of the control over the behavior of IDD clients by staff is accomplished informally. Clients are induced to engage in behavior valued by their staff and in exchange will be given a valued social role (Drinkwater 2005: 235). When a nursing home resident needed help to make a phone call at Murray Manor and he kept trying to get staff to assist him for over an hour, he was "making trouble" for the staff, rather than the staff refusing to assist in a reasonable request (Gubrium 1975:46). A female client in an apartment program with limited staffing support had a number of sexual encounters with different men. The supervisor for this apartment program said, "One individual, she is very promiscuous. She has gotten a lot better. She is her own guardian. They set up a meeting with her team, including her mom and dad and, …they are big influences on her and it seemed to work. I have had no reports of any kind of suspicious activity during the night. And she was one who had an alarm on her door that was turned on after 10 o'clock." This young woman with

developmental disabilities appears to have modified her behavior to avoid having to discuss her sexual partners with her parents in a formal meeting; it is not fully clear whether she is no longer engaging in sexual interactions, or if she is just better at keeping them secret from her assigned staff so that she does not have to discuss her sex life with her parents. Charles told me a story about a ISL staff who would intentionally invade the space that a client was trying to have sex in to disrupt his consensual sexual encounters, which his guardian did not approve of. This client began responding to these invasions of his privacy by exposing himself to staff when they followed him out in public to do this. This tactic was effective in driving them away but led the staff to start calling him a "deviant" and a "felon." Others in this field shared stories about getting positive behavioral responses from clients by demonstrating that they care about them. Clarissa says, "I tell people all the time, I don't care what a person's IQ is, they understand love. Everybody understands love, caring. People know when people care about them." Charles was particularly upset when he did an evaluation of a teenage client whose staff person used, "…her sexuality to get what she wanted out of the client, in terms of behavior." The client only wanted to interact with his attractive young staff person and was becoming increasingly frustrated with anyone who was not her; this prevented other staff people from being able to assist this client, through no fault of their own. Caregivers sometimes attempt to control client through bribery and other informal and/or inappropriate tactics. Staff are often encouraged to use a technique called the Premack Principle to encourage clients to complete less preferred tasks to gain access to something that is more preferred. An example is asking that a client complete a hygiene task such as showering before going bowling. This can become problematic when the reinforcement is

not accessible by other staff people, or is not appropriate for some reason While this behavior was not reported to be happening at Snowy Creek ISL, Joe had encountered this problem when he worked with a client at another agency where many of the staff people were bribing the client to complete hygiene and chores; when Joe arrived, the client would be irritated and refuse to do these basic things, because Joe didn't bribe him with cigarettes.

Narrative Framing of Client "Behaviors"

The narrative framing of client actions as "behaviors" are an almost ubiquitous justification of the imposition of social control measures over clients. Just as perceived social problems don't exist for a society unless it is recognized to exist by that society (Blumer 1971: 301, Blumer 1986), whether a particular behavior is treated as problematic or not is determined by the people involved (Fuller and Myers 1971:320; Holstein 2013:192). The ways in which specific behavior or patterns of behavior are designated as important or significant (or socially "marked") can have significant impact on the lives of those involved (McWhorter 2005, Holstein 2013, Emerson and Messinger 1972, Buckholdt and Gubrium 1979). The "looping effect" Goffman describes in Asylums (Goffman 1961) in which anything other than acceptance of the rules is marked by staff as "difficult" behavior that justifies those very rules and the incompetent status of patients, is routinely replicated in ISLs and Group Homes between the clients and staff in those settings. Many of the identifying behavioral features of people living in institutions for IDD clients have since been attributed not to individual characteristics, but to the specific contingencies in those institutional environments (Levinson 2010:31). These people may engage in behavior similar to that of unmarked peers (see Zerubavel 2018)

yet be treated quite differently due to their status as clients in placement. Clients are induced to engage in behavior valued by their staff and in exchange will be given a valued social role (Drinkwater 2005: 235). Staff discourage client behavior that they deem to be inappropriate, defined loosely as complying with the staff person's idea of proper conduct (Levinson 2010: 5). While client choice and rights are often discussed, client compliance with staff expectations and valued roles take precedence; non-compliance is often seen as a threat to the services being provided and overcoming this resistance is a major part of the work of staff members and other service providers (Drinkwater 2005: 240-1).

A number of respondents told stories about client "behaviors", often justifying the imposition of control measures over the clients as a justified response to these "behaviors." Staff and supervisors often operate within a narrative stressing values like safety and skill building, but the only time that power is discussed in this context is when *clients* attempt to exert influence over staff (Drinkwater 2005: 234). John defined "Behaviors" in the terms used by most people working in this field: "A behavior is a negative action. It's a problem. It's an issue. It's something that you are doing that is bad or wrong. And not just DSPs, people in our line of work in general…Everybody, we all go in and refer to it…Well, house X is a behavior house. It's not just the individual, the whole damn house is behaviors." Issues that could have been considered "troubles" for other social actors are treated as "deviance" or "problems" by caregivers (Emerson and Messinger 1977). Lewis recounts the story of a client who lost his ability to transition out of an institution and into a community placement because he had sex with a staff member; she was fired and his behavior was labeled as "inappropriate behavior." Staff

and supervisors often operate within a narrative stressing values like safety and skill building, but the only time that power is discussed in this context is when *clients* attempt to exert influence over staff (Drinkwater 2005:234). While many of the more routine "behaviors" in ISLs or Group Homes involve aggression toward others, property destruction, self-injurious behavior or attempts to run away, some clients will make false reports. Charles worked with a client who faked a heart attack, and when the EMTs arrived she began flirting with them, with all signs of cardiac distress appearing to melt away as the attractive EMTs walked through her front door and she began catcalling them. "Counselors [in the group home] sometimes focused on observable conduct to make accountable and confirm what they already knew about a resident's 'deeper' or 'inner' problems." (Levinson 2010:148).

The clients at Snowy Creek ISL don't really engage in "behaviors" as defined above, other than the occasional eating of odd foods at odd times before the team locked up most of the food. Sheila did talk about past experiences dealing with similar "behaviors", like the time that she was driving a van that was transporting all of the "behavior" clients from a day program back to the "Behavior ISLs" when a client sitting behind her pulled her hair while she was driving down the highway. She said that in all of her years of working with a variety of clients at multiple agencies, Sheila has had people attempt to physically harm her about ten times overall, with the most serious incident when she was bitten by a blind client who was mad at another staff person and bit her when she sat down next to her, meaning to bite the other staff person! Early in her career working in a Group Home, Sheila noted that many of the clients did not know anything about sexuality or how to appropriately relieve sexual tension. One client in particular

stood out, since "…he would just slam his junk in the drawers over and over…we just laughed…we didn't know any better!" The monitoring and control of the bodies of clients with IDD in residential placement takes up a great deal of time and effort of staff in these settings and often include unlimited and unquestioned staff input and interference in issues involving personal hygiene, grooming, diet and sexual behavior (Drinkwater 2005:235-6). One of the most serious "behaviors" was recounted by Joe, who was also assaulted by a client while driving. He pulled over on a bridge across a large river, and as soon as the vehicle stopped the client jumped out of the vehicle to attempt to run away and was almost immediately struck by a passing vehicle on the highway. The client survived but had to spend an entire month in the hospital recovering.

The almost universal use of the term "behavior" in this social setting is particularly interesting, as there is at least as much appropriate and desired behavior that clients engage in as there is inappropriate and undesired behavior, yet "behaviors" that are problems for staff and professionals are routinely socially marked as significant in this social world.

Safety as Narrative Control Framework

One of the most common narratives used to justify controlling the behavior of clients is keeping clients and others safe. Even in situations when an elderly person who does not have an IDD diagnosis, social workers can intervene over the objections of the elderly person in cases of "self-neglect", even if the elderly person rejects this narrative (Band-Winterstein et al 2013:125-132). The existence of an actionable issue worthy of outside intervention compared to a personal problem is socially constructed by different social actors in different, often contested, ways (Band-Winterstein et al 2013:133).

Exactly how "safe" a client needs to be, and what behavior is considered unsafe, and who gets to determine what level of safety is appropriate for the client is subjective. Clients are free to make some choices within structured, well-regulated ways, so long as they are making choices determined to be "appropriate" and "safe" as determined by staff and supervisors (Rose 1999: 72; Levinson 2010:39). Institutional needs played a significant historical role in the social construction of incompetence for clients and potential clients, with simultaneous social constructions of productive labor (within the institution) and the need to protect society from the incurable, dangerous people within the walls of the institution (Carlson 2005:142). John notes that almost anything can be labeled as a safety issue in ISLs or Group Homes. "It's *always* a safety issue! 'You can't sit by yourself with your girlfriend in the movie theater because your seizure condition might flair up. And we wouldn't be able to protect you.' Even though, sitting next to him isn't going to be more effective than sitting 12 seats over where you could see him but give them a little privacy." While many caregivers, advocates and clients discuss the importance of independence and the freedom of clients to largely do what they want to do, as long as they don't hurt themselves or others, the duty of caregivers to prevent clients from being harmed is routinely invoked to justify controlling client behavior. Clarissa notes, "Clients pretty much determine their day…. Unless they are doing something to put themselves in danger, of course. Or their roommate in danger… Then we want the staff to kind of…intervene, and then contact a supervisor." Intervention of the sort Clarissa alludes to may vary widely in the way that it is implemented. It may be gentle verbal coaching to help a client calm down, physical restraint of a client, or calling 911 to have the police physically gain control of the client or transport them to a local psychiatric ward. These

interventions would ideally be the least intrusive possible, but in practice, the choice of staff response in order to keep clients safe is determined by the caregivers on the scene and the occupational culture of the setting.

Liability for both staff people and agencies are another aspect of providing care that caregivers in these settings struggle with. There is a certain level of responsibility that they might have for something going wrong. John asks, “How can these people have natural lives when they live in an artificial world?...What is the consequence for me for allowing an individual to make a choice that harms him?” It should be noted that even while advocating for more client choice and autonomy, the power relationship between staff and clients is so embedded in the milieu that it appears to be hard for John to imagine NOT having the power to stop client choices. While clients nominally have the freedom to eat too many doughnuts and take a nap, they are typically pressured to make more appropriate choices as determined by what the staff people on duty decide is appropriate (Bannerman et. al. 1990:86). When asked if clients should be allowed to eat too many donuts or take a nap when they want, Clark responded as I would expect most caregivers in this field to respond. “Well, the donut part of that if they eat too much that could be a health issue. I’m not gonna say they don’t, they have the right to eat the donuts, but I think staff also has a right to…maybe monitor them so they don’t eat too much and get sick.” Staff and supervisors in this field continuously navigate a space between narratives supporting client choice and independence on one hand, and client safety and well-being on the other. Manipulation of the narrative of the situation at hand to present caregiver actions as reasonable and necessary, no matter what choice the caregiver made, is a skill most caregivers and supervisors learn quickly in this field. For

example, John had two clients that pushed these boundaries. One client John worked with LOVED to drink beer, and he was his own guardian, but he also took muscle relaxers. With advocacy assistance from caregivers, his doctor wrote a prescription for "Beer, PRN", or as needed, with the further instruction to staff that he should not take his routine muscle relaxer medication when he drank beer, to avoid side effects. Another client wanted to go fishing with his friends and did not want staff to tag along, even though he sometimes had unpredictable seizures that could pose a risk to him if he lost consciousness and fell in the water. Since he was his own guardian, he decided to check himself out of residential support to go fishing with friends, and the agency trained his friends in techniques to keep him safe in case he had a seizure. John noted that there is a certain dignity in being able to take a risk, saying, "We get so caught up in the safety, security and welfare [of clients] that sometimes we don't see that there are possibilities for choice, and control, and opportunity." This same client is also a cautionary tale, in that he decided to leave residential services altogether, and was found dead in his apartment one month later. John said it appears that he had a massive seizure, and it was unclear if he was taking his medication properly.

At Snowy Creek ISL, the food is locked up in their apartment to prevent "unsafe" food consumption, based on several narratives involving Alan eating "raw meat" and other possibly unsafe food items, and Alan is restricted to one coffee per day based on a physician's order Sheila requested a doctor to write. Joe is in support of restricting access to food if there is a physician's order or a right's restriction: "When food is locked up, its different. They took the rights away from you. But without those rights restrictions

[clients] can eat what they want. Staff can try to redirect, to encourage…but they have a right to eat what they want."

Psychological Tactics of Control

The process of identifying and labeling some people as clients or as people with other specific diagnoses is itself a very powerful psychological technique, sometimes referred to as "clientization". The socially constructed categories of "disabled" or the unmarked "able-bodied" and other socially marked and unmarked categories are specific to the "thought communities" that share narrative norms, traditions, and conventions (Zerubavel 1997:6). Labeling individuals with specific diagnoses can be a significant part of the social marking process of clients in this milieu. This clinical "marking" (Brekhus 1998) had effects beyond the clinic or doctor's office. People with diagnosed conduct or behavior disorders are typically discursively marked by non-medical and non-professional groups and are often treated differently based on this non-conforming or deviant social label (Hardwood 2006:5). These sorts of claims are made particularly when clients resist the narratives that staff and supervisors attempt to enforce; the resistance itself can be viewed as "proof" that the intervention was justified. Symptoms of mental illness can be characterized interactionally as byproducts of situations in which individuals are unable or unwilling to accept the narratives others accord to them; persistent conflicts over the individual's treatment plan disrupt the social setting and are a significant source of conflict (Goffman 1969:192-193). This clientization phenomenon occurs when people have issues that are socially constructed into problems by the people in the "psy-industry" (Donzelot 1979, Rose 1998, Rose 1999). Diagnoses, particularly mental illness diagnoses, are widely critiqued (Hacking 1986, Rose 1985, Rose 1998,

Rose 1999) and are often formed from a collection of socially constructed behavioral stories from non-professionals that are largely “issues” rather than symptoms (Weinberg 2013). These people may engage in behavior similar to that of unmarked peers (Zerubavel 2018) yet be treated quite differently.

Narratives detailing the psychological tactics and techniques used to control clients are common among caregivers in this social setting. The presence of “psy knowledge” (Donzelot 1979, Rose 1985, Rose 1998) is one of the most ubiquitous elements of the technologies of control found in ISLs and Group Homes. The narratives of psychiatrists, psychologists, therapists and others permeates almost every aspect of habilitative support for IDD clients. There is an element of ethical authority of the expertise of psychologists and psychiatrists, a level of professional power which is generally deferred to within the world of ISLs and Group Homes (Levinson 2010: 48). A sort of “proto-professionalism” gets passed down to supervisors and staff in these environments, who routinely use the orders and recommendations by psychiatric medical professionals to bolster their own authority to implement the goals and interventions for IDD clients in their care (Levinson 2010:49-50). If clients are particularly resistant to other methods of social control, professionals schooled in clinical psychology, behavioral psychology or other related disciplines are brought in to implement more advanced tactics, which can vary significantly but often involve fairly invasive behavioral interventions rarely seen outside of clinics or institutions (Drinkwater 2005:233; Taylor 2001:19-21). These professional interventions are especially difficult for staff to resist, as the narrative supporting intervention is for the safety and well-being of the person who is the current or potential client. This ever-present observation coupled with social control

elements is reminiscent of the Panopticon, which exerts power over prisoners in an automatic, continuous application of self-monitoring and self-control, effectively training the prisoner to function as their own guard (Foucault 1977:102-3; Drinkwater 2005:236-7). Settings like institutions and group homes are, "…forcing houses for changing persons." (Goffman 1961:12). Some scholars argue that community placements exercise *more* power and control over IDD clients than institutions due to the insidious nature of the application of modern power, in effect turning clients into their own monitors (Drinkwater 2005, Tremain 2001, Tremain 2002, Tremain 2005).

When I asked Don, "Do clients have the right to eat too many donuts and take a nap when they want?" Don: "Yes, they do. With this caveat. It is our responsibility to *adjust the environment and to adjust their thought process so that they do not want to do that*. So what I mean by that is, the clients have the right to eat all the donuts in the house. That doesn't mean we should buy 3 boxes of donuts. We should buy 2 donuts, and they can eat all the donuts in the house (emphasis added)." Using humor and personal charm is a common way to get clients to agree with caregiver requests. Brandy says, "And [using humor] is so much more effective than trying to force them to do your will. It doesn't work. And like I said, the good staff kind of innately seem to know that. And the bad staff, that you have to beat it into their heads, they are never going to do well. It either comes naturally or… I mean, I never worked with disabled people before this job. But it's like it came naturally to me. And I love working with the people who have severe behaviors. Because I like to manipulate their environment to get them not to do those things, you know?" Another example is when Luke was able to reframe the social interaction with Zane, a client who was attempting to use physical force to "elope", or

leave his apartment whether Luke wanted him to or not. Luke was sitting a couch to block the front door; Zane moved the couch while he was sitting on it! Luke didn't fight or show alarm or try to physically block the door (which may have escalated the situation to a direct physical confrontation.) He sat down on the couch and put his head down. Zane sat down next to him and asked, "Luke? Luke, are you okay?" "That guy never opened the door. He stopped hitting the windows. We got into my car. I took him to Wal-Mart. We went to buy some food." This narrative illustrates the complexity of this control: while clearly an example of psychological manipulation, the resulting interaction seems to have been both in the client and staff person's interests. Sometimes clients resist the programmed strategies to control their behavior, but if caregivers continue to pressure them, they may eventually use the program. Charles tells the story about a client he worked with who routinely engaged in significant aggressive and self-injurious behavior. She was trained by staff and supervisors on an anger management plan for over 18 months, before using it for the first time waiting at a doctor's appointment. Luke explained that clients respond to both calmness and fear from staff. When staff treat clients with respect and expect them to do well, he notes that they will not be as likely to be aggressive toward staff. He likened this to a story he related about five men calmly walking past a large dog without issue, but when the sixth man seemed startled by the dog the dog reacted by biting him. Luke went out of his way to explain that he was NOT trying to equate clients to animals, but rather that we all respond to the emotions of others, and that it is important to remain calm and not display fear of client behavior, or it may make aggression more likely. Lewis notes that a common tactic that caregivers attempt to change client behavior, which doesn't work, is trying to teach clients through

punishment procedures. Clients will often get preferred items taken away and then they have to “earn” these things back through prescribed behavior the team determines is important. Lewis notes that, “…caregivers just don’t know any better. It’s easy. It is hard to build skills that they need to have a good life.” Jessica shared a story about a client who insisted on cooking an entire five-pound package of sausage patties and eating it in a single setting as an example of guiding a client, but ultimately letting them learn from their own mistakes when possible. He cooked this huge package and placed all 50 patties on one plate, then poured ketchup all over a second plate to dip it in. Jennifer tried to dissuade him from eating it all at once, suggesting saving some for leftovers, making it last, following his suggested diet from his physician, etc. but he was adamant that it was his money, his food, and his choice. When he had eaten all but a few of the patties, Jennifer says that her client groaned, rubbed his belly and told her, “I think I made a mistake. I’m going to listen to you next time!” Luke was not comfortable with the term "control” over clients. “Influence. I like to look at it as influence rather than control. And it comes out as control because you are actually controlling a situation. But I feel that it enables me to influence [clients] in a way that they come from the negative to the positive.”

