

EDITORIAL: Falling Through the Cracks

No system is perfect. We need no citation to permit us to say this. It's like saying the sun rises in the morning. The evidence is clear to everyone. And because of this inevitable imperfection, there will always be those who fall through the cracks.

These truisms, however simplistic they may seem, are of considerable significance for anyone who happens to be on the receiving end. People with intellectual/developmental disabilities are, of course, enmeshed in numerous systems throughout their lives. For this reason, if for no other, it is important to consider not only the issues that have grabbed our attention, but also to consider those questions, people, and issues that have been missed or do not always garner the consideration they warrant.

There are a great many people with intellectual/developmental disabilities living active lives within a community of friends and family—living, in other words, the kind of lives we generally hope for them and for ourselves. The work of dedicated service professionals, families, researchers, and the growing number of self-advocates, have helped to create many positive changes in recent years. But there are still many whose lives are less than what they might desire, and less than we as advocates, allies, supporters, family, and friends work to help them to acquire. There are still issues and questions not adequately recognized, attended to, identified, or resolved.

It is not just issues, questions, and concerns that fall through the cracks. Too often, it is also the voices of those people most affected by them. To note this is to draw attention also to the fact that the voices of people with intellectual/developmental disabilities may be more likely to find expression in formats other than those typically found in an academic journal. The concept for this issue is, then, as much about including in the discourse other forms of expression and communication, as it is about including the ideas, comments, and opinions of people not often heard from, even though they are the subjects of our inquiries. The Journal on Developmental Disabilities has long had a policy of including a wide range of material in its publications. These policies were restated recently (Percy, Fudge Schormans, Martin, and Brown, 2008). It is not often, however, that this range of articles and sources are submitted to the journal. With this issue, we have made the attempt to seek out and include the voices of people with intellectual/developmental disabilities and those of others who are engaged in finding answers, seeking solutions, and improving the quality of life.

The overarching goal here is not about granting 'permission' to speak in this format, nor is it simply providing an opportunity to do so. It is also about establishing in the

Authors

Ted Myerscough,
Ann Fudge Schormans

Correspondence

fschorm@mcmaster.ca
tross@vex.net

Keywords

intellectual and
developmental disabilities

social realm an ‘authority’ of voice and an engagement that is genuine and participatory. The voices of people with intellectual/developmental disabilities have been devalued and discounted for so long, if indeed they were ever otherwise, that the power relations inherent in any discourse are difficult to overcome, sometimes to even to recognize. The effort here is to construct a foundation, a means, for people to be heard. The ‘authority’ of voice comes when people are listened to.

Knowledge, if it is to be of benefit to all members of society, cannot be confined to an exclusive domain of institutional ‘expertise’ and discourse. One of the goals of the Social Science and Humanities Research Council’s (SSHRC) Knowledge Mobilization strategy is to “improve research connections by facilitating reciprocal relationships between researchers and knowledge users for the (co-)creation and use of research knowledge” (SSHRC, 2009).

Likewise, the Canadian Institutes of Health Research (CIHR) defines knowledge translation as “the exchange, synthesis and ethically-sound application of knowledge—within a complex system of interactions among researchers and users—to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system.” (CIHR, 2004).

Both of these strategies include notions of reciprocity and interaction as fundamental to the process of knowledge dissemination and acknowledges the impact such relationships have upon knowledge development. But more than a relationship with researchers and “knowledge users”, such strategies should also acknowledge the importance of including those for whom the knowledge base is perhaps most important: the individuals who are confronted with the health and social issues while living their lives. This includes parents, families, friends, support workers, as well as the individuals living with intellectual/developmental disabilities. And for this to be genuinely productive, the “complex system of interactions” should not be viewed as a ‘top-down’ process, but one in which knowledge and information is exchanged in a dynamic, dialogical, inclusive, and transformative process.

The Articles

Songbird’s often heart wrenching poem is a stark reminder of the emotional burdens that are often carried by people with an intellectual or developmental disability, especially those for whom life has been particularly unkind. We are reminded of the work of poets like Allen Ginsberg’s *Kaddish* in which the author relates his experiences of growing up while his mother suffered increasingly from psychiatric illness. In *Let Me Say We Don’t Care About Them*, the poet’s anguish and anger, turned to rhythm, cadence, and stark, blunt imagery moves us towards an understanding on a visceral level of unchanging conditions and unnecessary suffering, of lives lived in ‘the system’ and children growing up with abuse and abandonment. The poem reminds us that in all the work we do, the ‘subject’ of our work is always an individual human being entitled to the same level of respect and dignity awarded to the more fortunate.

