JoDD
Journal on Developmental Disabilities
Le journal sur les handicaps du developpment
Volume 14, Number 1, 2008

When There Are No Choices: The Consequences of a Lack of Adult Living Placements for Young Adults With Intellectual and/or Developmental Disabilities Leaving Child Welfare Care

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Keywords

intellectual and developmental disability
transition
child welfare
rights
well-being

Abstract

Young people labelled intellectually and/or developmentally disabled (ID/DD) who are making the transition to adulthood often lack control over their lives as restrictions are imposed upon their individual choices and their participation in decision-making. For those who have been wards of the child welfare system, this period of transition is made even more difficult by a history of child maltreatment, a lack of familial support, and a dearth of adult living arrangements available to them. Through face-to-face interviews with young adults with ID/DD upon leaving child welfare care, and through focus groups with members of the wider 'community of interest' (including child welfare social workers, adult protective service workers, foster parents, and residential services staff), this research examined the impacts of residential arrangements and a lack of housing placements upon both the situational and developmental transitioning of young people with ID/DD into adulthood. The consequences for the young person's physical, mental, emotional and social well-being were related, in the discussions, to issues of choice and control, systemic barriers, devaluation, and rights. This paper focuses specifically on the themes of rights and well-being.

The transition from childhood to adulthood is one of the most stressful periods in human development (Lehman, Clark, & Bullis, 2001). For individuals labelled intellectually and/or developmental disabled (ID/DD) and their families/carers, it may well be the most stressful time, second perhaps only to the time of first diagnosis of impairment (McDonald, McKie, & Webber, 1991). For young people with ID/DD and their families, this transition point serves to exemplify the discrepancy between what is expected and what actually occurs. Labelled young adults typically hope for increased independence, for 'normal' adult outcomes (Lawrence, Brown, Mills, & Estay, 1993)—a place of their own, a career and relationships; aspirations which seldom differ from those of their non-disabled peers (Palmer & Wehmeyer, 1998). However, few (22%) are able to realize even basic criteria for success as adults and many lead very restricted lives—living with their families or in group homes, unemployed or underemployed, and socially isolated (Frank & Sitlington, 1993; Keogh, Bernheimer, & Guthrie, 2004).

Despite philosophies of normalization, integration, and community living, a dearth of adult living placements exists for persons with ID/DD. This is the case irrespective of the person's preference (or need) to live in a home of their own (with or without supports), or in a more formal, supported residential arrangement. There are long waiting lists and infrequent vacancies in small, community-based group homes, semi- or supported independent living arrangements, transitional residential programs, boarding and/or adult foster care (Lawrence, et al., 1993). This phenomenon, evident in North America and the United Kingdom (Audit Commission, 2003), arguably reflects the broader societal devaluation of persons with ID/DD. As articulated by Clark: "If people think of you as a person who has many possibilities, they will create the space for you to grow. If people think of you as a person with limits, they usually don't give you as much space and you grow less" (1991: 11). A lack of control is afforded this group: restrictions are imposed on individual choice, participation in decision-making, and determination of the types of services and relationships developed (Agran, Blanchard, & Wehmeyer, 2000; Bambara, 2004). Simply put, decisions are being made resulting in young people with ID/DD being placed in places not of their choosing.

But what of the situation facing individuals with ID/DD who are in the care of the child welfare? Does child welfare status pose additional challenges to transition? This paper presents results from a qualitative study examining the consequences of insufficient adult living placements for one group of young adults with ID/DD transitioning from child welfare care. As background to this question, a review of the literature available on transition, for young adults with ID/DD *not* in child welfare care, and for young adults *with* and *without* ID/DD in care, is presented prior to a description of methodology, research findings and discussion.

Background

The research literature on young adults with ID/DD who are *not* in child welfare care, reports that this group, frequently, has difficulty coping with both developmental and situational transitions. This is due to poverty, less well-developed coping and social skills, greater dependence on others, behavioural issues impeding integration and acceptance, family stress, social barriers, limited employment options and inadequate service provision. This process is circular, as limited opportunities, poverty and dependence inhibit the development of skills required for successful adult living, thereby further restricting opportunity and choice (Dowling & Dolan, 2001; King, Cathers, & MacKinnon, 1999, Modrcin, 1989). As a result of these developmental concerns and, particularly, systemic and attitudinal barriers to establishing themselves as adults, these young people are more likely to experience defeat leading to feelings of low self-esteem, inadequacy, depression and hopelessness (Konanc & Warren, 1984; Palmer & Wehmeyer, 1998). Young adults with ID/DD may become increasingly sentient of their own 'differentness' at this stage in their development. This awareness figures prominently in their construction of an adult identity and may reinforce feelings of alienation and rejection potentially contributing to self-protective, defensive behaviour patterns which serve to sabotage the transition process (King et al., 1999). Disconcertingly, such repeated failures are further argued to exponentially increase the risk of, and vulnerability to, self-destructive behaviours including social isolation, substance abuse and suicide (Sullivan & Knutson, 2000). Though they may have a clear knowledge of their needs and what is required to accommodate these, not being permitted to fulfil them impedes and/or frustrates development of a positive self-image (Clark, Olympia, Jensen, Heatherfield, & Jenson, 2004; Dane, 1993). Familial support alone is often insufficient—a broader community response is required for successful transition (Mech & Fung, 1998).

