

Internal use 524053
------------------------

# Application for a Grant

<b>Identification</b>						
This page will be made available to selection committee members and external assessors.						
Funding opportunity <b>Insight Grants</b>						
Joint or special initiative						
Application title <b>Social inclusion of children and youth with disabilities in Canada</b>						
Applicant family name <b>McConnell</b>			Applicant given name <b>David</b>		Initials	
Org. code <b>1480111</b>	Full name of applicant's organization and department <b>University of Alberta Occupational Therapy</b>					
Org. code <b>1480111</b>	Full name of administrative organization and department <b>University of Alberta Faculty of Rehabilitation Medicine</b>					
Scholar type	Regular	<input checked="" type="radio"/>	New	<input type="radio"/>	Research Group	
If New, specify category	1	<input type="radio"/>	2	<input type="radio"/>	3	<input type="radio"/>
			4	<input type="radio"/>	435-5	
Does your proposal require a multidisciplinary evaluation?					Yes	<input type="radio"/>
					No	<input checked="" type="radio"/>
Does your proposal involve human beings as research subjects? If "Yes", consult the <i>Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans</i> and submit your proposal to your organization's Research Ethics Board.					Yes	<input checked="" type="radio"/>
					No	<input type="radio"/>
Does your proposal involve activity that requires a permit, licence, or approval under any federal statute; or physical interaction with the environment? If 'Yes', complete Appendices A and B.					Yes	<input type="radio"/>
					No	<input checked="" type="radio"/>
	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Total funds requested from SSHRC (from page 9)	<u>140,366</u>	<u>145,366</u>	<u>124,927</u>	<u>0</u>	<u>0</u>	<u>410,659</u>

Family name, Given name  
**McConnell, David**

**Participants**

List names of your team members (co-applicants and collaborators) who will take part in the intellectual direction of the research. Do not include assistants, students or consultants.

Role

Co-applicant

Collaborator

Family name

**Emerson**

Given name

**Eric**

Initials

Org. code

**9121122**

Full organization name

**Lancaster University**

Department/Division name

**Division of Health Research**

Role

Co-applicant

Collaborator

Family name

**Llewellyn**

Given name

**Gwynnyth**

Initials

**M**

Org. code

**9661102**

Full organization name

**University of Sydney**

Department/Division name

**Faculty of Health Sciences**

Role

Co-applicant

Collaborator

Family name

Given name

Initials

Org. code

Full organization name

Department/Division name

Role

Co-applicant

Collaborator

Family name

Given name

Initials

Org. code

Full organization name

Department/Division name

Role

Co-applicant

Collaborator

Family name

Given name

Initials

Org. code

Full organization name

Department/Division name

<b>Research Activity</b>			
The information provided in this section refers to your research proposal.			
<b>Keywords</b>			
List keywords that best describe your proposed research or research activity. Separate keywords with a semicolon.			
social inclusion; disabilities; well-being; children; youth			
<b>Priority Areas</b> - Priority area(s) most relevant to your proposal.			
<b>Disciplines</b> - Indicate and rank up to 3 disciplines that best correspond to your activity.			
Rank	Code	Discipline	If "Other", specify
1	63408	Social Relations	
2	63208	Social Policy, Planning and Social Prevention	
3	63016	Life Span Development	
<b>Areas of Research</b>			
Indicate and rank up to 3 areas of research related to your proposal.			
Rank	Code	Area	
1	382	Youth	
2	200	Family	
3	330	Poverty	
<b>Temporal Periods</b>			
If applicable, indicate up to 2 historical periods covered by your proposal.			
From	To		
Year _____ _____	BC <input type="radio"/>	AD <input type="radio"/>	
Year _____ _____	BC <input type="radio"/>	AD <input type="radio"/>	

Personal information will be stored in the Personal Information Bank for the appropriate program.

Application WEB

Family name, Given name  
McConnell, David

**Research Activity (cont'd)**

**Geographical Regions**

If applicable, indicate and rank up to 3 geographical regions covered by or related to your proposal. Duplicate entries are not permitted.

Rank	Code	Region
1		
2		
3		

**Countries**

If applicable, indicate and rank up to 5 countries covered by or related to your proposal. Duplicate entries are not permitted.

Rank	Code	Country	Prov./ State
1			
2			
3			
4			
5			

Family name, Given name

McConnell, David

**Response to Previous Critiques - maximum one page**

Applicants may, if they wish, address criticisms and suggestions offered by adjudication committees and external assessors who have reviewed previous applications.

Family name, Given name

McConnell, David

## Summary of Proposed Research

The summary of your research proposal should indicate clearly the problem or issue to be addressed, the potential contribution of the research both in terms of the advancement of knowledge and of the wider social benefit, etc.

"Persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world" (United Nations, 2006, Preamble [k]). On March 11, 2010, Canada became the 82nd nation to ratify the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the first human rights convention of the 21st century. Ratification obliges nations to work to redress the profound social disadvantage of persons with disabilities so that they too can live with purpose, dignity and satisfaction. To meet this obligation, it is vital that nations have robust data to plan for, monitor and report on progress toward equalisation of opportunities for persons with disabilities.

**Aim and objectives:** This study will generate robust data on the social disadvantage and subjective well-being of Canadian children and youth with disabilities. The study has three objectives. The first is to determine the nature and level of social disadvantage faced by the 200,000+ young Canadians with disabilities, in early childhood, middle childhood and adolescence. The second objective is to investigate longitudinal pathways linking disability, social disadvantage and subjective well-being through childhood. The third is to hear from young Canadians with disabilities and gain insight into their expectations and experiences of social inclusion and exclusion.