At Snowy Creek ISL, Lisa noted that the experienced staff manipulated the circumstances and narratives so that Alan and Jason would agree to do what the staff person wanted them to do, such as eating out rather than cooking meals at home.

Notably lacking in these narratives of controlling client behavior is the fundamental question of whether caregivers should be controlling client behavior in the first place. It is an unspoken, unmarked element of providing care for adults with

intellectual and developmental disabilities among caregivers that they should be in ultimate control over the lives of clients. Psy knowledge is not just found within mental health clinics or institutions but has expanded to encompass life in general, particularly for IDD clients (Levinson 2010:120).

Client Counter Control Narratives: Framing Resistance

Clients do not always meekly accept caregiver attempts to control their behavior. The socially constructed categories of “disabled” or the unmarked “able-bodied” and other socially marked and unmarked categories are specific to the “thought communities” that share narrative norms, traditions, and conventions (Zerubavel 1997:6). By marking the unmarked as “able-bodied”, “non-disabled” or “temporarily abled”, advocates and allies for the disabled community challenge the socially dominant semiotic position of those who are typically unmarked in terms of disability (Zerubavel 2018: 66-67). From the perspective of clients living in them, ISL and Group Home living can share many characteristics with being imprisoned. For incarcerated populations, many of the basic ways to exert control and self-determination are very limited, and numerous scholars have documented keeping access to the few areas of control that are available to prisoners are VERY important to them (Bosworth 1999, Crewe 2007, Crewe 2009, Jewkes 2002, Ugelvik 2011). For clients, the ability to refuse to exercise when prompted by staff or to choose when to eat junk food may become crucial proof of autonomy just like the small pockets of self-determination in prison are protected and, “…in the process, small acts of everyday resistance are legitimized.” (Ugelvik, 2011). A client may see no issues with “dumpster diving” or masturbating multiple times each day, since “…social problems are what people think they are and if conditions are not defined as social problems by those

involved, they are not problems to them, even while they may be problems to outsiders…" (Fuller and Myers 1971:320). Some clients resist the restrictive aspects of the clientization process. A number of challenges to the process of clientization exist: individual challenges to these identities for themselves or others; collective challenges such as peer group resistance; competing perspectives with vastly different constructions of clienthood (i.e. "mental illness" versus "life issue"); and contending clienthoods (such as sexual assault nurse examiners needing to both preserve evidence and serve patient needs) (Gubrium and Järvinen 2013). Membership in a racial identity-based social movement can project a shared group identity for members, providing a sense of solidarity and agency referred to as "Strategic Essentialism" (Brekhus 2020:55). However, identities are situationally bounded (Gecas and Burke 1995; Holstein and Gubrium 2000), and the decentralized nature of ISLs and Group Homes, coupled with the complicated intersection of disability and other dimensions of identity make it difficult for most IDD clients in these small residential settings to form a cohesive group identity with other clients.

A number of narratives focused on client attempts to prevent this control; essentially counter-control narratives. Counter-control narratives often include the use of client aggression toward others or themselves. Researchers have examined how men with intellectual disabilities use sexual provocation to challenge the authority of staff people who are women (Thompson et al 1997). IDD clients can also exert some limited measure of power over staff or peers through the threat of aggression or other disruptive behavior, even though this tactic is limited in effectiveness as staff can always call for assistance, either from other staff or law enforcement, if clients attempt to overuse this tactic. Staff

seem to discount the physical assaults of clients toward them unless serious injuries result; the most traumatic accounts for caregivers were when clients were seriously injured during these crises. Rather than recount an incident where he got a scar from a client throwing a sharp object at him, Charles recounted an incident of client self-injury as the most dangerous situation he has been involved in. “So, you know, I’ve been beat up more times than I can count….It’s been probably easily over three dozen, four dozen times. That’s an estimate…The most dangerous situation, a client tore a Coke can apart and fashioned a sharpened edge and was slicing himself, refusing to comply with police commands, so they tazed him. And he hit the ground *really* hard, and that was probably the most dangerous situation I was in.” Brandy told the story about a serious assault in which she almost lost an eye and the client assaulting her almost died. Her client, James, was upset “when he didn’t get his way”, so he eloped from his ISL and staff followed. He ran out into traffic yelling “I want to be with Momma! I want to die!” A car stopped rather than hit him in the street, and staff said that he jumped up on the hood of the car and started pounding on the window. When the police arrived, he told them that he had been abused, that he had been beaten, and that he had been hit by a car and could not walk. The police carried him to their car (he weighs over 300 pounds) and transported him to the local emergency room for treatment and possible psychological evaluation. When he told the emergency room doctor that he was not in any physical pain, Brandy asked him, “Didn’t you tell the cops your leg was broken?” James immediately attacked her and followed her into the nearby bathroom where she tried to get away from his assault. He was scratching at her face and left bloody gouges almost to her eye, and eight security guards were unable to get him off of her until they sedated him with an injection.

The sedated him with such a heavy dose that he actually stopped breathing and had to be intubated. Another client used to attack other clients so often that he was assigned staff to stay with him at all times; when Lewis advised the administrators that he was using the presence of staff as protection, and that if staff would just take him to a safe location when he gave them a "code word" that he would attack others less frequently. The administrators refused, saying it would take too much staffing to support. Of course, when the client attacked others, a lot more staffing was needed to deal with the crisis than would have been needed if they had followed Lewis' plan.

Clients sometimes used their bodies passively in counter-control narratives; Ava noted how a client she worked with would just sit down in a store if she didn't want to leave when pressured by staff to do so; she even did this once when the store closed, but she refused to leave! Lewis described how some clients would suddenly go limp and drop with their full body weight if staff attempted to physically restrain them. This not only prevented staff who followed protocol from continuing the restraint, but it sometimes resulted in staff injuries. Clark worked with a client who would strip his clothes off, "…bend down and defecate in his hand and smear it all over himself. Thinking that with all of that on him, we wouldn't touch him." Jessica was furious with the day program staff when a client in her care reportedly smeared feces all over her face and neck, and the day program she was at called Jessica to pick her up without cleaning her up. As she was tying down the wheelchair in the vehicle, she noticed no smell! It was a lot of "poop"! Her client started laughing, says she tried to tell the staff at the day program it was a candy bar! She had stashed a chocolate candy bar in her bra, so she could eat it whenever she wanted, and it had melted! As John notes, clients may control more of the

interaction with staff than some staff are aware of. “We think we are the ones running things, and in so many cases the individual is running their own version of a behavior support plan on the staff member…I have a guy who loves to argue. And he will start any argument that he can start. Because an argument is attention….and he will suck staff into an argument all damn day long if he can possibly do it. Then it’s like, who’s actually running the show here?” Many clients have experienced various levels of abuse and neglect both in the family home and in residential placements, and a significant number of them seem to seek out ways to be hospitalized, because medical settings have been one of the safest settings they have encountered. Lewis shared a similar story about a 23-year-old client with, “…an abuse history as long as my arm, both in the natural home and in care.… for him, the only constant safe place was the hospital.” Narratives about clients engaging in counter-control measures can be quite serious. John worked with a client who was his own guardian and quite capable, who checked himself out of residential care and moved into his own apartment as a way to prevent staff and others from attempting to control his behavior. Unfortunately, he was found dead in that apartment within a month, apparently after suffering a massive seizure. John tells the story as a cautionary tale, suggesting that if the client had stayed in placement and continued to receive routine prescribed medication from staff that he might have survived.

A particularly effective counter-control narrative that clients sometimes engaged in was to accuse a staff person or other caregiver of abuse or neglect. If the accusation was deemed credible enough, or serious enough by others, an inquiry to look into the allegations would usually be triggered and the staff person would either be placed on leave or at least be moved to a different shift to avoid contact with the client making the

allegation. While numerous instances of staff and others engaging in abuse and neglect were detailed by respondents, there were also a number of these allegations that were presented as false allegations. While the abuse and neglect allegations of clients are rarely substantiated without additional support (bruises, video, supporting accounts from other non-client witnesses), these allegations are still a way for clients to exert some pressure on staff, supervisors or professionals, even if only for a relatively brief time.

Normative privilege is an important and understudied factor in how power and difference interact in social groups (Brekhus 1998, Brekhus 2020: 106); it seems likely that in order to gain access to “normative privilege”, John’s client risked his life in order to be free of the ISL setting. Some counter-control narratives are centered around others who advocate on behalf of clients. Don describes how a client he works with tells everyone that he meets that he is going to marry the actress who played Daisy Duke on the Dukes of Hazzard, Catherine Bach. He carries pictures of her around and hands them out to people, and his new case manager wanted to write a goal in his (Individualized Support Plan) to put a stop to this behavior. Don argued that he wasn’t harming anyone, and that there was no reason to try to control a set of behaviors that brought the client a great deal of pleasure and caused no problems, even if the case manager thought it was “weird.”

The best examples of counter-control narratives from the respondents at Snowy Creek ISL both came from Joe, though they occurred while he was working at different agencies. Joe recalled working an overnight shift where a client seemed to be upset, and he kept walking into the kitchen, then coming out and glaring at Joe. Joe went in to investigate and found that the client had turned on the stove, and Joe thought he was

attempting to try to blow up the house. Luckily, it was an electric stove rather than a gas stove, so no one was in much danger. Joe also recounted working with a client who would routinely shoplift from stores like Wal-Mart, then physically attack any staff person who said or did anything to try to stop the theft.

What does autonomy, freedom, or choice look like for individuals in the role of IDD Clients in residential placement? (Levinson 2010: 44-8) While the narratives here are instructive, it is important to note here that that a better source for counter-control narratives will be directly from the clients resisting this control. These are counter-control narratives as told by social control agents. Much like prison guards and prisoners will likely share very different stories about the counter-control measures used in prisons, clients would likely provide a very different set of these stories than staff and professionals in the field shared.

Narratives Used to Control Staff

Framing narratives to exert influence or control over staff behavior are commonplace among staff, supervisors, and other professionals in this field. Clarissa framed her perspective on the factors involved clearly:

> So here is my belief about the [staff] that we work with. I believe that there are probably a third of our people who are going to be great no matter who supervises them, no matter who is watching, no matter what…They are always going to do the right thing. There is probably a third of the staff people, that no matter what we do, no matter what training we provide, no matter who their supervisor is, they are going to fall on the other side of that. They are never going to be the people we want them to be….And then there is that middle group of people that I feel are kind of on the fence, that can be swayed by the culture of an agency, or by the people around them, within that house even. And depending on how it operates will go one way or the other, based on the leadership that they are under or the peer pressure that is there around them.

Framing narratives to control staff behavior fall generally into supervision tactics (both positive and negative), peer control over other staff people, the local occupational micro-culture of the agency or home, ethical and legal framing narratives, and narratives centered on state oversight and investigations. While these framing narratives are often contested by staff people or others, they appear to play a significant role in influencing the behavior of staff people in these settings.

Positive Supervision Narratives

Many of the caregivers in this social world framed attempts to influence or control staff behavior through positive leadership techniques, better training and supportive supervision. Charles says that it is important to lead by example, set clear expectations, and to include the reasoning behind what we are asking staff to do. John gives a specific way in which he leads by example as a supervisor. “But when I work in that house, I like sports, those guys like reality shows. We watch the reality TV shows, even if it is one we’ve watch 16 times before. Because I’m in their house. They aren’t there to watch my sports…And I don’t know if it’s training, or empathy, or some combination, but it’s about individual choice. It’s our whole job.” Teaching staff to use humor with clients in order to get them to do things rather than getting into power struggles is a key skill that Brenda always tried to emphasize. When a client is oppositional about using the restroom before an outing if staff people prompt her to do it, it was better for everyone when staff acted as if they would “race” her to the restroom; the client would giggle, run to “beat” the staff to the bathroom, and be much less likely to be incontinent in her clothes during the outing. John point out that, while staff people usually frame the choices they give clients, shaping the choices between those

preselected or preferred by staff, this influence over the client's choices can be used to help them build a better, safer life. For example, staff may encourage taking medication as prescribed, performing basic hygiene so as to avoid social embarrassment, and other choices clients may not choose independently but that, in the staff person's view, will benefit them. Taking an active role in helping clients rather than just preventing harm from coming to them, is a common narrative. Clarissa notes, "That is where I try to shift people's mindsets…That we are not just here to oversee the clients. We are not babysitters. We are here to give them a better quality of life." Jessica, an agency owner and active supervisor tries to support her staff and be the supervisor she wishes she had had when she was working as a Direct Support Professional (DSP) when she started in this field. She has very little staff turnover, reporting only two staff people leaving her agency in the last 10 years, and they left to get higher paying jobs in different fields. She actively monitors for staff treating clients as somehow subordinate to staff. "Oh yeah! I've had some of those employees who have had that, and I'm like, 'Stop. Recognize what you are doing. Because you are not a babysitter. They are not children. And without them you wouldn't have a job. So…even just little things, like…When we are working with someone about sitting at the table to eat your diner, instead of sitting the recliner and using it as a napkin, but *you* are sitting on the couch eating. Lead by example." Jessica reports spending a great deal of time in the ISLs with her clients and staff, and this active, supportive supervision seems to make a significant difference in getting staff perform well. Some agency rules are seen as overly rigid or even silly, such as not letting staff take clients to their home to visit their dogs or grab something from their house; Brandy

would sometimes tell staff, "You go ahead and do this [breaking the agency rule], just don't put it in your notes."

The staff and supervisors at Snowy Creek ISL shared narratives on positive staff supervision as well. When Sheila was supervisor several years ago, she got a call from a brand-new staff person who was very concerned that a client he was working with was brandishing a fork at them because they were upset about something. Sheila had worked with this client in the past and they had no history of even attempting to harm anyone, so she laughed and said, "Tell him to put the fork down!" The staff person said, "Put the fork down" and the client put the fork down! Joe shared a technique that he uses as a supervisor to try to get staff people to put in extra effort to do a great job, even when no one is looking. When Joe becomes aware of a staff person mistake, he feigns surprise, and makes them feel valued and respected. He tells them, "Well, I know how great of a staff person you are, and you would never do something like this on purpose. Is everything okay? Do you have all of the resources you need?" This is an example of how some scholars argue that both clients and staff members are "made up" in and through their ongoing work in group homes (Hacking 1986, Hacking 1999). It should be noted that Joe has attempted this approach with Sheila and has been unsuccessful in getting her to change her behavior, perhaps because she does not seem to really view him as having any real authority over her. The intersection of power and knowledge plays a role in whose interpretation gains acceptance and dominance in a social milieu (McWhorter 2005: xv).

Negative Supervision

Framing narratives for controlling staff people is often presented as supervision through punitive or negative tactics. Clark told a story about how he caught a staff person lying about when they were clocking in for work. The staff person was working at an apartment program, where they were supposed to be available to each of three different clients, each of whom have their own independent apartment. Clark had noticed the GPS for the agency vehicle going down the highway about 20 miles away from the apartments when this staff person clocked in for their shift, so he drove over to the apartments to see what was going on. About fifteen minutes after he arrived at the apartments, he saw the staff person drive into the parking lot. Clark confronted her and put her on notice that she isn't getting paid to drive to work, but that she should be at work when she clocks in. Interestingly, Clark did not fire her, and he also didn't write her up formally, because it would be an "automatic term" [termination] if he did, and he didn't want to lose the staff person. Clark noted that it "Makes it hard to do their job," as supervisors, because if they fire direct care staff people, that makes more work for that supervisor. Don suggests that setting up systems which make staff responsible for specific tasks. "Here is where you sign off for meds, here for money. If you don't sign it off, you are responsible for it. So people go, 'Oh. If I don't do the right thing, I am going to get caught.' That's the best way to keep people from doing the wrong thing….You just tell them, 'I promise you, if you do the wrong thing, you're going to get caught.' 'Oh, well I shouldn't do the wrong thing.'" Clark seems to agree with this approach and says that accountability for actions are what really controls staff behavior in this social world. He does not bring up how his lack of imposing accountability on the staff person he caught falsifying her timecard

would change *her* behavior. Brandy was a very hands-on supervisor. To change staff behavior, she says she would "call them out… So they knew they couldn't get away with it. I would catch them doing shit, and then I would just pop in unexpectedly. I guess it's more like I got trained to watch them more closely." Brandy gives a memorable example of a difficult situation in which she ended up firing a live-in staff person. A live-in "wasn't a good staff person. She was emotionally abusive to the clients and made them all attend church because she wanted to go to church." Brandy caught her sleeping on shift a lot of times. Brandy was finally able to fire her, but the staff person owned the house the clients lived in, "…so we basically packed up and went away in the dark of night one night. It was fucked up…There is no telling what she would have done. She was a vindictive little bitch….It would have been war." Brandy also cautions that a lot of clients will just go along with the demands of staff, even if they really don't want to. "Neither of those ladies has ever gone to church ever since they don't live with her anymore. So obviously it wasn't *their* choice. They were just doing what she wanted to make her happy. You get a lot of that, that the individuals do what they think will make the staff happy. Just to make things more copacetic and get along. You have to really watch out for that." Some agencies use a digital surveillance system to track agency vehicle operation. Alerts will be generated automatically and texted or emailed to supervisors whenever staff people speed or hit the brakes too hard. While Francis said that she is even trying to drive slower and brake more gradually when she is driving her own car, most other staff people seemed upset by this "Big Brother" sort of intrusion. John says that one staff person was caught driving dangerously with this technology. Within one 45-minute trip to a hot dog stand one county over, they drove over 90 MPH

fourteen different times, with a top speed of 114 MPH, in an agency vehicle with a client in the car. This person was terminated, but it is unlikely that anyone would have known about the dangerous road trip without the online automated reporting.

At Snowy Creek ISL, Lisa, Jay and Linda drive the agency vehicle without issue, but Sheila avoids driving any company car that will "snitch". Rather than conform to the agency's safe driving policies, Sheila argues that her notion of safe driving is correct and uses the physical discomfort of driving a small car as an excuse not to drive agency vehicles if pressed.

Peer to Peer Control Narratives

A number of framing narratives detailed how staff people control the behavior of their peers. John related a story about a staff person who was an exemplary worker around him and other supervisors, then turned into a bully, calling clients derogatory terms and bullying the other staff, "…just an absolute tyrant. An awful person." The other staff were afraid of her, so they went along with her orders and kept quiet about the screaming, yelling and other abusive behavior toward the clients in their care, despite being mandatory reporters of abuse and neglect. Several narratives centered around "fear of retaliation" if they reported wrongdoing on the part of their peers. Clark witnessed staff buying groceries for themselves with client funds and boldly taking the groceries straight back to their house when he was a DSP. He didn't report it at the time because he wanted to avoid a confrontation with all of the other staff in the ISL. Staff at the house were all related and most of the family was stealing from clients. John noted that sometimes staff are not willing to confront a peer directly, but they will sometimes make secret recordings of them, "…berating, degrading, insulting, swearing at an individual"

Jessica encourages her staff to text a supervisor, “Hey, you might want to pop in over here...” to put other staff in check if they need it, then follow up with support for the staff person and client before things get out of hand. In one story, Brandy related how staff A wanted the shift staff B had. They accused staff B of abusing a client by slamming her leg in a car door several times, but no there were no marks on the client’s leg the next day. Staff B was fired, but abuse investigation was *not* substantiated. “But I never believed it for a second. She was a good person. She loved this individual. She would never have done what the other person accused her of. And the other staff was not someone I really…trusted. I think she got the other lady fired so that she could get her shift on the other night and get her position.”

