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The Accessibility of Adulthood

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May 2011

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## **The Accessibility of Adulthood**

### **Introduction**

Popular perceptions of disability connote a lack – a lack of rationality, of autonomy, and of social understanding. These ideas are historically rooted and have served as justification for limiting the personhood of individuals with developmental disabilities. These individuals may be cut off from certain societal roles because society often views these individuals as “perpetual children” and permanent dependents. These metaphors of childhood reflect the misunderstanding of disability as a frightening force, an opposition against ideals of bodily perfection, autonomy, and reason that form the basis of personhood in America. A key issue stems from these lingering ideas and affects the self-perceptions and societal treatment of people with disabilities. Living within this framework, adults with disabilities have a particularly ambiguous status; their disabled status subsumes their adult identity, taking precedence over other identity markers. This ambiguity has ramifications for everyday interaction, altering the way in which adults with disabilities are treated in the economic and social spheres of adulthood.

Identifying “adulthood” in any context is a daunting task. Different social norms may influence how individuals within the society approach the topic, and even within mainstream society, paths to adulthood may consist of different markers that occur along different time frames, with breaks and personality-driven variation along the way. Given these variations, it is worthwhile to look at adulthood from two perspectives, from its unique behavioral influence on the subject’s self-perception and from its influence on the treatment of the subject by others. Adulthood is a time in which an individual faces 1) expectations about economic roles and markers and 2) a movement away from family-

regulated social groups toward close voluntary relationships. These roles, and the markers that indicate these roles to others, change both self-perception and external perception; as a socially based status, adulthood is contingent upon external as well as internal definition. Indeed, it is these two perspectives that I will be using to construct my analysis in this discussion of ethnographic data.

Since social groups are an important part of this process of gaining adult self-identity, it is important to look at how social relationships are affected and changed within the physical space of unique settings, one of which, the condensed community served as the site of ethnographic fieldwork. Here, many roles which are typically spread across many locations, each acting as a unique hub of interaction and relationship formation, are intentionally recreated. This term will be explained in more detail in a further section. Friendships and other relationships (romantic, familial) of people with developmental disabilities have recently gained study, though in the past they were not considered an important measure of the quality of care and thus did not receive as much attention as clinical measures (Mercer 2002:229). With, however, the advent of the social theory of disability, it has become more widely understood that disability is not an all-limiting concept, but instead a socially constructed one, and that the social aspects of disability also deserve study. And so, authors have written articles and books about the quality of relationships (particularly romantic relationships, which were previously suppressed and hushed for many years under eugenic philosophies) (Mattinson 1970; Pedlar et al. 1999; Perske 1988; Schwier 1994). Another subject of interest to researchers has been the nature of relationships between individuals with disabilities and the authority figure who support them, such as care staff, support administration, and parents

(Benchot 1984; Munford 1994; Pedlar et al. 1999). While these kinds of works have drawn attention to the ways in which inequality and perpetuated helplessness often are built into the expectations and institutions of care perpetuate, they have rarely expanded beyond the vertical power dynamics in the service-support system. By limiting themselves to these issues, these works have yet to discover the complexity of social relationships among individuals with disabilities, and how these individuals take an active role in the building of the condensed community.

Another concept frequently appears in connection with disability that seeks to minimize the effect of a disability in arenas of society – accessibility. Accessibility also has a popular perception, calling to mind concrete notions of handicap parking spaces, wheelchair ramps and special education classrooms. Dialogue surrounding accessibility connects closely with the built environment and those physical barriers which can be easily conceptualized and altered through legislation. But many aspects of a person’s social life cannot be tangibly represented in law, and accessibility must broaden its scope to account for these too. How does this change notions of accessibility? Accessibility requires more than a change in infrastructure – it requires a change in attitudes. Social accessibility requires complex attitude shifts, shifts about the cause and effects of disability. The accessibility of adulthood, namely the roles and relationships associated with this concept, is an area that I will discuss in this paper as a barometer from which to assess changing attitudes about disability.

Theoretical perspectives on disability have varied considerably depending on what issues they seek to address. Many recent theories have sought to address the discrimination and dehumanization that individuals faced in the eugenics movements,

forced institutionalizations, and through recent medicalization. These theories have sought to move disability out of the realm of personal abnormality onto the spectrum of human variation and difference. The social theory of disability looks at disabled individuals as part of a socially constructed minority. This minority has been the subject of different types of discrimination based upon the moral, philosophical, political and economic needs of the larger society, rather than as an biologically objective, medically based state. It shifts the focus from curing or normalizing a problematic individual, a policy which continues to define many institutions of disability today, to altering social attitudes. A disabling social relationship can be separated from the impairment, a separate label that stems from the physical or mental condition of the individual (Finkelstein 1980:4-5). Impairment is a form of human variation; it underlies disability, but does not cause disability. Instead, disability is created by the conditions of society's construction and culture that make aspects inaccessible to someone with a specific impairment. Society makes inclusionary changes, and with these changes, former disabilities may cease to be considered as disabilities while new impairments may become disabilities. Even in different physical settings, there is discontinuity about what is considered a disability, because certain impairments may no longer disable. Thus, the label is in continuous flux; the ever-changing uses of language demonstrate this. As with any other form of discriminatory attitude, when society changes, the social ramifications of a disability (or some aspect of it) increase or decrease. An offshoot of this social theory, the materialist perspective, suggests that disability arise from an economic basis, with "tangible economic causes" that stem from "lower economic worth" rather than from other people's general perceptions (Jaeger 2005:16). Both of these theories have



ramifications for the way in which people with disabilities are treated and for understanding the roots of disability. In some ways, notions of accessibility discussed earlier serve as the practical implementation of these theories and attitudes that define disability. If medical perceptions reign, accessibility will focus on cures and the individual, but if social understandings prevail, society will change building codes. The framework provided by the social theory offers a useful way to look explicitly at relationships; thus ethnographic field work and anthropological analysis are particularly suited to understanding the effects of disability on the lives of individuals.

In this paper, the language that I choose to use when describing people with disabilities will reflect my own implementation of social accessibility that arise out of the social theory. When speaking in the general, I use word choices that explain disability as a physical or social variation rather than as a concretely defined state. While at times, this may be taken too far into the realm of euphemism, I argue here that it is not. Explanations of disability here do not attempt to hide aspects of disability, but simply to provide information that is most relevant to the understanding of disability as a social construction, by looking at the individual differences and variation that lead to this construction. When speaking in the specific, no information will be shared about medical diagnosis or condition, but I will share information about the social effects of an impairment, namely how physically or socially independent a person might be. This language will facilitate an easier understanding of how an impairment affects the social workings of a larger community.

The ambiguities surrounding adulthood and disability manifest themselves within day communities for individuals with disabilities. These places serve a special purpose

of replicating aspects of external life and placing them into one physical location. At these social hubs, self-perceptions of individuals with disabilities interact and meld with the expectations of the institution and staff, creating a place with unique twists on typical social roles and interactions. An examination of the ways in which these roles and behaviors change within the condensed community will further not only our own conceptions of disability and show the complexities within social relationships, but also reveal how mainstream society places importance onto these roles and defines adulthood.

## The Setting

The ethnographic fieldwork that will be described and analyzed in the following chapters centers mostly around one site, the Glenford Work Activity Center (GWAC). This center is one of several adult day centers that are part of a larger county agency which serves the needs of individuals with developmental disabilities by offering services that aim to support the health, safety and life choices of these individuals and their families. The county agency runs early intervention programs, a school, adult day centers, in-home services, group homes, and additional recreation and community outreach activities; through these, it serves more than 1000 people. The agency uses the term “consumers” in its literature and in daily practice to refer to the individuals with developmental disabilities who partake in these services. Thus, in order to most accurately convey and reflect Glenford procedure, I will continue to use this term throughout the paper; the term itself will be discussed further in a coming section.

The Glenford Work Activity Center has a few primary functions that are made explicit in the name. It provides a combination of vocational training and opportunities and recreational programming. When first approaching the facility, the building’s outward appearance does little to signal the wide variety of activities that take place inside. A multitude of handicap accessible sidewalk entrances and parking spaces are visible when approaching the exterior. The building’s outer walls are tinted windows, in which everyone inside the building can look out, but people trying to look in see only their reflection. Upon entering, a visitor signs in with a staff member at the front desk, which has several offices behind it.

GWAC is a large building, with several large spaces that are connected in a loop by hallways. Walls are constructed using furniture (shelves, chairs) to create several smaller and distinct spaces (called “areas”) within the larger building. The areas are filled with tables and seating. Consumers are assigned to one of five areas based on the level of supervision that they need, from Area 1 which the lowest ratio of consumers to staff, with approximately 4-6 staff per 40 people, to Area 5 which has the highest, with approximately 1 staff per 3 people. Consumers spend most of the day in their assigned area; they may visit other areas with staff permission. Areas 1, 2, and 3 eat their lunch in a cafeteria room while people in Areas 4 and 5 have their lunches brought to them. There are also conference rooms, staff offices, physical therapy rooms where consumers go for special activities.

