



CENTRE FOR INCLUSION AND CITIZENSHIP

Submission to the Disability White Paper Consultation

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INTRODUCTION

Committed to research, learning, and knowledge exchange, the Centre for Inclusion and Citizenship is the only university-based research centre in Canada with a dedicated focus on intellectual disability policy and practice. The Centre was initiated through a partnership of university, government, community living agencies and supporters seeking to further the inclusion and citizenship of people with intellectual disabilities and their families locally, nationally and globally. More specifically, we were established to meet an identified need to conduct research based in BC to influence and inform policy and practice and to translate that knowledge into best practice.

Our submission is based primarily on evidence drawn from the numerous studies we have undertaken related to the full inclusion and citizenship for people with disabilities with a primary, though not exclusive focus on intellectual disability. In addition to our research base, we have drawn on relevant literature we have reviewed and our numerous community engagements with people with disabilities, families, support and service workers and professionals to augment our submission. We have appended a list of research projects, reports and community engagement events from which we have drawn.

ACCESS TO DISABILITY SUPPORTS

While our research indicates a relatively high level of satisfaction with the services and supports people receive through Community Living British Columbia, there is strong evidence that getting access to needed supports remains problematic. A quarter of respondents to *The Survey of Family Members of People With Disability Who Are Receiving Services From Community Living British Columbia* (N 852) (Community Living research Project (CLRP) 2009) indicated that they had requested paid supports, which had not yet been received at the time of the study. Of those who were waiting for paid supports, participants, on average, reported they had been waiting for 1 to 2 years. Results were consistent across regions. While the lack of access to supports presents an obvious challenge to individuals with disabilities, it must also be remembered that this has serious impacts on their families and the broader society both socially and economically as the alternative is usually a family member remaining outside the paid labour market. While we recognize that steps have been taken to try and address this, given the increasing demand due to ongoing demographic changes, access to services remains a serious barrier to ensuring all British Columbians have the support they need to be full and active citizens.

Recommendation:

British Columbia ensure sufficient funding is available to CLBC to ensure basic support needs are met in a timely manner for all eligible British Columbians and that consideration be given to a demand based funding model for CLBC.

RESIDENTIAL SUPPORTS:

Data from the Institute for Research on Inclusion and Society (IRIS) indicates that nationally, 38% of working age adults with an intellectual disability lives with their parents, as compared to 18% of working age adults without disabilities. Our own research indicates this number to be higher in BC

at 41% (CLRP, 2009). The numbers within residential settings also shows a move away from larger settings with only 23% living in settings with 4 or more persons. For those living in an independent home/apartment, 49% said it was rented, 25% said it was owned by the respondent, and in 11% of the cases, it was owned by the PWD. While the move away from larger settings to smaller more individualized arrangements is in line with best practice, our research indicates that serious attention needs to be paid to how this is done and to the supports which are provided to those in smaller settings. Detailed statistical analysis of the survey data showed that on six key outcome measures (*information and planning; access to and delivery of supports; choice and control; community connections; satisfaction; and, overall perception of outcomes*) findings indicate that on all measures other than *choice and control*, group homes and family model homes (home share), showed better outcomes than either independent settings or family homes (Stainton et al., 2011). While subject to interpretation this data does suggest that there is a gap in support for those residing at home and for those living in independent settings.

Recommendation:

Ensure adequate support is provided to those who are not using formalized residential supports.

HOME SHARE

Currently, 6564 individuals with developmental disabilities in BC receive residential support. Of these, 37% are in staffed residential contexts, while 63% are in shared or supported living. Of these 63%, the majority (over 3300) is in home share or shared living. In our in-depth qualitative study exploring the experiences of individuals with developmental disabilities living in home share, home share providers, and family members (N 68), participants repeatedly emphasized the importance of planning and finding the right match (Hole, et al., n.d.). However, our findings highlighted that transition planning rarely occurs, and many family members and home share providers identified that individuals are frequently placed where space is available, rather than in homes suited to their specific needs. Finally, we found that aging is an important factor putting stress on home sharing as a residential model. Participants emphasized the changing needs of both aging individuals with developmental disabilities in home shares as well as aging home share providers. Participants highlighted the importance of different kinds of supports and services necessary to meeting these changing needs as well as the importance of transition planning for later years.

Recommendations:

Ensure adequate support and services are provided to assist individuals transitioning into home share or between residential placements (e.g., transition from the family home to home share or shared living).

Housing should support individuals' participation as valued, appreciated equals in the social, economic, political and cultural life of their community.