Staff discretion is the informal way in which each individual staff member is given leeway in determining how they will carry out their duties and is a key element in staff resistance to the control of supervisors or other consulting professionals (Levinson 2010:118-9). The direct care staff person is generally deferred to in how they are going to carry out their duties, especially in the presence of clients. Staff do not always agree to use their discretion as other staff do, and disagreements on the best way to provide care is a common area of negotiation or even conflict among staff (Levinson 2010:126-7). The nature of the work of staff and supervisors is never-ending because the work that they do is interactive work that is “not subject to closure”, as “people do not stay fixed” (Lipsky 1980:78). The endless nature of the work makes staff discretion a necessity, as there is no way in which to ever truly completely perform all possible tasks in an ISL or Group Home. As long as an account of a good faith effort is presented, staff are generally able to pick and choose how they perform their duties beyond keeping the clients safe.

At Snowy Creek ISL, Lisa is resistant to input in how to do her job from her peers, while Sheila is exasperated with her not knowing what she has never been trained on, such needing to supervise Jason's shower so that he actually gets clean because he needs verbal prompts to do it properly. The informal knowledge imparted by peers on how to "really" provide care is often at odds with the rhetoric of the formal training staff go through (Levinson 2010:115).

Occupational Culture of Residential Placements

A framing narrative that was presented as controlling staff behavior was the occupational culture of either the specific or home or agency. Star noted that incompetent managers keep coming in and getting in their way, making up new, unnecessary rules and causing needless confusion. "Staff run this ISL….We know what works. Don't come in here and change things just because you can." In a placement in which physical restraint of clients and client assaulting staff were commonplace, Lewis said it was, "…hard not to have an us versus them mentality…when you are literally just like trying to survive." The "organizational embeddedness" (Gubrium 1987) of caregivers and organizational and contextual contingencies (Holstein 2013:195-6) play a significant role in decisions made in these environments and the stories that staff and others share about those decisions. The staff response to client requests, and the sort of requests that staff make of clients can be heavily influenced by role modeling from supervisors and peers. The informal knowledge imparted by peers on how to "really" provide care is often at odds with the rhetoric of the formal training staff go through (Levinson 2010:115). As John says, "At the end of the day, it is up to the staff to do what the individual asks them to do, or not." Staff often shape choices between choices preselected or preferred by staff. Rogue

programming that is not sanctioned by the agency or ISP team members can develop in ISLs and Group Homes, particularly when they are somewhat isolated or relatively unsupervised. Don found a list of ten "rules" that one of his supervisors made up and that the staff in the ISL were enforcing; he found the list and ripped it down, at least in the story he told me. This was *not* the series of events that I remember from being involved in this case firsthand, but this version does make Don appear to be a more proactive supervisor than my version of the narrative.

Both Joe and Lisa are convinced that Sheila and the other experienced staff people at Snowy Creek ISL manipulate Alan and Jason into doing what is most convenient for staff. Sheila recounted a horrible story she heard about staff members involved in the Carl DeBrodie case were said to have set clients up in a "Fight Club" scenario, which ended in Carl's death when he was hit in the head with a hammer during the fight and not given medical treatment (Hoover 2020). Joe talked about establishing a good occupational culture in a house as "A history of place." If something "weird" happens in the ISL, it will be reported, but not condoned, because there are certain ways things are supposed to be done in that place. He elaborated, saying, "You can make a good team in a house. And then it is no longer about just the money. It is about doing a good job for the clients and helping your team out."

Ethical and Legal Control Narratives

Ethical and legal considerations play a role in the framing narratives controlling staff behavior in ISLs and Group Homes. Several stories centered on clear violations of the law, including a story Sheila shared of the theft of over $35,000 in client funds by an activities director at a large agency; the story was that she was fired after being caught,

but got a job in another state doing the same thing! Another clear violation of the law was when some staff people started up a Fight Club between clients for their own amusement, particularly when a client, Carl DeBrodie, who was severely injured was not taken in for medical treatment (presumably to prevent investigation into the misconduct) and subsequently died. (Hoover 2020) John recalls a story where a staff person without a driver's license was driving an agency vehicle and got into a wreck. Their coworker agreed to lie and said they were driving, and they convinced the clients to go along with the story. During routine follow-up, everything came out when John asked a client what happened, and they replied, "Do you want me to tell you what *happened,* or what they *told me* to tell you happened?" Charles was very upset when a staff person was manipulating a client's behavior with her sexuality, which he felt was a serious ethical issue. Some narratives focused on the general effect that ethics had on staff behavior. Clark felt that staff do the right thing because they have the clients' best interests at heart. They love their job and care about the clients. "And I think it is just the opposite…for those who try to get over."

At Snowy Creek ISL, the experienced staff led by Sheila feel that they are providing a very high quality of service to Alan and Jason, treating them as family members and as important parts of their lives. This view of their informal, supportive interactions differs significantly from the ethical lens through which Joe and Lisa frame their relationship with the clients. Joe and Lisa feel that they are "bad staff people", or at the least are taking advantage of Alan and Jason.

Framing Narratives, Abuse and Neglect Investigations and State Oversight

Investigations into allegations of client abuse or neglect are a common topic when framing the narratives around staff behavior. The existence of an actionable issue worthy of outside intervention compared to a personal problem is socially constructed by different social actors in different, often contested, ways (Band-Winterstein et al 2013:133). Many of the narratives focus on how staff who engage in abuse or neglect often seem to get away with it. Charles noted, “Very little [abuse and neglect] is actually substantiated. Which is something I learned very early in my career. Just because I know that you are guilty does not mean that you are going to be found guilty. Because, the accuser or the witness that was present was a person with a developmental disability…because there is just no camera footage to prove it. So it is just one person’s word against another, and it is generally not enough to convict someone…” Don was frustrated when a staff person broke a window climbing into the ISL. She had left two non-verbal clients with significant disabilities in the house by themselves while she went to go get food and she accidentally locked herself out. Don fired her and turned her in to “The State” for neglecting the clients, but to his disgust the bureaucrats said, “No, that wasn’t neglect, because nobody got hurt.” This could be a significant problem for the field, because if staff are not added to the Family Care Registry as ineligible to work in this field, they can easily get a job working for another ISL even if they are fired for misconduct at the agency they worked for. Don noted with some irritation that even if abuse or neglect allegations are substantiated, state officials will often set the results aside if the staff person appeals. Sheila said that the staff people who were caring for Carl DeBrodie were reported for abuse and neglect on three separate occasions by the day

program he attended; Carl's team responded by pulling him out of the day program altogether. Since Carl later died while in the care of those staff people, legitimate questions have been raised about how effective the investigations run by the state are at protecting clients from abuse and neglect. Floyd told me that the time that he felt most physically endangered working in this field was when he caught a supervisor red-handed stealing EBT money from numerous clients, but her co-workers refused to believe him. She denied wrongdoing, and her co-workers accepted her framing narrative over Floyd's, until overwhelming evidence of her guilt was presented to the other leaders in the organization.

At Snowy Creek ISL, Sheila and her friends routinely joked about how abuse and neglect allegations are taken too far. When her son and Alan were about the same size they like to wrestle around WWE style; she mockingly asked, "Was that abuse?" Sheila was also irritated that when the case manager came by to do service monitoring in the ISL that Lisa didn't seem to know that they needed to put on a bit of a "Dog and Pony" show; when the person providing oversight from the state comes by, "…that should be common sense!" Erving Goffman's ideas describing frontstage and backstage social spaces is useful here; ISLs are frontstage social scenes during a case manager's service monitoring visit, while they are more like a backstage work environment most of the time (Goffman, 1959). Joe helped a staff person who was being pressured by a supervisor for sexual favors at a different ISL at the agency. The resulting investigation was not substantiated, he says, because the three or four other staff people who witnessed this behavior were also involved in "illegalities" and were explicitly threatened with exposure if they didn't back the supervisor's version of events. This supervisor was eventually

caught engaging in financial abuse of client funds, which required no witnesses to corroborate. Individual staff members are routinely reported for neglect or abuse by others; the "blue code of silence" police officers often follow does not appear to be as widespread among staff people, though it is more widespread than many would anticipate among direct care staff people.

Framing Narratives Used to Control Professionals

The framing narratives which influence the behavior of supervisors and other professionals in this field differ from those which are used to attempt to control staff behavior. This can be explained in part by the greater level of autonomy that supervisors and other professionals, such as case managers and behavior analysts, have in conducting their everyday work functions. Brandy describes her job as a supervisor as follows:

> I was a program manager…That meant that I supervised staff. I had to hire them and fire them, train them. I was responsible for taking my individuals to their medical appointments, to the emergency room if they needed emergent medical care.… And I worked a lot of direct care stuff too, you know, because when you don't have any staff and they are calling in sick at the last minute, then I had to cover….I was responsible for the care and well-being of mentally…of developmentally disabled individuals. I was responsible for the staffing and medical care and stuff. That's the short version."

As Brandy's description suggests, most supervisors also provide work as Direct Support Professionals (DSPs) on occasion, and almost all of them started in this field as a DSP. Other administrators, behavior analysts and case managers also had experience as both DSPs and supervisors. The most salient framing narratives for professionals in this field are ethical narratives, narratives avoiding blame, power struggles between agencies and "the state", keeping the community safe by "controlling" clients, and narratives focused on systemic issues in the field.

Ethical Framing Narratives

Many narratives attempting to frame the behavior of supervisors and other professionals in this field are presented in ethical terms. John had a client who was dating another client her mother didn't approve of. The mother demanded that the agency put a stop to the relationship, as the client's guardian. John declined to interfere in the relationship, noting correctly, "You are not the guardian of relationships for your daughter." The mother then pulled her daughter out of the agency and sent her to an agency willing to force the breakup with the boyfriend. While John's agency administrator supported John's ethical stance, many administrators would not have, given similar circumstances. Clarissa felt that while it was not technically illegal or an abuse/neglect violation, when she saw an agency administrator doing shots at the bar with a client who had addiction issues with illegal substances, it seemed like an ethical problem. Brandy sets high standards for herself and everyone else as a supervisor, and she noted that she was going to do it the job "right", even if others disagreed. Lewis portrays himself as a professional working at "The State" oversight agency, trying to ensure that residential providers have the tools to do what they are supposed to do to properly care for clients. He is also determined that he will work to "… also not let them NOT do it." Charles told an interesting story which nicely illustrates some of the complexities of ethical issues supervisors and other professionals in this field deal with. Charles worked with a client who was having sex with women in the bathroom of the ballpark near his house. The client's guardian was upset about the client engaging in this behavior, but Charles refused to stop it. He framed the situation as a refusal to physically restrain a client to prevent him from having consensual, safe sex. The previous residential

agency would invade the space these sexual liaisons were occurring in to disrupt this behavior; the client then began to expose his genitalia to the staff to drive the staff people away. This worked, in a way, but they then labeled him as a sexual deviant and a felon.

At Snowy Creek ISL, Joe is framing his decision not to terminate Sheila as an ethical one, in which he wants to make sure that terminating her would not result in a significant reduction in the quality of life for Alan and Jason, who have been with her for years.

Narratives Avoiding Blame

Supervisors and other professionals often used framing narratives to prevent blame from attaching to themselves, their agency or favored coworkers. When a client used aggression to keep staff with him almost continuously, administrators refused to sign off on a protocol which would have staff take the client to a safe place when he used a predetermined “safe word” or phrase, because they didn’t want to sign off on allocating increased staffing to one client; this seemed particularly nonsensical to Lewis, who noted that more staff than that had to respond to the routine physical altercations this client started. Brandy told a story about how she got in trouble for being too thorough in her reporting. “My [on-call] supervisor narrative would have great detail. And I got in trouble because I wrote, ‘This staff person said that her manager never told her that she was scheduled for this shift, and that is why she hadn’t come in for work.’ And, of course, that would make that manager look bad. I was told I wasn’t supposed to put those things in my reports.” Brandy was pretty sure that the reason she got in trouble was that the manager who looked bad was in a romantic relationship with Brandy’s boss, who didn’t want them to look bad, especially in writing.

Our supervisor at Snowy Creek ISL noted that when he moved into the office at a different agency, there was a big difference between what the staff people would report happened in the internal agency report compared to what the supervisors would report to "The State" in that report. "The wording would change," Joe said. One common framing narrative to avoid blame is to report client behavior in minute detail, while staff and other agency personnel's behavior is reported in official documents in much more general language.

Power Struggles Between Agencies and "The State"

The narrative frame positioning agencies and "The State" against one another in power struggles is one that many professionals use. Clarissa told the story of another agency that had 75 deficiencies on a Licensure and Certification inspection from "The State", and then agency administrators went on a vacation to celebrate! Clarissa said she would be crying if the agency she helps run had that many deficiencies. She thinks that personal and political connections between the agency administrators and top bureaucrats seem to be keeping the agency open, coupled with the agency's willingness to sue "The State". A case manager once wrote Don's agency up because there was a used condom wrapper on the public street in front of the ISL when she arrived to do service monitoring. On another occasion, a case manager wrote him up because the patched sheetrock repairs of damage from a client damaging the walls due to idiosyncratic behavior were white and didn't match the brown paint on the rest of the wall. Jessica was reprimanded for being dismissive toward a case manager in an IP meeting. For 8 out of the last 9 years, one of her clients had a reading program objective, which he says he wants in the annual IP meeting, and then refuses to participate in or sign up for a reading

program all year. "Wouldn't it be better to pick an objective that he would actually work on?" Jessica asked. Don noted that he got an intense amount of oversight from case managers when he was a smaller agency, but he noticed a change as he got bigger. "What I have come to realize, to be blunt, is the more clients I have, the less shit I have to take [from "The State"]." Kyle, a long term employee of "The State", noted that government workers like him are also oppressed by "The State"; not just residential providers. This parallels the narrative framing that prisoners sometimes use when they talk about "The System" (Ugelvik, 2011). Just as "the System" is socially constructed as an active opponent in prison life, "the State" is the active character that makes life more difficult for staff and supervisors and is often constructed as an active opponent by actors in the social world of ISLs and Group Homes.

Keeping Community Safe and Clients "Under Control"

Professionals often framed their narratives in terms of community safety, in keeping the broader community safe from the potentially dangerous or disruptive behavior some clients may exhibit. It is impossible to separate the treatment functions of residential care for IDD clients from the social control that is exerted (Trent 1994). Institutional needs played a significant role in the social construction of incompetence for clients and potential clients, with simultaneous social constructions of productive labor (within the institutions) and the need to protect society from the incurable, dangerous people within the walls of the institution (Carlson 2005: 142). Brandy illustrates an amusing example: "You know when you go to the doctor's office, you always have to wait for a long time, right? If you take someone who is blind, deaf and mute and they start taking their clothes off in the waiting room because they are tired of waiting, you get

put in a room right away!" Lewis notes how professionals can manipulate things in the name of community safety. Even though some clients were mandated by court order to be shifted to less restrictive environments if their official reviews were positive, professionals would slow down the pace of specific clients, particularly if they were viewed by those professionals as potential risks to people in the community (such as those accused of sexual abuse of children). Charles had a negative interaction with a small-town police officer while he was an on-call supervisor. The staff person Charles was supervising called 911 for assistance, since the client she was working with was large, had a history of physical aggression, and was making threats toward her and other clients in the home. Charles and the police officer arrived at the ISL at about the same time, and the officer began chastising Charles for not keeping his client "under control." Charles told him about the limitations of our field, and that it would be unethical to physically restrain someone for making verbal threats; they just wanted the police officer there to assist in deescalating the situation if possible, or to help by providing transportation to a local hospital if the client needed to be admitted short-term. The officer became even more irate with Charles, and at one point put his hand on his service weapon, threatening Charles. Charles was infuriated and stepped outside at this point and called the police officer's supervisor to report the incident.

At Snowy Creek ISL, Joe recounted a story where he was stuck between a client who would physically assault him if he intervened and the community expectation that he would not support a client who was actively shoplifting from stores. He was able to walk a sort of middle path by "reminding" the client to check his pockets while he was

checking out at the register. While the client still got irritated with him, he didn't attack him physically as he would if Joe had overtly "snitched" on him for shoplifting.

Framing Narratives and Systemic Issues in the Field

Whether direct care staff, clients, or administrators are accurate in their interpretation of social phenomena is irrelevant, in that the consequences of their definitions of reality, their social constructions of the social events, are certainly real in their consequences (Thomas [1928] 2003:81). Some occupations have a certain level of "role murkiness", such as forensic nurses who have to balance the conflicting occupational responsibilities of providing comfort and care for rape victims while simultaneously having a legal responsibility to preserve evidence of their sexual assault (Foley 2013). This "role murkiness" occurs routinely for staff people who are expected to simultaneously support and care for IDD clients while they are also required to control their behavior, even to physically restrain them to prevent these clients from causing physical harm to themselves or others. The work for staff and clients in these environments is never done, yet the nature of the vague goals and perpetual nature of self-improvement make it so that the goal of independence is never fully reached, since progress toward the goal is what the system demands of residential placements for clients (Levinson 2010:102-3). Attempts to control professionals such as clinical psychologists, behavior analysts, case managers and other specialists appears to be similar to the controls over other professional actors. These include potential threats to professional reputation, loss of business or clients, and loss of licensure for licensed care providers. Bureaucratic measures of control may be somewhat less effective due to the decentralized

nature of this occupational setting, yet professionals usually have competent reporters on hand to provide for accountability.

A significant portion of the framing narratives shared by supervisors and other professionals revolved around systematic issues facing the field of providing residential support to adults with intellectual and developmental disabilities. The shortage of staff people to provide care for clients in this field has been a significant problem for some time. As Lewis notes, "… nationally, there is currently a DSP turnover rate of roughly 50%, and in the state of [state name], we are at least at that. Some bigger agencies are having like thousands of hours over the course of a quarter that go unstaffed because they just don't have the bodies." This creates a behavior trap of sorts for supervisors, because they spend a lot of effort training new people to replace the ones who left, but then don't have the time or energy left over to retain the staff they have, so they are stuck in a cycle of continuous retraining. With the staffing shortage, Clark's agency has been hiring anybody who could open the door and get to the interview. They are trying to get away from that position due to problems that have resulted from less selective hiring, but Clark isn't sure how selective they will be able to be, given the current job market. In an attempt to attract and retain DSPs, some agencies are increasing pay scales. Brandy notes that a lot of the managers at some agencies were quitting, because they would make more as DSPs with overtime, they would not be on call on weekends, and then they "…aren't responsible for so much shit." Brandy found it very stressful to be a supervisor who tried to do a really good job for her clients in that environment and was, "Stressed to the gills." She was unable to resolve this problem and retired from the field altogether. While lock-down psychiatric wards, state hospitals and other institutions are generally deficient

environments, Lewis argues there are not very many differences between the interactions inside institutions and interactions that many clients and staff experience in community residential care settings. A certain level of interpersonal violence seems to be endemic to this field, regardless of the setting. As Clarissa notes, she expects to, "get smacked every once in a while" by some clients and has been physically struck dozens of times, roughly 100 times total, but "I can't think of any particular time that I felt that I was in danger from the clients….It's interesting, the staff pose more of a threat to me than the clients." While physical aggression is never a great thing, some behavior is treated as serious problem behavior when it is relatively mild in comparison. Serious problem behavior isn't, "…somebody pretending to hit you. It' s not slapping you. It is somebody biting somebody's hand, taking a chunk off." Lewis says. Meaningful and lasting change can be difficult to achieve in ISLs and Group Homes. A behavior analyst noted that he found it easier to change parent behavior when they were the caregivers rather than staff behavior because of the difference in motivation of the caregivers. Charles noted that the parents were willing to work harder and sacrifice for their children in order to get real, lasting behavior change, while in residential settings implementing lasting behavior change is often expensive and can cut into an agency's bottom line. The people best positioned within most residential care agencies to make significant changes in ISLs or Group Homes are the supervisors, who can train and monitor staff, but only if the agency head approves of the use of resources, according to Lewis. Charles wishes the general population knew more about ISLs so that bureaucrats and politicians didn't have so much unfettered control, and that more people would get involved and provide input into how their tax dollars support their fellow citizens in ISLs.

