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(Re)Claiming Adulthood: Learning Disabilities and Social Policy in Ontario

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Abstract

In this article, I will first explore the definition and significance of 'adulthood' for participants with learning disabilities in a disability self-advocacy movement. In particular, I will focus on self-identified markers of the transition to adult status. I will then examine the process of marginalisation as made manifest in government policy of the late 1990s within the province of Ontario, Canada. Finally, I will discuss the response of disability self-advocates to this policy initiative as evidence of the significance of adult status for persons with disabilities. This article is based on research conducted between September of 1997 and January 2003. During this time, I conducted over one hundred hours of combined interviews and participation observation with a local chapter of People First of Ontario (PFO) in the city of Welland (People First Welland, PFW).

Introduction

While the achievement of social adulthood is a key stage of life development for all people, the achievement of social adulthood is a status seldom granted to individuals with learning disabilities. This is in part due to the seeming incompatibility of key attributes of adulthood with societal perceptions of learning disability. For example, many persons with learning disabilities rely on the assistance of community service providers for residential, occupational and educational assistance, in contrast to societal ideals of independence (Devlieger, 1998). In failing to live up to the ideals of adulthood, 'people with learning disabilities challenge Western conceptions of an autonomous and reflective individual self and for this reason may be seen as threatening to basic cultural assumptions' (Davies, 1998, p103). This threat is addressed in several possible ways by governments and service providers. While individuals with disabilities may be placed in programs with the goal of developing behavioral characteristics more in line with the cultural ideals of adulthood, they are often categorized and marginalized as though they were children.

This article is primarily based on qualitative research undertaken by the author with PFO and PFW between 1997-1999, which included over one hundred hours of semi-structured interviews and participant observation within PFO and PFW. Follow-up interviews were also conducted with PFW members in 2003.

Self-advocacy and discourses of adulthood

Discourse within People First often takes the form of life stories that move from histories of oppression to present circumstances and futures of relative freedom. The individual self-advocate is the central concept in a cluster of images and values, including: independence, self-management, human, mind and voice, adulthood, and high-functioning. In contrast, the Government was accused by self-advocates of promoting false images of persons with disabilities as animal-like, needy, vulnerable, dependent, out of control, rooted in the body, low-functioning and child-like.

At one PFO board meeting, board members described what it meant to them to be labeled in a derogatory manner as a child. Participants agreed that the process had resulted in a 'hurt' that they carried with them into the present, that they felt angry or upset about being labeled in this way, and that being labeled had resulted in feelings of exclusion and alienation, confusion, and of being devalued. One executive member said:

> It did a lot of damage. I had to go in a different bus to a community school. I was 'special', the kids would call me the special kid on my block. I was really confused. Why was I different? I didn't look different.

Variations of this experience appeared in the life accounts of most self-advocates interviewed, presenting the image of childhood as an oppressive past to be overcome through the transition to socially recognized adulthood. To further illustrate this theme, I will present narrative excerpts from interviews with several self-advocates. For these individuals, definitions of adulthood followed three key themes: relative independence in decision-making and in lifestyle; social integration; and respect.

Martha

Martha, a 30-year-old woman, contrasted her experience of childhood discrimination and rebellion with newfound freedom as an adult. A label of 'learning disability' also had an impact on her educational experience. Martha said that she had attended several schools as a child. As a teenager, for one semester/year she had been placed in a special education class at Welland High.

> Martha: We went to Welland High; and we were put in one class with everyone that had disabilities; and we were like..just cut off from all the other kids...Like if we got in trouble, we got punished, like little kids...
> Tim: What do you mean, punished?
> Martha: Like um...we would have to sit on a stool...for ten minutes.
> Tim: Mm hmm.
> Martha: It was almost like we were five years old, and we were put on a stool for ten minutes, like time out. Like my sister does when [nephew] and [niece] are bad. She puts them in their room for ten minutes.

Martha's memories of her body on the stool were thus linked with images of family and the importance of claiming adulthood in her process of identification. Her post-secondary experiences stand in stark contrast to her memories of the special education class. At the age of 26, Martha applied for and received a grant to attend a vocational course at a nearby community college. One of the most positive aspects of college was the sense of integration it provided for Martha.

> Tim: So I think you said that this was your best experience at school, at the college. What was so great about it?
> Martha: Well, just...just, um...seeing, meeting all different people and getting to know all different people and just sitting in classes, and with all different type of people, just not just people that had disabilities. All different people, some people that had physical [disabilities], some people that didn't have any.