This transitional period is similarly difficult for young adults *without* ID/DD who age out of child welfare care. Many have no familial support—estranged from families of origin and/or without ongoing support of foster families or other carers (Loman & Siegal, 2000). Typically, they have little or no access to ongoing state support upon being discharged from care. The majority do not have continuous sources of emotional, financial, interpersonal and social support that are available to young adults not in care (Cashmore & Paxman, 2006; Courtney & Dworsky, 2005, 2006). Continuity and social support, in and beyond care, are, however, significant predictors of positive outcomes for children in care (Cashmore & Paxman, 2006). Histories of abuse and/or neglect, removal from biological families, placement in out-of-home care, and multiple moves frequently result in their being ill-prepared for independence. They are forced to transition with fewer resources, less support, at an earlier age, and in a less graduated way than other young adults (Cashmore & Paxman, 2006; Loman & Siegal, 2000; Mech & Fung, 1998). As a group, they typically experience poor outcomes: unemployment or underemployment; poverty and dependence on social assistance; mental health and/or substance use disorders; homelessness; without basic necessities; involvement with criminal justice systems; and having children they are unable to parent (Courtney & Dworsky, 2005, 2006; Hill & Stenhjem, 2005/2006; Loman & Siegal, 2000; Shin, 2004). As a result of the lack of appropriate living spaces and support, many return to families of origin (Courtney & Dworsky, 2006; Loman & Siegal, 2000). Very often the problems necessitating their removal from these families persist. Young adults are returning to dysfunctional, abusive and/or neglectful families who are ill-prepared to support them. Negative outcomes are a frequent consequence (Loman & Siegal, 2000).

Limited research exists on children and youth with ID/DD in child welfare care. “We do know that they are there, they are in need of such services, and that there may be many more in need of services than come to the attention of the system” (Baladerian, 2005/2006: 4). Even less research addresses the issue of transition from care for this group (Hill & Stenhjem, 2005-2006). This is the case despite the fact that there is growing evidence of a strong association between ID/DD and child abuse and neglect—children with ID/DD are more likely to experience maltreatment, and maltreatment increases the likelihood of having a disability (Fudge Schormans, 2003; Vig & Kramer, 2002). Children with ID/DD are over-represented in the child welfare population. While only about 1-3% of the general population has a developmental delay, it is estimated that, in Canada, 8.7% of children in child welfare care are so labelled. If one considers all developmental and physical disabilities, almost 25% of all children in care in Canada have a disability (Fudge Schormans & Brown, 2002). Children with ID/DD in child welfare care are an extremely disadvantaged group (Dowling & Dolan, 2001; Emerson, 2003). They are significantly more likely than their non-disabled peers in care to have experienced more severe maltreatment over longer periods of time and from multiple perpetrators (Fudge Schormans & Brown, 2002). They are more likely to be removed from the family home and to be placed in more intrusive residential settings for longer periods of time (Rosenau, 2005/2006). Typically, they present with multiple child functioning concerns. In addition, their caregivers similarly have markedly more risk factors for maltreatment than do parents of children without ID/DD who are reported for child maltreatment (e.g., single female parent; poverty; low levels of education; social isolation; cognitive, physical and mental health issues; personal history of being maltreated as a child). While clearly requiring support, these families are also significantly more likely to have few social supports (Fudge Schormans & Brown, 2002).

In addition to the above noted concerns, this group of young adults transitioning from care typically face numerous barriers (as a direct result of being in care) that impede their potential for self-sufficiency. As children in care, they must first address basic critical needs that children in more stable family situations do not have to deal with (Fudge Schormans, Renwick, & Coniega, 2006; Hill & Stenhjem, 2005/2006; Loman & Siegal, 2000); needs related to the experience (and consequences) of maltreatment, family separation, and attachment disruptions. They typically experience numerous disruptions growing up in care—changing placements, caregivers, schools, communities, workers, social networks, professionals, routines, and expectations. Often they do not receive appropriate special education services and transition planning because of maltreatment experiences, multiple school changes, and inconsistent advocacy for appropriate educational (and other) services (Fudge Schormans et. al., 2006; Hill & Stenhjem, 2005/2006). While it is clear that many (if not most) young adults *without* ID/DD in care face similar challenges, it is posited that the presence of ID/DD serves to increase a young person's vulnerability (Hill & Stenhjem, 2005/2006). Further, on the whole, child welfare workers are inadequately trained in 'disability'—disability knowledge and child welfare knowledge seemingly segregated in different systems. There is also tremendous confusion and lack of clarity between children's disability services, child welfare services, education, and adult disability services with regards to who is responsible for what (Baladerian, 2005/2006; Hill & Stenhjem, 2005/2006). The "prognosis for successful transition to independence is cloudy" (Mech & Fung, 1998:33).

Method

Participants

Participants were drawn from a metropolitan city in Ontario, Canada. A purposive, self-selected, convenience sample of five transition-aged young people labelled ID/DD and having been in child welfare care (either a ward of the child protection agency or of the Crown, and having resided in a child welfare supported residential placement such as foster and/or group home care) was selected. The researcher relied on the wider "community of interest" (Barnsley & Ellis, 1992)—child protection workers, adult protective service workers (APSW's), foster parents, residential staff and operators in the city—for access to potential participants. The result is an admittedly biased and limited sample, decided on the numbers of potential participants put forth by those on whom the researcher was dependent, and on the basis of participants' ability to effectively communicate their experience.

Potential participants were approached by their APSW, residential staff, or former foster parent and apprised of the intent and voluntary nature of the research. They were asked if they would like to participate and whether they would grant the researcher permission to contact them. Only one young person approached declined to participate. The sample included female (*n*=4) and male (*n*=1) participants, and users of both verbal (*n*=4) and alternative communication (*n*=1) methods. They were between the ages of 19 - 21 years. All were residing in either a children's or adult group home, or adult institutional setting, at the time of the research. Most participants had been assigned additional labels (i.e., mental health (*n*=1), physical disability (*n*=1) and behavioural designations (*n*=4)), and were described by their caregivers as functioning in the moderate (*n*=1), mild (*n*=3) or borderline (*n*=1) range of intellectual impairment. As they were all over age 18 years and were no longer eligible for child welfare mandated services, all had recently left child welfare care. Persons identified as having severe or profound impairments were not included due to a lack of resources to meet the communication needs of this group. Information regarding the participants' past, their family of origin, reasons for their placement in care, or their experiences in care (those not explicitly related to transition), was not solicited by the interviewer. In the course of the interviews the young people revealed, however, that all were Crown wards and had experienced multiple moves while in care. Further, disability was invariably a factor in their child welfare placement. For four of the participants, child maltreatment also figured into the decision to place them in care.