At Snowy Creek ISL, Joe is worried that if he were to upend the ISL by terminating Sheila that the other long-term staff would likely leave as well, and that there is no guarantee that the brand new staff people that he may be able to hire would do a better job than what the stable job that the staff are doing now, even if he would like to push the staff to do better. Joe is unable to reliably expect that his agency can hire new staff to backfill openings, which puts pressure on him to retain staff, even if he does not think they are doing a great job. This pressure is felt by supervisors throughout the entire industry, as the staffing shortage continues to worsen.

Conclusion

Framing Narratives are used extensively in ISLs and Group Homes to attempt to control the behavior of clients, staff, supervisors and other professionals. The effectiveness of framing narratives appears to correlate closely with the relative power of the different social actors attempting to implement them or resist them in a given context. Staff are able to use a variety of framing narratives to influence the behavior of clients in their care to great effect. This is in part due to the power imparted by the role of staff person over clients, but also results from the minimal capacity of many clients to effectively resist framing narratives they dislike. Framing Narratives are less effective when used to control staff people in this field. Staff are often able to resist with counter-narratives of their own, and the traditional hierarchical power that supervisors have over employees (such as the threat of firing them) is reduced in this social world, both by the staffing shortage and the decentralized nature of much of this work. The most effective means of exerting power over staff people does seem to involve the use of framing narratives, in the positive leadership techniques and supportive supervision that some

effective supervisors use to shape the behavior they want to see from staff. Supervisors and other professionals in this field have so much autonomy that they are effectively able to resist most framing narratives that they want to. Effective use of framing narratives for supervisors and other professionals in this field is best implemented by convincing them that the Framing Narrative being presented should be embraced rather than resisted. For example, framing new work tasks as important protections to prevent client abuse may help shift supervisor behavior to embracing the new work task rather than resisting it. No matter the context or the intended target of Framing Narratives in this social world, the ability to shape the definition of the situation is a powerful tool that is widely used to good effect.

Chapter 4:
Identity Narratives

Identity narratives are used by social actors to exert power over others in the social world of ISLs and Group Homes. This power is used in a variety of ways, from benefiting clients by advocating for their individual rights to covering up misconduct of staff stealing money from clients. Debates among scholars over key aspects of identity (or the self) are numerous and ongoing: the core self, malleable self, an evolving self, multiple selves, reflexive self, unknowable self (Cooley [1902] 1964; Gergen 1991; Goffman 1959; Holstein and Gubrium 2000; Linton 1998; Mead 1934; Strauss 1959; Zurcher 1977). A common shared understanding of the meaning of the identity under consideration is necessary for this interactive process (Biddle 1979; Holstein and Gubrium 2000). Individuals have multiple identities (Biddle 1979; Gecas and Burke 1995; Holstein and Gubrium 2000; Zerubavel 1991, Brekhus 2020) and yet each person has their own unique identity. Possessing a marked identity is more salient in most instances than having an unmarked identity: sexual orientation is more socially significant for gay people than straight people, and race is more significant to racial minorities than for white people. (Zerubavel 2018: 54) "Unmarkedness" is not simply a default because of statistical majority, but also a result of "social *dominance*". (Zerubavel 2018: 32) "In fact, *unmarked identities are not even considered identities*…. Rarely, for example, would we ever characterize someone as "able-bodied" or "averagely experienced….***Social dominance, in short, involves the privilege of being considered 'normal' and thereby assumed by default and taken for granted***."(Zerubavel 2018: 56-57, emphasis in original)

The ways in which identity narratives are deployed can be either overt expressions of power relations or subtle attempts to exert control over another person through shifting how they view others, or even themselves. Narratives, particularly the "languages of the self", are the tools with which social actors make sense of their social reality (Gergen 1991:5-6), and how they both shape their identities and are shaped by those very identities (Zerubavel 1997). Narrative work is central to understanding how identities are constructed, negotiated, and challenged. The ways language and identity are used to inform the behavior of individuals within a specific social setting can be better understood through ethnography (i.e. Anderson 1999, Goffman 2014), and context is used in everyday life as a resource. (Garfinkel 1967) Identities, or selves, are collaborative efforts that individuals craft for themselves in an interactive, dynamic and socially accomplished process (Brekhus 2020: 127; Gubrium and Holstein 2000:101; Fine 2012:167). The identities available to individuals are greatly influenced by the identities available within the given social context (Gubrium and Holstein 2000:101) and cannot be chosen or discarded by the individual alone (Berger and Luckmann 1966:1-3). Identity is mediated and co-produced within an organizational context (Gubrium and Holstein 2001:104). Current options for identity formation are closely tied to past interactions and are developed through connecting the present through the lens of a shared past within social groups; identities are anchored through shared understanding of identities (Fine 2012: 161-7). For example, descriptive work is needed to construct Alzheimer's Disease (Gubrium 1986), though the individuals who are assigned this identity and their close relatives often resist this identity, at least for a time. The socially constructed categories of "disabled" or the unmarked "able-bodied" and other socially

marked and unmarked categories are specific to the “thought communities” that share narrative norms, traditions, and conventions (Zerubavel 1997:6).

Identity is a fluid, complex, contested, and complicated concept. (Brekhus 2003, Brekhus 2020) The relative value of identities varies in relation to other identities as well as by situation. (Brekhus 2020: 123) In the social world of ISLs and Group Homes for adults with intellectual and developmental disabilities (IDD), identity narratives play an important role in almost every aspect of the lives of those living and working in these environments. Within the situational context of ISLs and Group Homes, examining the possible identities formed by clients, staff and others provides critical insight into not only the identity formation process in this social milieu, but also provides insight into how these identities may influence behavior. For example, if a staff person sees themselves as a person whose job is to protect the community from the clients they work with, they may react to client noncompliance very differently than a staff person who views themselves primarily as a supportive counselor. The authentic performance of accepted identities can also influence who is included or excluded within specific identity groups, in essence determining who belongs and who does not. (Brekhus 2020: 76-77) The process of marking some individual identities and roles but not others can have far reaching social significance, including stigmatizing certain identities. (Goffman 1963) Impairment is not the same thing as disability. (Tremain 2005: 9) Clients are typically marked as disabled, while staff are unmarked, and therefore, assumed to be within the default societal category of able-bodied. (Drinkwater 2005: 235) This dominant narrative is complicated by the prevalence of disability and impairment among many staff people,

as well as the difficulty in specifying just what makes a person able-bodied (Zerubavel 2018:9).

Identity is intensely personal, yet socially constructed from available narratives within specific situational contexts. Self and identity are important topics that have been explored by numerous scholars (Biddle 1979, Gecas and Burke 1995, Holstein and Gubrium 2000, Brekhus 2020). "Identity is central to human meaning, social life, and social interaction. We often think of identity as a personal matter, individual matter, but identity is intensely social both in its formation and in its implications." (Brekhus 2020: 1) While staff people do not have a lack of attributes (often including diagnoses involving both physical or mental impairment), many of these attributes are imbued with social power by their unmarked status within this social world or largely ignored if they are not empowering. (Drinkwater 2005: 234-5)

To better understand the role that identity narratives play in exerting power over other people in this social world, I am relying heavily on the theoretical work of Wayne Brekhus and Erving Goffman. I am applying Brekhus' study of the sociology of identity (Brekhus 2020) to this specific milieu, focusing my analysis of the role identity plays in the application of social control into three areas of theoretical focus: identity authenticity, identity multidimensionality and identity mobility. Goffman's conceptualizations dealing of stigma as it applies to both clients and caregivers is also quite relevant to analyzing how power is used through identity narratives within this social world. (Goffman 1963)

Identity Construction in the Social World of ISLs and Group Homes

Identity is socially constructed through multiple simultaneous social processes. Changes in our socially constructed selves are also accomplished through interactive social stories (DeGloma and Johnston 2019: 625), with new challenges and fresh opportunities to reformulate personal or collective identities (Gubrium and Holstein 2000; Brekhus 2020:126). The "two vectors" on the process of making up people are labelling from above and pressure from below (Hacking 1986). These social processes include the claiming of identities that may be available and accepted by others within the social context; the navigation of the multiple selves that an individual may inhabit in a variety of ways to a variety of degrees; and the fluid nature of how these identities might change over time. The interpretive search for meaning within the "webs of significance" we spin for ourselves highlights the importance of narratives within the social construction of reality (Geertz 1973: 5). "Marking traditions" differ across social contexts, and the author notes that "…in reality, nothing is inherently marked or unmarked. Both markedness and unmarkedness are products of marking conventions and vary across cultures as well as among different subcultures and across different social situations within the same society." (Zerubavel 2018:24) The process of identity construction is complicated and dynamic in general, and the social world of ISLs and Group Homes poses particular challenges for the people who work and live within this milieu.

Identity formation narratives in ISLs and Group Homes are not weighted equally in terms of significance. Various dimensions may play unequal roles in the formation of a

particular type of identity (Brekhus 1996: 502) with different dimensions gaining salience based on a number of contextual factors. In this social world, identities that pose a threat to safety ("Aggressive Clients" or "Sexual Predators") often receive more intense levels of social control from staff and supervisors. Specific "washing over" effects of some markedness occur if a dimension is provocative enough (Brekhus 1996: 507). The ability to shed such an identity once acquired is extraordinarily difficult for clients in these positions. A client I worked with was accused of having sex with minors and has been labeled as a sexual predator. She claims that she got in trouble over ten years ago when she agreed to have sex with two young men in their teens (with no intellectual impairment) and then when they got caught, they blamed her and said she forced them to participate. There is no real way for her to shed the stigmatized identity she has been saddled with. Sex offenders are not only widely socially excluded and stigmatized (Quinn, Forsyth, and Mullen-Quinn 2004: 211), but the stigma of this label is so strong that a "courtesy stigma" Erving Goffman (1963) attaches to the offender's entire social network. (Tewksbury and Connor 2013:219) Within the ISL and Group Home community, large and aggressive IDD clients are often shunned by members of the public as well as other clients and staff who are not assigned to work with them directly, and a courtesy stigma (Goffman 1963) can attach to people associated with these individuals who are seen as unpredictable and dangerous.

The slightest amount of some detected behavior is enough to impact some marked identities, the "mental one-drop rule", while other quite obvious behavior is not marked as deviant unless there is overwhelming evidence (i.e. the "mental entire ocean rule.") (Brekhus 1996: 514) Mental illness among clients is more likely to follow the "mental

one-drop rule", while mental illness in caregivers is assessed using the "mental entire ocean rule" in this social world. Deviance is created through the process of labeling of specific behavior, and individuals who engage in this behavior, as deviant. (Becker 1963) The stigma attached to clients is not uniform, and staff people who are "wise" to the social world of IDD clients may react very differently than people outside this world. (Goffman 1963: 29) The voices of clients are not given equal weight. In some cases, clients are not able to communicate with caregivers or others effectively, either because they do not have adequate support and training (consider Stephen Hawking without specialized adaptive equipment) or possibly because they are not even aware of the way others view their identity, due to cognitive impairment or disinterest. Differences among the clients cause multiple fractures across the potential unified identity category of "clients". Some clients in ISLs and Group Homes are severely physically impaired and have no mental disability at all. Most clients in ISLs and Group Homes have some level of intellectual impairment diagnosed; many have labels alleging mental illness, though a "looping effect" may be responsible in part for some of these mental illness diagnoses; The "Looping Effect" occurs when a patient reacts to an environmental event (such as mandatory room inspections or rigid bedtimes or mealtimes) with anything other than acceptance of the rules, this "difficult" behavior then justifies the imposition of the rules and the patient's status of incompetence. (Goffman 1961: 35) This process observed by Goffman in a hospital's psychiatric ward decades ago are replicated routinely in Group Homes and ISLs today. "Counselors [in the group home] sometimes focused on observable conduct to make accountable and confirm what they already knew about a resident's 'deeper' or 'inner' problems." (Levinson 2010: 148)

The world of ISLs and Group Homes is diffused and decentralized, and this social world differs in significant ways from home to home and state to state. Staff members generally have low pay, high job expectations, and have a high turnover rate. The occupation of staff person is not a cohesive one with a shared occupational identity, like that of nurses, fire fighters or accountants. The lack of a widely shared identity among clients makes cohesive client identity difficult to establish. Many clients don't care or aren't aware of identity politics issues, while many who do can pass and don't really want most disabled chiming in, diluting support of idea of their agenda. Politically active participation in "identity politics" of people with disabilities fighting for change in both societal views of those with disabilities and the self-conceptions of the disabled focused on the rejection of stigmatizing narratives and challenging inequalities in societal structures for those labeled disabled. (Anspach 1979). The way in which some people in this setting are marked as disabled while others are unmarked sets up a significant power disparity, a ripe area for the analysis of power relations based on a system of differentiation (Foucault 1982:223).

Identity narratives in this social world are assessed through the theoretical framework presented by Wayne Brekhus in *The Sociology of Identity*; the concepts of identity authenticity, identity multidimensionality, and identity mobility. (Brekhus 2020) "*Authenticity* refers to the ways in which people try to authenticate personal selves or group membership. *Multidimensionality* refers to how people navigate multiple intersecting elements that make up their self-identity or collective identity. *Mobility* refers to the strategies and cultural currencies people use to navigate transitory and migratory

shifts in their selves or in their collective identities across space and time." (Brekhus 2020: 1, emphasis in original)

This social world is a useful analytical site for analysis for several reasons. As "everything perceived is only evident when surrounded by a familiar and poorly known horizon" (Foucault 1977:144), by analyzing these identity narratives within this unfamiliar social setting, the process is more clearly discernable than within more familiar social scenes. The stark differences in levels of power between clients and staff, as well as between staff and supervisors and other professionals is evident, making this a useful social space in which to analyze how this form of social control operates. One of the primary goals of ISLs and Group Homes, if one that is not overtly discussed by most people in the field, is to provide a mechanism of social control over clients with disabilities; to protect the broader community from them and their potentially disruptive or dangerous behavior. Luke noted that in the part of Africa that he was raised in, people with intellectual and developmental disabilities are sources of shame for many families and still hidden away from the public gaze or left to fend for themselves on the streets. While he was impressed with the relative compassion and dignity he sees people with IDD treated with in the United States, he was surprised to hear that a similar approach toward the disabled was the norm in this country just a few decades ago. The legacy of the asylums and other large institutions designed to lock away and control patients diagnosed with IDD still looms large over this field.

Identity Authenticity in ISLs and Group Homes

Identity Authenticity in ISLs and Group Homes plays out very differently among different groups in this setting. Authenticity among client identities, staff identities and

professional identities are all being deployed in different ways and are all being influenced by different factors within this social world. The identities available to individuals are greatly influenced by the identities available within the given social context (Gubrium and Holstein 2000:101) and cannot be chosen or discarded by the individual alone (Berger and Luckmann 1966:1-3). Individuals still engage in a great deal of effort to attempt to influence which categories they belong in and which categories they do not belong in.

A coherent and consistent identity, a true self, is a widely valued aspect of identity for social actors within ISLs and Group Homes. An authentic self or identity is simultaneously unique to each individual, yet can also occupy a standardized role within social organizations. (Goffman 1963: 57) An assumption that each person has a singular, true identity is often overly simplistic and can be harmful. (Brekhus 2020: 99) One identity is insufficient, and our identities are achieved through dynamic social interaction within our micro-communities and are mutable rather than rigid. (Fine 2012: 164) The fluid nature of identity does not mean that it is based on the individual's whim or that a stable identity is not desirable: identity is still a socially constructed phenomenon, despite the complicated, complex and changing nature of social reality. (Brekhus 2020: 155) Identity authenticity can be deployed in very different ways, even when it is the "same" identity being deployed. (Brekhus 2020, pp. 80-1) Duration is a factor that can play a significant role in identity construction. Whether an identity is permanent or temporary, when a person can gain access to the identity or when it is no longer available, and if the person can make an authentic claim to the identity can all be determined by the duration

of specific socially marked behavior or attributes (Mullaney 2006:84-5; Brekhus 2020:150-1).

A number of challenges to the process of clientization exist: individual challenges to these identities for themselves or others; collective challenges such as peer group resistance; competing perspectives with vastly different constructions of clienthood (i.e. "mental illness" versus "life issue"); and contending clienthoods (such as sexual assault nurse examiners needing to both preserve evidence and serve patient needs.) (Gubrium and Järvinen 2013). When children were studied in both an institution and in the community, contrasting clinical and social systems to demonstrated that "mental retardation" was an "achieved status"; and behavioral differences were described as features of each system to demonstrate that the constitution of normal "depends on system specific role performance, conformity and expectations." (Mercer 1973: 22)

Impression management strategies (Goffman 1959) are attempts to present identity characteristics consistent with the identity the actor is attempting to present, and sometimes to avoid being marked with a stigmatized, or "spoiled identity" (Goffman 1963). The rejection of stigmatizing narratives and challenging inequalities in societal structures for people who are labeled as disabled has been a focus of advocates and people with disabilities fighting for change in society. Politically active participation in "identity politics" of people with disabilities fighting for change in both societal views of those with disabilities and the self-conceptions of the disabled has been a core part of the disability rights movement. (Anspach 1979). Individuals display social cues for others when they make identity claims, and their narratives are often a key component of these identity claims, whether they are trying to shape the audiences' perception of the identity

to resist, or to embrace an identity the audience may attach to them. (Goffman [1963] 1999; Holstein and Gubrium 2000; Scott and Lyman 1968) The way an individual pronounces certain words, the words they use and their mannerisms are all combined with content so that other social actors may determine “who” someone is. (Biddle 1979; Holstein and Gubrium 2000).