When conducting research, I spent most time interacting with individuals in Areas 1, 2, and 3, who typically have high to moderate levels of physical and/or social independence. The daily routine in these areas depended on the individual. People engage in a wide variety of typically craft-based activities – coloring, completing puzzles and word searches, painting, music, movies, video games. Several times a week GWAC offers transportation to field trips sites such as the library. At times, a staff member will lead a craft project for a small group of interested consumers. Consumers tend to have habitual seats, though some variation exists. Many people remain at GWAC all day - from its opening at 9am to closing at 3pm.

Some (not all) consumers participate in work and even among consumers who do work, schedules may vary, though typically each person works for a few hours a day, several days a week – certain people work more and others work less. Though some

individuals work off-site once or twice a week in open market employment, most stay on-site, working on jobs contracted through GWAC. GWAC receives contracts from companies to complete repetitive piecework tasks and pays consumers based on the number of items finished. When GWAC does not have a contract, there is no work for consumers, and activities become the focus. Individuals typically begin coming to GWAC after completing high school and stay indefinitely – there is no upper age limit – therefore, many people have attended the center for years and have firm routines. Each year, an individual will have a formal meeting with a staff team to discuss goals for the year, in terms of employment, behavioral modification, area placement, health, etc. Based the conversations in this meeting, a plan for the year is developed. Ultimately the individual or their guardian has the final consent of all portions and can veto any portion of the plan.

#### Participant Observation, Interviews, and Consent

Conducting research among individuals with varied and individualized styles of communication, information processing, and social or physical independence has ramifications for the ways in which the researcher collects and interprets information. Methods such as participant observation and interviewing must be done in ways most accessible to the participant, and consent must be obtained in such a way that ensures it is clearly understood, through additional verbal or visual explanation, and then freely given.

I was exposed to the site for the first time during a my first year of college at a service day, in which students spent the day engaging in games and craft activities with consumers at a group home. The following year, another student and I co-founded a student organization (based off of one that had existed in years earlier) and began to

organize ways for Glenford consumers and college students to spend time together, through campus events, regular volunteering, and weekly storytelling-creating workshops. The semester before beginning this research, I had been part of the weekly storytelling workshops and had developed relationships with several consumers already. I continued with these workshops during the research period and used the network that I had built through my past experience at GWAC to enter the broader community. The purpose of this student organization volunteer work was not to “help” Glenford consumers in any way, but to provide opportunities for social interaction and mutual understanding. As I developed a sense of how complex social relationships were at this center, I sought to understand more about the community and began to mold my questions into a research paradigm. Thus, the transition from social action to research was smooth and did not require a radical shift of perspective. The “volunteer” socializing that I was involved in was already similar to how I approached fieldwork – there was simply additional explanation of my new role to consumers and more notes that needed to be taken.

For this research, participant observation methodology was the primary means of data collection. It took place at the Glenford Work Activity Center and as opportunities arose in the surrounding community. I visited the GWAC premises several times each week to build connections with consumers and staff and engaged myself in the happenings of Glenford in order to familiarize myself with the behaviors and social organization within. For interviews, Glenford Center staff was actively involved in the selection process of interviewees and, when I first arrived, they suggested consumers for me based on consent and that individual’s level of comfort interacting with strangers.

Then throughout the research process I expanded outwards from those suggestions and met new consumers, but since I was operating within a larger legal and bureaucratic system, I sought preliminary advice from supervisors before considering anyone for an interview, to ensure that all legal and protective measures were followed.

While working with consumers and staff (as well as the Institutional Review Board of Oberlin College), I saw that the legal status of individuals with developmental disabilities may at times reflect their ambiguous social status within society – questions of guardianship and legal consent arise in all areas of life. Although these individuals have attained the legal adult age (consumers at the adult center are over the age of 18), precautions are in place to provide protection and additional supervision of legal activities. In dealing with these various bureaucracies, I made sure that all legal actions accorded with Glenford's agency policy since research participants ultimately operated under the legal protection of the agency. If individuals were legal adults and self-guardians, they signed for themselves a clearly structured consent form in order to participate. With all staff and consumers, I also verbally explained the consent form and answered any questions before they signed. If a family member was the legal guardian, I obtained consent from both the individual and their family member. Some consumers had guardianship from a private state organization. Due to the difficulties of obtaining consent from this organization, I did not conduct formal interviews with the individuals protected by this organization, although I did interact with them on a daily basis and build relationships. Their voices are reflected more broadly in the general social dynamic of the center.

Interviews of consumers and staff supplemented this information and allowed

consenting interviewees to explicitly state their attitudes about adulthood and disability. As an outsider coming from a different background, I strove to minimize the potential for an imposition of my own ideas about disability onto the individuals with whom I spent time, particularly since these individuals might have more varied means of communicating their opinions. Individuals with developmental disabilities (and perhaps accompanying physical disabilities) might use fewer words or gestures, a slower pace, and have differences in voice modulation and articulation that make it common for a listener to misinterpret statements (Woodhill 1994:207-208). As Woodhill notes there is a clear relationship between the pervading stereotype of the voicelessness and the way in which American society communicates and perceives communication; he argues that this communication has implications for individual personhood. A speaker who operates outside of these typical ways of speaking and posturing faces a disadvantage and his or her statements are often viewed with less seriousness. Another communication-based issue that has limited the voices of individuals with disabilities is the notion of surrogacy, in which the caretaker speaks for the individual with the disability and could impress his or her own ideas onto the individual who is represented. (Ramacharan and Grant 1994:233). However interesting the reasons behind these common miscommunications, I clearly did not want to perpetuate this. Quite to the contrary, the aim of my research was to reveal the voices of individuals with disabilities as they appear within their community, interactions, and self-perceptions. Therefore, to minimize this effect in my research, I had spent time with each interviewee prior, getting to know speaking styles around peers, around staff members, and me. I did not want my own understandings of individual levels communication to influence the quality of data collection, and I was



interested in how these individual levels of communication might change the perspective of the each person.

A flexible structure of questioning allowed for individual tailoring of question specifics and interviewer delivery methods; thus the format could remain accessible to all individuals while still covering the same broad topics that pertain to the transition from youth to adulthood, including schooling, jobs, friendships, relationships etc. The format of each interview and amount of time needed varied according to the individual's preference, and because I knew the individuals very well before interviewing them (from field work and prior volunteering), I was alert for nonverbal cues of discomfort. For some, the interview might occur a few questions at a time, with frequent breaks for walking around. Others sat and answered questions in the traditional format. At any point, the individual could permanently end the interview, and I would periodically ask whether the individual wanted to continue. I recorded the interviews, so as to best understand consumers, regardless of their speech capabilities. There was always the opportunity for individuals to ask me any questions or talk about anything else that we had not yet discussed.

As an interviewer, participants shared information with me about their status within the social framework of GWAC. The contents of all interviews are confidential and in order to maintain the privacy of participants, pseudonyms are used instead of real names throughout notes, interview transcripts, and this final product. Furthermore, the name of the county agency, Glenford, is also a pseudonym.

### Language

An immediate question of language arises when writing about individuals with developmental disabilities. How one should describe in words people who place themselves, or are placed by others, into this category? There are several considerations, the primary of which is the maintenance of individuality and respect. The language of disability has changed with each new understanding or approach to disability, leading to a renaming and reclassifying of affected individuals. In the United States, disability rhetoric has historically been connected to several social movements, each of which brought change to the treatment of people with disabilities and reflected the broader role of disability in society (Stockholder 1994: 161). Language and rhetoric have linked disability to medieval Christian morality; the legacy of pity and compassion remains, though the terms “fool” and “simple” have gone out of use. In the wake of the 18<sup>th</sup> century enlightenment period, which emphasized the advancement of intellect and rationality, terms such as “half-wit” moved individuals with disabilities from the moral to the intellectual arena, and in the 19<sup>th</sup> century disability became centered around Social Darwinism. (Stockholder 1994: 161-170) More recently, 20<sup>th</sup> century terminology has medicalized disability in an attempt to rid disability of moral connotations, with medical diagnoses and classifications providing the accepted terminology. Each historically-situated approach has promoted terminology that links disability to broader intellectual and social trends. And though some of these movements may have appeared progressive for their time, under the social movements that promoted these terms people with disabilities were dehumanized and maltreated.

Since language impacts the perceptions of those exposed to it, there is certainly a need to ensure that out-of-date and offensive labels fall out of use; change is necessary,

though for this to happen, the deeper understandings that define the term must also change. But the almost continual process of renaming is even more interesting than the specific labels chosen throughout history, in that it stems from the difficulties of finding a mutually meaningful label (Stockholder 1994: 176). Through this constant stream of reidentification, society reinforces an unstable identity for individuals with disabilities; this rhetorical confusion mirrors the unstable and marginalized place of disability in society. Disability activists today prize the person-first approach, a way of referring to people with disabilities as individuals whose disability does not fully define them – disability is not the first thing that the listener or reader will encounter during a description. (Blaska 1993:27). This shift moves language away from more medical terminology accords with a theoretical shift towards a social theory of disability. It reflects the idea that disability is not inherent in an individual, but appears through the setup of a society that created expectations and norms. And since conceptions of what connotes a disability and how disability fits into the surrounding society change continuously, a researcher must choose terms carefully that reflect respectful and non-judgmental attitudes that also account for the many other aspects of a person's character. Throughout this research, I have chosen language that recognizes that disability is only one part of a person's identity and personality.