Attention to and planning for demographic shifts (e.g., an aging population) in policy and practice is necessary when considering residential options including home sharing.

COMMUNITY CONNECTIONS

Respondents to the above noted survey were asked how often their family member engages in activities with individuals who do not have developmental disabilities. While 13% said daily, 37% reported at least once a week. Ten percent said once a month, 8% said less than once a month, and 22% said never. This suggests that while services are providing good support in most cases, we have not made substantial gains in achieving fully inclusive lives. The response to this is complex and diffuse reflecting both the need for a more broadly accepting community and a more intentional focus by supports to not only provide high quality service but also to do so in such a way that promotes a broader inclusion within society. Practically, transportation presents a substantial barrier. Forty-five percent of participants reported having access to transportation support and this was consistent across the province. (CLRP, 2009).

Recommendations:

Ensure service contracts include promoting inclusive lives and community connections as key deliverables.

Improve transportation access for PWD including improved handiDart services and access to adaptive vehicle technology.

OLDER ADULTS

Both our own research and the literature confirms a growing issue of aging adults requiring supports as parent who have been providing care age. Too often, the response is crisis driven rather than a planned thoughtful transition. Our research indicates that early planning which encompasses, access to appropriate supports and services, transition plans, decision making and financial planning is key to effective support for aging adults. (CLRP, 2008; Hole, Stainton & Wilson, 2013).

A further issue relates to access to health care supports for aging adults with intellectual disabilities. Too often these become mired in jurisdictional disputes and there is a deficit of appropriate support within the health care system for this population. Our research indicates that aging adults with intellectual disabilities experience barriers to access across the continuum of healthcare services. Often, their complex medical histories and difficulties with medical visits make obtaining primary healthcare a challenge. In terms of home support, there is great variation in access to “mainstream” services as well as Health Services for Community Living. We also learned that hospitals are ill prepared to provide population-appropriate care for aging adults with intellectual disabilities as this is the first time that a large cohort of this group is aging in the community. In particular, there is a sense that adults with intellectual disabilities are often discharged too early under the assumption that they have access to nursing supports in the community.

Recommendations:

Provide age related transition planning support to older families and individuals in a pro-active manner. In particular, Advanced Care Planning activities need to be developed that take into account

the unique situation of aging families, such as the lifelong caregiving relationships that exist between parents and their children with intellectual disabilities as well as the challenges some individuals with intellectual disabilities may have in understanding death and the issues this raises for families engaging in planning at end of life.

Improve coordination between health and community living services.

Improve access to basic health care services for people with intellectual disabilities.

TRANSITIONING YOUTH

Transition has been a major focus in British Columbia over the past several years with several key initiatives undertaken since the Centre undertook the bulk of its research in this area. Overall the combination of qualitative and quantitative research undertaken by the Centre indicated a disjointed system, poor planning process either not undertaken at all or undertaken very late in the process and without coordination across key actors. While recent efforts to improve transition such as the automatic respite funding, common assessment platform and the pilot navigators project should have positive benefits, none of these will significantly address the most common concern raised in the research which was the lack of timely and sufficient access to needed supports.

Recommendations:

Access to coordinated planning supports for all youth who qualify for CLBC supports beginning at age 16.

Timely access to needed supports to implement transition plans at age 19.

DAY AND EMPLOYMENT SERVICES

As with transition, the area of employment support has recently become a more intensive focus for CLBC and MSDSI. Our research confirms the widely acknowledged under-representation of people with developmental disabilities in the labour market. We further identified that significant numbers are not only not in the labour force but also have no alternative day supports. While 51.5% of survey respondents indicated they 'participate in a day programme' a further 37.8% indicated that their son or daughter 'stays at home'. Only 21.9% indicated they worked for pay which could be full or more commonly part time, with a further 6.6% indicating they were looking for work.

The Labour Market Agreement for Persons with Disabilities represents approximately \$90 million per year in cost-shared expenditures, according to its 2012 Annual Report yet, the vast majority of working-age adults with disabilities remain without work. Support and service models to facilitate individual employment opportunities for people with intellectual disabilities have been developed and proven effective over the past 30 years by both research and practice. These support models involve specialized elements that represent major differences from a generic rehabilitation or vocational counseling model. These elements include:

- Early opportunities for work experience and training, preferably beginning in early adolescence
- In-depth marketing and job-development to build relationship and capacity among employers to include people with disabilities;
- Hands-on, strategic, on-the-job coaching to teach task mastery, develop customized accommodations, and build natural supports in the workplace;
- Long-term access to service and ongoing supports to support job retention and career development.