Client Identity Authenticity

The direct voices of clients were not included in this research, for several reasons. Ethical and methodological reasons for this omission are included within the previous chapter dealing with methodology, but the theoretical justification for not interviewing clients should additionally be addressed. This research focuses on how relatively powerful agents of social control use narratives and identity to attempt to control others. While narratives that staff and professionals share about clients may provide a great deal of insight into how these narratives are used to attempt to control others, the direct narratives about how clients see themselves are less relevant to this analysis, given the relative lack of power clients have over others. The narratives of clients, including how they see themselves and how they attempt to influence others are very important narratives; they are simply part of a very different sociological project. A project studying police work would include a great deal of discussion of the suspects they interact with, but the ways in which those suspects view their own identity are not necessarily pertinent to the ways in which the police officers build their social world. Likewise, staff and professionals in this field build client identity narratives, but not necessarily for the same purposes that clients would.

Clients in ISLs and Group Homes have an incredibly diverse array of skills, abilities, intellectual capacities, physical characteristics, family backgrounds, cultural

preferences, political beliefs, sexual preferences; just as any other large group of people have. One unifying characteristic they share is the bureaucratic status of being a client, who has been labeled as developmentally disabled enough that they need to be supported in an ISL or Group Home.

Stigma is an issue that all clients in ISLs and Group Homes deal with, but it is not an issue that is universally experienced by different clients. Clients who are significantly physically impaired and those who have obvious markers of disability like a protective helmet or the distinctive facial characteristics of people with Down's Syndrome, are never able to "pass" as a person without a disability; they have "discredited stigma" rather than "discreditable stigma" (Goffman 1959: 41-42). Clients who have no observable or obvious social cues that they are intellectually or developmentally disabled *can* "pass" as a person without a disability, or as a part of the "unmarked" majority (Zerubavel 2018). This social marking of some roles and behavior while leaving others unmarked results in an empowering of the unmarked social elements as the normal or default social status (Brekhus 1996, Brekhus 1998, Brekhus 2020). One story that illustrates this was related by a supervisor, John. He said that a client came up to him one day and said, "'We in the high-functioning group decided that we'd really rather not go on outings with the low-functioning group.' And I am like, 'Thanks for teaching our individuals that language, guys. Now they are segregating against themselves. The segregated people are segregating against themselves.'" While worrying about self-segregation, John may have missed an important point that the client was trying to make to him; the clients who could wanted to go into the community and pass as unmarked, if only for a time. "'Normals' have constructed themselves through the exclusion of and

differentiation from others, such as criminals, mad people, and disabled people" (Foucault 1988:146). The inclusion of staff in the social group might jeopardize the attempt for some of the clients to "pass", but the presence of the "low-functioning" group surely would. John's concern that the staff people had taught the consumers language to discriminate against their fellow consumers appears to have been a naïve interpretation; the clients have already sorted themselves out socially and were trying to get the staff people and supervisors to acknowledge their authentic identity claim as higher-functioning clients. "In fact, *unmarked identities are not even considered identities*…. Rarely, for example, would we ever characterize someone as "able-bodied" or "averagely experienced….***Social dominance, in short, involves the privilege of being considered 'normal' and thereby assumed by default and taken for granted***."(Zerubavel 2018, pp. 56-57, emphasis in original) Insiders who are "wise" to the world of developmental disabilities often feel that they have to argue that adults with IDD are authentically and fully human, deserving of equal consideration as those not labelled as disabled. Charles argues that clients deserve the same quality of life as him, "but are treated as less than fully human by a lot of people." Clarissa feared during the early days of the COVID-19 pandemic that her clients would get ventilator access after non-disabled people, because they are valued less by society. She had a client in another state that was not allowed on the transplant list for an organ she needed; Clarissa was sure this due to her client's disabled status. Clarissa was also concerned that when one of her clients was hospitalized for complications from Covid-19, that since they would not allow staff people to be in the hospital to provide medical advocacy for him, that he would not be capable of advocating for himself and could have worse outcomes as a result of his intellectual disability.

Staff narratives often lump all clients together into shared identities, though this seems to shift with the point that they are trying to make. Caregivers made statements like, "Clients all have 'liabetes'! You know, lots of lying. Hiding meds, saying they did something they didn't do…There is a lot of that, especially with the girls…. Because the mentally disabled girls are all kind of stuck in their tweens a little bit, emotionally" Sheila sometimes lumped clients together as a collective group, such as when she said, "[Clients] see the commercials for soda, and then when they go the restaurant, they don't just get one or two refills, they get 10 refills of soda!"

While staff, supervisors and other professionals do discuss client identity, the pragmatic aspects of the overall social relationships often take precedence over any authenticity claims clients may make for themselves or that others may make on their behalf. The documented narratives presented as part of the bureaucratic technology that follows every client around allows these human service organizations to work on them as clients. This requires that these clients who have already gone through the "clientization" process have to retain this client status in order to continue to receive services from residential providers, case managers, and others. (Gubrium, Erika K. 2013, Spector and Kitsuse 1987, Prottas 1979, Gubrium and Järvinen 2013, Band-Winterstein et al 2013; Foley 2013: 187; Goffman 1961:375) "Clientization is a general process of turning people into clients suitable for the application of human services… service institutions and providers construct the clients they need for their work." (Gubrium, Erika K. 2013, p. 137) The function of many of the narratives about client identity authenticity, that are shared by staff and professionals, are at their most basic level the reinforcement of their authentic status of being a client in need of services. Clients who directly challenge

aspects of this narrative, who resist the authority of staff and other agents of social control, are inevitably overwhelmed by the response of staff and professionals to control their “behaviors”. For example, Clark and his team sought to get the “promiscuity” of his client “under control” when she was having more consensual sex than her staff (and parents) were comfortable with; the staff and supervisors engaged in a variety of interventions to reduce the number of reported consensual sexual partners that she had until her reported sexual behavior was reduced to near zero rates. The shift of overt, challenging sexual behavior that disrupts staff and guardian notions of acceptable client behavior has been replaced by no sexual behavior being reported by staff. While is seems more than likely that the client’s sexual behavior just became more covert rather than suddenly non-existent, this still accomplished the apparent goal of the team: to prevent the client from flagrantly expressing her sexuality in a disruptive way that is inconsistent with “appropriate” client behavior. If Clark’s client is sneaking around and having sex, Clark, his agency and the staff working underneath him all have plausible deniability. They are no longer “letting” her have multiple sexual partners; this removes the pressure from the other team members and the client’s guardians (and parents) who no longer have to “accept” that their adult child with intellectual disabilities enjoys consensual sex. Clients resist these attempts of staff and professionals to control their behavior through identity narratives by challenging or resisting various auxiliary characteristics of their “client” identity. While the auxiliary characteristics of clients that are challenged may vary widely, staff and professionals always have access to the tactic of mentally “lumping” (Zerubavel 1991) the client together with other clients who are constructed as incompetent and incapable of making knowing decisions on their own behalf. This

process justifies increasingly coercive measures to control the client's behavior "for their own good."

Staff Narratives of Identity Authenticity

Staff and supervisors and other professionals try to authenticate personal selves or group membership in several ways. The narratives which caregivers use to demonstrate that they are authentic staff people or professionals in this field focused on narratives which highlight the ability to handle difficult or dangerous situations with clients, personal characteristics of both good and bad staff, or ethical issues.

Staff use narratives that demonstrate their ability to handle difficult or dangerous situations with clients as proof of authenticity as competent staff or supervisors. Most staff people or supervisors presented stories of physical assault or even injury at the hands of clients as no big deal or as part of the job. Sheila's story of sitting down next to a client, who had complete visual impairment, and getting bitten by her, when the client was really mad at another staff person and didn't realize who had sat down next to her is demonstrative of the cavalier way in which staff would recount pretty serious injuries but dismiss them as part of the job. Some staff people claimed never to have been directly harmed by clients, though they also shared stories like Kyle's, detailing how he was able to keep a client calm enough not to assault him while he was tearing apart the vehicle they were riding in. Staff people also recounted how they had to navigate incredibly difficult and socially embarrassing situations with clients, like when Ava had a client who sat down in a gift shop and refused to leave, even after the shop was closed and the employees called the police. Jessica still has a scar on her arm from her first weekend shift as a staff person, when she was scratched by a client in the McDonald's parking lot, then the client spent most of the weekend smearing feces all over the ISL. She had no

training or support from the agency or supervisor. "And the whole time I was like, 'What in the hell have I gotten myself into? Why am I doing this?' And here I am, over twenty years later!" Staff recounting these "war stories" help authenticate their identity as "real", competent staff people.

Some supervisors share stories about how they helped clients through life threatening situations to affirm their status as competent supervisors. When Brandy was an on-call supervisor, a client with a complicated genetic disorder had pneumonia, so she took him to Urgent Care, but later that evening his fever spiked. Brandy knew from her experience that this was very dangerous and not explained by the pneumonia, so she called 911 and the client "coded" on the way to hospital. "So by the time he got to the ER his lungs were totally occluded, and he was in intensive care for like 3 months. If I had not called the ambulance, he would have been dead. Because the staff who was working with him wouldn't have known."

Supervisors also share narratives about they routinely work long hours to demonstrate that they are committed to the jobs and the staff and clients they are supporting. Joe tells the story of working 157 hours in a week, which has 168 hours total, rather than have "bad staff" work in an ISL Brandy recounted how she routinely worked over 80 hours a week in order to get everything done, "Because I have high standards for myself. My individuals deserve the best from me."

Narratives centering on the personal characteristics of staff people and professionals in this field are used to delineate what makes a good staff person, and what makes a bad one. Good staff people are a vague group of people who essentially are able to remain unmarked, and therefore not "bad". Jessica has a diverse group of "good" staff

working for her. “We have such a gamut of employees. It’s great. I think it takes all kinds to make it work. Because what works for this person [gestures to her left] doesn’t work for this person [gestures to her right]. And you’ve got to know those personalities and know who’s going to mesh with who.” While Jessica notes that every employee needs support and direction from active supervisors, and has been able to retain her diverse workforce for years without having and “bad” staff people, other supervisors are more likely to blame the individual staff person if things go wrong. Jenny notes that she trains staff, but that they “won’t listen to me!”; Jenny is convinced that good people are good staff and bad people are bad staff. She did not note any follow-up guidance or support for the staff members other than her initial lecture on what they “should” do. The presence of a good “work ethic” or the idea that staff are either empathetic or they are not, was a common narrative among supervisors and staff. Bad staff people were seen to be lazy by Lisa and others, or prone to viewing the job as being either a “babysitter” or a “warden” by Don. Only staff people who are caught overtly engaged in abuse or neglect of clients are typically labeled as “bad” for long. For example, John shared a narrative about a “bad” staff person. A client came to him and said, “I don’t like being called a retard…Sally calls me a retard…All day long when you guys [supervisors] aren’t here. She calls me lazy. She calls me stupid. She calls me a retard. She calls me dumbass.” The other staff were afraid supervisors wouldn’t do anything if they reported her because she had been promoted to a lead DSP position, because she was the hardest worker in the building when supervisors were there; when they left, “…she turns into the worst drill sergeant in the history of drill sergeants and just screams, hollers. She bosses her coworkers around and belittles them. She is just a total tyrant, just an awful person.”

Even if supervisors terminate an employee in this field, the desperate staffing shortage makes it easy for them to get the same job at another agency nearby, unless they are officially placed on the list of those with substantiated abuse and neglect charges by "The State." Respondents always positioned these accounts of good characteristics of supervisors or staff people to align with their characteristics, increasing their identity authenticity claim to the identity of a good supervisor or staff person.

Ethical and moral narratives also played a significant role in caregivers establishing and maintaining an authentic identity as a good staff person or supervisor in this field. Treating both staff and clients ethically and morally was important to many of these narratives. When asked why she does the right thing when there is almost no chance that she would be caught doing the wrong thing, Jessica responded, "Morals! I want to be able to lay my head down and know that I did what I needed to do and not what I could just get away with. So, I just feel like, a lot of people have that "If you didn't see it, it didn't happen," mentality. And it's like, "NO! It's just not in my DNA! .... I think it is either in your DNA or it is not. I would like to think that most people who do what we do are in it for the right reasons and have the same morality. But I know that I've seen it over the years, and it's like, 'No.'" Advocating on behalf of clients getting fair treatment, either by not restricting their rights needlessly or through medical advocacy was also presented as a common way in which professionals could maintain authenticity as a good member of their work group, whether that was as a supervisor, a case manager, or as a behavior analyst. Brandy noted that a "bad" staff person appeared to be willing to lie and get others in trouble in order to get a preferred shift, while Joe told a story about a "bad"

supervisor who used his position of authority to pressure a staff person to engage in an unwanted sexual affair.

Identity Multidimensionality in ISLs and Group Homes

Identities are combinations of a number of intersecting elements, and identity multidimensionality refers to the ways in which these multiple intersecting elements are navigated by individuals and groups (Brekhus 2020:1). The intersectionality of multiple identities can often create very different social circumstances for those experiencing both simultaneously, rather than one or the other. The intersection of multiple identities may result in a great deal of complexity. Intersectionality examines more than one variable (race, gender, class, nationality, etc.) at a time (Said 1979). While social scientists often focus on broad categories of identity in their analysis, individuals often treat a combination of identities as more salient in shaping their social views and identity (Brekhus 2020:106). The simultaneous interaction of multiple axes of marginalization is *not* the same thing as the sum of the different individual axes of marginalization, and that analysis must consider the axes together (Hill-Collins 2019, Brekhus 2020:105). The lived experience of the intersectionality of being both a woman and being black is qualitatively different than being either a black man or a white woman, for example, and that various identity categories are not operating independently of one another but are intersectional and complexly interwoven (Hill-Collins 2019). Identity attributes for clients, staff and others in this setting can be viewed as the ingredients in a recipe, with the marked attributes standing out and the unmarked attributes blending in as present, yet not worthy of comment (Brekhus 2020: 110-111).

There are several aspects of this multidimensionality that are significant in the identity narratives of the social world of ISLs and Group Homes. Labeling individuals with specific diagnoses can be a significant part of the social marking process of clients in this milieu. This clinical "marking" (Brekhus 1998) had effects beyond the clinic or doctor's office. People with diagnosed conduct or behavior disorders are typically discursively marked by non-medical and non-professional groups and are often treated differently based on this non-conforming or deviant social label (Hardwood 2006:5). These people may engage in behavior similar to that of unmarked peers (see Zerubavel 2018) yet be treated quite differently.

Client Identity Multidimensionality

While the common element of a client's identity is the status of disability, many other salient identity narratives play a significant role for client identities. The need to protect clients from society, issues related to perceived mental illness, and broader identity category membership along various axes such as race, class, gender, sexual orientation, etc. are all factors that intersect with the disability status of clients in this world.

Clients are routinely positioned as potential victims who need to be protected from "society" by caregivers. Many clients do have a limited understanding of the ways in which they can be taken advantage of by others, leading to potential exploitation by bad actors. The same could be said for most of us, whether we are talking about vulnerability to the influence of advertising, con artists, or being taken advantage of by loved ones. Lewis noted that adults with disabilities are treated by most people as "forever children who will always need a parental figure to tell them what is right and what is wrong and to guide their lives." Clarissa recounted a story about a client whose

family would come to his ISL to visit and routinely leave with money, a television, or a bunch of DVDs or a radio. In response, she advocated for the client to meet the family at a restaurant and to limit the money he could take to the meeting to $20.00, so that the family "couldn't take advantage" of him financially. While this appears to be a clear case of an intellectually disabled person being taken advantage of by others, his potential status as a member of that family who wants to provide whatever assistance he can to help the family out complicates this scenario. The client's identity as a person in need of protection AND as a member of a family in desperate need of resources collided, and Clarissa and the other (white, middle-classed) members of his team removed his ability to financially assist his family during their visits. Sheila recounts a somewhat humorous story where she took a client, Jason, to a friend's house and he was given a doggy biscuit. When the dog came over to Jason to get the doggy biscuit from him, Jason couldn't give it to him; he had eaten it! The sad back-story to this is that when Jason was living with his biological family, he was reported to be living outside with the dogs before being removed from the home and put into placement. Attempted interference in the consensual sexual activity of clients by their support teams is presented as a positive step in "reducing her promiscuous behavior" in Clark's narrative and is presented as a violation of the client's innate rights to express themselves sexually with willing partners in Charles' account; the primary difference appears to depend on the preference of the narrator. John tells a story about a guardian who removed her daughter from a group home when John refused to follow the guardian's instructions to "force" her daughter to break up with her boyfriend, though no mention of sexual activity was ever made in that narrative. Clarissa shared her outrage as she recounted the story of a moderately

intellectually impaired client who was forced to pay child support out of his social security benefits to the mother of his child, a former staff person of his! It is unclear how a client who is clearly the victim of sexual assault ends up financially responsible for a child resulting from his being victimized, but perhaps the cultural bias toward a father's financial responsibility toward his children outweighed his status as a person with disabilities.

Multidimensional identity components often include mental illness, behavioral, and medical issues in the world of ISLs and Group Homes. While all clients in placement have intellectual or developmental disability diagnoses, a significant portion additionally have additional diagnoses such as conduct disorders, depression, bipolar disorder, eating disorders, phobias, obesity, high blood pressure, cancer, cerebral palsy, etc. Whether the mental illness diagnoses which are applied to Dual Diagnosis clients are accurate or not (see Goffman 1961 for a scathing assessment of the social construction of the psychological diagnosis of mental disorders), the application of this label does complicate the identity narrative of the client that is accepted by the staff and professionals on their team. Clark shared a story about a client in a lock-down facility "Who did things to babies. Sexual things. He…he needed to be there. One of his protection mechanisms, if someone asked him to do something he didn't want to do, or if staff was coming after him, he would take off all of his clothes and he would bend down and defecate in his hand and smear it all over himself. Thinking that with all that on him, we wouldn't touch him." Clark's inclusion of the stigmatized identity of the client appears to help justify Clark and the other staff people "coming after him" and potentially deflect sympathy away from the client.

Race, class, gender, sexual orientation, religious beliefs and other identity dimensions that are significant for most of us are also important to people in ISLs and Group Homes. The unmarked status of a white client versus a black client in Brandy's story is a clear example. "Dangerous? Oh, well, I've been violently attacked many times, by Randy probably at least 10 times. And the worst was James. He almost scratched my eye out. I had big, bloody gouges down my face…And this happened *in* the ER! It took 8 security guards to pull him off of me. He is a big, strong black guy. And he was enraged." While Randy's race (white) is unmarked, James' race (black) is marked. Whether this is because for most white people in America today, "white" is the unmarked, default racial category and "black" is marked, or if there was additional intent in focusing on James' race is not totally clear. After a case manager and his son assisted a client when he moved, the client offered to buy them lunch as a way of saying thanks. The case manager and his son declined, and the client asked, "'Are you sure? This may be the last time a ni@@er offers to buy you food!'…and my son was just like, [makes a stunned expression.]" Kyle and his son are both white, and the client was described as "a big African American guy." While told in a humorous way, the unspoken racial divide between this client and these two white guys was being played with by the client in the story, who seems to have "Code Switched" when using the "n word" to refer to himself with a non-black audience in order to tease the case manager and his son a bit. When a client, Alan, asked for help in exploring different queer identities, his Sheila felt fully justified in side-stepping the entire issue on "non-standard" sexual orientation or gender identity. "*Please,* talk to a professional about *that*!" While Sheila felt comfortable in taking him to drag shows and indicated that she would support whatever decisions he

ended up making about it, but she indicated that she didn't know much about the gay community, and that she was nervous in trying to help him make decisions about his identity in this way. When a gay client wanted to move in with another client who was also gay, he faced opposition from case managers at "The State", who didn't want to "allow" this to happen. Jessica advocated for this client, who was his own guardian when the process started. He made some mistakes (Jessica was vague on this point) and the client ended up losing his guardianship status during this period. He was appointed a guardian by the court, and this guardian did not approve the move. "He gave up on fighting that fight. Because they took any control away from him. And I just felt like that was so…wrong. And how crippling to him. To take that power away. Because he wants to live with somebody else who happens to be gay and he is gay. When it could just be that you have that common interest…You know, that common life experience." Two men living together in an ISL is the norm in this field; if the sexual orientation of the clients was unknown to the case managers and others on the case, the move likely could have occurred without issue. It should also be noted that in this particular case, the client was wanting to leave a large, politically well- connected agency to go to live in Jessica's smaller agency with significantly less political power. The story as told by Jessica suggests that the case managers and other bureaucrats at "The State" seized upon the issue of two gay men living together to stall the move, then when the client wanting to move was determined no longer suitable to be his own guardian used their connections to keep him, and his funds, where he was. This theme of client choices being honored only when it doesn't run counter to the interests of the most powerful groups involved on their

team is a common one in this social world. Phrased differently, clients are only allowed to make meaningful choices when those choices are acceptable to those with real power.