Another consideration for my language choice in this paper is institutional policy and the public persona which the organization itself strives to project outward to the community and to those whom it serves. By aligning itself with the use of certain terms, the agency makes a statement about how it juggles legal necessities with public image, and ultimately relates to those it serves. In the previous section, I mentioned that the

agency's public reports, website, and staff use the term "consumer." The term reflects the organization's movement away from medical terminology and towards an idea of service satisfaction. "Consumer" has only been adopted in the past few years and reflects a change in public image, not in the service offered. Formerly, consumers were called "client-employees," in order to emphasize the work that individuals do at the center and to differentiate these individuals from the staff that supervise them. The term changed to "consumer" to reflect an increase in focus on the non-work activities available to individuals. Since some people do not necessarily work, the term "client-employee," which had apparently taken on negative connotations, was not thought to be applicable. Instead, "consumer" highlighted that these individuals were receiving services and activities (including work) that were provided by staff. Additionally, "consumer" focused more on the importance of the individual's role in decision making. This terminology is part of a larger trend across many organizations and states.

This word has implications for the self-perception of the individuals with disabilities at GWAC, since they frequently hear themselves referred to as consumers on a daily basis. Though at times the consumers themselves might replicate this term, most do not. When an outsider, such as myself, does use this word, it is used to distinguish between staff and other consumers. It was more common for me to have to ask whether someone was a consumer or staff member than for a consumer to volunteer this information to me.

With these considerations, when referring to consumers, I have chosen not to share their specific diagnosis. There are several reasons behind this. Firstly, I do not always seek out and know the diagnosis myself, nor do I think that a specific diagnosis

would increase my understanding of the social perspective that I am using. I am interested in examining the social ramifications of disability, not the medical ramifications, where perhaps this terminology would provide more relevant distinctions. The information that I provide instead reflects the consumer's level of physical or social in- or inter-dependence, again reflecting social relationships. When relevant, I provide my observations about each person's communication abilities, because this has social implications. My language is meant to reflect the idea that, for these individuals, disability is only one aspect of their identity. My choice is in direct contrast to the immediate societal demand for information about the diagnosis of individual with a disability. During the course of my work, it was a common occurrence that, when I explained to outsiders the nature of my project and the population I was engaging with, people would ask for more specifics about the medical diagnosis and severity of consumers. Though I tried to moderate my descriptions with person-first, non-medical terminology, I was often pushed and asked more probing questions by them. It was clear from their tone that they were not trying to perpetuate biases or discriminate in any way, but they simply felt that this label was the most important piece of information that they could know. To many, the medical label replaces the recognition of individual personality; after knowing the diagnosis, all behaviors become indicators of the medical symptoms. However, it is important to recognize that personality, socialization, and background influence an individual with disabilities just as much. When one has spent his or her life with a certain kind of disability and around others with a variety of other disabilities, being "disabled" becomes background noise in a much more complex identity.

## The Condensed Community

Since disability needs to be understood in a broader context of social interaction, it is important to think about how physical setting plays a role in the formation of relationships and personal identity. Since people with disabilities have historically occupied different physical spaces than people without disabilities, this issue becomes even more important. Typically in society, a person acts out many aspects of his or her identity in different physical locations and around different social groups. This is a defining characteristic today, because an individual's identity takes shape under the direct influence of interactions with others (Rijsman 2004:143). Around different social groups, the same behaviors and interactions may carry different meanings; as a result, a person will, whether consciously or not, behave in specific ways around certain groups, creating distinct roles for himself or herself. Since roles may be compartmentalized in this way, it is possible for a person to associate certain roles and behaviors with certain physical locations. Family roles may occur predominantly in the home, vocational roles in the workplace, consumer roles in stores, etc. Individuals within each social group will have to adjust their self-image and behavior to fit the rules and norms of the group (Coulon 2004:110). Thus, external variables and social cues (concerning the body, behavior, and markers) influence the internal self-perception of role (Rijsman 2004:142). For this reason, the transition to adulthood is extremely interesting, because in that adulthood is a time of shifting relationships and increased access to new social groups, self-perception changes accordingly. These newly accessed social groups create a person's adult identity. The social structures and mechanisms of identity creation largely support a separation of identity roles by location and social group.

Individuals with developmental disabilities have long been excluded from these physical locations and social roles because their “differential status tends to stem from a deficiency in those characteristics which participation in social structure and determination of equal status have been defined” (Rioux 1994:79). Since, seemingly these individuals appear unable to seek out and enjoy equal rights in the same way as their mainstream counterparts, notions of equality have been revised for them. Equality does not mean that people with disabilities are treated in the same way as people without disabilities; instead equality becomes synonymous with the provision of care and well-being through institutions. These newer institutions, based upon service-support models of the 20<sup>th</sup> century have shaped the way in which society places disability within the marginalized realm of the institution.

Today, individuals with disabilities no longer stay within the total institution. Neither, however, do they participate fully in the variety of settings available to the mainstream individual. Instead, many adult social roles are enacted within day communities, often specifically designed for individuals with disabilities, places that I call condensed communities. There is value to these condensed communities; though they are a product of a marginalizing society, they can also be places of community and support for people who are otherwise excluded from mainstream avenues. Without judging the value of these places, it is possible to see that the condensed community has implications for the ways in which adults with disabilities experience and realize their adult identities and roles, so I will begin by elaborating on it further.

The condensed community differs from mainstream society and from the total institution in an important way – it is a place in which multiple social roles, usually

separated by location or distinct social groups, unite within one setting or building. In the sphere of disability, this type of community has developed in the aftermath of reform of the 19<sup>th</sup> century's total institution. Like the total institution, its philosophical underpinnings stem from a social-support model of disability, which emphasizes care and custodial services (Radford 1994:15). In the total institution, people with disabilities lived entire lives in the shadow of one building, with all adult social roles and situations played out under one roof. For the most part, American society has distanced itself from these limiting tendencies, but since there is still a need for social support of disabled individuals, the institutional setting persists. Total institutions have been replaced by the condensed community, a place that houses many (though not all) of the social spheres of a disabled adult. The many adult roles (friend, employee, leisurer, romantic partner, etc) that for a typical American adult are spread among many physical locations, are concentrated to this one day institution. Indeed, day centers can be the only other place outside of the home where individuals will regularly go. But since consumers ultimately go home at the end of the day, it is not a total institution; certain home roles are preserved outside of the condensed community.

The Glenford center clearly operates within the structure of a condensed community. Thus it can provide examples of how the condensed community affects conceptions of adulthood, understood through markers such as employment and its economic ramifications, and social relationships. The day center is designed to encompass both work and leisure roles, and typically distinct social categories blend together and influence social interaction between all the individuals present, staff and consumers.



## Factors of Adulthood

Within mainstream society, adulthood is tied to ideas about aging in general. An analysis of the transition to adulthood, or of any kind of development through stages, requires more than looking for external markers and material changes that reflect the change in social status. While these markers and changes are important, they gain further meaning when viewed along a time scale. For different groups of people, the same societal transitions can occur along different time scales. These markers include age (based on birth year) as well as 1) small material markers of independence such as cell phones, internet access, housekeys, cars and 2) large lifestyle markers such as change in living situation, employment. Age markers help other people to categorize an individual and modify their own behavior accordingly; thus these symbolic attainments of age affect one's social interactions, which thus contributes to a change in how others perceive that individual's age. In the case of people with disabilities, the transitions to adulthood tend to occur over a longer time frame. In our society, these symbolic markers and material changes tend to have an economic or legal basis. They are rooted in the change from education to vocation and monetary independence and on the attendant changes that come from refocusing one's activities from education and learning to the production of goods.

Yearly changes in age, birthdays, mark progress through an individual's lifespan and can become symbolic of larger themes of aging. Certain birthdays are imbued with importance because they confer legal rights, such as voting or alcohol consumption. Others are imbued with social significance that symbolizes a new stage in life, such as the "sweet sixteen" or the "over the hump" 50<sup>th</sup> birthday. Typically, increased age comes

with tokens of increased independence. For example, during a conversation about birthdays, Danielle, a 20 year old consumer living with her family and working at GWAC, excitedly said that she was looking forward to getting her own room for her 21st birthday. She'd get to pick out what it looked like - her own bed, a new dresser, and a DVD player (this last one garnered the most excitement). This increased age brought with it a series of new choices that she would get to make, about decorating her room and regulating the people who were allowed to enter. Though this birthday did not come with any attendant changes to her position at Glenford, her home life gave significance to this birthday milestone, which was inextricably tied with her changing role in family life. For Danielle, an increased age comes with the expectation of increased independence – this is marked by having a room of her own. This independence is tied closely with increased choice within her home realm, with a noticeable omission of concern for how her increased age would change her status as a legal and social adult outside of the home.