**Methods:** The study has two components. The first component involves secondary analysis of the National Longitudinal Survey of Children and Youth (NLSCY). The NLSCY, which commenced in 1994, is a comprehensive long-term study of child development and well-being in Canada. Longitudinal structural equation modeling will be employed to test hypotheses about connections between disability, socioeconomic disadvantage, social relationships (support and participation) and subjective well-being (e.g., life satisfaction, suicidal ideation). The second component involves responsive interviews with a purposive sample of youth with disabilities. A flexible interview process incorporating visual aids and expressive media will explore youth expectations and experiences of social inclusion and exclusion.

**Outcomes:** The outcome of this study will be enhanced theoretical understanding with practical application. The study will result in deeper understanding of the day to day realities and challenges faced by young Canadians with disabilities. This understanding is vital for developing policy and effective supports to advance the rights and equalise 'life chances' for disabled children and youth. This research will be of interest to youth with disabilities, their families and advocates; health, rehabilitation and other community service providers; and, government officials and social policy makers committed to the full implementation of the UNCRPD.

**Roadmap to Social Inclusion:** The study will culminate in a series of 'research into policy and practice' roundtables. In northern and southern Alberta, youth with disabilities will come together to reflect on the research findings and draft a 'Roadmap to Social Inclusion'. A second series of roundtables will bring together decision-makers, users of research information, parents and youth with disabilities to hear about the study findings, and contribute to the 'Roadmap to Social Inclusion'. The final 'Roadmap' will elaborate on goals/aspirations, and discuss potential strategies at local, provincial and national levels, to advance the rights and well-being of children and youth with disabilities living in Canada today.

On March 11, 2010, Canada became the 82nd nation to ratify the United Nations Convention on the Rights of Persons with Disabilities. Ratification obliges nations to work to redress the profound social disadvantage of persons with disabilities so that they too can live with purpose, dignity and satisfaction (United Nations, 2006, Preamble [y]). To meet this obligation, it is vital that nations have robust data to plan for, monitor and report on progress toward the equalisation of opportunities for persons with disabilities. This study will generate robust data on the social disadvantage and subjective well-being of Canadian children and youth with disabilities. The study has three objectives. The first is to determine the nature and level of social disadvantage faced by the 200,000+ young Canadians with disabilities. The second objective is to investigate longitudinal pathways linking disability, social disadvantage and subjective well-being over the course of childhood. The third is to hear from young Canadians with disabilities, and gain insight into their expectations and experiences of social inclusion. The outcome will be enhanced understanding of the lives *and life chances* of disabled Canadian children and youth.

## CONTEXT

Disability-based inequalities in the life conditions and well-being of children and youth in the developing *and* developed world are now well documented. Compared with their non-disabled peers, youth with disabilities report lower levels of happiness, lower overall life satisfaction, and substantially higher rates of suicidal ideation (Albrecht & Devlieger, 1999; Burton & Phipps, 2010; Emerson & Hatton, 2008; Emerson, Honey, Madden & Llewellyn, 2009). However, little is known about the pathways linking disability status to well-being in childhood and adolescence, although some data is now emerging. In one recent study, involving secondary analysis of waves 1 and 6 of the Household Income and Labour Dynamics in Australia (HILDA) survey, Emerson et al. (2009) found that the comparatively poor well-being of Australian adolescents and young adults with disabilities likely reflects their increased risk of exposure to adversity and reduced access to resources, rather than the presence of health conditions or impairment *per se*: *Under conditions of low socioeconomic disadvantage and high social support, no disability-based inequality in well-being (i.e., life satisfaction) was found.* These provocative findings suggest that disability-based inequalities in well-being may be socially patterned and preventable.

There is a dearth of information pertaining to the social relationships (support and participation) of Canadian children and youth with disabilities, *vis a vis* their non-disabled peers, including data on peer relationships and participation in sport and leisure activities. There is, however, substantial data linking child disability to socioeconomic disadvantage in Canada and elsewhere (World Health Organisation and the World Bank, 2011). For instance, findings from the 1996/7 Canadian National Population Health Survey and the 2001 Statistics Canada Participation and Activity Limitation Survey (PALS) revealed that children with disabilities are substantially over-represented in low income households. In 2005 nearly one in five (19.1%) Canadian children with disabilities were living in households that fell below the Low-Income Cut-Off (LICO) compared to 13.4% of their non-disabled peers (Statistics Canada, 2008). The relationship between disability and socioeconomic disadvantage is likely to reflect the operation of a number of distinct processes. For example, supporting a child with disabilities may entail direct and indirect costs, including loss of income, that increase the chance of families descending into poverty and decrease the chances of them escaping from poverty (Emerson, et al., 2010). PALS data revealed that the employment activity of approximately 60% of families with children with disabilities was reported to be affected by care demands: Some parent-carers quit working, others turned down promotions or better jobs or cut-back hours of work (Statistics Canada, 2008).

One task for disability researchers is to identify the pathways connecting disability to socioeconomic disadvantage and social support and participation. Another task is to identify the pathways connecting socioeconomic disadvantage and social support/participation to the subjective well-being of children and youth with disabilities. For youth at large, there is good evidence linking socioeconomic exposures to well-being by way of family stress processes and, to a lesser extent, differential family investments in child well-being (Bradley & Corwyn, 2002; Conger & Donnellan,

2007; McConnell, Breitreuz & Savage, 2010). There is also evidence suggesting that social support and participation have both direct and indirect effects on the well-being of children and youth. Directly, social participation can promote a sense of belonging and self-worth (Carter, Swedeen, Moss & Pesko, 2010; Criss et al., 2002). Indirectly, social support may buffer the effects of stressful life circumstances and events (Fergusson & Horwood, 2003). Whether, or to what extent these pathways operate in the same way for children with and without disabilities is yet to be determined.