Staff Identity Multidimensionality

Identity multidimensionality plays a key role in the construction of identities for staff people in this social world. Staff people incorporate a very wide array of identity narratives, which seems to draw from a very wide cross section of the population. Entry into the field is often through happenstance, with almost all of the people in this field getting started because they needed a job and seeing an entry level position that sounds somewhat interesting to them, so they gave it a shot. Blue collar workers, single parents, immigrants, college students, empty nesters, and students needing volunteer hours in Occupational Therapy or Physical Therapy are all groups that begin work in this field. As an entry level position, being a staff person is a relatively easy job to get, and as a low-paying job, it is a relatively easy job for most workers to replace economically if they so choose. Navigating different audiences as a staff person, managing multiple selves as a staff person and trying to be the type of staff person you want to be are three dominant aspects of understanding staff identity multidimensionality as presented in my interviews.

Most of us present different selves to different audiences at different times to accomplish different goals. When staff and clients are by themselves in ISLs or Group Homes, there is the lowest level of oversight and supervision over staff, and the staff person is under the least external pressure to perform to any particular standard. This "backstage" setting (Goffman 1959) allows for less formal interactions between staff and clients and may be a great time for rapport building and a fluid and supportive social interaction when staff support clients in their daily lives, and the clients are flexible and understanding of staff preferences and job duties or personal errands. When other staff

people are present, there is more accountability present, as other staff people would be credible witnesses if staff engaged in misconduct; however, most staff people seem to be averse to turning people in for wrongdoing, even if they witness this occurring themselves. Clark noted his reluctance to say anything when several other staff at an ISL he worked at were stealing groceries from clients. Lisa's treatment at the hands of the more experiences staff members at her ISL after turning them in demonstrates some of the informal sanctions staff can impose on their peers, including social isolation and negative social interactions. This is in direct violation of the mandatory reporting of suspected Abuse or Neglect everyone who has direct client contact has to complete and is somewhat surprising. The setting of ISLs and Group Homes becomes more of a "frontstage" space (Goffman 1959) when supervisors, administrators or case managers or other workers from "The State" are on site. Things are cleaned up more, staff are more attentive to clients, and staff people usually try to put their best foot forward to demonstrate the best staff performance that they can. At Snowy Creek ISL, Sheila actually complained that Lisa didn't "even know enough" to put on a "dog and pony show" for the case manager when she came by the ISL for service monitoring. John recalled a staff person who called clients names and screamed at and bullied staff and clients alike when it was just her and her peers, but when supervisors were on site, "she was the hardest worker in the building." When staff are confident that supervisors will never really drop in during their shifts, they will ignore their guidance altogether and just do things as they are trained by peers in the field to do them, according to Jenny. Staff are much more likely take on the supportive staff persona that their supervisors want them to when they receive positive role modeling and supervision. Jessica's practice of

encouraging staff to text supervisors that they should “drop in” when their peers are not performing well allows for peer-to-peer relationships to remain stable while additional support and training is made available to staff people when they need it. Several respondents noted how staff and supervisors feel most scrutinized when they are being investigated for allegations of abuse or neglect, and some staff will become defensive or hostile toward either supervisors or administrators accusing them of engaging in abuse or neglect.

Navigating multiple dimensions of identity simultaneously as a staff person is complicated by issues of race, class, gender, cultural differences and other dimensions many people consider part of their core identity. A supervisor at an agency that employed a large number of staff people from Africa dealt with a number of issues related to language barriers and cultural misunderstandings. When a number of staff people from this tight knit immigrant community began to turn in resignation notices, she realized that there may be a problem. Clarissa discovered that an American born supervisor was treating the African immigrants poorly. She recruited some cultural insiders to help her understand the problem, and they had not reported the supervisor’s misconduct to her because there was a cultural assumption that she was aware of and supportive of his methods. Once she fired this supervisor and did some other things to bridge the cultural gap, staff stopped leaving the agency and staff morale improved. Minority staff members are routinely exposed to racist and sexist taunts from some clients when the clients are upset, challenging their ability to be a supportive staff person while wanting to stand up for themselves and be free from bigotry in the workplace. The prejudice is sometimes on display between staff people and others, as when Sheila suggested that a decision maker

was easier to manipulate to oppose women in positions of authority at the agency "because he is Middle Eastern, and you know what they think of women in charge."

The different roles that staff people are expected to occupy vary significantly and can be a difficult identity dimension for staff to navigate. Being a good staff person means different things to different people, as does being a bad staff person. Staff are expected to provide support for clients in living their lives, including in having the freedom to make choices, while simultaneously keeping the clients safe and free from harm. Significant differences exist between what constitutes good and bad staff people, but no staff person that I interviewed thought of themselves as a bad staff person, even when other people I interviewed claimed that they *were* bad staff! Good staff people were identified to have some of the following identity dimensions: a good work ethic; ability to use humor; willingness to put the needs of the client before their own; ability to stay calm under dangerous conditions; willingness to follow the rules, even when it would be easier not to; keep the clients safe; willingness to work hard to benefit clients; tolerating physical assault or even injury as part of the job; accepting verbal abuse from clients, even vile racist, sexist or other verbally abusive comments from clients without responding "inappropriately"; being willing to help out fellow staff to benefit the clients; taking clients for appropriate outings in the community; tracking and logging all progress toward individual goals for each client; helping clients keep their living area clean; helping ensure clients get all appropriate hygiene tasks done; tracking all financial transactions clients make to the penny and keeping receipts ready to be audited at all times; being pleasant and socially attentive toward clients; following any Behavior Support Plan that may be in place; following all appropriate Rights Restrictions that are

in place for the client; reporting any suspected abuse or neglect of clients; keep current on all documentation; stay up to date on all required training; etc. While this laundry list of things that “good” staff people do is impossible for any staff person to adhere to at all times, all staff people do perform *some* aspects of this identity at *some* times. This complex identity narrative of a good staff person can be constructed by each staff person to include what they think that they actually do, while discounting or minimizing what they do not. Part of the emotional and defensive responding that is often exhibited by staff people when they are confronted by supervisors or investigators from “The State” may be an attempt to refute the identity dimension of “bad” staff person they are being confronted with. This may be part of the reason that some staff people like Sheila and several others, seem to actively avoid situations in which objective evidence of wrongdoing, like driving recklessly with clients in a company vehicle with onboard monitoring of driving performance. In this way, all staff people can construct a good staff person identity for themselves, even if they are seen as bad staff people by others. If someone attempts to stigmatize them with a subjective identity trait linked to a “bad” staff or supervisor identity, they can attempt to counter this narrative by presenting alternative identity claims which align with a “good” staff or supervisor identity.

Professional Identity Multidimensionality

The multidimensionality of professionals such as supervisors, administrators, behavior analysts, case managers and other professionals in this field is similar to many of the same pressures as staff, with a few significant differences that are worth noting. The professional nature of these positions make it more difficult to get or replace these jobs, so supervisors and other professionals may value their positions more than staff people and view threats of being fired or disciplined more seriously as a result. Clarissa

shared a story which highlighted some difficulty she had in navigating different dimensions of her identity. She was accused of racism over writing an attendance policy, because there was not enough time for staff from Africa to make the trip to their home country to visit family and return without violating the policy for full time staff attendance for the agency. “And that was hurtful. My son is biracial, so it just never seemed to me that somebody would call me racist for, like, writing an attendance policy!” As an agency administrator, Don refused to have his staff people transport a client across the state with marijuana that his guardian purchased for him illegally. During an IP meeting for this client on Zoom, the guardian yelled at Don, “You cocksucker!” While Don, who is an educated, middle-aged white guy, was laughing about this story, it does highlight the mother’s inability to effectively navigate her different identity dimensions in order to be an effective advocate for her son’s needs in a professional space. There were also some socioeconomic status and racial undertones in the story, indicating that the guardian was poor and from an urban setting attempting to impose what seemed to her to be a common-sense solution to a problem that a middle-class white woman would have solved by transporting her son to a local dispensary with his medical marijuana card.

Identity Mobility in ISLs and Group Homes

Additionally, different identity traits are valued by different audiences in differing, sometimes opposing, ways. Just as sexual orientation can be an individual’s master status at all times, only in certain bars and other social situations, or it could be a more blended part of a person’s identity (Brekhus 2003), disability as an element of identity can be deployed by individuals in different ways in different contexts or at

different stages of their life. Collective identities emerge from dynamic social interaction and are influenced by institutional and situational factors (Gecas and Burke 1995; Goffman [1963] 1999; Holstein and Gubrium 2000; Ross and Nisbitt 1991; Scott and Lyman 1968). The narrative environments and contexts people operate in are intertwined with their identities (Gubrium 2005).

Clients and Identity Mobility

Clients in this social world struggle with Identity Mobility. Identity Mobility refers to, "…the movement of identity across time and space. People move across different social contexts and deploy identities as portable resources that they activate or amplify in some settings and deactivate or tone down in others. Identity is not stationary or fixed but shifts with physical space and social location" (Brekhus 2020:130-1). The master status of client with an intellectual or developmental disability is reinforced by the social and physical space in which they live, and clients are usually dependent on the assistance that this status entitles them to from caregivers. The clientization process (Gubrium, Erika K. 2013) has been completed by the time these people are ISL or Group Home residents, and the ability to transition from this status is very limited for most clients. Very few clients or their guardians decide to check them out of ISL or Group Home services; there is a long waiting list for ISL and Group Home services, so when a client is able to secure this level of support, it is rare for them to let go of it. While these clients may be able to explore identities beyond those compatible with and IDD client status, those clients who stay within this world find their identities very much locked into place. This identity mobility for clients is restricted by challenges to change from the team both in the name of benefitting the client and in ways that benefit caregivers. As Lewis noted, adults with disabilities are treated as "forever children" who will always

need a parental figure to tell them what is right and what is wrong and to guide their lives." Charles argues that while some people with mental illness diagnosis are able to get successful treatment and be accepted into society without the stigma of their condition being front and center in their identity, there does not appear to be a similar path out of an IDD master status. Clarissa expressed this commonly held belief among caregivers clearly, "Why is Brandon his own guardian? He is lucky the agency is taking care of him and looking out for him and protecting him. There is a fine line between restricting [a client's] rights and doing what is best for people."

Restricted identity mobility for clients is typically presented as being in the client's best interest, often for their health, welfare or safety. A case I consulted on involved a young woman who lived in an ISL hundreds of miles away. Her diagnoses included intellectual and developmental disabilities including Prader-Willi Syndrome. This is a genetic disorder which, among many other complications, leads to various symptoms including constant hunger. As is common for many people with Prader-Willi Syndrome, the food in her house was under lock and key to prevent her from engaging in potentially life-threatening overeating. Several years before I reviewed the case, her primary care doctor wrote a physician's order that she only be allowed to consume 1,000 calories per day, so that she would lose weight. In the intervening years, she had lost a great deal of weight, and was no longer obese. Her current team still restricts her daily calories to 1,000 per day based on the old physician's order. While most of us can take physicians orders seriously or ignore them each day as we see fit, this is not the case for most clients in ISLs and Group Homes. This is particularly true in an ISL where staff people lock up food to enforce the physician's order. The very system designed to protect

this person from herself and the physician's suggestion of a very low-calorie diet in order to help her lose weight was not flexible enough to register that her obese weight status had changed to a status of normal weight.

Identity Mobility for Staff and Professionals

Staff, supervisors and other professionals have significant room within this social world for identity mobility. The most salient impact of this social world to the identity mobility of caregivers at all levels is the increased identity currency that is gained through experience in working with adults with intellectual and developmental disabilities. The ways in which caregivers can evolve over time into more competent, more effective caregivers and professionals can be reflected in shifting identity narratives over time. Relationships with clients can change work relationships into meaningful relationships, much like family bonds. For example, Joe was attacked by a client while driving over a bridge over a large river. Joe pulled over to assist the other staff person in calming the client down, and to prevent a wreck. As soon as the car pulled to a stop, the client jumped out of the car, directly into traffic on the highway and was struck by a passing vehicle. The client was in the hospital recovering from his injuries for over a month, and Joe was one of the main staff people who stayed with him in the hospital. During this time, the client stopped being aggressive toward Joe and started calling him "Dad". Even though Joe has not worked at that agency for over five years, whenever that client has a bad day his staff will call Joe, and he is able to help the client calm down over the phone.

Identity Narratives as Technology of Social Control in ISLs and Group Homes

Identity Narratives are a critical aspect of how social control over others is enacted within this social world. Challenges to the authenticity of social actors are strategically deployed to decrease their power in a given situation. The multidimensional aspects of identity narratives allow for the skillful selection of the aspects of a social actor which will most support the course of action the narrator is trying to achieve. The mobile nature of identity narratives allow for the shifting of this focus as needed, and indeed, allow for the manipulation of the identity of others. This process is sometimes used to shift the identity of the subject in order to change them into their own agent of social control, to transform them into the agent of their own social control.

Chapter 5:
Summation, Findings and Recommendations for Policy Change and Further Research

Narratives from in-depth ethnographic interviews of respondents with roles within the social world of ISLs and Group Homes were analyzed to better understand the intersection of narratives and power in this social world. ISLs and Group Homes provided a decentralized setting in which to better understand the exercise of power and the role of narratives in a social world preoccupied with changing the behavior of others. The stark contrast in the power between clients and staff is similar to other situations in which power imbalances occur in society. Understanding how narratives are deployed in this social world is likely to improve our understanding of how narrative power operates in other social milieus. The patterns of narrative power usage between staff and clients in residential community placements are likely to be found in the ways in which a police officer interacts with an unhoused person they encounter on patrol, in interactions between a foreman and a worker with illegal immigration status, or in the accounts of caregivers and toddlers with injuries. In these examples, the nearly unlimited power to use framing narratives to dominate the social construction of the interaction and the power of identity narratives to influence the accepted identity status of those involved is possessed solely by the more powerful group. While there is certainly potential for abuse of this power, this power also appears to act to control powerful actors through the internalization of narratives. For example, many staff people go far beyond the requirements of their job to provide the best care they can at great personal cost. This appears to be influenced by the internalized framing narratives they have accepted about

why a client may use aberrant behavior (such as physical aggression or self-injurious behavior), as well as identity narratives they have of themselves which require calm and nurturing care provided in the face of difficult circumstances. In other social worlds, the police officer who spends a great deal of time and energy helping an unhoused person find shelter, the foremen who helps their undocumented worker get access to needed resources, and the parent who sacrifices their sleep to comfort a child with a toothache all demonstrate behavior influenced by the power of narratives.

The accounts related to the use of power in the social milieu of ISLs & Group Homes fell within two categories: attempts to influence the accepted definition of the situation, or framing narratives, and attempts to influence the accepted interpretation of who specific people are, or identity narratives. The power to interpret events and to frame the narrative that becomes the accepted definition of a situation is an incredibly effective tool, and one that all respondents used. Attempts to influence aspects of the accepted identity of either themselves or others was also demonstrated by all respondents. Narratives play a key role in attempts to control the behavior and interactions of everyone within this social world: clients, staff, supervisors and professionals alike. The ways in which clients, staff and supervisors use these narratives to attempt to influence others differs significantly. The reported success rate of different groups of people in this social world in effectively using framing narratives and identity narratives also dramatically different. Clients are almost always unsuccessful in effectively getting their definition of the situation to be accepted if that definition is opposed by any caregiver. In contrast, supervisors were routinely successful in imposing their narratives on others and having it accepted by them.

Framing Narrative Findings

Analysis from the framing narratives provided by respondents include a number of interesting and unexpected results. Consistent value being placed on the same ethical or moral issue by the same respondents was expected, but almost every respondent used the same value in different ways in different narrative contexts to achieve different narrative goals. For example, John spoke at length about the importance of honoring client choices and accepting the "dignity of risk", yet later recounted how that same client was found dead in an apartment after he had refused all residential services and moved out of the group home he had been living in. John framed the death as the likely result of the client not taking the medication to control his seizure disorder. Respondents reported that the political power of different organizations produced wildly different abuse and neglect investigation outcomes based on the political power of providers of ISL & Group Home services. This was shocking because investigative oversight is presented across the field as much more egalitarian and fact-based than respondents report is the case in reality. Findings related to institutional lives in the community, the desensitization of staff to violence, the universal powerlessness of clients without allies, the starkly uneven application of rules, and the fear that prevents misconduct reports are all discussed in greater detail in this section.

Institutional Lives Outside of Institutional Walls

The widespread presence in modern ISLs & Group Homes of the same techniques of social control of patient's behavior found in the asylums of the past was also quite surprising, running counter to the widely accepted narrative of improved quality of life and choices for clients. The "Insane Asylums" that were the default residential setting for

adults with intellectual and developmental disabilities in the United States decades ago were rightly condemned as problematic, and we have thankfully removed a significant percentage of adults diagnosed with intellectual and developmental disabilities (IDD) out of these substandard environments. Unfortunately, many of the horrors of institutional life have been replicated in these community settings like ISLs and Group Homes. While significantly cheaper and much more decentralized than the state-run facilities that most clients were removed from, ISLs and Group Homes are not a panacea for the problems criticized in large institutional settings. The technologies of social control that were present within these institutions, and the abuses that clients were subjected to, have simply been transported into community settings, essentially transforming isolated apartments or houses into small institutional wards in many cases. The problem is that the utter social control, the sheer level of physical, financial, psychological and social domination of staff over most clients in these settings allow for the replication of all of the worst aspects of institutional life to be reproduced in the community. The number of respondents that had experience in lockdown facilities, both state-run programs and psychiatric wards of hospitals, was also surprising. Respondents with experience in both institutional settings and in ISLs & Group Homes reported significant similarities between the lived reality of a client in a lock-down facility and restrictive ISLs and Group Homes in the community. This runs counter to the dominant narrative in the field which frames client experiences in community placements as significantly better than client experiences in habilitation centers or psychiatric wards.