For the purposes of this paper, I have loosely grouped these age markers into two categories, one of which is economically based and the other of which is relationally based. Economically based markers include job, salary, and all the choices that come with salary (such as living arrangements, purchases). This is the part of adulthood expressed in the “work” aspect of the work-activity center. Relationally based markers are closely related to economically based markers, but focus more on patterns of social grouping that are unique to adults. These come through most strongly in the “activity” and leisure portions of the work-activity center. Although I have grouped these markers in this way due to certain causal or behavioral continuities, the categories frequently interact and overlap with each other.

## Economic Implications of Adulthood and Disability

Since the perceived ability to work (or not work) has long defined which people are considered “disabled,” it seems appropriate to begin a discussion on the importance of work in America. Increased independence is often seen as the goal of youths who are transitioning into adulthood, and in our society, this independence requires financial support. Though many would hearken to the almost mythological Puritan work ethic as the foundation of this belief, this ethic does not necessary hold a prime motivating position today; beginning in the 1960s, people “began to think of work as a way to achieve personal fulfillment” and more recently as way to gain spending money for leisure activities (Csikszentmihalyi and Schneider 2000:8-9). With increasing flexibility and personal choice concerning one’s specific job, a job is “more and more perceived as an extension and a fulfillment of individual potential, and therein lies its main value” (Csikszentmihalyi and Schneider 2000:10). The job does not define the individual, but *is* the individual. Those with disabilities, since they may have difficulty holding standard jobs, figure uncomfortably into this structure of identity definition. Because vocation is an important aspect of identity, people with disabilities may be viewed as ambiguous and unidentifiable by others.

But people in American society are not born seeking employment – it is a marker of adulthood. A “positive evaluation of work...seems necessary to socialize children into adulthood,” and youths transitioning into adulthood must learn the new rules, goals, and behaviors that are required in order to reap the rewards of this employment-driven society (Csikszentmihalyi and Schneider, 2000:11-12). There is a perceived separation between work and leisure activities, though a study by Schmidt and Rich suggests that activities

that lessened the distinction between work and play were considered preferable and provided pleasure and business as well as the personal construction of esteem and worth (Csikszentmihalyi and Schneider 2000:75). This popular attitude that turns work and leisure into an opposing and antagonistic relationship further leads to role compartmentalization. The specific path that a transitioning youth takes into vocation can vary greatly based upon family and socioeconomic background, access to information through social networks or education, personal expectations and perceptions, and external expectations (Csikszentmihalyi and Schneider 226). During the first years of employment, a young person changes jobs frequently; Topel and Ward found that two-thirds of jobs lasted less than a year, though it is unclear whether this derives from low wages or from a purposeful searching process, in which identity, as well as vocational path, is searched for (Hamilton and Hamilton 2006:265). But the many sources that address this subject show that vocation has become a key factor of adult identity.

How does this relationship between work and emergence into adulthood change when an individual has a disability, specifically a developmental disability. Some of the aforementioned variables, such as access to information through social networks or education, personal expectations and perceptions, and external expectations by the presence of a disability are all affected, while others such as socioeconomic status do not change with the presence of disability. In some cases, people with disabilities are not encouraged or expected to work – this is seen as unrealistic in the face of challenges that the individual will encounter. In the recent past, it was common for youth with disabilities to have decisions about the future made for them. This practice may be changing in light of secondary education's attempts to develop decision making and

personal advocacy (Levine and Wagner, 2005:219). But this changing understanding is slow to take root in everyday practice, and the decisions of caretakers and family influence many people at GWAC, who follow a path that is determined by the available path offered by the local institution (for example, it is accepted that people who graduate secondary schools will attend a workshop). Employment still represents a person's identity, but in many cases with disability, the difficulties in gaining employment reflect and enhance the difficulties in gaining broader social acceptance. It is a stated goal for high school students with disabilities to achieve competitive employment, yet the "average rate of unemployment for adults with disabilities tends to be around 70 percent, while the unemployment rate for other adults tends to be around 5 percent" (Levine and Wagner 2005:218; Jaeger 2005:13). When a person with disabilities is employed, it is more of a reflection of parental or institutional expectations rather than a reflection of individual identity. In the case of people with disabilities who attend adult day centers, the identity provided by work is conferred rather than chosen. Leisure becomes an acceptable alternate path to employment, because even at work centers, it may be difficult to find continuous work or contracts so everyone is not able to work all the time, even if they would want to. While support services may attempt to fill the typical social work role, competitive work environments, which value profit and maximum output through efficiency and minimum input, are not structured to present equal opportunities to people with developmental disabilities who may work at slower speeds and need additional or altered training.

An unemployed or semi-unemployed individual not only misses out on a key process of adulthood, but also misses out on the economic benefits that come from salary

and enhanced social status. If they receive familial financial support, the individual's decisions must ultimately pass through the filter of this authority before these decisions can be put into practice.

Thus, as seen above, for Danielle as well as others within mainstream society, adulthood is symbolized through the attainment of age markers; these, in turn, are also closely tied to employment and salary. In the United States, the transition to adulthood steers a youth toward employment, which is seen as a necessary goal before one can gain markers of adulthood and fully develop adult relationships. Although the paths from school to employment in this country can be varied (sometimes even with a delay of unemployment), there is still strong push for people to take the route laid out by institutional structure. The cessation of schooling brings individuals into new environments, in which more established workers inform novices who have no prior access to this new social and vocational knowledge. Young adults enter the work force and people with greater skill guide these newcomers through what Vygotsky has termed, the "zone of proximal development." (Pelissier 1991:81). People with developmental disabilities follow this path also, with schooling programs often including vocational components, though competitive employment is extremely difficult to obtain. In a mentally and physically competitive society, people with disabilities have a more difficult time entering the job market, and therefore a much more difficult time attaining material markers of their success. Both of these elements of employment are extremely important, in that they directly affect the behavior of others toward an individual, and therefore, multiple aspects of the identity building process. And since identity is composed not only of self-perception but also of external perceptions, to be an adult, one must have not only

have both the experience of employment and the material trappings that come with salary, but have external behaviors of others change as a result.

This connection between age markers and salaried employment can be seen in how individuals at Glenford talk about their work. Many of the individuals who work at GWAC or at local competitive employment will readily talk about their salaries. While the specific salary may be unknown, salary is one strong motivator for work. Some consumers with higher levels of social independence will have a certain, perhaps limited, amount of control over their money. While family may be the prime financial control, consumers do take pride in saving their money for desired items, from inexpensive items at weekly Wal-Mart trips to items such as cameras and DVD players. The purchase of these items carries with it a level of choice – there are a variety of items that the individual can buy. Or, individuals may also choose to save their money for longer periods of time to buy bigger things: cars, big trips, and even rented housing.

Now it is time for the ethnographic sections, in which these economic factors are examined at Glenford. The relationship between consumers and their salary can be seen in the following. One older consumer, Terence, spoke often, and almost exclusively, about three predominant aspects of his life – his work, his family, and his recreation. From conversations with him, it became evident that these aspects formed the basis of his social adult identity, yet also interacted in ways contradictory to traditional ideas about adulthood.

Our first conversation began when we made eye contact across the room. Terence smiled at me, looked away, and laughed as if he was laughing at something outrageous that I was doing. He started saying something to me, and since I was too far away to hear him, I went over and introduced myself.

After a minute of conversation, Terence said that he enjoyed talking but had to go and take the garbage can around soon. Yet he continued talking to me and started telling me about his job. He listed the rooms that he cleaned and the rooms that weren't part of his responsibilities.

I asked whether he liked his job.

"Yes, and it's good money too," he said, eagerly. He continued, saying that he hoped his brother wasn't spending it all, because his brother, with whom Terence lived now, was taking care of his money now. "Well, he better not be spending it, because I'm older than him and I can get him," he boasted, enjoying this idea of sibling payback. "He better not be, because I'm older and I can get him." And with that, Terence walked over to the large wheeled garbage bin, and began his duties.

In a second conversation, a few weeks later, Terence and I were talking again and since he was standing by himself along the locker row of Area 2, I asked whether he was working today. He said indignantly, "I'm just waiting for him to finish," gesturing at another man who was walking around with the trash can, "I start at noon! [pause while he waits for my reaction] I'm just waiting for him to get finished...[another pause] I can't start until he finishes!"

When I asked Terence if he had any plans for the weekend. He said, with relish, that he was going to watch TV shows. He'd gotten a new TV from his dad for Christmas. So, he had put away the old one. He had three or four television sets, because his dad had given him new ones.