*Preliminary research by the applicant:* Recent research by the applicant and his research team found that many Canadian children and youth with disabilities face multiple and entrenched disadvantage. Funded by a SSHRC standard grant (ID: 410-2009-1134), a stratified random sample of over 500 parent-carers of children with disabilities completed annual surveys, 2009 to 2011, providing data on various dimensions of family life. The data revealed that almost half of the families experienced persistent under-employment, financial hardship, social isolation (i.e., few social supports) and stress. Further, the study found that the social engagement and participation of children and youth with disabilities was strongly associated with family financial and social resources. Notably, just 26% of the children and youth with disabilities were regularly involved in integrated sports or leisure activities, and almost half had no non-disabled friends at all. Building on this research, the next task is (1) to investigate how children and youth with disabilities are faring, *vis a vis* their non-disabled peers, using nationally representative and longitudinal data, and (2) to hear from young Canadians with disabilities about their lives, family relationships, and their expectations and experiences of social inclusion and exclusion.

## **INNOVATIVE ASPECTS AND THEORETICAL FOUNDATIONS**

*A social-relational perspective on disability.* Historically, negative social outcomes were regarded as the tragic but inevitable consequences of impairment. This study takes a different view. Negative social outcomes are understood to be contingent rather than inherent, the result of social relationships and arrangements that exclude persons with impairments (Barnes, Oliver & Barton, 2002). Rooted in disability studies, this research will investigate the social conditions or contingencies underlying disability-based inequalities in subjective well-being.

*Situating children and youth with disabilities as experts on their own lives.* Historically, the views of children about their lives have not been considered worthy of research. Research about children has focused mainly on the process of becoming: viewed through adult eyes, children were seen to play a relatively passive role, reacting in fairly predictable ways to natural processes going on inside of them, and social processes going on around them. This study takes a different view. Grounded in the 'new' sociology of childhood, children and youth are viewed not merely as 'human becomings' but as human beings, they are viewed as social actors, capable of making sense of and affecting the world around them (Corsaro, 1997; James & Prout, 1997). This study takes the views of children seriously.

*A lifecourse perspective on well-being.* The limited extant knowledge about the life conditions and well-being of children and youth with disabilities is based predominantly on cross-sectional data. Some notable exceptions include Liptak, Kennedy and Dosa (2011), Shahtahmasebi, Emerson, Berridge and Lancaster (2011), Wendelborg and Tossebro (2010) and King et al. (2009). Building on this work and emerging life course models of health inequalities, this study will utilise and collect longitudinal data to investigate and enhance understanding of how early life conditions may influence later life outcomes.

## **RESEARCH METHODS**

The study has two components. The first component (1) involves secondary analysis of the Canadian National Longitudinal Survey of Children and Youth (NLSCY). The planned analysis has been approved, and permission has been granted by SSHRC to access the secure micro files stored by the Research Data Centre (Project ID number: 11-SSH-UAB-2876). The second component of this study (2) involves responsive interviews with a purposive sample of youth with disabilities (12-19 years of age), exploring their expectations and experiences of social inclusion and exclusion.



### *(1) SOCIAL INCLUSION: SECONDARY ANALYSIS OF THE NLSCY*

The NLSCY is a long-term study of child development and well-being in Canada, consisting of several longitudinal and cross-sectional samples. Commencing in 1994, a total of eight biannual cycles of data collection have been completed. The data is collected directly from respondents and includes data from the Person Most Knowledgeable (usually a parent), and self-report data from youth. Children/youth with disabilities are identified in the NLSCY using a set of standard questions. These include, ‘Does... have any long term condition/s or health problems which prevent or limit his/her participation in school, at play, or in any other activity for a child his/her age?’ and, ‘Does this child have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing similar activities (i.e., due to a condition that has lasted or is expected to last > six months)?’

In our preliminary analysis of public use NLSCY Cycle 1 data, we found that there were 811 children with disabilities (3.7%). *This number will increase substantially as the younger children in the sample enter school and disabilities are identified.* Compared with their non-disabled peers, a greater proportion of the disabled children were living in low income households (28.4% vs. 24.0%) and/or in a neighbourhood deemed by parents to be a poor place to bring up children (8.0% vs. 4.7%). Further, a greater proportion of 10 and 11 year old disabled youth reported being bullied (7.4% vs. 1.8%), and feeling like an ‘outsider’ (13.2% vs. 4.8%). Based on parent report, the children with disabilities were less happy and satisfied with their lives than children without disabilities (OR = 0.29-0.42,  $p < 0.001$ ).

#### ***To address Objective 1: determining the nature and extent of social disadvantage***

The social inclusion/disadvantage of children and youth with disabilities will be examined using three NLSCY cross-sectional samples. Specifically, we will utilise (1) Cycle 1 data to compute estimates for children aged 4/5 and 8/9 in 1994/95; (2) Cycle 4 data to compute estimates for children aged 4/5, 8/9, and 14/15 in 2000/01; and, (3) Cycle 7 data to compute estimates for children aged 4/5, 8/9 and 14/15 in 2006/07. *Cycle 7 is selected because there are no 8/9 year old children in Cycle 8.*

Table 1. Cross-sectional samples

Age groups	Cycle 1 94-95	Cycle 4 00-01	Cycle 7 06-07
4/5	3,728	7,882	3,675
8/9	3,514	2,697	5,321
14/15	-	2,252	1,943
Total	7,242	12,831	10,939

Note: there are limitations to the generalizability of cycle 7 data for children aged 14-15

*Selection of indicators:* Following the approach taken by our international collaborators in the United Kingdom and Australia, we used the United Nations Convention on the Rights of Persons with Disabilities to identify domains of social inclusion, and then identified items contained within NLSCY that could be employed as indicators within these domains (Emerson, Honey & Llewellyn, 2008; Emerson, et al., 2009). The domains include, but are not limited to, socioeconomic resources (articles 27 & 28); social relationships, including support and participation (articles 19, 29 & 30); family environment (article 23); and, subjective well-being (article 25). Example indicators are presented in Table 2.