In addition to the transition-aged young people, the research also used a purposive, self-selection, convenience sampling methodology to recruit members of the above-noted community of interest for this research. The same organizations and individuals who had been asked to assist with recruiting transition-aged young adults, were asked if they would like to participate in the research. A sample of twenty four participants was drawn from four different groups in this community of interest. They included: five social workers with case responsibility for transition-aged young adults with intellectual disabilities in child welfare care; four APSW's employed by a community agency that assumed case responsibility upon the young person's leaving care; ten child welfare-affiliated foster parents, and five staff and operators from the children's residential sector. (All but two of the participants from the community of interest were female.) Four focus groups, one for each of the different community groups, was held. One of the foster parents, unable to attend the focus group, was interviewed separately as were two of the residential service operators.

While the four social service groups comprising the community of interest are equally involved in this problem, each has a distinct role and function and potentially different perspectives. Inclusion of this community of interest was intended to build upon the analysis of the experience of the young persons but not detract from the significance imparted upon the experience of the young people.

Study Design

The paucity of information in this research area suggested the use of an exploratory, cross-sectional, qualitative research design, employing modified grounded theory as the guiding methodology. Premised upon participatory, empowerment and narrative research models, this design minimizes researcher control over participants' definition of their experiences, thus facilitating the development of idiographic knowledge (Rodwell, 1998) regarding the experiences of young adults labelled ID/DD in their transition from child welfare care. Cognizant that the marginalization and oppression of persons labelled ID/DD is mirrored by their absence and lack of representation in research (Blacher, 2001; Rioux, 1994), this study sought to situate the young people themselves at the forefront of the research. This type of research design may provide the opportunity for people to take some control over the research, and, at the very least, provides a symbolic opportunity for people to speak for themselves (Roberts, 1994).

To augment a review of the literature and facilitate the pertinence and effectiveness of the research, a preliminary focus group, comprising 1-2 members from each group in the community of interest (*n=6*) was conducted to formulate the research questions/guide. Open-ended discussion of issues related to the lack of living options for transition-aged young adults with ID/DD in care led to the identification of, and consensus regarding, the most pertinent issues and questions to be asked of the young people and the focus groups. Numerous barriers (e.g., time, transportation, and accessibility) precluded the participation of a young labelled person in this focus group, necessitating an individual interview to achieve this input. This contribution may thus have been somewhat compromised; however, the young person interviewed proved an enthusiastic and valuable collaborator. Two research guides were developed. The first included broad-based, open-ended questions while the second provided a more specific, detailed 'menu' approach to accommodate any participant experiencing difficulty with open-ended questions or needing greater clarification. Questions were added or refined in accordance with the emergent nature of grounded theory methodology.

There was an expressed preference on the part of the transition-aged young adult participants for individual interviews over focus groups, for reasons of nervousness, apprehension at speaking in front of strangers, a desire for more individualized attention, and greater comfort on one's "home turf". Consequently, in-depth, semi-structured, open-ended qualitative interviews, lasting approximately 1½ to 2 hours, were conducted by one of the authors in the homes of the participants or location of their choice at a time convenient to them. Participants were given control over the degree of privacy of the interview. Participants were able to have a support person present during the interview if they wished—one person requested this for the entire interview, a second wanted the support person available in another room should s/he require assistance at any given time in the interview. Interviews commenced with a review of the young person's understanding of the intent and process of the research, to assuage concerns that consent to participate was voluntary and based upon accurate information and understanding. Participants signed consent forms written in language adjusted to meet their needs. Participants were not comfortable with being audio-taped so hand-written notes were taken by the researcher during the interview. Given their history of being in child welfare care, the participants were very familiar with note-taking during interviews and appeared quite comfortable with such.

It is Morgan's (1988) assertion that focus groups permit participants greater control over the discussion. Separate focus groups were held for each of the community of interest groups at the agencies where participants worked and, with permission, were audio-taped for later transcription and analysis. Focus groups lasted approximately 1½ hours. Participants had been informed of the research goals and process at first contact. At the time of the focus group, these goals were reviewed and participants read and signed requisite consent forms. Following this introduction to the purpose of the research, the focus groups largely managed themselves with minimal direction being required of the researcher who used the research guide simply to ensure all research questions had been addressed.

The process of individual interviews paralleled this experience. The young persons with ID/DD quite willingly offered their stories. Their familiarity with the subject and ability to articulate their own meanings, experiences and perceptions of this situation was such that use of the augmentative guide was, again, seldom required. In capturing the voices, the emic perspective, of labelled young adults themselves, the research achieves relevance and validity (Caracelli & Greene, 1997). The research design necessitated time spent with the research participants. The resultant long interviews provided thick, rich description for analysis, thus enhancing trustworthiness, dependability and transferability of the data (Cresswell, 1998).

Data Analysis

In grounded theory methodology, theory is constructed from the data. Charmaz (1983) describes this methodology as a process wherein data collection and analysis proceed simultaneously. The analysis moves back and forth between the data itself and the theoretical frameworks that underpin it (in this case, transition to adulthood, housing, ID/DD, and child welfare status). Audio-tapes from the focus groups were transcribed by one of the researchers. Hand-written notes from the interviews with the young adults were analyzed in the same manner as the transcripts. Using a line-by-line open coding analysis, data from each individual interview and focus group was coded inductively and, as conceptual categories, themes, and patterns emerged they were examined and tested via a constant comparative method with subsequent interviews and transcripts. The use of axial coding, and then selective coding, allowed the researcher to relate categories to sub-categories, clarify concepts and integrate and refine the emerging theory (Charmaz, 1983; Strauss & Corbin, 1998).