This conversation reveals the close ties between earning and adulthood. Terence's job as garbage collector in the facility produces an avenue into a typical adult moneymaking role, and from his words one can see that this gives him a great deal of pride. He works for several hours a day in a job that keeps him engaged with staff and consumers at GWAC and he earns a wage that satisfies him. But the full financial supervision of his family, where his brother collects and stores his wages, means that he is unable to access his money. There is a disjunction between the daily amount of time that he spends concerned with his job in comparison to the amount of fruitful gain he receives back from it. The focus of his work is on moneymaking, but his status as a developmentally disabled adult makes it difficult to access his funds without essentially gaining the permission of his family. Consequently, although he is involved with the



adult working role, he does not directly control the products of his labor. This particular economic aspect of his age (which contrary to other perceptions, is in fact present) does not match the economic changes that should result from it. With this job, he should be able to access other markers of adulthood, possessions such as televisions, yet he does not without relying on external people.

The primary source of his recreational life, his television sets, were always attributed to his family – Terence never mentioned wanting to buy anything and seemed connected to his salary only in the abstract. He had only reactive control – the potential to “get” his brother after his brother might spend the money. He was acutely proud of his status as an adult earner, yet at times aware that the interconnectedness of his work and family roles contradicted with his own stated ideas about age. Like a mainstream worker in a competitive job, Terence works and makes a salary of which he is proud. The job serves to fill his time at the work-activity center and allow him to contribute to his daily community. However, though he is primarily motivated by salary, his status as an earner does not mean that people treat him as an earner. This fundamental disjunction places him in an ambiguous identity. Because he is not directly receiving his salary, the direct benefits of this employment are those of the benefits found in a leisure activity, where one does not get paid.

The name of the center, Glenford Work Activity Center also reflects the role disjunction experienced by Terence. Here, leisure and work become intertwined and connected by the ambiguous adult status of individuals with disabilities as wage earners and productive members of the community. A consumer navigates complicated notions of working and participating in leisure activities or socializing. In mainstream society,

these roles would be distinct, taking place in different physical locations and at different parts of the day. A person works somewhere, and then gains money to spend on other areas of his or her life (here loosely recognized as leisure), but this separation does not occur to the same degree with people with disabilities. This economic role haziness is alluded to in other research. Pedlar discusses the idea that meaningful work is necessary in order to live a “textured” life. This is a life which the authors define as “empowerment-in-community,” where individuals have encouragement to participate in the mainstream community and to develop meaningful relationships (Pedlar et al, 1999:11). Here, it is important to state that, while issues surrounding employment can be complicated by attitudes toward people with disabilities, work is indeed often viewed positively by individuals in the work-activity centers. Through work, participants gain a sense of accomplishment. However, even in these positive cases, there is still a fundamental difference in the approaches and expectations of work concerning people with disabilities that becomes evident when looking at these institutional structures. While vocation and employment were the basis of GWAC’s formation, the activities have shifted focus toward leisure programming. Work and leisure activities take place in the same areas, blurring the physical boundary between worker and leisurer. Salary is typically below minimum wage, because it is calculated based upon the number of repetitive tasks completed. With minimal salary, this work begins to edge toward volunteer work, work that is unpaid, personally satisfying, and ultimately a leisure choice. The name “consumer” even implies a downplaying of the employment element of the center, and instead, a view the center, with activities that include employment, as purchasable and chosen leisure.

The condensed community, which provides support to people with developmental disabilities clearly affect the ways in the distinction between work and leisure operates, thus affecting the economic benefits that the disabled person is able to gain from his or her work. The implicit message is that a person with developmental disabilities does not fit into the social values system of employment; the person's identity roles are not connected with work, but with leisure, and is thus not a contributive adult member of society. Though work and other economic markers of adulthood are available to some consumers, we will see in the next section that these markers do not confer the same external perceptions of adulthood on individuals that they would on mainstream individuals.

#### Age Perception and Contradiction

Economic markers of adulthood can be found by looking at the material culture of adulthood. These markers signal adult status to those nearby, who behave accordingly. These can include, birthdate age, living situations, cars, cell phones. A relative age is the translation and implementation of these symbols into a change in social relations. This relative age is shown through situational behavior; it governs the interactions between individuals and it in turn also impacts one's self perceptions. Sometimes relative age may align with typical age markers but at other times the two may send distinct and potentially conflicting information between two parties; a difference in relative age may occur between two people regardless of the presence or absence of these economically based markers. In short, person's relative age can at times contradict typical age expectations. For people with developmental disabilities, confusion about age appears when objective and materially based age markers do not align with the expected relative

age behaviors. These two ways of looking at age and transitions are certainly interconnected.

Even when an individual earns wages and is able to purchase markers of adult identity, unlike mainstream society, these markers may not alter other peoples' perceptions of the adult. The distinction between the symbols of adulthood and the social change that these symbols usually create is important when looking at how individuals with developmental disabilities face the transition to adulthood. These economically based, material markers do matter and consumers still seek to attain them. Chris, an upper middle-aged, physically and socially independent consumer, formerly attended GWAC, but had since moved to a different branch. One day, he returned to visit, showing the staff the new blue PT cruiser which he had just bought and driven to GWAC. He was smiling as staff talked to him and he received many accolades from them. A few staff members joked that he would have the windows down calling to women and playing loud music and driving to strip clubs, and he laughed along, enjoying his place among the staff. Though this attainment of economic independence was highly regarded by staff, their praise revealed that other aspects of his adulthood (particularly sexuality) were contingent on his economic earning. The car, and his ability to drive it, symbolized a kind of independence that brought him closer to staff than to consumers. This appeared to be a milestone achievement for him, and did temporarily change the way that other people treated him and the way in which social groups interacted with him. However, the very enthusiasm with which the staff reacted to a purchase that would not be impressive for any other middle-aged man, shows how rare this kind of accomplishment is, and perhaps, how temporary the social change that follows.

Usually, however, though a material marker of adulthood and accompanying independence is present, it may not change the dependency with which the consumer is viewed.

A female consumer, 20 year old Danielle, was particularly vested in the status that came along with having a cell phone. Almost every time that I spoke to her, she would make a point to take out her phone and show it to me. One day Danielle had taken out her phone and was texting. She kept looking from her phone to me, and back again, so I asked her about it. She started telling me that she was texting her dad. I asked whether she ever received messages back. She told me that she had received one message and sent 30 messages. She then sent one more and asked whether I wanted to see. She showed me the screen, and I saw that she indeed had one message in her inbox, but to my surprise, I saw 31 messages in her drafts folder. I asked her if she'd sent it and if she thought that her dad had received it. She replied affirmatively.

It appears that she was taught that saving a message as a draft constituted sending it. Perhaps this was a parental measure to keep her from sending messages and costing money, while allowing her the prestigious marker of "texting," just like others her age. In this case, one marker of adulthood (or at least transitional adulthood) conflicts with her family's treatment of her. While the family affords her the symbol of adulthood, this symbol does not effect a change on its interactions with Danielle, thus compromising Danielle's claim to the increasing independence of adulthood.

Thus, adulthood in America is partially contingent upon the economic markers that signal adulthood (such as employment, possessions). However, even when these markers are present, they do not serve their social purpose, which is in effect, to change the way in which people view and interact with the individual holding these markers. This may be partially because people with disabilities, though they may have jobs, are not viewed as full employees. Few people work and control their resulting salaries, without the influence of family members. There is a blurring between the work and leisure roles

which are present in the condensed community, and this blurring ultimately also affects social relationships at the Center. In mainstream society, certain markers may correspond with objective ages; these markers then influence how other people treat the individuals and thus his or her relative (perceived) age changes accordingly. In the condensed community, objective age and relative age may be unrelated. An adult with the markers of salary and apartment, may in fact, still be treated as a dependent, though this may contrast with self-perceptions of pride at carrying this adult role and earning salary.

In many cases, consumers may participate in the adult economic realm and feel like they are gaining status from employment and purchased markers of status. However, gaining these attributes does little to change how consumers are perceived by those whose adult status is unambiguous – the staff at GWAC. At the heart of these economic markers, the contrast between self-perceptions and external perception reveals how our society relates to adulthood.

## Social Relationships and Entering Adult Roles

As discussed earlier, adulthood comes with a change in economically based factors that then influences how a person interacts with social groups around them. This in turn influences that person's transitioning self-identity. During the transition to adulthood, the nature of social interaction changes in several ways, preparing the individual for a diversity of distinct adult roles and relationships. An adult must juggle relationships with coworkers, authority figures, romantic interests, and peers. These relationships are often spread across multiple physical environments and provide different benefits and challenges to an adult individual. Research has shown that ties of friendship are more "pervasive and active," especially when compared to interactions with neighbors and coworkers (Verbrugge 1977:576). There is an element of choice and self-determination in adult friendships that is not present in other relationships and that differs from childhood friendships. In childhood, friendships are forged under the influence of parental and educational supervision, both of which can exert strong pressure on which friendships are made and maintained between children. Adulthood and the resulting relationship networks are marked by a movement away from one's immediate family and towards the creation of new social circles and a new immediate family. These new relationships are "highly homogeneous in social and demographic statuses, attitudes, interests, intelligence and personality traits" (Verbrugge 1977:577). Physical space has a strong influence on these friendships, because people with similar roles and attitudes have a higher likelihood of interacting within the same spaces.