*Hypotheses:* One hypothesis is that children and youth with disabilities are more likely than their peers to be exposed to multiple disadvantages (operationally defined as three or more indicators of social disadvantage). Another hypothesis is that there was no significant change in the relative life conditions (material and social) of children and youth with disabilities between 1994/95 and 2006/07. The third hypothesis is that adolescents with disabilities, in 2000/01 and 2006/07, report relatively poorer subjective well-being, including but not limited to a higher rate of suicidal ideation.

*Analysis for Objective 1:* Rescaled sample weights will be used in all of the analyses. After screening the data, descriptive statistics will be computed and univariate comparisons made between children and youth with and without disabilities on each indicator within each domain, at each of three points in the life course (early childhood, middle childhood, adolescence), and at each of three historical reference points (1994/5, 2000/01, 2006/07).

Table 2. Example indicators of social inclusion

Domain	Example Indicators (NLSCY Items)
Socioeconomic Resources	jobless household : LFS_Q2, LFS_Q17; parent educational attainment: EDA_Q4; income and income ratio to low income cut off: HINHgD4A; food insecurity: PAR_Q31A/B
Social Relationships (support and participation)	child peer relationships: A1-A4; feeling like an outsider: B10; incidence of bullying and victimization: C7-C9; participation in community and social activities: B11A-E, E1A-E.
Family Environment	parent stress: HLA_Q12A-Q12L; family functioning: FNC_Q1A-Q1M, positive parenting: PAR-Q30A-Q31H
Subjective well-being	youth reported current and future life satisfaction: C3-C4; suicidal ideation: D2-6

**To address Objective 2: relationship between disability, social disadvantage and subjective well-being**

To investigate pathways linking disability, social disadvantage and subjective well-being, this study will utilize data from the original longitudinal NLSCY cohort. Specifically, the sample includes an estimated 6,000+ children (including 300+ children with disabilities) who were aged 0-5 years at the time of selection in 1994, and for whom data was collected at ages 4/5, 8/9 and 14/15 (See Table 3).

Table 3. Participant age categories by NLSCY Cycle: longitudinal study sample highlighted

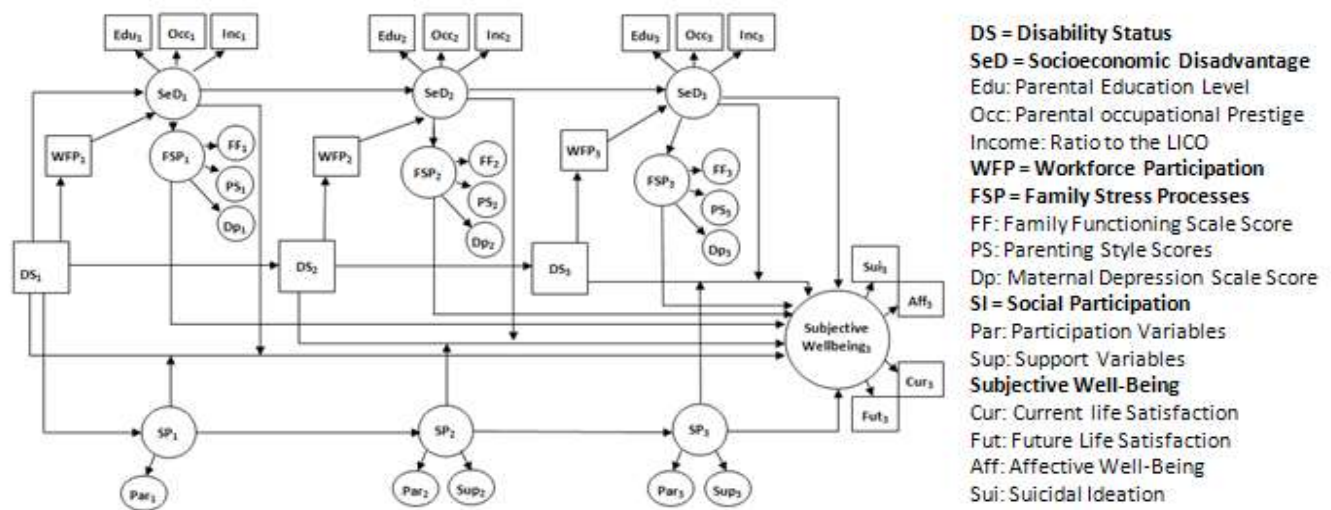
Age in 94'	Cycle 1 94-95	Cycle 2 96-97	Cycle 3 98-99	Cycle 4 00-01	Cycle 5 02-03	Cycle 6 04-05	Cycle 7 06-07	Cycle 8 08-09	Estimated Sample	
0	0	2	4	6	8	10	12	14	1,227	Early Childhood
1	1	3	5	7	9	11	13	15	1,274	
2	2	4	6	8	10	12	14	16	971	Middle Childhood
3	3	5	7	9	11	13	15	17	943	
4	4	6	8	10	12	14	16	18	907	Adolescence
5	5	7	9	11	13	15	17	19	884	