British Columbia has a proud history of providing these elements as part of its support models for people with developmental disabilities, but currently their consistency and universal availability is far from adequate. What's more, performance indicators and accountability systems do not ensure service consistency with what is known about effective practices for this population. The result is a spotty patch-work of practices that range from sheltered workshops to inappropriate volunteerism and prevent our statistics from telling a success story.

Only 55.7% of survey respondents indicated they were usually or always satisfied with the day employment supports their family member receives, though 65% felt they always or usually had positive outcomes for their family member (CLRP, 2008). In a further study (Cohen et al., 2010) which included an analysis of those making use of the earnings exemption provisions, we found take up to be extremely low with less than 16% of people on PWD claiming earnings exemptions (Goldberg & Stainton, 2008). Given that most people rely on benefits, taking full advantage of the exemption would provide a significant increase in total income as well as provide a platform for a move off of benefits into full time employment. To date, there has been little focus on supporting individuals to maximize this exemption. The same study also looked at the use of social enterprise as a means for employment for people with disabilities. While these proved effective in many cases, what was also clear was that to be successful, the disability related support needs required funding outside the revenue of the enterprises themselves.

Our recent evaluation of the Equipment and Assistive Technology Initiative (EATI) (Jongbled et al., 2013) found that: EATI is meeting unmet needs for assistive technology among people with disabilities in BC. It is impacting peoples' lives by enabling them greater participation in society, for example, to get out in the community more, to do fun activities, and feel increased confidence in their abilities; EATI is impacting people with disabilities in their move towards employment. It helps people become engaged in doing volunteer activities, develop new skills and increase their ability to communication; joint decision-making has helped EATI to adapt to new participant needs, to be flexible in its provision of funding, and to be effective in supporting participants in their movement towards greater labour force participation.

Recommendations:

Implement proven strategies for enhancing the employment outcomes for people with intellectual disabilities.

Establish a transparent system of outcome measures for all LMDA funded and related programmes for people with intellectual disabilities based on securing paid employment.

Improve access to and quality of the range of day supports.

Design and implement a strategy to enhance uptake of earnings exemptions.

Continue to support the development of social enterprise but separate out disability support costs from enterprise cost and revenue.

Build on the lessons of the EATI program using the participation model and ensuring timely access to assistive technology.

INDIVIDUALIZED FUNDING

Individualized Funding (IF) was a cornerstone of the CLBC model but has not had the uptake which was anticipated. The current review by CLBC is a timely and important process that needs to continue. Our extensive literature review of IF internationally indicates that user satisfaction is high and significant positive outcomes accrue when effectively implemented and that IF models tend to outperform traditional block funding models on these measures. A detailed analysis of CLBC IF contracts showed that IF models generally are less costly than traditional block funding models (Stainton et al, 2013).

Recommendations:

Continue with a detailed review of IF through CLBC to identify barriers to take up and implement measures to enhance access and take-up.

DIVERSITY

An overwhelming majority of respondents to the family member survey (79%) of PWDs were reported to be Caucasian/White. Seven percent were identified as being Aboriginal. Eight percent were described as being Asian. Finally, just over 6% were identified as other.(CLRP, 2008) These figures generally under represent the population base of BC with regards to ethnicity, though no firm conclusions can be drawn from this as to the actual make up of the CLBC client base. Through our discussion with community we have heard that there is a lack of attention to and availability of culturally appropriate supports within the community living sector. Further this also seems to be the case with the LBGTQ and aboriginal community. While at this point we have no strong evidence there is enough concern to recommend a more thorough analysis of the response to diversity within the community living sector.

Recommendation:

CLBC undertake a detailed review of how well they, and the broader community living sector, responds to issues of diversity.

POVERTY AND INCOME SUPPORT

Evidence over time has confirmed that the vast majority of people with developmental disabilities live below the low income cut off. This is not surprising as most are dependent on benefit systems

which do not breach this threshold. In our survey of family members eighty-two percent of participants indicated that they received PWD benefits, which was the only financial support that the majority of participants received. 17% of participants reported receiving Canada or Quebec Pensions Plan and Old Age Security pension however only 8.8% also indicated they receive the Guaranteed Income Supplement. Given the lack of additional income one would expect this figure to be closer to that of those receiving OAS. It should also be noted that 20% of participants said they received other income that was not listed. While measures such as the Registered Disability Savings Plan (RDSP) may over time mitigate to a small degree the low income status of people with disabilities, it is unlikely that the RDSP or efforts to improve the employment picture will result in a significantly improved economic outlook for people with disabilities in the near future.