It is acknowledged that there are limitations to this study. The small sample size is compounded by having had only one interview with each participant. Acknowledging the inclusion of representatives of each of the involved groups in the development of the research guides and as research participants, the researcher must concede the potential directing effect of the research guides. In addition, resources precluded participants' being offered the opportunity to review interview and focus groups transcripts, or a final draft of the report.

Results

There was unanimous agreement that the lack of appropriate living options for transition-aged young adults with ID/DD had become a problem of monumental proportion, one needing to be addressed in as humane and timely a fashion as possible. Study participants articulated several consequences for the young adults. Significant concern was expressed as to where the young people were being placed; the residential arrangements being made for them by others, the appropriateness of these provisions, and the vulnerability of many of the young adults leaving child welfare care. The scarcity of adult advocates and protections afforded this group; issues of separation and attachment, of lost relationships and supports; inconsistent philosophies and practices between the children's and the adult sectors; and the effects on planning and the transition process itself were posited as potentially threatening. The consequences to the young persons' physical, mental, emotional and social well-being were believed to be magnified by this vulnerability. Issues of choice and control were central to the discussions. These consequences were collapsed into a number of themes: research participants' concerns over *adult placement availability*; what they perceive to be the *reasons for lack of placements*; and *impacts on young adults labelled ID/DD*. In addition, the theme of *impacts on young adults labelled ID/DD* is further broken down into the sub-themes of *placement in inappropriate settings*, stalled *developmental transitions, emotional and behavioural impacts, self-blame, disruption of relationships*, and limited *opportunities for choice, determination and participation in decision-making*. From these themes, the researchers identify four fundamental, dynamic and inter-related elements pertinent to our understanding of the lack of adult living options for young adults with developmental disabilities: well-being, systemic barriers, devaluation, and rights. This paper focuses on rights and well-being. As will be made clear in the discussion section, each of these interconnected themes and sub-themes address the core elements of human rights and well-being. Results are presented in a manner that forefronts the perceptions of the young adults. Selected perceptions and comments of the transition-aged young adults are quoted and italicized for identification, with the subsequent discussion being a compilation of the data from the focus groups and individual interviews. Unless stated to the contrary, reference to an opinion of the focus group implies consensus within the focus group.

Adult Placement Availability

> *Even when you learn the stuff you need to know to move, you know, like cooking and cleaning and stuff, you still can't move cause there's nowhere to go.*

This assertion was uncontested by any of the participants in this study. All were unified in the belief that adult living placements (a home of their own (with or without supports), or a more formal, supported residential arrangement) were insufficient to meet demand.

Reasons for Lack of Adult Placements

> *…the government keeps closing things down because they cost too much.*

The transition-aged young adults consistently identified "no money" to be their understanding of the reasons for the dearth of adult placements. Three believed their advocates were actively trying to secure them an adult placement but were stymied by lack of availability. While, undoubtedly, these opinions would have been formed, at least in part, through discussions with workers, advocates and carers, they typify the opinion of all participants in the study. Each focus group similarly referenced changing sociopolitical and econonomic forces and priorities as a significant factor. There was agreement among the focus groups that no "new money" was available to rectify the problem and that those with authority recognized that without additional dollars, the adult sector was largely stagnant. As noted by members of three focus groups, adult service providers had proven creative in their use of existing funding but the impact of this on the waiting lists for adult living placements was minimal at best. A lack of co-ordinated planning between the child and adult service sectors; confusion regarding responsibility for transition-aged young adults with ID/

DD; and inconsistency in ministerial and departmental commitment and response to this population group figured in the problem. Two focus groups particularly expressed their conviction that the poverty of attention awarded this issue had as much to do with the devaluation of persons with ID/DD as it did with economics. Tenacious attitudinal prejudice ("…they're 'retarded' so what does it matter" and "they're not going to notice the kind of care they get or if something changes anyway") combined with ignorance on the part of the general public and those in power. As stated by a participant in one focus group "the young adult's" rights are not even a consideration – the only interest in this problem is because of the costs involved".

Impact On Young Adults With ID/DD

> *Inappropriate placement.*
>
> *I don't know where I'm moving. I don't know when, they keep changing it on me. It drives me nuts. I don't want to stay here (in a children's residence)...I want to live in a house, but they say I can't.*

Both the focus groups and the interviews with the participants with ID/DD yielded information as to the prohibiting effect of the dearth of placements on situational transition. Young adults are finding themselves unable to leave children's foster homes or children's group homes or are living in places not of their choosing. The transition-aged young adults labelled ID/DD interviewed resided in a variety of settings, however, the shortage of adult placements meant that the majority had been forced to remain in children's residences and had no idea when they might be able to move to the adult service sector. Further, these placements (in children's residences) themselves, were threatened by financial and licensing uncertainties. Children's services providers, reluctant to discharge the young adults into a void, nonetheless were feeling increasingly pressured (by government regulating bodies) to do so.

> *I'm moving soon. It's not where I wanted. I have to have a roommate but I don't want one.*
>
> *I've moved lots of times since I left my foster home. I couldn't get used to them, they weren't good places for me."*

One participant with ID/DD still residing in a children's home was scheduled to transition to a supported adult apartment program (not of her/his choice) in the near future. Another had been abruptly relocated to a long-term care health facility intended for seniors following several years of uncertainty. A third was currently living in an adult service group home s/he was not comfortable living in after having 'bounced' through three inappropriate adult placements. In all three cases, the decision (made by others on behalf of the young adult) to accept these placements was predicated upon the lack of available options.