*Analysis for Objective 2:* Multiple imputation (MI) will be employed to deal with item non-response. Which MI method is used will depend on the nature of the missing values. Longitudinal structural equation modelling (LSEM) will then be employed to test hypotheses derived from the latent path model depicted in Figure 1. The LSEM analysis will be conducted under the guidance of statistician Dr N.G. Narasimha Prasad, University of Alberta. There are 8 hypotheses: 5 principal, 3 conditional:

- The relative socioeconomic disadvantage of children with disabilities will increase between early childhood and adolescence (i.e., the downward social mobility hypothesis).
  - The relationship between child disability and socioeconomic disadvantage is at least partially mediated by lower levels of parent employment.
- Children with disabilities will report poorer subjective well-being in adolescence, that is, by comparison with their non-disabled peers.
  - The relationship between disability and subjective well-being is at least partially mediated by higher lifetime exposures to socioeconomic disadvantage and lower social support/participation.
- Children and youth with disabilities will be exposed to higher levels of family stress than their non-disabled peers, in early childhood, middle childhood and adolescence.
  - The relationship between child disability and family stress processes is at least partially mediated by socioeconomic disadvantage.
- The relationship between socioeconomic disadvantage and subjective well-being among Canadian youth, with and without disabilities, will be mediated by family stress processes.
- Socioeconomic exposures and social support/participation will moderate the relationship between disability status and subjective well-being in adolescence.

The first step in the LSEM analysis will be to evaluate the measurement model using confirmatory factor analysis (with robust weighted least squares estimation) (Anderson & Gerbing, 1988; Flora & Curran, 2004). Once the measurement model is established, multiple group analyses will be conducted to determine the consistency of the model across children with and without disabilities. The correlation matrix for all latent variables will then be generated and the full latent variable path model and study hypotheses will be tested using the longitudinal structural equation modeling (LSEM) procedure in Stata v.12. To assess overall goodness of fit, we will compute the chi-square test statistic, the comparative fit index (criterion value >.95) (Bentler, 1990), and the root mean square error of approximation (criterion value <.60) (Steiger, 2000). Bootstrap estimates of direct and indirect effects will also be computed.

Figure 1. Latent variable path model



## (2) SOCIAL INCLUSION: AN IN-DEPTH QUALITATIVE STUDY (OBJECTIVE 3)

We affirm the right of children to express their views freely, in their own way, and on all matters concerning them, *and* to have their views taken seriously (United Nations Convention on the Rights of the Child, articles 12 and 13). In this component of the study, youth with disabilities will be heard: a purposive sample of 90 young people with disabilities will be interviewed annually, 2012-2014. Additional participants may be recruited depending on the theoretical sampling needs of the study.

Interviews will explore:

- how disabled youth negotiate the experience of disability in their everyday life
- their expectations and experiences of social inclusion and exclusion, including but not limited to school and peer relationships, and participation in recreation/sports and other social activities
- sources of present ‘well-being’, and future outlook (e.g., projected life satisfaction)

Potential participants will be identified from the “Sustainable family care” project database (SSHRC 410-2009-1134). This database, which is securely stored by the applicant at the University of Alberta, includes contact and demographic details of a stratified random sample of Alberta families caring at home for children and youth with disabilities. All families on this database have expressed interest in participating in future research and have given their consent to future contact. Of the more than 500 families listed, 316 have a child with disabilities who will be 12-19 years of age in 2012/13. Potential participants will be selected to ensure representation of youth with physical impairments and youth with cognitive impairments. Further, potential participants will be sampled to ensure representation from both urban and rural areas, and low and higher income households. All youth who can communicate using speech and/or with the use of a communication device are eligible to take part.

*Data collection:* Informed consent will be obtained from the youth as well as their parent/s. A letter will be sent to potential participants and their parent/s informing them about the study, and this will be followed by a phone call. A home visit will then be made to meet the youth who have expressed an interest in taking part. The purpose of this home visit is to establish rapport, determine the youth's preferred communication style, obtain informed consent, and arrange a time for the first interview. Interviews will be conducted at a time and place of the participant's choosing (e.g., at home). The interviews will be conducted by 5 graduate (PhD) students in the Rehabilitation Science program at the University of Alberta. Before data collection commences, the student interviewers will receive intensive training in conducting research interviews with children with disabilities.

The interviews will be responsive (Rubin and Rubin, 2005). With permission, the interviews will be audiotaped and later transcribed in full. A flexible interview guide, including 'grand tour' questions (Spradley, 1979) and general topics (with prompts) will be utilised. We anticipate that some youth will prefer a more structured interview process, and others a less structured process that simply opens a space and opportunity for them to express their views and understandings in their own way (ARACY and the NSW Commission for Children and Young People, 2009). Following the approach used by Stalker and Connors (2003), and by the Applicant in prior studies involving young adults with intellectual disabilities (e.g. Mill, McConnell & Mayes, 2010; Llewellyn & McConnell, 2002), each interview will be adapted to the particular communication style and abilities of the participants. Visual aids and activities (e.g., drawing, mapping, collage, story writing) will be incorporated into the interviews, when appropriate, to support the participation of youth who are less verbally skilled. After each interview, a plain English summary will be written-up and sent to the participant. Participants will be invited to review the summary of their interview and contact the research team by email or phone if there are any corrections to be made, or anything they would like to add.

*Rigour:* Rigor will be achieved through prolonged engagement (three years); an iterative process of data collection and analysis with regular participant (member) checking of emerging findings; deliberate search for and scrutiny of exceptional/unusual cases; critical reflective dialogue between research team members about the research process and emerging findings; and, the maintenance, by all members of the research team, of journals detailing the research process, including any difficulties encountered (Kincheloe, 2005; Krefling, 1991; Miles & Huberman, 1994; Mayan, 2009; Strauss & Corbin, 1998).