In her account of adult life, Martha emphasizes the importance of independence (e.g. having her own apartment) and being respected as a 'normal' person with regular employment. These themes also appeared in interviews with other individuals.

Rachel

Rachel is a lively 39-year-old woman who was hesitant to share much of her early childhood experiences. Rachel refers to her parents as both being 'slow'. Although she felt the effects of her family being labeled in this way, she now says, 'you take your mom and dad just the way they are'.

In part, her reluctance to talk about her childhood was due to a poor memory of these times, but she also felt that her childhood had been 'tough' and oppressive. At the age of 12, her parents had both died, she had been separated from her two brothers and placed in an institution almost two hundred miles away from her home, where she lived for the next 24 years. Rachel described her experience in this facility in very negative terms.

> Rachel: It really hurt for a long time to deal with (my parents being slow). It hurt for months, it hurt. And then when I went to (the institution), it's an institution for the mentally retarded. Tried to change the name around. And then you must be a can of beans.
> Tim : Well how were you labeled?
> Rachel: By being slow. Slow and you can't read and you're just that dumb. Dumb and stupid, put it that way.

Rachel feels that a key factor contributing to this image of herself as 'dumb' was the staff's denial of her ability to communicate through reading and writing. After she was discharged from the institution at age 36, she attended a school and picked up these skills, proving that she had 'fooled' the institutional staff into underestimating her. In these statements she claimed a sense of personal agency, a triumph over some of the oppressive experiences of childhood and early youth.

> Rachel: It hurt, I couldn't read, thinking I was stupid, I couldn't read. Thinking I was bad, more handicapped than anything because I couldn't read, then when I came out and went to school...then I started going to literacy to learn to read. And then when I pick a lot of the reading up, I couldn't spell, I couldn't do nothin'. And then they came along and I can read and I can write, I could also figure out numbers, that one I couldn't do. That hurted a lot. But I fooled them...now I could do more stuff I never thought I could do. I can do my own budget, I can volunteer, I can work, do my own groceries helping (my friend).

Similar to Martha, Rachel spoke of the importance of independence, particularly in the form of having 'my own place', an apartment that she shared with one other person. Rachel had also felt very isolated and separated from her family during this time, and said that institutional life had taken her self-confidence away. After 24 years of living at the institution, staff began to discuss the possibility of placing Rachel in a group home. She lived in several homes in the institution's town, and then moved to Welland. She was placed in the Supported Independent Living Program, through which she was able to get her own apartment. While in the institution, she had heard about People First, and joined the self-advocacy organization when she moved to the city. For Rachel, 'speaking up' was a prime reason for joining the group.

> Tim: Why are you a self-advocate?
> Rachel: Speak up for yourself, so you're not a doormat.
> Tim: What do you do as a self-advocate?
> Rachel: You solve problems and you leave it in the group,

> you don't go bringin it back.

Rachel values her current sense of social integration as an adult, and the respect that she has gained through her volunteer experiences. Today, she has worked at a public library through the local Supported Employment program, and currently works at a senior citizens home, leading the residents in Bingo games.

In Rachel's life account, she positioned her own sense of identity in terms of being a 'helper', moving away from her former state of 'looking dumb' to gaining empowerment through learning to read and write, and through assisting other participants at self-advocacy meetings. At one meeting, the group decided to send a thank you card to a speaker from a regional meeting. Rachel walked around the meeting tables behind the other participants, pausing to help several members to write their names. One of the advisors said 'she knows who to help'. When she gets to George, a man with cerebral palsy, she places her hand upon his, helping him hold the pen and print his name (the hand-over-hand approach was also used by myself and Rachel's friend Reba in our interactions with George).

Bonnie

In several interviews, respondents defined adulthood in terms of having a sense of ownership and control over their current living situations, and the freedom to make decisions for themselves. Bonnie, a 30-year-old woman who lives in a geared-to-income semi-detached house with her husband and pets (one cat, two guinea pigs, and birds), told me that:

> Bonnie: Adulthood means being able to take care of your own house, and the responsibility of paying bills. It also means being responsible for pets. Being an adult means to choose your own career, without being told that you can't. You can stay up as late as you want.

The importance of relative independence carried over into other areas of her life, as Bonnie repeatedly stressed the importance of independent decision-making as a sign of adulthood. For example, she mentioned that adulthood meant 'the right to have children'. This is particularly significant, as a key issue for discussion at self-advocacy group meetings was the history of forced sterilization for persons with disabilities in Canada. Adulthood for Bonnie also meant social integration.