The following sections will demonstrate the complexities of these uniquely adult relationships, looking both at relationships with staff and relationships with other

consumers. To many who still hold the assumption that a developmental disability negates the ability to form complex attachments, the results may be surprising. It is important to understand these new ideas about individuals with developmental disabilities in order to acknowledge and counter the popular stigma of asocialness that continues to follow these individuals and take a toll on rights to citizenship and access to complex environments. At GWAC, the condensed community blurs typically separate roles in interesting ways that at times give initiative and leadership to consumers while also changing the importance of certain social markers (particularly age and gender) in the formation and maintenance of relationships.

### Friendships at GWAC

Role ambiguity surfaces in the formation of friendships and acquaintanceships. With few exceptions, individuals come to this institution daily, sometimes for decades of their adult lives. As with any group of people in close contact, consumers come to know each other's personalities and preferences very well. But in the condensed community, a certain extra social knowledge also emerges, which patterns friendships and relationships in a way that simultaneously breaks down and reaffirms the differential between staff and consumer. This social knowledge takes on a more personal nature than is found in other work or leisure settings. Individuals with developmental disabilities and staff discuss personal matters that, outside of the condensed community, would not be discussed – and they do so very casually. Peers and friends at the Center know intimate details about each other's needs, both emotional and physical. When one consumer, Amy, (very socially engaged with the Glenford community although she does not usually speak more than one word sentences) once began growing angry and violent toward a visitor, a



second consumer came over and sternly told Amy to leave. She demonstrated a clear knowledge of this woman's past violent behaviors and temporarily stepped into the role of a staff member to tell this consumer to modify her behavior. At other times, these two women are peers who joke and interact on an equal level, as members of the same institution.

A second example of this nuanced and personal knowledge occurs also when consumers in some of the more restricted areas of the Center leave their area without permission. During my visits, this happened several times – one consumer would leave his or her area and enter a second area. A consumer in the second area would rush over and tell him or her to go back. Then the staff would hear this altercation and reinforce the message of return. Interestingly enough, this would not happen to everyone who left his or her own area – there seemed to be an understood distinction among the consumers about who really needed to be supervised, versus who had more independence and therefore more freedom to walk around without obvious permission or a staff guide. The rule about notifying staff before leaving an area is flexible, and the consumers at the Center understand and enforce the intricacies of it based upon this unique social knowledge of their peers.

Thus we can see the knowledge gained during peer-relationships at the Center beginning to blur the distinction between staff and non-staff; many consumers not only take on care responsibilities for others, but also use this role ambiguity to uphold institutional rules. Friendship at the day center carries with it responsibility, because a consumer's relationship with the staff contributes greatly to his or her notion of friendship. Typically, when asked open-ended questions about their friends, consumers

will talk about staff before they talk about their peers, even though the consumer may interact with staff members less frequently than with fellow consumers. As a result, many conceptions of friendship come from the model that the staff provide. When a consumer sees a staff member telling someone to return to his or her own area of the workshop, then the consumer later does same, modeling the duties and responsibilities seen in staff-consumer friendships.

The staff at the Center fill many roles – they are caretakers, friends, behavioral models, and ultimately, authority figures. As mentioned earlier, many individuals with developmental disabilities in the condensed community list staff members as their best friends. The degree of mutuality, however, within these relationships is complicated by the different goals of the consumers and staff. While the staff certainly are close with the consumers with whom they work, there is not the same degree of primary attachment that the consumers feel towards them. The imbalance of friendship is one issue that people with developmental disabilities may face. Different and potentially conflicting objectives layer each interaction. Categories are blurred, yet reinforce the institutional structure of caretaker and consumer. Here is one example, an interaction between Kelsey (a young consumer in her 20s who typically communicates via gestures and sounds) and Frank, a staff member:

Kelsey often walks into Frank’s office, whether the door to the staff office is open or closed. They begin a dialogue (almost a script) of joking that gets repeated at almost every interaction - Frank begins joking around with her, calling her a “putz,” and she smiles as she stomps her foot and waves her hands in mock indignation. If Frank is working, Kelsey interrupts, patting Frank on the back, until he begins talking to her.

Often, he will make the game interactive, writing "Kelsey is a putz" on his computer and playing around with the computer readback system. He explains to me that by typing things onto the computer he is trying to get Kelsey to work on her reading skills.

An institutional adult day center operates under a variety of objectives – providing vocational training and opportunities, a social community, and the resources for individual daily care. Staff are the instruments through which each of these objectives is accomplished and thus they become pivotally involved not only as promoters of certain goals, but also as invested participants in the community. In this interaction, Kelsey sees Frank primarily as a friend – neither the physical nor symbolic boundary of the office door fazes her. Frank does have a real and close relationship with her (as evidenced by not only his actions, but also by his statements about her – he says that these interactions are the highlights of his day), but he is also working to achieve several goals with his friendship – enforce reading skills, social skills, and ultimately he has authority over when the situation ends. There is a tension within these meaningful relationships, between the power differential inherent in the institutional system and between the constant physical and emotional closeness of individuals in the condensed community.

Relationship formations at this Center have further identity ambiguities that stem from its status as a condensed community. Indeed, as with any specific group, trends in the friendship development are present. For many people, one's age becomes an identity marker that influences social relationships. Age cohorts determine friendships, particularly during childhood, adolescence, and early adulthood – these age groupings are institutionalized in school and work positions. But within the condensed community distinctions based upon age hold less social relevance, since the roles held by “disabled

individuals” and “aged individuals” have stark similarities. Both these segments of the population are perceived as less productive and less rational, with the popular idea that old age is a second childhood. The links between disability and childhood are also clear in the myth of the “perpetual child.”

This blurring of typical age distinctions and cohorts manifests itself in examples throughout the Center. Consumers who have just graduated high school may be close friends with individuals who are much older and vice versa. I noticed an example of this early in my field work. While talking about a young consumer in her 20s, a staff member mentioned to me that this consumer’s best friend at the workshop was a much older woman. He didn’t know what held them together, but these two friends were inseparable. This sparked my interest, and I began to look for other examples. Sure enough, it was apparent that age distinctions held less relevance in this institution than in the outside world. One older woman spoke fondly of her “foster mother.” Later, I found out that this foster mother was years younger than the consumer; when I later spoke to this foster mother, she chuckled and said that it felt odd to be called “mother” by someone older than her. While it may have been odd for the caretaker, the consumer did not think it at all worthy of further comment. Clearly in this example, age functions less as a definitive social marker of relationships than perceived notions of responsibility and functioning. In the outside world, individuals of different ages might be separated by work hierarchies, wealth hierarchies, activity preferences, and care practices. However, in this facility, consumers typically do the same activities and crafts, the same piece-work jobs, and receive care from staff; therefore aging does not have the same social implications. In a sense, disability and aging “limit” the individual in the same way,

affecting social mobility, work, independence. Therefore, there is an equality of age that can be seen within friendships at the Center. However, this Center is not a utopia of stripped social markers. Other categorizations are extremely important in determining friendships. Gender is highly important, and close male-female relationships among consumers tend to be labeled as romantic attachments. Much of the conversation is dominated by talk of boyfriends and girlfriends, which is encouraged by the staff, who acknowledge the sexuality of the consumers.

### The Preserved Home Roles

The preservation of home roles distinguishes the condensed community from the total institution, since consumers of GWAC all go home (whether a family home, group home, or independent home) at the end of the day. Thus, the home role still plays an important, even determining, role in relationship formation for people with disabilities, particularly those in a condensed community, where relationships do not follow these same patterns. For people in the condensed community, the home is not just another physical location for a social group. This role has a substantial amount of control, both direct and indirect, over other relationships. Typically, during the transition to adulthood, there is a gradual separation from parental figures and towards more independently maintained groups of friends and family; this “recentering” becomes a strong indicator of adulthood (Tanner, 2006:49). While mainstream adults may be moving away from their parents as primary support networks, this is often not the case for people with disabilities; parents may still be primary confidants and problem solvers. And they certainly hold the reins of economic support (Aquilino 2006:204). Even when a parent or caretaker does not intend to filter relationships, he or she has access to transportation, money, and

scheduling authority that indirectly influence relationships. Ultimately, the caretaker controls access to other physical spaces that provide a forum for choice within interaction; this, as discussed above, is the critical distinguishing factor of adult relationships. These physical spaces are hubs for people with similar interests and of similar demographics upon which meaningful relationships are built. In this example of online interaction, we can see both the importance of public friendship and the importance of the home role in regulating these friendships.

Jeremy, Robyn, and Sarah, three younger staff in their 20s and 30s, were sitting near each other at one of the work tables, and as I walked over, I heard them talking about the social networking on Facebook. Jeremy and Sarah were graduates of public high schools and had likely encountered this by their high school peers.

Jeremy was the most involved in friend seeking, and he was bragging that he always just talks people, even to strangers when he goes on Facebook. When I asked why, he responded that he just wanted to get more friends. Friends were clearly his ultimate goal, and the number of friends he had became a source of prestige. But the social interaction involved was key means to this prestige. Jeremy turned to me, saying that he had 400 friends.