*Analysis for Objective 3:* Interview transcripts will be exported to NVIVO9, a software program designed to facilitate the effective management of large quantities of qualitative data. The analysis will commence once 15 interviews have been completed. The method of constant-comparison (Glaser & Strauss, 1967) will be used to analyze the data. This iterative process involves moving backwards and forwards between the data and the emerging insights/categories/themes. The first step involves coding meaningful 'chunks' of data. These are then compared and contrasted to develop appropriate categories. The process of constant-comparison continues until relationships between categories are elaborated, and higher levels of abstraction are reached. The outcome will be a rigorous analysis resulting in rich insights and findings that are well-grounded in the data.

## **SYNTHESIS (& TRIANGULATION) OF COMPONENTS 1 AND 2**

The findings from Components 1 and 2 of this study will be integrated in the interpretation and write-up of the study findings. Youth accounts of their everyday lives, including their experiences of social inclusion/exclusion, will provide a context ('thick description') that will help us interpret the findings from our analysis of the NLSCY data (*i.e., what do the data mean?*). Likewise, the findings from the analysis of NLSCY data will help to 'frame' the findings from the qualitative component of this study (*e.g., how much, how many, etc.*). Through this synthesis, we will enhance understanding of the social inclusion (& disadvantage) and well-being of Canadian children and youth with disabilities.

## REFERENCES

- Albrecht, G.L. & Devlieger, P.J. (1999). The disability paradox: high quality of life against all odds. *Social Science & Medicine*, 48, 977–88.
- Anderson, J.C. & Gerbing D.W. (1988). Structural Equation Modeling in Practice: A Review and Recommended Two-Step Approach, *Psychological Bulletin*, 103, 411-23.
- ARACY and the NSW Commission for Children and Young People. (2009). *Involving children and young people in research. Why do it and what are the challenges?* Retrieved October 2009 from <http://www.aracy.org.au/>
- Barnes, C., Oliver, M. & Barton, L. (2002). *Disability Studies Today*. Cambridge: Polity Press.
- Bentler, P.M. (1990). Comparative Fit Indexes in Structural Models. *Psychological Bulletin*, 107 (2), 238-46.
- Bradley, R. H., & Corwyn, R. F. (2002). Socioeconomic status and child development. *Annual Review of Psychology*, 53, 371–399.
- Burton, P., & Phipps, S. (2010). In children's voices. In S. B. Kamerman, S. Phipps & A. Ben-Arieh (Eds.), *From child welfare to child well-being* (Vol. 1, pp. 217-230). London: Springer.
- Carter, E.W., Swedeen, B., Moss, C.K. & Pesko, M.J. (2010). "What Are You Doing After School?": Promoting Extracurricular Involvement for Transition-Age Youth With Disabilities. *Intervention in School and Clinic*, 45(5), 275-283.
- Criss, M. M., Pettit, G. S., Bates, J. E., Dodge, K. A. & Lapp, A. L. (2002). Family Adversity, Positive Peer Relationships, and Children's Externalizing Behavior: A Longitudinal Perspective on Risk and Resilience. *Child Development*, 73, 1220–1237. doi: 10.1111/1467-8624.00468
- Conger, R.D. & Donnellan, M.B (2007). An Interactionist Perspective on the Socioeconomic Context of Human Development. *Annual Review of Psychology*, 58, 175-199.
- Corsaro, William A. (1997). *The Sociology of Childhood*. Thousand Oaks, CA: Pine Forge.
- Emerson, E., & Hatton, C. (2008). The self-reported well-being of women and men with intellectual disabilities in England. *American Journal on Mental Retardation*, 113(2), 143-155.
- Emerson, E., Honey, A. & Llewellyn, G. (2008). *The Well-Being and Aspirations of Australian Adolescents and Young Adults with a Long-term Health Condition, Disability or Impairment*. Retrieved Sept 1, 2010 from The Australian Research Alliance for Children & Youth (ARACY): <http://www.afdsr.org/publications/>
- Emerson E., Honey A., Madden R., Llewellyn G. (2009). The Well-Being of Australian Adolescents and Young Adults with Self-Reported Long-Term Health Conditions, Impairments or Disabilities: 2001 and 2006. *Australian Journal of Social Issues*, 44(1), 37-53.
- Emerson, E., Shahtahmasebi, S. Lancaster, G. & Berridge, D. (2010). Poverty transitions among families supporting a child with intellectual disability. *Journal of Intellectual & Developmental Disability*, 35(4), 224-234.
- Fergusson, D. M. & Horwood, L. J. (2003). *Resiliency to childhood adversity: results of a 21 year study*. In *Resilience and Vulnerability: Adaptation in the Context of Childhood Adversities*. (Ed.) S.S. Luthar, (pp. 130–155). Cambridge University Press: Cambridge.
- Flora, D.B. & Curran, P.J. (2004). An empirical evaluation of alternative methods of estimation for confirmatory factor analysis with ordinal data. *Psychological Methods*, 9, 466–491.
- Glaser, B. G. & Strauss, A.L. (1967). *The Discovery of Grounded Research: Strategies for Qualitative Research*. New York: Aldine De Gruyter.
- James, A. & Prout, A., (1990). *Constructing and Reconstructing Childhood. Contemporary Issues in the Sociological Study of Children*. London: Falmer Press.
- Kincheloe, J.L. (2005). On to the Next Level: Continuing the Conceptualization of the Bricolage. *Qualitative Inquiry*, 11(3), 323-350.
- King, G., McDougall, J., Dewit, D., Petrenchik, T., Hurley, P. & Law, M. (2009). Predictors of change