Repeated reference was made to the life situation of those young adults with ID/DD who, for myriad reasons, were "falling through the cracks". Identified as especially vulnerable were young people with 'borderline' intellectual disabilities who are often not eligible for adults services; those with a dual diagnosis of ID/DD and mental health issues because of ongoing debates over ministerial responsibility (developmental services versus mental health services); and those individuals with behavioural issues, falling under the moniker "hard-to-serve". Other stories were put forth by labelled participants and the focus groups of young adults with ID/DD being placed in boarding home arrangements with alarmingly inadequate supports, totally unprepared for this degree of independence. Several participants and the focus groups had knowledge of other young adults with ID/DD ending up on the street, accessing hostels and street youth services as the only avenues of support. An additional consequence to insufficient options and services was that experienced by those young persons caught in the 'revolving-door' between life on the street and either mental health or penal institutions. All four focus groups recounted tales of young adults being placed in inappropriate placements and the resultant turmoil. Most of these placements eventually broke down resulting in the young adult bouncing from one inappropriate placement to the next. Three of the four focus groups relayed that some young people with ID/DD are returning to their familial home when no alternatives exist. In light of the fact that the young adults in this study had been wards of the child protection system, this was seen as a potentially dangerous outcome. Some young people were known to be returning to violent, abusive and/or neglectful parents, intent on mercenary motives (access to the young person's disability-related social assistance).

Developmental transition.

> *It's like a weird feeling to be still living in a children's home, it's like I can't grow up, you know…sort of like they're punishing me, like I'm still just a little kid.*
>
> *I hope I'm not gonna have to stay here 'til I'm 25, 26, 27, 28...I'm a full grown woman adult. I shouldn't be in a children's home...it's not proper fitting.*

Certain developmental consequences are consistent with this outcome, most notably the sense of a "lost" adulthood. Labelled participants conveyed the importance of the right to "grow up" and pictured for themselves fairly stereotypical adult lifestyles, incorporating community membership, an adult home, friends, activities and responsibilities. An awareness of the "rules" of being an adult, of managing one's behaviour, taking care of one's possessions, and of still having to do chores was prevalent. Interestingly, most adamantly defined their need for some form of continued support. Revealing a realistic grasp of their own potential and needs, the participants carrying additional labels of behavioural and mental health difficulties quite clearly did not believe these "problems" would be eradicated by a move to an adult setting. Nor did they avow to being able to manage completely independently simply because they were now adults. They did, however, as a group, believe they would be happier in an adult living placement of their choosing. For one labelled participant, the many years of uncertainty preceding placement in an appropriate adult home was simply "lost time".

> *There's too many rules, the rules are too strict...I want more freedom, not the freedom to go out and kill people or be stupid, you know...but, to, you know, do what I want sometimes, go where I want, see people...*
>
> *I feel unhappy here...it's sort of O.K. 'cause staff are teaching me things but I'm too old...I don't really get along with the kids.*

Participants with ID/DD invariably voiced their preference not to be living with young children: two articulated the degrading effects of being submitted to children's rules as a result of living in a children's program. Three focus groups broached the topic of the inappropriateness of mixing young children and young adults within the same residential program. Developmentally, the mix is contentious as the needs of the two groups are radically different. Such a mix seriously impedes the ability of the service provider to accommodate the young adult's right to privacy and for sexual development. Argued along the parameter of the right to be safe, the situation is less tolerable given the safety issues stemming from behavioural outbursts of the larger adults and consternation over the potential for sexually inappropriate activity between the two groups.

> *Staff are always jabbing at me...It's like a bribe; you know what a bribe is? They say you have to do it or you can't move... I don't like it...They say "control your behaviour" but they know I'm upset that I can't move... It makes me feel bad.*

For a number of labelled participants, group home staff and carers were interpreted to have radically raised their expectations and the demands placed upon the individual that they learn new skills, control their behaviour and, become more responsible. One of the focus groups provided information that supports this. The young people were given mixed messages; told first to demonstrate and accept the increased responsibility traditionally accompanying adulthood but then, through maintenance in a children's residential setting, precluded from exercising these expectations and responsibilities.

All four focus groups discussed the negative consequences of moving a young adult before they were ready. 'Ready' referred not only to the more practical considerations of skill development and a transition period to become accustomed to the new setting, but also to developmental readiness, a level of maturation facilitating developmental transition. This highlights the importance of individualizing the process so that needs and preferences dictate the time of the move, as opposed to chronological age or availability. Conveyed by the groups were stories of successful transitions incorporating these ideas. Those transitions not providing for individual "readiness" tended to break down and led to multiple moves, increasing psychological harm and emotional upheaval.

> *Emotional and behavioural impacts.*
>
> *angry*
> *worried*
> *afraid*
> *upset*
> *unhappy*

These emotions were consistently identified by participants with ID/DD as accompanying the uncertainty and delays encountered in transitioning to adult living options. The four focus groups confirmed the experiencing of the above-noted emotions, and stated that young people, blocked from transitioning, also endured other emotional and behavioural consequences. One group revealed that the anxiety created by the frustration and uncertainty precipitated a resurfacing of unresolved past issues and/or traumas, in some instances activating a crisis in relationships with others. This same group relayed that some young adults "have figured out that if they create a crisis, a behavioural crisis, then they can force staff and APSWs into a move" however, in light of the shortage of adult living placements, it was unlikely that a forced move would result in either an adult placement or a placement of the young person's choosing.