Meanwhile, while Jeremy started talking pointedly to me about his friend count, Robyn and Sarah had begun their own conversation. They were speaking in a very different tone about a very different aspect of Facebook. They had heard Jeremy saying that he talked to strangers online, and they began talking about safety and privacy. Sarah talked about her Facebook, and it was only after listening for a few minutes that I realized she was talking about her mom's Facebook. Robyn spoke about how she never talked to strangers and only talked to friends. As each young woman spoke, the other would nod knowingly and reply in the affirmative. They went back and forth like this for a few minutes, at times laughing at this fun, but tense and clearly somewhat anxious topic. They would stop periodically and listen to Jeremy, but mostly look mildly shocked by his uses of Facebook to interact with strangers and make friends.

Both women looked happy with their use of Facebook and seemed to relish the safety afforded by their close connection on Facebook with family. Through this heavy supervision, their family stays highly involved and interconnected with Facebook friends.

Indeed, the family member or caretaker has nearly all the leverage in the friend making process – they are the face of the individual for whom they are caring, whether it’s a literal face (sharing a picture and parent’s information on Facebook), or whether it is the face of transportation. Transportation and staffing are the limiting factors for family life in group homes. Consumer friends at GWAC would sometimes talk about visiting friends at other group homes, but these visits could not be carried out casually; they had to involve the coordination of staff and vehicles, and it was rare for consumers who did not live together to spend time together outside of the center. In this way, in the life of someone with a developmental disability, the distinct adolescent subgroups of family and friends may blur together, since the individual has little agency to control his or her comings and goings. Adolescents and young adults typically strive to make these groups of family and friends as distinct as possible, in response to tensions over impending adulthood its accompanying privileges.

Though it is one adult role out of many, the home role exerts a heavy influence over adult relationships at the condensed community. I met Luisa as she was being introduced to the consumers at GWAC. It was her first day at this work activity center (she had previously attended one of the other WACs).

She said that the move was really hard. Not only had she switched WACs, but she had also moved into a new group home and wasn’t sure that she would be able to get along with everyone. She said that she missed her friends from the old WAC and that she didn’t have any friends here yet. She spoke mournfully, and after I asked the initial questions, she directed the conversation and steered it toward her concerns and sadness. She began talking about how much she missed her friends, including the bus driver who drove her to GWAC daily. She was looking forward to the following day because she was going to visit them. Outside of these planned transitional visits, there were not enough resources to allow her more frequent visits.

I asked Luisa why she had left her previous work center. She said that she moved because her sister had said that she [sister] might be able to get a better job. Luisa had lived with her sister, but when her sister moved, looking for a new job, Luisa had to move into a group home and that it made her upset because she was away from her family and friends. I asked whether she'd ever wanted to move out of her sister's house (perhaps into her own apartment), and she said that she had never wanted to move.

This story relates to several categories of discussion, beginning with the importance of friendship to the consumers at Glenford. The ties formed at these day centers provide the bulk of non-familial social relations. For a majority of consumers, they will spend years, even decades, with a somewhat varying, but also fairly stable group of peers who are their social and work connections. The routine at a day center emphasizes this stability, with consumers often sitting in the same places, performing certain jobs and activities on certain days. Familiarity is esteemed, and friendships among consumers and staff contain personal and nuanced social knowledge. This familiarity provides an amount of comfort to all involved – staff who are in charge of caring for the varied needs of many consumers and the consumers themselves who gain a sense of know-how and leadership around the premises, since they know when and where many of their daily activities take place.

Being accustomed to this highly crafted atmosphere of stability, the daily routine of friendship exchanges and activities can become extremely important to a person. When a drastic change is made, it upsets the social sphere, leisure sphere, and work sphere. Because relationships do have complexity, like friendships outside the center, it takes time for the label of friend to apply to a person and an individualized and unique connection to reform. In Luisa's case, though these multiple roles of friendship are strong, the home role that she fills heavily impacts her ability to maintain these other



social relationship. Her friendships are filtered through the needs of her caretaker, in this case, first her sister and then the group home employees.

Indeed, there are unique aspects to friendships within the condensed community of the workshop, particularly relating to matters of blurred staff-consumer boundaries and minimized age distinctions; interestingly, although these friendships operate almost entirely within the condensed community, they are most strongly influenced by the home role, which retains indirect control. But why is this so important? There are several implications to this research. Individuals with intellectual disabilities have often been viewed as less socially capable than the rest of mainstream society, and this key loss of humanity has led to the denial of rights and agency for many individuals. Research into the ways in which individuals with developmental disabilities take initiative and responsibility for their community and engage in meaningful friendships and peer relationships reveals a social agency and capability that has long been denied. However, this agency comes at the cost of other aspects of adulthood. While the blurring of staff-consumer boundaries gives some agency to individuals, it also reinforces institutional roles of caretaker and consumer, which at times continue to limit these individuals. Additionally, the minimization of age differences, while it creates a more accepting community, reflects how individuals with developmental disabilities face marginalization from broader society.

### Gender and Sexuality

While social divisions such as age may have a lesser impact on social relationships in the condensed community of GWAC, gender still plays a large role. Of course, gender issues cover a wide variety of topics, but this paper will specifically be

talking about the nature of romantically based interactions between consumers. Romance is an important aspect of the adult life, one that reflects a movement away from primary childhood home roles, to the creation of new home roles. To transitioning youth, romantic relationships begin as an “informal extension of friendship groups,” and thus there can be many degrees of romantic partnerships that vary along a continuum of social and physical closeness (Collins and Van Dulmen, 2006:221). These relationships have a distinct set of social rules and thus ultimately serve as a distinct social role. There is research to show that these romantic attachments, which often lead to stable family unit creation, take a predominant role over adult friendships, which may decrease in importance (Collins and Van Dulmen, 2006:221).

Gender’s influence on consumers stems from, of course, real and present desires for physical and emotional companionship. In the past, social phenomena, such as the Eugenics movement and the later medicalization of disability, have seriously compromised and dismissed the sexuality of individuals with disabilities through a tie to reproduction. Though these social movements differ widely in the motivation and method behind the suppression of sexuality, they both have implied a damaging tie between sexuality and intimate companionship. But there are many kinds of intimate relationships that add meaning to adult life and that cover a wide range of levels of sexual behavior. At times, however, even relationships which are non-sexual companionships or are precursors to overt sexual relationships have been discouraged.

At the Glenford Center, gender and sex are a frequent part of the daily dialogue. It has an almost ritualized place within the conversation. For staff, it is a way to reinforce connections with consumers and begin a series of jokes that bring enjoyment for all

involved – conversation participants and outside listeners. Without fail, when a consumer or staff member asks someone about a crush, boyfriend, or girlfriend, he or she gets a smile or laugh from the recipient of the question. While these conversations about romance occur frequently, as with the previous discussion about age, a distinction that needs to be made between the symbols of romantic attachments (such as conversations about the romance, the status of boyfriend or girlfriend) and the affect of these symbols upon behavior at the Center.

Romantic relationships are meaningful at GWAC in that they have a strong impact on the individual and on the behaviors exhibited between individuals, even interactions outside of the immediate romance; this can manifest itself in several ways. Romance and the idea of romance and sexuality certainly make up a significant part of an individual's self-perceptions and goals. It also frequently becomes part of relationships between the individual and people in whom he or she is not romantically interested, particularly staff members who tie sexuality into the normal routine of the joking relationship. Between consumers and non-consumers, joking dialogues about boyfriends, girlfriends, sex, etc, were frequent parts of conversation that reaffirmed the familiar and close relationships between staff and consumers, while also keeping a distance from serious matters that may relate. Once, when a male consumer was hesitant about meeting a new group of people (women), a staff member called out to him, "I can't believe you don't want to spend time with the ladies!" Staff are not the sole initiators of this dialogues – consumers also initiate this talk, demonstrating their comfort with the matter. A talkative young consumer, Ben, would come up to me occasionally (or we would be in the middle of another conversation) and jokingly ask whether I would marry him. This

was a routine of joking for him – I had heard him frequently say that to others. I replied that I had heard he'd proposed to all of the student volunteers who do storytelling with him, and I asked what he was going to do with so many wives. He laughed, and began talking about one person in particular, telling me to tell her that he was going to buy her a ring for “Five hundred, hundred, hundred six hundred dollars,” laughingly. He then mimed blowing me a kiss. Jokes of this sort show a level of openness about romantic relationships and a flirtatious conversational style that pervade GWAC. The joking element, however, serves another purpose. While it connects individuals with familiar subject matter, it also reveals tension about the topic. Because these jokes are most commonly used between individuals who serve different roles in the hierarchic institution, they also serve as ways to perpetuate distance. These jokes can be made comfortably about a tense topic because there is little risk of an actual relationship crossing the hierarchy and breaking down the separate roles of staff and consumers. Jokes of this sort are infrequent occurrences between consumers, who, when not talking to staff or outsiders, tend to view relationships with increased seriousness.