- over time in the activity participation of children and youth with physical disabilities. *Child Health Care*, 38(4), 321-351.
- Krefting, L. (1991). Rigor in qualitative research: the assessment of trustworthiness. *The American Journal of Occupational Therapy*, 45(3), 214-22.
- Liptak, G.S., Kennedy, J.A., & Dosa, N.P. (2011). Social Participation in a Nationally Representative Sample of Older Youth and Young Adults with Autism. *Journal of Developmental & Behavioral Pediatrics*, 32(4), 277-283. doi: 10.1097/DBP.0b013e31820b49fc
- Llewellyn, G. & McConnell, D. (2002) Mothers with learning difficulties and their support networks. *Journal of Intellectual Disability Research*, 46(1), 17–34.
- Mayan, M. J. (2009). *Essentials of qualitative inquiry*. Walnut Creek, CA: Left Coast Press.
- McConnell, D., Breikreuz, R. and Savage, A. (2011), From financial hardship to child difficulties: main and moderating effects of perceived social support. *Child: Care, Health and Development*, 37: no.doi: 10.1111/j.1365-2214.2010.01185.x
- Miles, M.B. & Huberman, A.M. (1994). *Qualitative Data Analysis (2nd edition)*. Thousand Oaks, CA: Sage Publications.
- Mill, A., McConnell, D. & Mayes, R. (2010). Negotiating autonomy within the family: The experiences of young adults with intellectual disabilities. *British Journal of Learning Disabilities*, 38, 194-200.
- Rubin, H. J., & Rubin, I. S. (1995). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage.
- Shahtahmasebi, S., Emerson, E., Berridge, D. & Lancaster, G. (2011). Child Disability and the Dynamics of Family Poverty, Hardship and Financial Strain: Evidence from the UK. *Journal of Social Policy*, 40(4), 653–673.
- Spradley, J.P. (1979). *The ethnographic interview*. Fort Worth: Harcourt.
- Stalker, K. & Connors, C. (2003). Communicating with disabled children. *Adoption & Fostering Journal*, 27(1), 26-35.
- Statistics Canada. (2008). *Participation and Activity Limitation Survey 2006: Families of Children with Disabilities in Canada*. Ottawa, CAN: Statistics Canada, Social and Aboriginal Statistics Division. (Catalogue no. 89-628-X no. 009)
- Steiger, J.H. (2000). Point estimation, hypothesis testing, and interval estimation using the RMSEA: Some comments and a reply to Hayduk and Glaser. *Structural Equation Modeling*, 7, 149–162.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage.
- Wendelborg, C. & Tøssebro, J. (2010). Marginalisation Processes in Inclusive Education in Norway: A Longitudinal Study of Classroom Participation. *Disability & Society*, 25(6), 701-714.
- World Health Organization and the World Bank. *World Report on Disability*. Geneva: World Health Organization, 2011.

## **KNOWLEDGE MOBILISATION PLAN**

We will employ a combination of strategies to ensure that the study findings are widely disseminated. These include conference presentations (e.g., IASSID World Congress; Statistics Canada conference), and publications (e.g., web-accessible report and publications in scholarly journals). However, the dissemination of knowledge, although necessary, is an insufficient condition for successful knowledge mobilisation. Therefore, we will engage stakeholders—bringing policy-makers, users of research information, parents and most especially youth with disabilities together—in a series of ‘research into policy and practice’ roundtables to participate actively in the process of elucidating implications for policy, practice and future research.

### *UNCRPD reporting requirements*

States parties to the UNCRPD are obliged to report to the UN at regular intervals on their progress towards the equalisation of opportunity and social inclusion of disabled people. The findings from this study will assist Canada in meeting this obligation. A full report of the study findings will be delivered to the Minister of Human Resources and Skills Development Canada, the lead department addressing the UNCRPD. The full report will also be available on-line at [www.ualberta.fdsa.ca](http://www.ualberta.fdsa.ca).

### *Anticipated refereed publications*

1. Social inclusion of Canadian children and youth with disabilities, 1994-2007.
2. Social determinants of subjective well-being among youth with disabilities: A LSEM study
3. Youth with disabilities: Expectations and experiences of social inclusion
4. A ‘roadmap to social inclusion’ – developed *by* and *for* youth with disabilities

### *Collaborating to develop a ‘Roadmap to Social Inclusion’*

Four Roundtables will be convened, including two in northern Alberta and two in southern Alberta. The first two roundtables (one in the north, one in the south) will bring youth with disabilities together, including but not limited to participants in Component 2 of the study, to reflect on the research findings (including challenges and aspirations) and draft a ‘Roadmap to social inclusion’. Youth with disabilities will be invited to bring a support person of their choice with them to the roundtable.

The second two roundtables (one in the north, one in the south) will be open to decision-makers, users of research information, parents and youth with disabilities, and their advocates. At this second roundtable, participants will hear about the study findings, and respond to and expand the draft ‘Roadmap to social inclusion’. The final ‘Roadmap to social inclusion’ will include a statement of goals/aspirations, and discussion of potential strategies at local, provincial and federal levels, to advance the rights and equalise opportunities for children and youth with disabilities living in Canada today.

Family name, Given name

McConnell, David

**Intended Outcomes of Proposed Activities**

Elaborate on the potential benefits and/or outcomes of your proposed research and/or related activities.

**Scholarly Benefits**

Indicate and rank up to 3 scholarly benefits relevant to your proposal.

Rank	Benefit	If "Other", specify
1	Knowledge creation/intellectual outcomes	
2	Enhanced theory	
3	Enhanced research collaboration	

**Social Benefits**

Indicate and rank up to 3 social benefits relevant to your proposal.

Rank	Benefit	If "Other", specify
1	Social outcomes	
2	Enhanced policy	
3	Training and skill development	

**Audiences**

Indicate and rank up to 5 potential target audiences relevant to your proposal.