> Bonnie: As adults, we can be more involved with the community. I'm a member of different organizations, like Moose Lodge. Children can't be members, except if their parents are members. You're only a member because your parents are members.

For Bonnie, adulthood began when she moved out of her family home.

> Bonnie: I was treated like a kid when I lived with my parents. I became an adult when I left home. When I went to school in the states. When I moved to (service-provider-funded residence).

She felt that adulthood was also a time to overcome the limitations of her own childhood by providing children with resources that she never had.

> If I had a child with a learning disability, I would give it Hooked on Phonics (child linguistic program) and the ABCs and all those things I didn't have... My foster parents think that my disability is due to my placement in so many different foster homes, I never had a chance to settle down and find what my capacity was. If Hooked on Phonics and ABCs were around then, I would probably be in college like me sister-in-law.

James

A sense of social independence also informed James' life account. James was a long-standing member of PFW, and had held the position of treasurer in the local chapter for several years. James had a developmental disability, and suffered from seasonal depression. This is one reason why he kept himself busy, and spent a significant amount of time volunteering at a sheltered workshop supported by a local disability service provider. He described adulthood in terms of personal independence:

> James: Doing things for myself, like computers and stuff. I go to the workshop with [another self-advocate], and I work on computers, and do contracts at the workshop...I go to hockey games and playing pool, go to the mall and walk around on my own. Kids can't do nothing on their own.

For James, as for other respondents, a sense of independence and social integration overlap in the emphasis placed on 'going places on my own', such as hockey games and the local shopping mall. James took particular pride in having his own basement apartment, secured through the housing program of a local disability service provider. "Living by myself is very important, having my own place."

James identified the transition to his adulthood in terms of both age and the gaining of independence. "I became an adult when I turned 20. I was still protected a bit, but I could do things on my own."

Jessica

Jessica is a 40-year-old woman who lives in a Christian community for persons with disabilities. In an interview, she described adulthood as characterized by choice and social integration. In contrast to life in an institution, Jessica could develop friendships with individuals of her choice from the larger society.

> Being treated like an adult means that friends can call me up and invite me over...to have a friend to go shopping with, to talk about adult things, and to joke around with each other... We can have people over.

For Jessica, adulthood meant being given respect as a mature person who could make her own decisions. In turn, respect contributed to her own sense of self-confidence, something that she did not experience as a child.

> You want to do more things. I got the confidence that I can do it. Children are scared when they make a mistake, 'I might fall on my face'. As an adult, if you make a bad decision, you learn.

Sharing the sentiment of other respondents, Jessica described the importance of having 'her own place', an apartment shared with two other people. Selection of housemates was based on mutual friendship, rather than institutional placement. However, in moving to this new apartment, staff at Jessica's supporting agency had been reluctant to grant her the respect and independence that she desired. Jessica recalled some of the resistance she had experienced:

> We had to tell people to stop treating us like little kids. Don't do things for us, hold our hands. At the old town-house [supervised residence], we had to ask; now we make our own decisions. People treat us like equal like everyone else.

In sharing her apartment with friends, and in receiving some services from her supporting agency, adulthood for Jessica was a status of relative self-sufficiency, not of absolute individualism.

Carl

This theme of social independence also informed my interview with Carl and his mother. Carl is a 20-year-old man who lives in his own apartment on the top floor of his brother's house. Carl's mother described him as an 'excellent child'. She seemed proud of her son's ability to live relatively independently, distinguishing him from other people with disabilities. Carl does his own cooking, and is responsible for regularly making a grocery list for his own needs. He walks down the street to the barber's shop by himself, but most other trips are escorted by support workers or family, and any visitors must first make arrangements through his family.

> Mom: He's unique too, compared to some of them. I'm not referring to (self-advocates), but he's the only one with his own apartment, the others are still living at home with their parents... He has to pull his weight, he has to pay his rent, buy his groceries and pay his share of the bills, so this doesn't give him much spending money. He doesn't miss much, he does everything, there's just some things he can't do.

However, while Carl's mother was proud of her son and his achievements, she was reluctant to grant him respect as an adult. She focused on Carl's status as her child to the point of neglecting his status as an adult who could speak for himself, and at several points in our interview she addressed Carl as if he were a young child.

Through the accounts presented above, I have indicated the significance for my respondents of claiming the status of adulthood. Thoughts of childhood were often marred by memories of institutionalization, discrimination and control. In contrast, adulthood was characterized in terms of empowerment through the gaining of relative independence, social integration, and personal respect. Testament to the significance of adult status was the resistance demonstrated by these individuals and other self-advocates to Ontario provincial policy of the late 1990s that promised to amalgamate services for children and for adults.