Participants with ID/DD discussed behavioural changes they experienced as a result of the stress and uncertainty posed by their situations. Some had experienced behavioural regression while others, formerly not deemed to have behavioural issues, began to display behavioural outbursts not typical of them. Depressive reactions, emotional regression, anxiety, physical manifestations of stress, psychosomatic complaints, and confusion were common. The focus groups reported that individuals displaying behavioural difficulties were often passed over by adult service providers with the 'cream-of-the-crop' being placed first. Alarmingly, the young adults, in committing behavioural offences, were at increased risk of being charged under the adult correctional system: the consequences being more severe than those experienced as a child. Concern was expressed by the focus groups that the root and communicative intent of the behavioural changes was often ignored and that the community and, sometimes carers, were seeking "legal resolution to behavioural problems as opposed to the usual methods of problem-solving". Criminal charges were not believed to be the required response: adult options were required. Three focus groups also believed that situationally-induced behavioural manifestations were prompting the increased use of medications as a means of controlling these behaviours.

Self-blame.

> *I get worried about making a good decision, you know...what if I pick the wrong decision and it's bad for me...It'll be my fault...If I don't control my behaviour I can't move... I have to learn all this stuff first...*

Labelled participants unanimously decreed governmental funding decisions to be the reason for the lack of adult residential spaces. Nonetheless, two members of this group also ascribed responsibility for not moving, or moving into an inappropriate placement, as resting with themselves. One young person attributed not moving to their failure to learn the requisite skills quickly enough. This was deemed a common response by one focus group; further citing that an unhealthy competition around learning life skills deemed to lead to adult placement often develops among young adults in the children's residential services. Self-esteem and competence suffer as the young person's experience is that of failure to achieve personal goals or effect change in their lives. The accruing self-blame when transition does not occur was speculated by this focus group to extend to residential staff and foster parents who, in personalizing the situation, believe themselves to have failed the young adult.

Disruption of relationships.

> *I miss _______, I don't get to see my friends now 'cause I'm too far.*
> *Nobody from______(children's residence) comes to visit, I don't see them anymore.*

Those labelled participants who had relocated to adult residential services were united in their sense of loss of many of the relationships they had enjoyed previously – relationships with foster families, carers, peers, and school and community members. The participants in this study had all been wards of the Crown for the better part of their lives and most had limited, if any, contact with families of origin. Those with ongoing contact reported their relationships with birth families to be problematic, not 'good' for them. Often the strongest attachments formed by the young adults were with the foster family or group home staff. The young adults themselves attributed this loss, in one case, to a lack of effort on the part of significant others to stay in touch, and, in another case, to the distance between the children's and the adults' placements. Three focus groups agreed that disruption to relationships was a seemingly inevitable corollary to relocation but cited a number of reasons for such. It is rare that a young adult will receive adult services in their 'home' community—many being relocated to other cities across the province. Transition plans often fail to incorporate measures to maintain relationships. As well, two of the focus groups noted that certain adult service providers view continued contact with foster parents and/or children's service providers as an intrusion as opposed to a benefit and may actively restrict and/or sabotage maintenance of these relationships. The critical importance of consistent relationships given that these young adults have come through the child welfare system, subsequently experiencing not only the initial trauma of removal from the family home but, in all probability, the trauma associated with multiple moves, appears to be neglected.

Choice, self-determination, and participation in decision-making.

> *…I'm not sure (if I could have said no)...I don't think I had a choice so I didn't try.*

What was clear from the stories of those young adults having relocated to the adult sector was that either, or both, the decision to move and where to move were not within their control. One participant, adamant that s/he had been telling others for some time of her/his desire to move, was presented with two options that were deemed unsuitable. In the opinion of the young person, successful transition was not a realistic possibility in either of these settings yet s/he felt punished for declining these obviously inappropriate opportunities. The next placement offered was not interpreted to be a choice: the individual was informed s/he would be moving. Not believing her/himself to have any power over this situation the individual did not try to question or challenge it and acquiesced to the placement. A second participant similarly felt forced to accept the first adult placement made available. Unless filled immediately, the placement would have been lost. As the placement was in a different city, the young person was not able to finish her/his school year and graduate with her/his classmates—an outcome that still rankles.

Two of the focus groups addressed the issue of those young adults who feel unable to speak up, assert their choices and demand participation. It was deemed a rarity that a young adult labelled ID/DD, having been in child welfare care, would have the confidence, psychological strength and/or skills necessary to do so. The abusive backgrounds and effects of being in care, common to many children in the child welfare sector, combined with the oppression, stigmatization and devaluation accompanying the label ID/DD, and multiple and disruptive moves diminished the likelihood of such traits sometimes leading to learned passivity. Repeated experiences of not having your wishes regarding residence respected, only exacerbated this.

> *…my worker said there was an adult place and I should take it… 'cause there's not many adult places...it's because of my age, I had to move...I didn't want to leave…*

The focus groups delved deeply into the theme of young adults being forced to move against their expressed wishes. Adult placements were accepted by others (foster parents, group home operators, APSW's and child welfare social workers) *on behalf of* young people. Others' perceptions of the long term needs of a young person (given the lack of supports and uncertainty inherent in remaining in a children's placement), combined with the shortage of placements, motivated some workers and carers to accept any adult placement 'now' as there were no guarantees another would be forthcoming.

> *It's (the APSW's) decision when I move... and staff are in charge too 'cause they have to agree or I can't...I'm not in charge...the government's in charge...*

While the interests, needs, preferences and choices of the young people themselves should be a primary focus in transition planning, transition decisions were being made instead on the basis of economics, availability, and government agendas. The focus groups expressed concerns over the negative impact of accepting any adult placement simply because one had become available—to say it was "unfair" minimized the impact of being made to move when one did not wish to. While those involved with this population felt themselves to be conscientious in their efforts to both discover and accommodate the wishes and preferences of the transition-aged young adults, it was generally recognized to be more symbolic than real given the lack of available placements and the inadequate response of funding bodies to this issue.