Three articles investigate complexities of referrals and admissions for programs and treatment in light of diagnostic assumptions and conundrums. The first of these, *The Clinical Profiles of Women With Intellectual Disabilities and Affective or Adjustment Disorder Utilizing Mental Health Services* by Anna Palucka, Margaret Reid, and Anjali Holstein, reports on problems distinguishing maladaptive behaviours and signs of emotional distress in women using mental health services.

Later, in *Review of Admissions of Individuals with Autism Spectrum Disorders to a Specialized Dual Diagnosis Program*, Prichard, Palucka, Reid, & Lunsy discuss key issues confronting people working with individuals who have a dual diagnosis of ASD and psychiatric disorder: the difficulty of accurate diagnosis when there are overlapping symptoms and the inability of others to deal adequately with problem behaviours.

Following this, Michelle Fattigh Smith provides an overview of the referral rates of girls for diagnoses related to ASD in *Disproportionate Referral Rates May Falsely Impact the Ratio of Girls and Women on the Spectrum*. In the paper, the author explores the social behavioural differences of boys and girls that are not necessarily acknowledged in the standard diagnostic definitions and tools. She also explores the range

of potential effects that the lack of proper diagnosis might entail for these girls, the social and personal relationship problems that affect their health and well-being throughout their lives and the increased potential of suffering abuse.

An issue of increasing importance is that of parenting with an intellectual disability. In *Addressing the Needs of Parents With Intellectual Disabilities: Exploring a Parenting Pilot Project*, Katie McLean and Marjorie Aunos describe and evaluate a unique project in Montreal that supports parents with ID/DD through supportive workshops. Based upon international research and best practices, the innovative program was developed by the research departments of the West Montreal Readaptation Centre¹ and Centre de Réadaptation Lisette-Dupras. The curriculum for the program was based upon the needs of the individual participants and then delivered through a parenting group. The authors briefly outline the shift in social and institutional perspectives regarding the ability of people with ID/DD to parent, from programs of sterilization to the present perspectives that are more accepting but are nonetheless insufficiently researched. With so many parents with ID/DD losing custody of their children, the importance of programs and support strategies is undeniable.

In their brief report, *Services for Adults and Adolescents with ASD in Ontario—Parent and Professional Perspectives*, Stacy White and Jonathan Weiss explore the differences in perception of availability and quality of services between parents and service providers. These differences may reflect issues of access to information and resources; they may also be based upon differing priorities, needs, and, therefore, evaluation criteria. A key conclusion, it seems to us, is the authors' assertion that it is "crucial for parents and professionals to consider each others' goals, needs and responsibilities (as well as those of the client) when determining whether programs are indeed effective". For this to occur effectively would require direct dialogue and participation of all those concerned. This kind of dialogue is often missing in program development.

1 Editors' Note: Although the Centre de réadaptation de l'Ouest de Montréal translates its name as "West Montreal Readaptation Centre", the term 'rehabilitation centre', more common in Ontario, is used in the text when referring to the centre.

The fascinating photos from the video project *Our Compass* provoke a range of responses, thoughts, and questions and encourage us to look beyond stereotypes in images of people with intellectual disabilities. That people with ID/DD have sexual lives still causes discomfort for many in our society. That their sexual lives might include sexualities other than heterosexual can be even more difficult for some people to accept. A collaborative work by a group of lesbian, gay, bisexual, transgender and questioning (LGBTQ) youth labelled with intellectual disabilities and/or Asperger's syndrome, the series of photos taken from *Our Compass* convey a complex range of 'positions' taken up by people with intellectual disabilities in social relations, i.e., the positions occupied in relations of social power that are often evident in images. The photographs of Diane Arbus, for example, portray people with ID/DD as 'oddities' at best, 'freakish' at worst. Here, individuals with ID/DD take control of their own representation. No passive, pity-inducing poses and expressions here. As authors of their own identities, they portray themselves as active, challenging, critical, and engaged. Wedding cakes, skirts, limos, synth-guitars, street-level confusion, and cots in a mountain setting. These things convey hopes, dreams, humour, critique, desire, and a place in the social world.

Two articles discuss inclusion of children with ID/DD in the public school system. Both of the authors requested that they remain anonymous. This was necessary to respect the confidentiality and privacy of individuals mentioned. There was also some concern that speaking openly might lead to reprisals.

The first article, written by learning resource teacher working with special needs children in the public school system, provides a glimpse into the array of needs that a teacher can encounter in a single class and the struggle to provide an equitable education in a difficult situation. While arguing that lamenting a lack of money and resources to properly develop an inclusive educational system does not help to address the realities of the situation, the author nonetheless concludes that more training for educators, specific to special education needs, is the key to the system's ability to provide it. But, significantly, the author also notes that the only way for a program of inclusion to work,

with or without the ideal resources, is for all of the interested and concerned individuals in the community to be involved in the process. This would involve dialogue and sharing of information, not within a structure that imposes education staff as the experts, but one in which all participants are treated as equal collaborators.