Making services work for people

The struggle of persons with disabilities for recognition as adults has been waged in social and political arenas. Emerging after the Second World War, parents' groups had advocated for better education for their disabled children, and at the third Congress of the European League of Societies for the Mentally Handicapped, 'clearly into focus came...the adult - a member of society, endowed with both natural and political rights' (Dybwad 1998, p5). For many people in the disability rights movement, the International Year of Disabled Persons (in 1981) offered a first opportunity to voice their concerns rather than being spoken for.

Within the province of Ontario, pressure from self-advocacy organizations and a shift in the provision of services to adults led to the primary provincial disability service provider changing its name, in 1965, from the Ontario Association for Retarded Children to the Ontario Association for the Mentally Retarded. Although the movement towards community living within this province has been cloaked in the rhetoric of respect and dignity, disability self-advocates have recently identified the threat of a provincial policy initiative to combine children's and adult services.

In April 1997, the provincial Ministry of Community and Social Services released its policy document Making Services Work for People: A new framework for children and for people with developmental disabilities (MSWP). Children and people with learning disabilities are presented as subjects for crucial areas of reform, 'for it is children and those with developmental disabilities who are most vulnerable and least able to express their needs themselves' (Ministry of Community and Social Services, 1997, pi). For the purposes of this article, it is important to recognize both the association between children and persons with disabilities, and the juxtaposition of the needy/vulnerable/non-verbal/disabled/individual with the autonomous/verbal/ independent/individual.

Presenting a disjuncture between the growing needs of children and persons with disabilities, and a scarcity of government resources, the document calls for a new framework of services to increase system efficiency while maintaining and improving service quality. The vision statement for these changes, as presented in the Ministry's Business Plan, reads:

> An affordable and effective services system that supports and invests in families and communities to make them responsible and accountable, in adults to make them as independent as possible. A services system in which children are safe and people most in need receive support. (Ministry of Community and Social Services 1996, p1)

As one aspect of these changes, the Ministry emphasizes a shift from government responsibility to increased community accountability for persons with disabilities. The rhetoric of 'community', the 'local' and 'family' (as opposed to state) and 'shared responsibility' (as opposed to state-control) for the 'vulnerable'/'those most in need', fits well with the over-arching theme of then-premier Harris' 'common sense revolution', and seems to answer the concerns of disability advocates and self-advocates for person-centered planning and individualized funding for persons with disabilities. The Ministry introduces MSWP as representing four shifts in policy direction:

> ...from government responsibility to shared responsibility...from services that respond only to entrenched problems, to services that anticipate, respond earlier and reduce the need for futures services...from services organized by agency, to services that respond to individuals and families....and from addressing needs through growth, to doing better within existing resources' (Ministry of Community and Social Services 1997, pp3-4).

The goals, as presented in the policy document, are as follows:

> to provide a 'consistent range of core services for children's and developmental services'; to support those 'most in need' with essential services; to provide supports earlier; to provide easier access to services;

> needs-based support; service through local systems which 'make the best use of resources'; reduce administration costs and reliance on government-funded sources; and to provide 'a coordinated set of services funded by the Ministry of Community and Social Services and other funders when necessary' (MCSS 1997, p6).

System features to be implemented towards these ends include: coordinated information mechanisms, centralization of access points, case resolution function, a single point of access for some residential services and supports, integrated or coordinated assessments, single agreement for services, reduced costs of administration. More specifically, these plans call for the development of regional access and assessment centers, similar to the recent developments in long-term care for the elderly (43 access centers), through which concerns and needs relating both to children and disabled adults will be addressed.

While the Minister in charge has denied rumors of amalgamation between these two service sectors, the Corporate Review Report from the Hamilton Area office suggests otherwise: 'criticism is expected from some stakeholder groups (particularly from the developmental services sector) regarding the creation of a single children's services/developmental service systems approach' (MCSS 1998, p3).

In fact, resistance to MSWP centred around the collapsing of childhood and disability into a single dependent/vulnerable policy category.

Response from self-advocates: reclaiming adulthood

There has been a strong outcry from the disability rights movement, family organizations and key service providers to this initiative. The document appears to emphasize children's services over adult developmental services (p9-10), prompting concerns amongst PF members and advisors over disability services funding being redirected to children's services, returning to a model of persons with disability as eternal children without adult rights.