Recommendations:

Review current benefit rates to ensure an income level at or above the low income cutoff and consider indexing this to ensure rates remain at or above this level.

Review those currently on Old Age Security to identify those eligible for Guaranteed Income Supplement.

SUPPORTED DECISION MAKING

Article 12 of the UN Convention on the Rights of Persons with Disabilities affirms their right to full legal status. In order to actualize this right a robust and accessible system of supported decision making is required. BC is fortunate to have some of the most progressive legislation in the world in this area and an effective community agency to inform and support this in NIDUS. Work by IRIS notes that in Canada, among adults with intellectual, learning, memory or psychosocial disabilities, over 17% (nearly 107,000 people) make none or only some of the decisions about their everyday activities.(Institute for Research and Development on Inclusion and Society, Disability and Inclusion Based Policy Analysis, 2012)

Our 2008 survey indicated that only 22% of PWD have a Representation Agreement. Effort to educate the community and the legal profession about these decision making instruments is required to enhance the take up of Representation Agreements.

Recommendation:

Provide sustainable funding support to NIDUS to both provide education and advice and to maintain an accessible database of Representation Agreements and other decision making instruments.

A WHOLE OF GOVERNMENT APPROACH

Over the past years, there have been several attempts at providing a cross government lens and approach to disability in BC. In order to achieve the goals set out in the White Paper, change and coordination will be required across all facets of government. The Institute for Research and Development on Inclusion and Society (IRIS) has developed a detailed and thorough process to assist policy makers and analysts in departments and agencies across Government in developing

policies and programs that are fully inclusive of people with disabilities. It provides guiding principles for inclusive policy development and points to key factors affecting the lives of people with disabilities and provides a set of guiding questions for undertaking policy formulation, implementation, evaluation, revision and policy coherence (*Disability and Inclusion Based Policy Analysis*, IRIS, 2012). This has been successfully implemented in other Provinces and would provide a strong and tested approach for making significant cross government progress of the goals set out in the White Paper consultation to make BC the best jurisdiction in Canada for people with disabilities.

Recommendation:

British Columbia consider partnering with the Centre for Inclusion and Citizenship, Institute for Research and Development on Inclusion and Society, and the Canadian Association for Community Living to undertake a comprehensive policy review and analysis based on the Disability and Inclusion Based Policy Analysis process.

Appendix

Centre for Inclusion and Citizenship Research Reports

Baumbusch, J., Hole, R. & Stainton, T. (2011) *Examining the Organization of Healthcare for Aging Adults with Intellectual Disabilities in British Columbia: A Critical Interpretive Policy Analysis*. Vancouver, BC: Centre for Inclusion and Citizenship.

Hole, R., Stainton, T. & Tomlinson, J. (2011) *Supported Employment for Adults with Intellectual Disabilities: Social and Economic Outcomes: A Review of the Literature*. Vancouver, BC: Centre for Inclusion and Citizenship.

Hole, R., Stainton, T., Charles, G., & Yodanis, C. (2008) *Home Sharing: A Review of Current Practice and Policy with Recommendations*. Vancouver, BC: Centre for Inclusion and Citizenship.

Jongbloed, L. & Stainton, T. (2013) *Equipment and Assistive Technology Initiative (EATI) Evaluation*. Vancouver, BC: Centre for Inclusion and Citizenship.

Stainton, T., & Hole, R. (2008) *Adult Community Living Supports in British Columbia: An Exploration of Family Member and Self Advocate Experiences*. Vancouver, BC: Centre for Inclusion and Citizenship.

Stainton, T., Asgarova, S., Feduck, M. (2013) *A Comparison of Cost and Service Utilization Across Individualized and Traditional Funding Options Through Community Living British Columbia*. Vancouver, BC: Centre for Inclusion and Citizenship.

Stainton, T., Hole, R., Brown, J., Charles, G., Yodanis, C., Powell, S. & Crawford, C. (2008) *Community Living Research Project Report on The Survey of Family Members of People With Disability Who Are Receiving Services From Community Living British Columbia*. Vancouver, BC: Centre for Inclusion and Citizenship.

Stainton, T., Hole, R., Charles, G., & Yodanis, C. (2008) *Non-residential Supports in B.C. An Exploration of Family Member and Self Advocate Experiences - A Plain Language Summary Report*. Vancouver, BC: Centre for Inclusion and Citizenship.

Stainton, T., Hole, R., Charles, G., & Yodanis, C. (2008) *Residential Alternatives in B.C.: An Exploration of Family Members and Self Advocate Experiences*. Vancouver, BC: Centre for Inclusion and Citizenship.