Desensitization to Violence

The casual acceptance of physical violence that many staff related to me in interviews was widespread. Most respondents shared shockingly violent narratives,

which appeared to serve as a sort of rite of passage, solidifying their identity as an authentic staff person. While there were a few respondents who noted that they rarely or never experienced violence at the hands of clients while on the job, most respondents shared tales of serious injuries and described the literal scars that clients had inflicted on them. These narratives were almost always framed as an unfortunate situation or as a problem created by staff, and rarely placed responsibility for the violence on the clients who hurt them. Working with some clients appeared to be paired with expected, occasional episodes of physical aggression, but these episodes were almost never linked to problematic identity traits of clients. The exceptions were two clients who resided in the state hospital setting who were portrayed as sexual predators.

Clients Powerless Without Allies

Clients in ISLs and Group Homes are essentially powerless if they do not have an advocate. Multiple narratives from respondents demonstrated that when other staff people, supervisors or other professionals did not stand up for clients, the clients were not able to effectively influence the framing narratives defining the situations central to their care. Clients who had no allies had the entire system align against them to force them to choose between "appropriate", desired outcomes chosen by others. Many of the reported contested framing narratives appeared to incidentally be of benefit to clients but upon further analysis were only occurring due to a power struggle between members of their support team. The way these power struggles were depicted were very similar to the way in which the welfare of children in a contentious divorce is the overtly contested topic but may be secondary to the rivalry between the parents getting the divorce. Clients were never able to impose their definition of social reality in a contested setting without the support of other people with more social power. While it is not possible to determine

what the “real” motivation of advocates for clients might be, opposition to other team members and the advocate’s presentation of self as strong advocate of clients with IDD may increase social status or a “good staff” identity narrative claim.

Client powerlessness in framing anything of importance was so ubiquitous that the interview respondents did not even seem to be able to see it. While there is a great deal of discussion about client rights and client choices, there were *no* narratives in which clients were able to get their way in the face of unified opposition within the system. An interesting exception was a client who had lived on the street for a year and a half in the past; she could choose to stay in her ISL or leave the system entirely and return to the streets, which reduced the amount of pressure staff people felt comfortable placing on her. Staff people, even the staff people who argued most vehemently for clients to have their way, were more than willing to use their position of power over clients to overrule them if it was “important” enough. These issues of importance usually centered around safety concerns and liability concerns; if a client’s choice crossed a particular threshold determined by the staff member, then staff would reframe the situation from a client choice to a safety issue and impose their definition of the situation on the clients. While narrative power to influence what happened in their lives was usually absent, many clients were reported to use false allegations of abuse or neglect to get specific staff removed (at least temporarily) or to use intense problem behavior to get hospitalized, and even to eventually be transferred to another residential agency. The change of physical setting sometimes resulted in access to new advocates who might be willing to support their narratives.

Uneven Application of Oversight

Rules are applied differently to different agencies in the world of ISLs and Group Homes. While it is not too surprising that some agencies get additional consideration from state oversight agencies, the sheer magnitude of difference reported in these interviews was shocking. Large agencies that provide services to a large number of clients are able to use their power and influence in ways that smaller agencies cannot. The differences in political connections among different agencies creates a wildly different set of standards of staff and agency conduct that are tolerated. Large agencies and those with political connections are able to prevent investigations from starting, keep embarrassing stories out of the public eye, and generally get "looked after" by the oversight agencies at multiple levels of bureaucracy in a way that is not accessible to smaller, less politically connected agencies. Conduct that would get smaller agencies shut down or get their license to provide services revoked are tolerated by bureaucrats. Floyd, a state worker, said it most succinctly, "The traveling rules applied to Michael Jordan just like they applied to everyone else in the NBA, but the referees just never called traveling on him. Large agencies get to play by 'Jordan Rules'." While there was widespread agreement among respondents that politically connected agencies as being preferentially treated, independent corroboration of this phenomenon is beyond the scope of this research. It should be noted that Michael Jordan did get called for traveling by referees, despite the way it was framed by Floyd. Likewise, the perception of differential treatment of different organizations is widely accepted as true in this social world, even if it is not an objectively true narrative.

Fear of Peers Prevents Misconduct Reports

Staff people and supervisors are trained to be mandatory reporters of suspected abuse or neglect of clients and are not supposed to work with clients without completing this training. The training describes the different forms that abuse or neglect of clients can take, including physical, sexual, verbal or financial abuse as well as various forms of neglect. The training clearly positions everyone working with clients as mandatory reporters of any *suspected* abuse or neglect. Despite this training there were a number of respondents who described staff who knew about client abuse and neglect yet refused to report it as required. The fear of retribution from the accused party was the reason cited over and over, coupled with the commonly held belief that most allegations of abuse or neglect do not end with the removal of the alleged abuser. While a similar phenomenon is present among police officers who are reluctant to report fellow officers guilty of misconduct (often referred to as the "Code of Silence" or the "Blue Wall of Silence"), it was surprising to encounter a similar phenomenon occurs in an entry level job with very little occupational identity such as direct care staff. The fear of retribution, even from peers, seems to be enough of a threat to have a serious chilling effect on reports of misconduct. Many allegations of misconduct are reported by supervisors who catch subordinates engaged in abuse or neglect, and there are also a number of cases of both clients and staff making allegations against staff people they do not like out of spite. The abuse and neglect reporting system has been effectively weaponized by many people, though most allegations leveled by clients against staff are disregarded without additional proof supporting the client's claims. The American cultural reluctance to turn in rule-breakers may also have a chilling effect on staff reporting misconduct of their peers.

Identity Narrative Findings

Analysis of the narratives provided in the interviews led to a number of findings related to identity narratives. The marked nature of the client identity compared to other identities in this milieu, the weakening of narratives when challenged by counter narratives and the most effective type of identity narratives were the most significant results of the analysis of identity narratives.

Client Master Status

The identity that was most consistently marked within this social world is that of the client diagnosed with intellectual or developmental disabilities. While the precise term that these people are labeled with varies from organization to organization, the function of these terms are identical; to mark these people as the objects of the human service organization, to "clientize" them. There was no real discussion of the identity as a client being resisted by clients in ISLs and Group Homes, but this could simply be a selection bias reflecting that people who are able to convincingly refuse a client label are not in these placements in the first place. Adults with intellectual and developmental disability diagnoses in ISLs and Group homes are called a variety of terms: client, consumer, individual, participant, resident, etc. The staff people, supervisors and other professionals in this social world are likewise referred to with a wide array of occupational titles. The difference is that clients are labelled, or marked, with a stigmatizing label, while staff are free to remain essentially unmarked, powerfully "normal" (Zerubavel 2018).

Contesting Framing Narratives and Identity Narratives Weakens Them

Identity narratives that were contested by others could be more effectively resisted. Presenting a counter-narrative seemed to be a very effective way to counter the imposition of an unwanted identity narrative. One of the clearest ways that this phenomenon was demonstrated in the data was the triangulation of three respondents who worked in Snowy Creek ISL. The identity narratives they attempted to impose on one another were generally incompatible with one another; the same staff person could not be simultaneously a "lazy, bad staff person" and a "great, experienced staff person who goes above and beyond for the clients". The indirect use of identity narratives to attack the credibility of others, such as Sheila's claims that Lisa was younger than she actually was or that the supervisor Joe didn't know as much as Sheila about reporting requirements made any claims Lisa or Joe might make against Sheila less powerful. Sheila's attacking or discrediting potential critics was used to minimize expected attacks on her identity. The lack of power and credibility most clients have in this setting might help explain how they are less able to use counter narratives to effectively weaken the narratives claims of staff or professionals.

Internalized Identity Narratives Most Effective Social Control

The most effective method of social control over others in this social world occurred when clients or staff were reported to internalize an identity narrative presented by someone else. This internalization process effectively turned the receptive person into their own monitor. By accepting another person's definition of who they should be, the client or staff person becomes their own monitor, embracing identity traits that align with the accepted identity narrative and eschewing those identity traits or behaviors that might

undermine the identity being claimed. The individual client or staff person is then imposing the desired social control on themselves much more effectively and consistently than any outside agent ever could. This powerful technique can be used for what most observers would consider to be good ends, such as getting a client to ask for help rather than hitting her head against things until her forehead splits open. Most observers would also consider the increased discretionary effort a staff person may exert if they see themselves as a "great staff person" to be a good thing as well. This same process can also be used to shape identity in powerful ways that are not beneficial to most observers, such as keeping sexual abuse a secret or being a team player and looking the other way when a fellow staff person uses the client's EBT card to buy themselves some food. The most effective examples of this technique being used focused on emotional appeals to the client or staff person's identity.

Theoretical and Policy Implications

Narrative power plays a role in the application of social power. The ability to impose the narrative that dominates how others see a contested situation clearly allows for individuals or groups to impose their will on others. The ability to accept or dismiss the identity claims made by others in a social setting is another way in which to influence the behavior of others. The ability to effectively use narrative power can also be associated with certain social roles. For example, a case manager may be more effectively able to impose their will on a client or a direct care staff person than they can a supervisor or an agency administrator with political connections. While some staff people are going to be more effective than others in imposing their will on others, all staff people begin with an advantage in narrative power over all clients by virtue of their social

role. Likewise, supervisors inherently have more power to define a situation or an identity status, like "good staff person" or "bad staff person" than the staff person does in this social world.

Power relationships are reproduced by the cultural expectations that accompany the different roles. A great deal of the narrative power that a social actor has to influence the behavior of others in this field is based on their ability to define the situation in a particular way or to shift the accepted identity narratives. For example, when a supervisor is able to convince staff people that the self-injurious behavior of a client is a reaction to past trauma rather than attention seeking behavior, this can effectively influence staff interactions with that client long after the supervisor is off site. Use of identity narratives that characterize the client as a victim of circumstances that entitle them to empathy from staff, as well as pushing the narrative that the staff people are "good staff" people who do great work with difficult clients can also influence staff behavior.

This research suggests the use of narrative power in different social settings with power imbalances reproduces this power imbalance in these settings. The inability to provide an effective counter narrative either in framing the situation or to identity claims make it very difficult to oppose a narrative. The ability to control the dominant, accepted version of what happens in a social setting and who people are is central to gaining social control over others. While this social process is easiest to see when narratives are effectively unopposed, a similar process likely plays out in social settings where narratives are more effectively contested.

Another theoretical implication of this research is how much easier it is to control the behavior of others when people in the subordinate social role accept the authority of

people in the dominant social role in the social scene. Significant problems that arose in the respondent accounts often occurred when clients were unable or unwilling to accept the control being imposed over them by others. Clients who routinely used physical aggression or who were routinely noncompliant with staff demands made it difficult for staff people to do their jobs. This often led to increasingly intense responses to "gain control" over clients. This could be physical restraint by staff, calling for police intervention, or the involvement of behavior analysts or physicians to get the "problem" behavior under control. The exercise of real power is in the ability to shift the narrative to make the subordinate role in the paired group dominate themselves; the real power is not in the private interactions between the social actors, but in the social acceptance of and deference to the powerful side of the dyad.

There was no systematic attempt to verify the claims of the narratives presented in this research as "true". The unit of analysis was the narrative that was presented. In triangulating the different narratives where they overlapped, it is apparent that they could not all be fully accurate. For example, Lisa's assertion that Sheila and some of the other staff at the ISL are "bad" staff, Sheila's framing of herself as a dedicated and committed staff person with deep personal connections to the clients in the ISL, and the supervisor Joe's contention that while Sheila has decades of experience, she is almost impossible to supervise cannot all be fully accurate. These narratives all achieved the same goal for each respondent: to frame the respondent as competent and justified in their actions and approach. These narratives all attempted to do this by highlighting different negative identity traits of rivals while using identity mobility techniques (Brekhus 2020:130-131) to position their own positive identity traits to their own benefit.

These finding lend themselves to several policy implications. This research may increase understanding of better methods to deal with staff misconduct, identify techniques that may improve "good" staffing behavior in the field, and a caution that setting changes don't always improve outcomes.

This research suggests two effective tactics to reduce the occurrence of "bad" staff behavior in ISLs & Group Homes. The first tactic is the disruption of problematic staff behavior accomplished by disrupting extremely powerful social cohesion between staff (such as close family members working together in an ISL) and giving them anonymous methods of reporting wrongdoing. Respondents who recounted the ways in which people were afraid of retribution were intimidated into silence rather than reporting abuse and neglect all had one shared element in their stories. Each of the potential whistleblowers stated that they wanted to report the abuse or neglect, but they felt too vulnerable to retribution, fearing that the alleged abuser would not be held accountable for their wrongdoing and that the reporter would essentially be punished for coming forward. If there were ways to report the problematic staff behavior without getting implicated, all of the potential whistleblowers indicated that they would have reported the incidents. A supervisor who has had really good staff interventions encourages her staff to prompt her by text to "pop in" if something they are concerned about is going on with another staff person. This allows them to effectively report the problem while giving the whistleblower plausible deniability, because the supervisor just "pops in" and will often immediately see the issue and deal with it. Real behavior change is often accompanied by objective evidence, which can be used to hold people accountable for wrongdoing. An example is the online agency vehicle monitoring that sends alerts to supervisors when

unsafe driving behavior occurs. Cameras in common areas of ISLs could be combined with anonymous reports from other staff, who may suggest “taking a look at the tape from yesterday” in order to successfully report abuse or neglect anonymously, since tape review could have caught the behavior without anyone “snitching.”

A second policy implication based on the results of this research would be to use framing narratives and identity narratives to improve staff behavior. If supervisors build up the “good staff” identity narrative of the staff people in meaningful ways, it would, if effective, lead each staff person to serve as their own supervisor who can provide constant monitoring to provide “good” staffing to the clients in order to maintain a “good staff” identity. Close supervision with a trusted supervisor allows staff to have their framing narratives adjusted in real time if they are reacting poorly to a specific situation. Manipulation of the identity narrative suggesting that they are a “great staff person” may encourage additional discretionary effort from staff, making it a self-fulfilling prophecy.

The third policy implication based on the finding of this research is that simply moving people out of institutions and into ISLs and Group Homes is a first good step in reducing the negative impacts of institutional settings, but it is insufficient if there is no oversight to ensure the technologies of control and the abuses common in institutional settings do not get replicated in ISLs and Group Homes. Specific training of state oversight personnel, usually referred to as case managers or service coordinators, may be necessary to teach them how to recognize signs that inappropriate technologies of control are being used in the community.

Potential Areas of Improvement for Research

This analysis would be very difficult for other scholars to replicate. A significant portion of the study design, interview techniques and data analysis were informed heavily by the author's extensive experience in and familiarity with the social world of ISLs and Group Homes. Another potential area for improvement with this research is that the voices of clients are only indirectly heard through the narratives of staff, supervisors and other professionals. This is a particular shortcoming when it comes to understanding the subtle tactics that clients may use to resist the social control of staff in this social world. While there were numerous, valid reasons to exclude clients as potential interview subjects, if the concerns about confidentiality could have been adequately addressed, they potentially would have enriched the data set. A final consideration is that the unit of analysis in this research is a narrative. Not only is it difficult to say with precision when a particular narrative begins or ends, it is also impossible to determine the veracity of the claims respondents made in their interviews. Some narratives shared in interviews were not accurate, according to my independent knowledge of the situations described. The Thomas Theorum suggests that the narratives do not have to be real in order to have real effects in the social world (Thomas [1928] 2003: 81).

Conclusions

Attempts to use power to exert social control over others is a very common social phenomenon. The analysis of framing narrative and identity narratives in the social world of ISLs and Group Homes makes this social phenomenon easier to observe, due to the clear difference in social power between clients and other social actors in this milieu. Real social control is interactional, ubiquitous and often hidden within social

relationships and identities that may vary somewhat in every social situation. Learning more about the role of narratives in influencing the behavior of others is a complicated, yet worthwhile endeavor. Based on this study, some interesting conclusions can be drawn.

The internalization of identity narratives can be an incredibly powerful way to influence future narratives and behavior. Respondents such as Brandy, Joe, Clarissa, Jessica, Luke, Charles and John all described themselves as ultimately responsible for the well-being of the clients in their care. They each recounted making significant sacrifices of time, energy, professional risk and risk of personal injury in order to do what they thought was right for their clients. While all respondents positioned themselves as heroes within the narratives they told, if this identity narrative of being a self-sacrificing protector and defender of "their" clients is *truly* internalized, encouraging this internalization process could be a key aspect of improving the discretionary effort of caregivers in this field. While potentially false identity claims were not investigated, some respondents did appear more interested in their reputation than outcomes for the clients in their care; the salient narrative difference between those who seem to have truly internalized this identity narrative and those who paid lip service to it seemed to be the willingness to sacrifice something significant in order to benefit clients in a meaningful way.

The power dynamics in the social world of ISLs & Group Homes are instructive in how narrative power is effectively used. The ability of caregivers to use narrative power to dominate clients in these settings is clear and stark; clients ultimately either get allies to assist them or they ultimately lose every contested, meaningful choice regarding

their care. This reflects the power of the position of the staff people, supervisors and professionals in being able to dominate the accepted definition of any contested situation and to dominate the accepted identities of the social actors involved. Narrative power over other caregivers was much more effectively resisted than narrative power over clients. This appears to be the result of the ability of most staff people to counter any framing narratives or identity narratives much more effectively through their own counter-narratives. The contested narratives at Snowy Creek ISL are a clear example of how complicated the use of narrative power can become when it is contested. Most attempts to use narrative power more closely resemble the contested and unclear narratives observed between staff and supervisors in ISLs & Group Homes than the clear and effective use of narrative power between staff and clients. While more study of this phenomenon in different settings is needed for verification of this social phenomenon, this suggests the use of narratives to influence others is widespread yet is most clearly observable when significant power imbalances between social actors is present and the interaction is simplified.

Being a client in an ISL or Group Home is an identity that serves as a master status, which serves to mute or wash out other identity characteristics within this social milieu. The unmarked status in this social world of being a staff person, supervisor or other professional in the field gives the double status of NOT possessing the disabled person stigma (even though many caregivers do have a variety of physical and psychological disabilities) and of having an occupational role which entitles interference in the lives of clients. While issues of race, class, gender, sexuality, nationality, education level, mental health status and various other identities are all present and interacting,

none of these came close to being as meaningful as the client/non-disabled identity in this social world.

Being accused of abusing or neglecting a client within the social world of ISLs & Group Homes is similar to the stigma of being accused of being a racist. The subjective nature of the evidence of this identity narrative being “true” or not makes countering accusations of abuse or neglect very effective. The stakes for the person accused of abuse or neglect are typically more intense and personal than the stakes for their accusers. Absent some permanent record of the abuse or neglect, such as a video or audio recording, it is very difficult to substantiate accusations of abuse or neglect of clients. The apparently false allegations leveled against staff people by clients, or even by other caregivers, also gives cover to caregivers who actually *do* engage in abuse or neglect of clients, who can just claim it is another false allegation. The increased use of body cameras by police officers has at least partially addressed this issue in law enforcement, by providing an objective record of what transpires between police and those they interact with. Similar measures, whether they are body cameras worn by staff or cameras in common areas of ISLs and Group Homes may serve to protect clients more than the current system. The current system of mandatory reporting of suspected abuse or neglect by staff is often not followed by staff who suspect abuse or neglect, and when staff do report suspected abuse or neglect of clients, decisive measures to prevent further abuse or neglect are rarely implemented.