A similar argument is made in the interview with a person who is a parent of child with an autism spectrum disorder, a special education teacher, and an academic researcher. The interview, a conversation with Ted Myerscough, is a discussion of some of the fundamental issues encountered in his/her experiences in each of these capacities. In the discussion, it is made clear that inclusion requires input and participation at all levels, and the argument is made that such participation would necessarily prove to be transformative for all involved. The overlapping roles of this individual offers a perspective that is rooted in sometimes conflicting positions and emotions. While the immediacy of parental love and responsibilities may take precedence over the more distanced viewpoints of teacher or researcher, the person's perspective is perhaps more balanced than most and he/she is able to very clearly point to the sources of conflict and avenues for change.

The needs of people with intellectual/developmental disabilities and dementia are the focus of the article by Manji and Dunn. Grounded in a social model understanding of disability, and taking a case study approach, the authors present their research into the efforts of staff and professionals at a small community-based group home for adults with ID/DD and dementia to empower the adults living in the home to the greatest extent possible. They cite two important social processes to be at play: marginalization and supported empowerment. Citing both the perceived benefits and also the challenges to empowering individuals with ID/DD and dementia, in particular as abilities deteriorate and needs change, they point to the value of further investigation into the possibilities of such an approach.

Grove, Grove, and Myerscough examine the conditions for people with intellectual disabilities in time of war. Their search for information on the topic indicates that little or no data has been gathered on the specific impact and needs for people with intellectual disabilities during

armed conflicts. At best, occasional mention may be made when talking of people with disabilities in general, yet even then most of the investigations and discourse centres around those people whose disabilities were a direct result of the conflict. While the need for more investigation is clear when considering care for people currently living with armed violence, it is also of great importance when addressing the needs of refugees and immigrants, and the people with ID/DD among them, who seek out the safety of more peaceful nations.

Taking a Grounded Theory approach, Neben investigates the effects dealing with aggressive behaviour has upon developmental service workers and the effects, in turn, that that has on the people with ID/DD that they support. How does one stay caring, responsive, engaged, and motivated in such circumstances? Caring for the carers has long been acknowledged as a key issue for service provision in many professional fields; it is also an area that may not be given enough attention.

Peter Johnson's article is about the situation for men with ID who have also committed acts of pedophilia. This is a complex topic for many reasons. Above all, is the challenge to overcome the feelings of ethical affront, revulsion, and anger that most people experience when confronting the victimization of children. But, Johnson argues, surely this is what is required in order to understand, consider, and gather the knowledge needed to help these men and, therefore, to also best protect children from the threat posed by the drives that victimize everyone. Importantly, Dr. Johnson's work is an excellent example of the potential of clinically directed investigations and the contribution clinicians do and can make to research.

The informal round-table discussion held by a small group of self advocates, recorded and reported in *Rights, Respect and Tokenism: Challenges in Self-Advocacy*, demonstrates a determination and clarity of perception around fundamental issues of social participation. Genuine participation cannot be proscribed and predetermined. It must come from within, and not be imposed from without (or, more accurately, in our social order, from the top down). The purpose of any self-advocating group must be its own.

The Omissions

Not surprisingly, there are issues we have not addressed here. Issues of poverty and incarceration in correctional institutions, issues of employment and post-public school education. And too many more. Sadly, it may be a long time before they may all be addressed.

The point isn't to suggest there is a perfect system at hand, but to locate the cracks in the systems we have, and will have, through discourse and inclusion, to investigate collaboratively with mutual respect and recognition, and to, perhaps, even be a little bit changed by the things we learn.

References

- Canadian Institutes of Health Research (CIHR). (2004). Knowledge translation strategy 2004–2009: Innovation in action. Retrieved, July 26, 2010, from <http://www.cihr-irsc.gc.ca/e/26574.html>
- Percy, M., Fudge Schormans, A., Martin, L, and Brown, I. (2008). Scope of articles for publication in the Journal on Developmental Disabilities (JoDD). *Journal on Developmental Disabilities*, (14)3, v–ix.
- Social Sciences and Humanities Research Council (SSHRC). (2009). *SSHRC'S knowledge mobilization strategy, 2009–2011*. Retrieved, July 26, 2010, from http://www.sshrc-crsh.gc.ca/about-au_sujet/publications/KMbPI_FinalE.pdf .