> Initiatives that concern our members most include... the proposal to link supports for persons with 'developmental handicaps' with those of children, a link the members of People First and other advocates have been fighting for many years: 'We are not 'eternal children' as some would like to characterize us' (letter from PFO Advisor, July 15, 1997).

At one PFO board meeting, executive members agreed to work with the Ontario Association for Community Living, a key provincial service provider, on key issues emerging from the government's proposals, including the amalgamation of children's and adult services. While several of people found it difficult to say much about the recent policies when questioned during interviews, a general consensus had emerged that PFO would resist the proposed amalgamation, as the combined focus on children's and adult services presented a return to the institutional experience of 'being watched' like criminals or children, invading the individual's privacy and sense of control over self and body.

In May 1997, the president of PFO sent a letter to the Director of the Developmental Services Branch for the Ministry in Toronto, asking him to cancel the initiative, as:

> it makes us feel very threatened...it invades our privacy, talking about many very personal things...this report makes us feel like we're children or even babies and that we are not trustworthy...it makes us feel like people are trying to control us and that they will be watching us so they can give us marks on how we do things...we are worried that this will be used to take away the supports that we need in order to be part of our community.

One of the most common remarks by self-advocates concerned the assertion of adulthood for persons with disabilities. During one meeting, an advisor to PFW tried to explain the intent behind MSWP.

> Jaclyn: what's upsetting for some people is they're going to put children's services and services for adults with developmental disability all under the same board, so they're lumping all the adults and People First members and everybody in with the children. And they're saying if you want to get services, you can get them from a central place. So what's upsetting some people is the fact that they're adults and they don't want to be lumped in with children.

At this point, another member named Chris joined in the conversation. Chris' statements draw on local examples to help explain the discussion, using the local Association office as an example.

> if you go into the board office, would you rather go to the same place that dealt with both kids and adults? What do you think as real adults, you know, we want them to help...When we go in to talk to them, we expect them to have things about adults.
> Chris: we're not children, we're adults. The government shouldn't be doing...shouldn't be putting the adults together...we're two separate groups.

Jaclyn added that if people were treated like children, the government might also disregard their rights as 'real' adults. As Bonnie said

> some of us were a bit angry. We didn't think it was

> right. We're over 21, we're adults. We thought that we might not get the money that we need.

The concern over being treated as children appears in contrast to a strengthening disability-oriented family movement in Ontario. One of these organizations, the Family Alliance of Ontario, organizes an annual march on the seat of the provincial government in Ontario, which has in recent years focused on Making Services Work for People. I attended the 1998 protest, as did Mary, George and Jaclyn. Protestors carried signs reading 'Our Kids Can't Speak for Themselves' and 'Keep Our Families Together', and parents spoke out as advocates for their disabled children. Although there was not much discussion amongst PF members regarding these organizations, the PFW advisors said that they were concerned about parent advocacy overshadowing self-advocacy efforts. The fear of infantilization was compounded by the association of children and adults with developmental disabilities as populations facing common problems of system access and vulnerability, and also by a perception that the policy was directed more at the children's sector than at the adult developmental sector.

Conclusion

The individuals interviewed for this study clearly placed emphasis and importance of the status of adulthood, particularly in terms of valuing social integration, relative social independence, and receiving respect which was due them as adults. Respondents often juxtaposed expectations of respect and treatment as adults with oppressive experiences of childhood and youth, in particular experiences of forced relocation to institutions in which they were often devalued and abused. Martha also recalled experiences of degrading punishment for persons with disabilities within the educational system. (Re)claiming adulthood, then, appears to be central to the self-identity of these respondents. From this perspective, we can begin to understand the significance of resistance by organizations such as PFW and PFO to a policy initiative proclaimed by the provincial government as liberating and empowering.

While the government of Ontario has moved ahead with implementing MSWP, including the establishment of regional central access points for new referrals to developmental services, it remains unclear as to exactly what the impact and implications of this initiative have been. In a discussion with the Executive Director of the primary service provider in Welland, I was informed that advocates and self-advocates remain concerned about the amalgamation.

> Children usually receive short-term services, including therapy. For adults, it usually requires a longer-term commitment. The amount of intake in adult services is much less than for children, and yet we have to follow the same policies. It's unclear whether Making Services

Work for People has made things better or not, or what the implications have been.

What remains clear in the perceptions of persons with learning disabilities and their advocates is that they have once again experienced discrimination, in the guise of policy which promises to facilitate service delivery but in the process to deny them the status and rights of adulthood.

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