All four focus groups articulated that the uncertainty around transition led many workers and carers to decide to exclude the young adults from transition planning for fears of upsetting them. The inability to provide concrete information or accommodate preferences, and the resultant anxiety, self-blame, behavioural and emotional upheaval for the young adults prompted this exclusion. These decisions were made despite cognizance that they exclude the young adult and run contrary to, and violate, those beliefs held by focus group members as to the rights of the transition-aged young adult: the right to choice, to control, to participate in decision-making, and to live as an adult. One focus group participant summed up the situation this way: "philosophy takes a back seat to pragmatism". As stated by another focus group member: "the transition-aged guys seem to lose all these rights; to protection, to advocacy and to choice."

Discussion

In their discussion of the issue of insufficient adult living placements for young adults with ID/DD leaving child welfare care, the inaugural focus group made a number of important points. The subsequent research revealed a high degree of consistency between the stories of the young adult participants and the focus groups with the inaugural focus group, suggesting both awareness of the problem and consensus as to the consequences for the young adults in question. There is clearly also an allegiance between the themes, sub-themes and elements expressed in this research and the literature reviewed. While the four inter-related elements of rights, well-being, systemic barriers and devaluation emerged clearly from the data, only rights and well-being are addressed here.

Rights

Many involved in disability issues advocate the use of a 'rights' perspective; conceptualizing disability as an issue of human rights, equal opportunity and ethics and insisting that persons with a disability are entitled to the same rights as non-disabled persons (Accreditation Ontario, 2000; Rioux & Frazee, 2003). The right to participation; a good quality of life; treatment as an individual; respect for differences; and the amelioration of disrespectful conditions are believed representative of societal values of citizenship, democracy, equality, self-determination and social justice (Rioux & Frazee, 2003). A mutually reciprocal relationship exists between rights and respect, with respect implying value (Miller, 1993). Applied to the question of housing, a rights perspective emphasizes the right to a home of one's choosing in the community of choice, with ready access to the support services required for successful adult living. Selection must be based upon options demonstrating flexibility to meet individual preferences and needs (Dunn, 1996).

The data in this study clearly supports the perception that such rights are actively denied this population group as they are offered no 'real' choices, either in where or how they live, upon leaving child welfare care. Consistent with the literature for young adults with ID/DD *not* in care (Dowling & Dolan, 2001; Frank & Sitlington, 1993; Keogh, et al., 2004; King, et al., 1999; Lawrence, et al., 1993; Modrcin, 1989), and for young adults *without* ID/DD who are *in* care (Cashmore & Paxman, 2006; Loman & Siegal, 2000; Mech & Fung, 1998), the participants in this study report a lack of options, opportunities and supports for situational transition. This deprivation, economically rationalized, facilitates and, seemingly legitimates, the reported denial of the right to self-determination and the opportunity to participate in, and/or control, decision-making regarding one's life plans and is, again, consistent with research literature for young adults with ID/DD *not* in care (Agran, et al., 2000; Bambara, 2004). Compelling arguments (supported by the literature) were put forth by participants with ID/DD and the focus groups as to the value of the right to self-determination; on self esteem, on setting and attaining personal goals, on facilitating respect from others (Agran, et al., 2000; Bambara, 2004; Morris, 1997), and for the successful realization of transition based upon individual need (Dowling & Dolan, 2001; King et al., 1999).

The young adults in this sample could clearly, and realistically, identify and communicate their own needs and preferences, rebutting the notion that an intellectual impairment automatically negates these abilities. Adhering to a social constructionist view of disability, questions of competency are countered by queries as to the barriers to participation in decision-making. The findings in this study reinforce the belief that, with support, all persons can be facilitated to exercise some degree of choice (Brown, Belz, Corsi, & Wenig, 1993; Clark et al., 2004; Dane, 1993). While the four focus groups acknowledged these abilities and the right of the young adults to self-determination and/or participation in decision-making, the exercise of these abilities and rights is often restricted, paralleling the experience of young adults with ID/DD *not* in care (Agran, et al., 204). Admittedly, this is sometimes blocked by these supporters/carers/advocates in the name of protection from undue anxiety. Participants with ID/DD and focus groups both noted that such protection can infantilize young adults and deny 'typical' risk-taking and learning opportunities that may facilitate growth (Brown et al., 1993). The determination of the validity of excluding young adults from transitional planning thus becomes a subjective, and individualized, decision, a weighing of costs and benefits, of rights and protections. A mutually reciprocal relationship exists between rights and respect (respect implying value): a lack of respect for the collective, or group, precipitates a denial of human, economic and political rights which could then foster collective respect (Miller, 1993).

Well-Being

Rights, as exemplified by choice and self-determination, are an important measure of well-being, specifically the impact of having autonomy and choice over one's living environment (Vandergriff & Chubon, 1994). From a disability rights perspective, well-being is measured by the extent to which persons with ID/DD are afforded the same opportunities for choice, community presence, competence, and respect as their non-disabled counterparts: those same factors demonstrated to be vital to non-disabled persons being of equal import to those labeled disabled (Bach, 1994; Lawrence, et al., 1993; Palmer, 1998). Social well-being is defined as incorporating three elements: the development and realization of freely chosen life plans, societal responsibility for ensuring the conditions to achieve those plans, and justice in the distribution of these conditions (Bach, 1994). The concept recognizes that while people may not be equal in talent, social productivity, or willingness to serve their community they are entitled to make choices about how they wish to live (recognizing the mutual interdependence of persons and the need to respect others' rights to self-determination) thus emphasizing rights over deservingness and making the connection between the accordance of rights and individual well-being.