Stainton, T., Hole, R., Charles, G., & Yodanis, C. (2008) *Residential Alternatives in B.C.: An Exploration of Family Members and Self Advocate Experiences - A Plain Language Report*. Vancouver, BC: Centre for Inclusion and Citizenship.

Stainton, T., Hole, R., Charles, G., & Yodanis, C. (2008) *Supports for Seniors with Developmental Disabilities in B.C.: An Exploration of Family Member and Self Advocate Experiences*. Vancouver, BC: Centre for Inclusion and Citizenship.

Stainton, T., Hole, R., Charles, G., & Yodanis, C. (2008) *Supports for Seniors with Developmental Disabilities in B.C.: An Exploration of Family Member and Self Advocate Experiences- A Plain Language Report*. Vancouver, BC: Centre for Inclusion and Citizenship.

Stainton, T., Hole, R., Charles, G., Yodanis, C., Powell, S. & Crawford, C. (2008) *Young Adult Transition from High School to Adult Life An Exploration of Family Member and Self Advocate Experiences- A Plain Language Report*. Vancouver, BC: Centre for Inclusion and Citizenship.

Centre for Inclusion and Citizenship Publications

Hole, R., *Nunn, N., *DeVolder, B., & Berg, L. (March 2012). *Western Canada Case Study Research Project – Supports and Accommodations for Disabled People with Intermittent Work Capacity in Two Organizations in the Okanagan Valley*. Human Resource & Skill Development Canada, Office of Disability Issues, May 2012. 63 Pages.

Hole, R., Robinson, C., Stainton, T., Lige, S., & Crawford, C. (in preparation). *Home sharing and people with intellectual disabilities: Tips from the experts, to be submitted to American Journal on Intellectual and Developmental Disability (March 2014)*.

Hole, R., Stainton, T., & Wilson, L. (2013). *Ageing adults with intellectual disabilities: Future hopes and concerns of self-advocates and family member experiences*. *Australian Social Work*, 66 (4), 571 – 589.

Hole, R., Stainton, T., Robinson, C., Crawford, C., & Lige, S. (2012). *Home sharing: A study of resident and stakeholder views*. *Journal of Intellectual Disability Research*, 56 (7-8), 781.

Stainton, Tim & Clare, Isabel C. H. (2012). Editorial, *Human rights and intellectual disabilities: an emergent theoretical paradigm?* *Journal of Intellectual Disability Research*. V. 56- No. 11. pp. 1365-2788.

Stainton, Tim (2012) *Empowerment and the architecture of rights based social policy*. In Johannes A. (ed.) *From Institutions to Individuals: on becoming person centred*. Vancouver: Spectrum Press. p.p. 89-99. (Reprint of 2007 article in *British Journal of Intellectual Disabilities*).

Stainton, Tim, Brown Jonathan, Crawford, Cam, Hole, Rachele & Charles, Grant (2011). *Comparison of community residential supports on measures of Information & Planning; Access & Delivery of Supports; Choice & Control; Community Connections, Satisfaction; and, Overall Perception of Outcomes*. *Journal on Intellectual Disability Research*. Vol.55 Pt. 8 pp 732–745.

Watson, S., Stainton, T & Sobsey, D. (2012) *A Right to Exist and to Life-sustaining Measures*. D. Griffiths, F.Owens & S. Watson (Ed) in *The Human Rights Agenda For Persons With and Intellectual Disabilities*. New York: NADD Press. Pp.19-37.

Centre for Inclusion and Citizenship Community Engagement Events 2010-2014

Also Here, Also Queer: Building Inclusive Communities for LGBTQ People Labelled with Intellectual Disabilities

Creating Community

Defining Our Future

Exploring the World of Social Capital

Ethnicity, Race and Culture: Towards an Inclusive Community Living

Helping People with Intellectual Disabilities Have Their Own Aspirational Voice: From Non-Verbal to Uniquely Verbal

How to Engage Community: Starting New Conversations with Neighbours

In From the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century

Living with Autism: Adults with Autism Spectrum Disorder Speak Out!

Moving Beyond IQ in Defining and Diagnosing Intellectual Disability: Service Eligibility Inequities for People with Brain-based Disorders

Pride and Prejudice: Canadian Ambivalence Toward Inclusion

Quality of Life & Intellectual Disability: Concepts and Measurement

Research with Relevance

Securing Our Rights

Swings and Roundabouts: The Social Inclusion Agenda in Australia and its Impacts

The Age of Empathy; the Exile of Autism

Understanding Our Past: The History of Community Living