Narrative power is an important social phenomenon, and it is hoped that this research may play a part in better understanding the role of narrative power in other social settings.

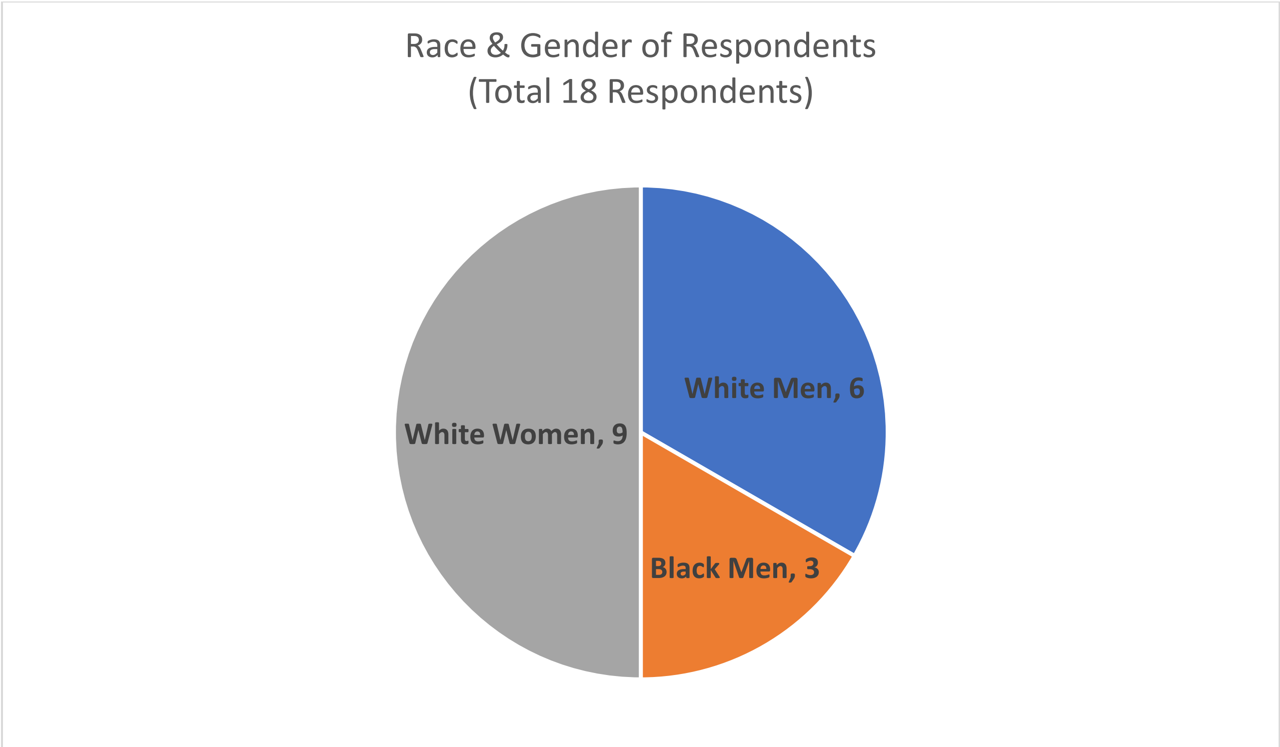
Appendix A- Semi-Structured Interview Questions

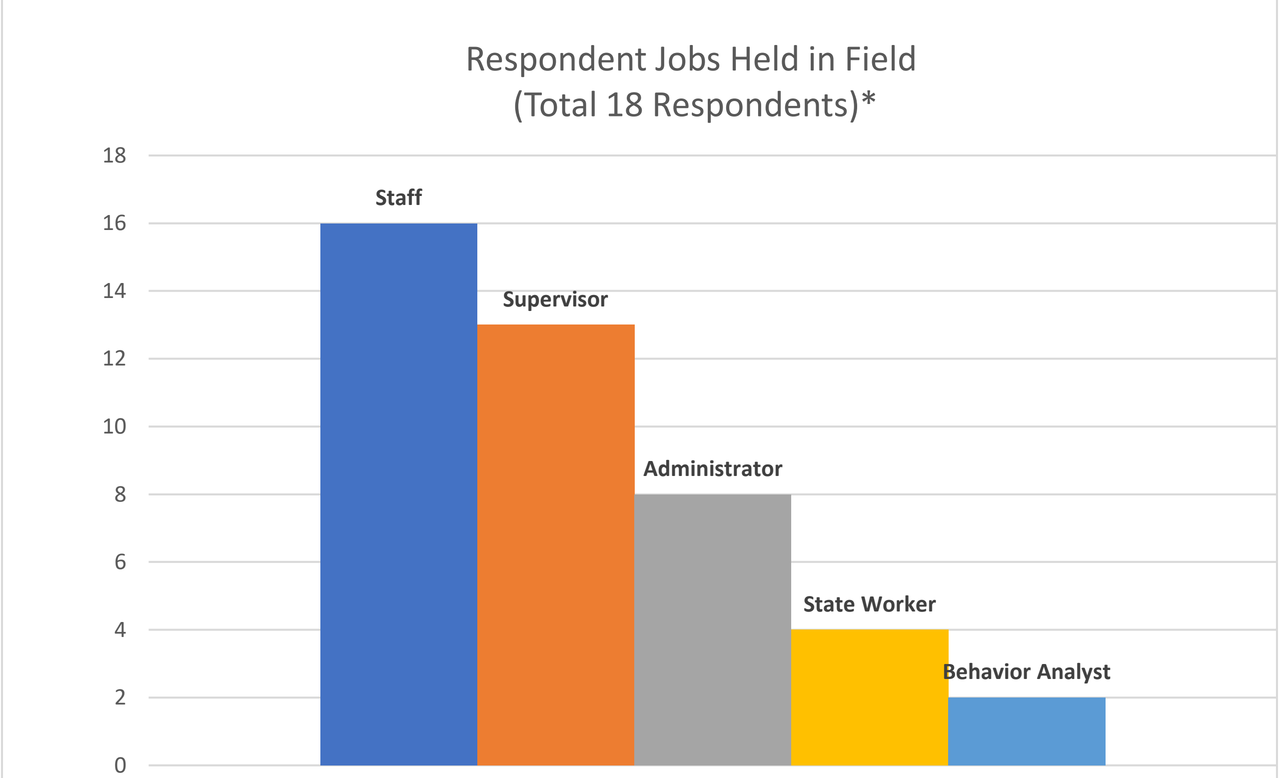
Statement regarding confidentiality, mandatory reporting of abuse/neglect, option to stop at any time or refuse to answer any question without penalty. Identity protection measures: any record will be used to make detailed notes with identifying information of interviewed person (and any other people or organizations) modified to protect identity.

1. What is your current occupation (or occupations if more than one)? What other jobs, especially in this or related fields, have you had?
2. How do you explain your occupation to friends or family unfamiliar with the work you do in this field?
3. How long have you been working in this field and what led you to work with people with intellectual and developmental disabilities?
4. Could you describe one of the most dangerous situations you have been involved in while working in this field?
5. Is there anyone in this field with a job similar to yours that you think does a really bad job? How or why?
6. What is the one of the funniest stories you have from working in this field?
7. Do clients have the right to decide to eat too many donuts or take a nap when they want? Why or why not?
8. Think back to when you first started this job. Have you changed at all during this time? In what ways?
9. How would you describe the different types of clients you have worked with?
10. Who really decides what happens or doesn't happen in ISLs or Group Homes you have worked in?
11. What is the wildest/most unbelievable story you have from work?
12. How would you describe the different types of staff people or supervisors you have worked with?
13. How do you get people you work with to stop doing something that they should not be doing? Please share an example of this.
14. Many people describe a big difference in what they include in the "official" paperwork in this field versus what really happens. Have you ever witnessed anything like this?
15. Is there a type of client or type of behavior that you try to avoid working with? Please explain.
16. What do you think are the most important parts of your job, that you make sure happen before anything else?
17. What are things you are supposed to do as part of your job that you put the least effort into or think are the least important?
18. What is it that keeps you coming back to work in this field? Was there ever an event that made you want to quit?
19. Who is one of the most challenging people you have worked with in this field? Can you share a story about an incident that really stands out?
20. What motivates you to do a good job when you know you wouldn't be caught if you didn't? Do you think most people who have your job are motivated by the same things you are?

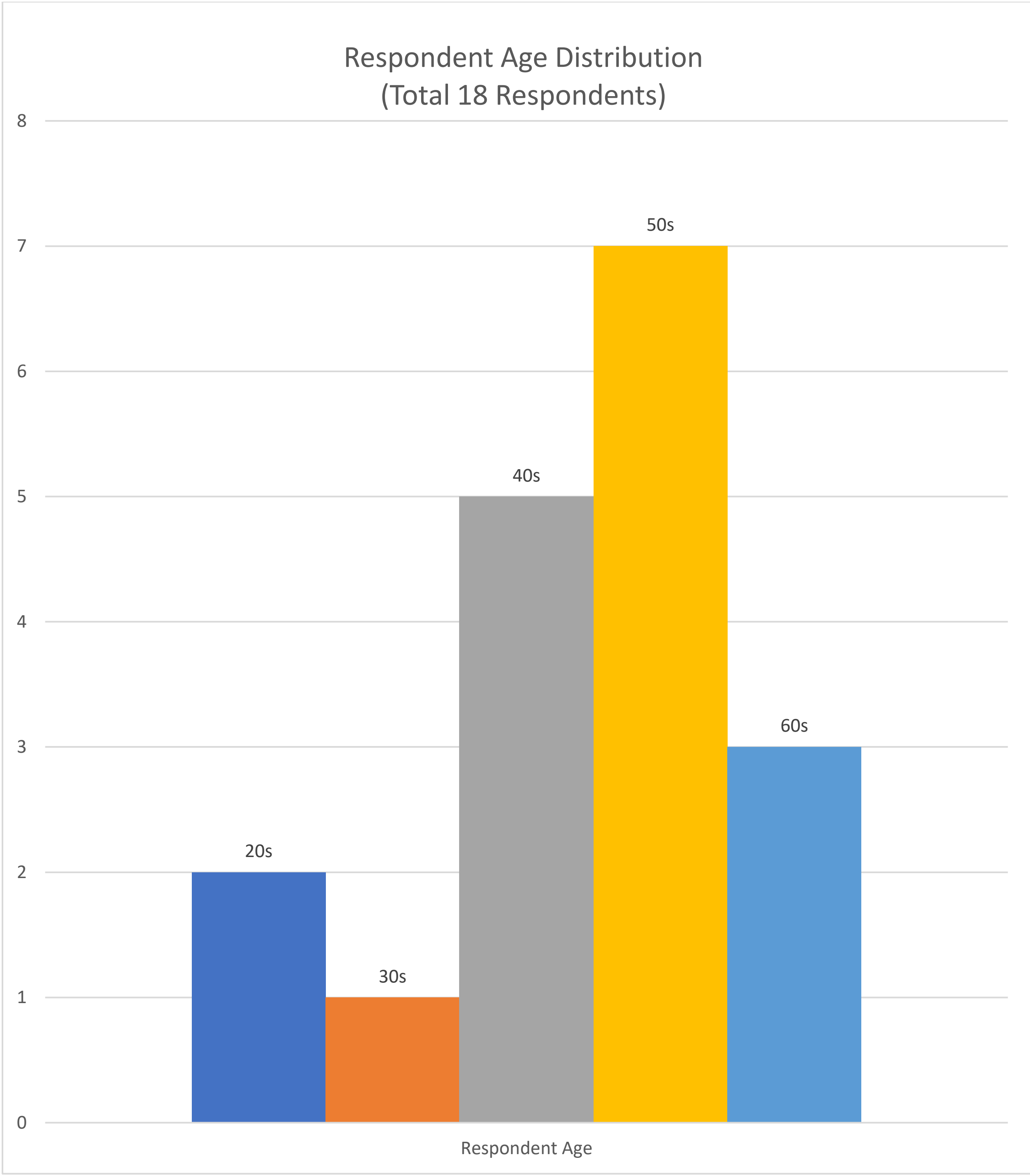
21. Have you ever worked with an incompetent staff person, supervisor, or professional in this field? Can you share a story that illustrates this?
22. Do you know of someone with a job similar to yours who has gotten away with doing something they shouldn't have? Please tell me the story.
23. What is one situation that you look back on that you wish you had handled differently?
24. How did the Covid-19 pandemic and the response impact your job?
25. How do other people try to get you to do certain things while you are working? Do you have a specific example?
26. Is there a particular event at work that you will always remember? If so, what happened?
27. What is one of the worst things you have seen a staff, supervisor or other person do while working in this field? Do you know what happened afterward?
28. Twenty Statements Test (Kuhn and McPartland 1954). [12 minutes maximum]
    The Twenty Statements Test: From (Kuhn and McPartland 1954): Instructions on a single sheet of paper: "There are twenty numbered blanks on the page below. Please write twenty answers to the simple question 'Who am I?' in the blanks. Just give twenty answers to this question. Answer as if you were giving the answers to yourself, not to somebody else. Write the answers in the order that they occur to you. Don't worry about logic or 'importance.' Go along fairly fast, for time is limited."
    Who am I?
    1.____
    2. ____
    3. ____
    4. ____
    5. ____
    6. ____
    7. ____
    8. ____
    9. ____
    10. ____
    11. ____
    12. ____
    13. ____
    14. ____
    15. ____
    16. ____
    17. ____
    18. ____
    19. ____
    20. ____

Appendix B: Respondent Demographic Information





*Note: Most Respondents reported multiple jobs in this field


Respondent Age Distribution
(Total 18 Respondents)
8
7
6
5
4
3
2
1
0
20s
30s
40s
50s
60s
Respondent Age

Appendix C: Narrative Coding Grid

			Framing Narratives Used to Control Clients									Framing Narratives Used to Control Staff						Framing Narratives Used to Control Professionals					Identity Authenticity		Identity Multidimensionality			Identity Mobility					
Respondent	Total # of Narratives	Framing & Identity Narratives	Physical Restraint	Physical setting	Documentation	Financial Control	Informal Social Pressure	Client "Behavior"	Safety	Psychological Tactics	Client Counter-Control	Positive Supervision	Negative Supervision	Peer-Peer Influence	Occupational Culture of Placements	Ethical and Legal Control	Abuse & Neglect Investigations/Oversight	Ethical Framing	Avoiding Blame	Power Struggle vs "State"	Community Safety & Clients "Under Control"	Systemic Issues in Field	Client Identity Authenticity	Staff Identity Authenticity	Client Identity Multidimensionality	Staff Identity Multidimensionality	Professional Identity Multidimensionality	Client Identity Mobility	Staff & Professional Identity Mobility	Roles	Gender	Race	Age
1	44	78	4	0	2	0	2	12	3	6	2	3	1	0	2	1	0	6	2	3	4	5	3	4	1	2	3	4	3	Professional, Supervisor, Staff	Male	White	40's
2	55	128	4	8	5	1	0	11	4	11	3	4	2	0	6	4	4	5	0	4	3	27	8	8	0	1	4	1	0	Professional, Staff	Male	White	30s
3	113	316	1	12	6	4	8	11	10	15	8	9	11	4	11	20	12	32	8	4	2	33	19	21	16	14	6	10	9	Professional, Supervisor, Staff	Male	White	40s
4	71	249	5	6	1	1	5	24	8	13	12	7	12	3	6	5	2	11	4	0	5	15	18	39	8	17	13	3	6	Supervisor, Staff	Woman	White	60s
5	65	212	6	1	7	5	11	18	7	11	8	11	3	2	12	2	1	18	3	12	5	17	10	14	8	7	8	3	2	Professional, Supervisor, Staff	Woman	White	40s
6	79	236	1	1	3	0	5	17	4	6	1	7	12	2	11	7	6	23	15	20	7	27	16	21	10	6	2	5	1	Professional, Supervisor, Staff	Man	White	50s
7	53	135	1	4	0	0	4	16	4	4	4	1	7	1	3	9	7	10	4	1	5	11	8	14	4	5	2	4	2	Supervisor, Staff	Man	Black	50s
8	70	250	4	9	4	6	1	9	7	5	1	13	9	5	16	10	7	25	3	6	8	20	14	25	7	16	10	1	9	Professional, Supervisor, Staff	Woman	White	30s
9	59	146	1	4	4	0	5	18	6	18	1	16	4	3	6	1	0	3	0	3	0	2	10	19	5	11	3	1	2	Professional, Supervisor, Staff	Man	Black	50s
10	40	149	3	1	0	1	3	7	4	2	5	6	6	3	8	12	10	11	2	2	3	18	5	16	2	10	4	2	3	Professional, Supervisor, Staff	Woman	White	60s
11	51	156	1	2	3	2	2	2	1	0	0	0	0	1	5	6	13	17	8	11	4	26	6	25	2	12	3	2	2	Professional, Staff	Man	White	30s
12	40	103	0	1	1	1	8	3	3	3	1	1	2	10	15	12	7	0	0	0	0	0	2	17	1	9	2	0	4	Staff	Woman	White	20s
13	83	286	3	7	2	2	6	14	6	18	10	3	4	0	6	9	6	25	9	17	2	24	15	29	14	18	14	11	12	Professional	Man	White	60s
14	45	126	1	0	5	1	6	12	7	6	5	5	7	6	9	14	3	0	0	0	0	2	7	11	6	10	0	1	2	Staff	Woman	White	20s
15	35	96	1	2	4	1	3	8	4	5	4	2	1	4	5	8	3	0	0	0	0	0	3	14	4	15	0	1	4	Staff, Supervisor	Woman	White	30s
16	86	252	0	1	2	0	3	13	6	1	0	3	4	8	8	15	9	18	4	0	0	16	23	42	20	30	7	5	14	Staff, Supervisor, Professional	Woman	White	50s
17	45	120	3	2	2	0	3	12	5	3	4	3	3	1	2	6	5	3	2	0	1	7	4	16	7	13	2	3	8	Staff, Supervisor	Woman	White	50s
18	56	206	0	1	2	3	5	10	3	8	6	12	10	6	12	10	8	13	2	2	0	13	10	22	11	20	4	5	8	Staff, Supervisor	Man	Black	30s
Totals	1090	3244	39	62	53	28	80	217	92	135	75	106	98	59	143	151	103	220	66	85	49	263	181	357	126	216	87	62	91				
Percent of Total	Percent of Total		1.2%	1.9%	1.6%	0.9%	2.5%	6.7%	2.8%	4.2%	2.3%	3.3%	3.0%	1.8%	4.4%	4.7%	3.2%	6.8%	2.0%	2.6%	1.5%	8.1%	5.6%	11.0%	3.9%	6.7%	2.7%	1.9%	2.8%	Combined Total			
																														3244			

Framing Narratives Used to Control Clients	24.1%	Identity Authenticity:	16.6%
Framing Narratives Used to Control Staff	20.3%	Identity Multidimensionality:	13.2%
Framing Narratives Used to Control Professionals	21.1%	Identity Mobility:	4.7%
Total Framing Narratives:	65.5%	Total Identity Narratives:	34.5%

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