Having arguably ascertained the denial of the right to a freely chosen, and societally supported, life plan for transition-aged young adults leaving child welfare care, the information culled from this research further suggests significant negative consequences to their well-being. The implication in the research literature that the basic needs of many transition-aged young adults are not being adequately met is revealed in the recollections of the inappropriateness of much of the transition-related activity. For example, insufficient resources; young persons falling through the cracks; placement outside of their home communities; blocked situational and developmental transitions; or forced and hurried moves are outcomes common both to young adults with ID/DD *not* in care (Audit Commission, 2003; Dowling & Dolan, 2001; Frank & Sitlington, 1993; Keogh, et al., 2004; King et al., 1999; Lawrence, et al., 1993) and to their counterparts in care who do *not* have ID/DD (Cashmore & Paxman, 2006; Loman & Siegal, 2000; Mech & Fung, 1998). Services and supports would appear to be dictated by the definition and diagnosis of disability as opposed to that of adulthood, effectively subsuming the experience of adulthood within that of disability. Concerns that the transition to adulthood is unduly prolonged, if not indefinitely postponed, and that young adults with ID/DD are prohibited from receipt of the same opportunities as their non-disabled counterparts (Dowling and Dolan, 2001) suggest support for this contention. Konanc & Warren (1984) and Palmer & Wehmeyer (1998) report upon the emotional outcomes of transition-related situations for young adults with ID/DD *not* in care. The young adults with ID/DD who are in child welfare care in this study would seem to be especially vulnerable. The alarming recounting of behavioural and emotional manifestations of the turmoil associated with blocked transition and the intrusive measures that have been implemented to 'manage' or 'control' these reactions are further testimony to the negative impact of this problematic situation on the well-being of the young adults thus caught. Environmentally-induced behavioural and emotional responses to an untenable situation are often not recognized as such and are, instead, managed on an individual level (Brown et al., 1993; Sullivan & Knutson, 2000).

The impact of disrupted relationships on the emotional well-being of those young adults with ID/DD who are in child welfare care, participating in this study, is also highlighted. Mirroring research findings for young adults *without* ID/DD in care, for the labelled participants in this study, important social and emotional relationships with caregivers, schools, friends and others are often severed. The young adults in this study are not supported to have ongoing sources of emotional, interpersonal and social support typically available to young adults not in care (Cashmore & Paxman, 2006; Courtney & Dworsky, 2005, 2006). Addressing needs related to relationships, while critical, is inhibited by professional, agency or systemic dictums (Brown et al., 1993; Cashmore & Paxman, 2006; Loman & Siegal, 2000) which deny environmental/systemic responsibility for such.

Fromm (1994) suggests that a person's sense of their own value depends both on her/his own evaluation of success and upon the judgement of others. As reported in the literature (Lawrence et al., 1993; Palmer & Wehmeyer, 1998), young adults labelled ID/DD are fully cognizant of societal expectations for transition: the consensus among participants in this endeavour is that they share these expectations. Similarly they have a good understanding of their needs and the supports they require to fulfil them (Clark et al., 2004; Dane, 1993). The reported damage to self-esteem accruing from this situation and the resultant experiences of failure and self-blame are indicative of additional negative consequences to well-being. The extraordinarily high incidence of abuse of this population group (Sullivan & Knutson, 2000) seems unlikely to diminish in a system fostering acquiescence. The tendency of workers/carers to paternalistically 'rescue' the young adults to spare them the emotional upheaval accompanying the situation may inadvertently reinforce quiescence as the young adults are forced to relinquish control of their lives to others (McCallion & Toseland, 1993).

Conclusion

Let me out of here…this isn't right…I'm very angry. I want my freedom.

This final statement from one young participant exemplifies the flavour of the information provided in this study by the group of young adults with ID/DD leaving child welfare care and is supported by the data stemming from the focus groups with the community of interest and from the research literature. The results of the study reveal both the normative and unique needs and perceptions of this group as well as the seriousness of the problem of insufficient living placements upon leaving child welfare care. While there is arguably much correspondence between the issues raised by this group of transition-aged young adults with those pertinent to non-disabled youth in child welfare care and to young adults with ID/DD not in care, there are some notable differences. The presence of an intellectual or developmental disability would appear to make this group more vulnerable than their counterparts in child welfare care who do not have disabilities (increased dependence on others; more limited coping and self-care skills; fewer options for self-support; greater systemic and attitudinal barriers to community participation). In addition, a history of child maltreatment conjoined with the experience (and effects) of being in care and a lack of ongoing familial or carer support distinguishes them from their peers who have ID/DD but who are not in care.

The young adults' stories reveal a questioning of the commitment of their workers/carers, and of the expectation that these people will better meet their needs. Recognizing the difficulties facing social workers and caregivers who are being asked to do more with less, the focus groups admitted the need for greater advocacy efforts, on behalf of, and with, this group of young people.

At the close of the interview each young adult participant was asked to imagine that s/he had been called to a meeting of all the professionals, government bureaucrats, and funding bodies involved in the transition problem and was asked what s/he would like to say to them. One participant responded: "...it is very important for people to be allowed to move and to be treated with respect". This research has attempted to represent the voices of the transition-aged young adults themselves, to tell their stories and to authenticate and validate their experiences. Other voices (those of involved professionals and caregivers) have been employed only to support the voices of the young people. It is recognised that of the population of transition-aged young adults labelled ID/DD in child welfare care, only five voices were captured, thus weakening the generalizability of this sample to the larger group. Nevertheless, the knowledge generated here, based upon real life experience rather than simply theory or assumption, illustrates the need for action towards change. There is no pretence that this research will emancipate this group or the community of interest, neither will it dramatically alter the dominant discourse of disability. It may, however, stimulate thought towards action and influence those in the community of interest.

> *They (those responsible for the situation) are stupid. I'm angry…they need to listen to people.*

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