Certain events, such as dances, are organized by GWAC and serve as a time of increased social attunement to romance and as a sanctioned time for limited flirtatious activity. While dances are a time for friends from different areas to come together, there is also an excitement and chatter in the air that comes from the prospect of dancing with a member of the opposite gender, an act that is highly valued as a romantic activity. Those who are not dancing stand or sit around the perimeter of the dance floor, watching. Some people dance by themselves on the outer circles of the dance floor, but at the core is a group that dances in the center. Sometimes same-gender friends would dance together in

pairs (typically women dancing with other women), though there were some male-female pairs. At the Valentine's Day dance, Dave asked Lynne to dance, and giggling, she accepted. Dave and Lynne danced together for the rest of the time, holding hands; while dancing, Lynne continued to laugh and converse with the other ladies while dancing, as would Dave.

This dance activity highlights the importance of casual flirtation within gender relations within the condensed community of Glenford. Though no serious relationships result from this kind of socialization, the initial steps toward romance are taken. As can be seen from the reaction of Lynne and her female friends, dancing with a male consumer is a highly exciting and important event, one which must be shared with nearby friends. Thus, while flirtations at GWAC are not always gateways toward serious relationships, they have a strong purpose in reinforcing same-gender relationships and bringing friendships closer. The flirtatious socializing that occurs between consumers and the joking relationships that occur between staff and consumers lend an atmosphere of romantic openness that lays some of the groundwork for more serious relationships. However, the primary effect of flirtation does not seem to be to create new romantic relationships, but to reinforce and strengthen existing ones. Sexuality is an important part of not only romance, but friendships, and should be recognized as such.

While casual joking and flirtation make up most of the daily behaviors, serious and consistent romantic attachments do exist and do make up an important part of a consumer's social life. These relationships take many forms, from one-sided attachments, to mutual relationships, and on occasion, marriage.

Lynne talks often of her boyfriend, a family friend of whom she always carried a picture. From our conversations, it appeared that he was a

close family friend, but likely not a reciprocal boyfriend. During one encounter, I saw her smiling and reading a piece of paper, and when I looked over I saw that it was something she had written. After a few minutes of her looking it over, folding it and opening it up again, she asked if I wanted to see it. What she showed me was the following: a handwritten note to this boyfriend. It was framed in the form of questions it asked him whether he wanted to participate in activities with her, such as boyfriend, marriage, honeymoon, movies, dinner. It progressed through stages of a relationship. At the end of the note, she signed Love, Lynne, and as an addendum "YES!" I asked about this last part, and she said that it was because she was telling him yes. I asked whether she would give this note to him, and she said yes. I asked what he thought that he would say, and she wasn't sure.

It did not bother her that this was a one-sided relationship. She was both the asker of questions and the answerer. Because it was one sided, her role as girlfriend was able to take place entirely within the physical location of the condensed community of the workshop, as an overlapping part of her other adult roles. In fact, her role overlapped so much that it became entirely a way for her to socialize with friends. Because this relationship defined and developed itself within the condensed community, this in turn changed her ideas about the progression of a relationship. Note writing became an important form of initial courtship. The stages that one would expect to occur only in the most serious relationships, such as marriage and honeymoon, were discussed in the beginning of the note, while the actual "datelike" stages seemed to come after marriage. The physical location of the condensed community played an important role in her conception of a relationships; because she did not have the autonomy to go to dates on her own, she conceived of marriage as the thing that needs to occur before the two people can go out together. The treasured and much-looked at picture served to bring physical connection to Lynne and her romantic interest, a need which is important to many consumers, who are used to seeing their primary social group at GWAC every day.

Another example of a serious romantic relationship can be seen through an older consumer couple, Bertie and Dave.

Bertie and Dave spend their days in two separate areas. Because Bertie is in Area 1 and Dave is in Area 2, they do not have much opportunity to interact during the day, but still maintain a long-term relationship. They talk about each other often, and during craft times, will make crafts for the other person.

In the weeks preceding Valentine's day, I saw Dave showed me a drawing that he was making on construction paper and told me that he was getting married. He said that it was for a woman in Area 2 and that they were getting married in two weeks. He repeated "Talk to parents" many times, and when I asked further, it seemed that he still needed to talk to her parents. I asked what would happen after he got married, and he wasn't sure.

A few days later, I had a conversation in Area 2 with Bertie. She was focusing hard on painting for a Valentine's card. I asked whether she was making this card for anyone specific, and she said that she was making it for her boyfriend in Area 2. I remembered that it was Dave, and told her that he'd mentioned that they were going to get married and live together. She nodded. She told me that this was true. She could also show me a picture of him, and she went to her lunchbox and pulled out a picture of him. I asked how they'd met and how long they'd been together. She said that they met at OWAC and they'd known each other for a long time. I asked why she'd wanted to be his girlfriend, and after staying silent for a minute, she replied that it was because he loved her.

This couple demonstrates the affections and aspirations held by many consumers as they form meaningful relationships and pursue them fully through institutions such as cohabitation and marriage. Since it is uncommon for couples to live together, interactions take place within the condensed community and thus become difficult to differentiate from friendships, since each individual is, in this one location, trying to juggle the roles of worker, friend, romantic partner. Once again, family and caretakers have the ultimate control over the situation, as can be see from Dave's reference to Bertie's parents. It is important to note that there are exceptions to this, in several consumers who either were married, or had been in the past. These relationships were

strong, and even when divorce resulted, the period of marriage was still looked upon as a positive time, during which personal character developed from close interaction with another person. Marriage led to cohabitation and social independence, both of which were favorable.

Thus casual joking and flirtation as well as more serious 1:1 attachments serve several unique roles in the condensed community, which influence how these romantic relationships function. In this close community, where work and leisure roles overlap, casual relationships are not seen as a way to achieve closer intimacy, but as a way reinforce relationships that cross hierarchical boundaries of society. Gender is an important tool in creating friend bonds, and it does so effectively, but it also derives from a tension between disability and sexuality. The joking nature of casual romance implies a strange comfort with a personal topic that would otherwise not be discussed between members separated by social status; jokes about cross-status relationships would certainly be a tense topic. But these jokes reveal that in practice, the implication of lower sexuality for people with developmental disabilities still holds sway. In this case, jokes are safe because there is no threat that they could refer to a real occurrence. The perceived sexuality of individuals with developmental disabilities is still subject to ideas from the social legacy of eugenics and medicalization.

However, between individuals with developmental disabilities, sexuality is a part of everyday life and is extremely important aspect of adulthood and adult roles. Consumers connect with each other and have goals and plans. For people with developmental disabilities who become involved in serious relationships, these relationships are able to have meaning without necessarily following the path of



conventional mainstream relationships. These relationships must adapt to physical distance and regulation by caretakers. Though they may look nontraditional, these relationships provide a highly sought-after status and, because (unlike mainstream relationships) they are tied so closely with friend and work roles, they also provide a way to discover other aspects of one's own individuality and adulthood.

## Conclusion

Thus, the condensed community provides a lens through which we can further examine the segmentation of adult roles within society, looking more broadly at questions of personhood and adulthood. Here, the economic and socially based roles of an adult come together in unique ways, with relationships blurring in a way that shows the everyday responsibility that consumers take in the maintenance of the day center's activities and structure. For an individual, the self-perception of adulthood is certainly present, in part due to the structure of the work-activity center, which creates accessible work and leisure roles and in part due to the development of increasingly nuanced social relationships. The relationships that people choose reflect not only their personalities and activity preferences, but a wider array of social markers, including age, status, job, family, etc, the importance of each of which is minimized or emphasized according to the needs of the condensed community and the broader societal expectations about disability. While some markers, such as age do not appear to be as important as they would be in mainstream relationship formation, gender and family affect daily interactions in noticeable ways.

The implications of this research into adulthood and disability are important. The social capabilities of individuals with developmental disabilities are frequently questioned in discussions of rights and service provision. This work helps to demonstrate that not only do individuals within the community fulfill complex, overlapping roles, but that they take initiative and leadership in the maintenance of their community. However, when doing this, consumers are also perpetuating the roles of caretaker and consumer, which can reinforce societal limitations.

Though individuals with disabilities are able to achieve the markers of adulthood such as employment, friendships and romantic relationships that contribute to self-perception of themselves as adults, there is not necessarily a matching perception from others. Though adulthood is often a time for transitioning away from family members, many adults with disabilities have finances and even social relationships monitored and filtered through family and caretakers, either directly or indirectly. There is a notion of dependence that does not always match up with the nuanced social relationships and goals of consumers.

Thus, roles and relationships in the condensed community offer us the chance to dissect these markers, noting absences and changes, and look at how these absences and changes impact peer-relationships. This community offers a chance to look at the important role that an individual with a developmental disability might play in a complex community, something that, due to societal limitations and stigmas, cannot frequently be seen in the mainstream. The recognition of this reaffirms the need for social accessibility and complex attitude shifts toward disability. Participation in adult roles is a signifier of broader social inclusion, since it depends on not only self-perception but the perception of others and thus, examining it allows one to assess changing attitudes about disability. Additionally, the adult roles within the condensed community are roles which are a part of mainstream society. By looking at them in a microcosm, one can more fully understand how the interactions between self-perception and external perception work together within these roles to create a notion of adult personhood.

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