Rank	Audience	If "Other", specify
1	Federal government	
2	NGO and community organizations	
3	Academic sector/peers, including scholarly associations	
4	(Other) - Specify	Youth with disabilities and families
5	(Other) - Specify	UNCRPD Monitoring Committee, UN



Family name, Given name

McConnell, David

### Expected Outcomes Summary

Describe the potential benefits/outcomes (e.g., evolution, effects, potential learning, implications) that could emerge from the proposed research and/or other partnership activities.

This study will enhance understanding of social inclusion and well-being among Canadian children and youth with disabilities. At present, our knowledge about children and youth with disabilities in Canada comes mainly from the Statistics Canada Participation and Activity Limitations Survey (PALS). This data-set has two well-known limitations. Firstly, it does not permit investigation of any longitudinal association between indicators of social inclusion and outcomes such as subjective well-being. Second, it does not permit comparisons between children and youth with and without disabilities. Our analysis of the National Longitudinal Survey of Children and Youth will redress both of these limitations. Firstly, our analysis will determine the nature and level of disadvantage faced by children and youth with disabilities. Moreover, our analysis will enable comparisons over time, that is, to determine whether the life conditions of children and youth with disabilities improved between 1994 and 2007, a period of significant policy intervention. Second, this study will investigate pathways linking disability in early and middle childhood to subjective well-being in adolescence. This analysis is vital for developing policy and effective supports to advance the rights and equalise 'life chances' for disabled children and youth. In addition, this study will enhance understanding of the expectations, aspirations and experiences of youth with disabilities as they negotiate disability in their everyday lives. One tangible outcome will be a 'roadmap to social inclusion', developed in collaboration with youth with disabilities, based on the knowledge created by this research.

## RESEARCH TEAM, STUDENT TRAINING, PREVIOUS OUTPUT

### A. Description of Research Team and Project Timeline

D. McConnell, *Applicant and Principal Investigator*, (0.4FTE, 60% contribution) will be responsible for the overall coordination of the project team, on-time implementation of the study protocol, administration of the project funding, and write-up of study findings. Dr McConnell will appoint and supervise the project coordinator, and is primary supervisor of the six graduate research students who will contribute to this project.

E. Emerson, *International Collaborator* (20% contribution) will work closely with Dr McConnell in overseeing the analysis of the NLSCY data. Dr Emerson will also take the lead in performing cross-national comparisons—comparing the findings from this study with findings from similar studies undertaken in the United Kingdom and Australia.

G. Llewellyn, *International Collaborator* (20% contribution) will work closely with Dr McConnell in overseeing the analysis of the qualitative data. Drawing on her extensive experience of qualitative research involving children with disabilities, Dr Llewellyn will also contribute to the training and supervision of the graduate student interviewers, and co-facilitate the ‘Research into Policy and Practice Roundtables’ and development of the proposed ‘Roadmap to Social inclusion’.

	Year 1	Year 2	Year 3
Month 1-4	<ul style="list-style-type: none"> <li>• International team meeting</li> <li>• Interviewer training</li> <li>• Participant Recruitment</li> </ul>	<ul style="list-style-type: none"> <li>• International team meeting</li> <li>• Wave 2 Youth Interviews</li> </ul>	<ul style="list-style-type: none"> <li>• Wave 3 Youth Interviews</li> <li>• Complete qualitative analysis</li> </ul>
Month 4-8	<ul style="list-style-type: none"> <li>• Screen NLSCY data</li> <li>• Wave 1 Youth Interviews</li> </ul>	<ul style="list-style-type: none"> <li>• Qualitative analysis ongoing</li> <li>• NLSCY data analyses Obj.2</li> </ul>	<ul style="list-style-type: none"> <li>• Draft final report</li> <li>• International team meeting</li> <li>• Research Roundtables</li> </ul>
Month 9-12	<ul style="list-style-type: none"> <li>• Complete NLSCY data analysis: Obj.1</li> </ul>	<ul style="list-style-type: none"> <li>• Complete NLSCY data analyses: Obj.2</li> </ul>	<ul style="list-style-type: none"> <li>• Complete Final report</li> </ul>

### B. Student Training Opportunities

This study will create research training opportunities for graduate students in a vibrant, multi-disciplinary team setting, the Family and Disability Studies Initiative, Faculty of Rehabilitation Medicine, University of Alberta. The team environment fosters interactions between students and researchers across the research and scholarship career spectrum, including prospective research students enrolled in professional masters programs, higher degree research students (Masters and PhD), postdoctoral fellows, early career and senior academic researchers.

*The project will directly support a total of six doctoral students:*

- Ms Amber Savage, MSc(OT) will contribute to Component 1 - analysis of the NLSCY data. Ms Savage is currently completing intensive training in Structural Equation Modeling, taught by Dr L Heyduk, an internationally renowned expert on the subject. Ms. Savage will also contribute to the write-up of the data and dissemination of findings.
- Five other doctoral students (four current, one commencing in 2012) will receive research training and contribute directly to this project. They are Camille Dube, MSc (OT), Elly Hyun, MSc (OT), Laura Pacheco, MSW, Lindsay Hahn, MSc (OT) and Sonia Cherrier (MPsych). These students gained entry to the Rehabilitation Science graduate research program with outstanding academic merit. These five students will receive advanced training in interviewing children and youth with

disabilities, and in analysing qualitative data. They will each complete 15-20 interviews per year. As a group, they will meet regularly with the Applicant, D. McConnell, and with G. Llewellyn and the trust administrator to debrief, discuss and reflect on their emerging insights, and share ideas with regard to interview methods (e.g., what is working well). They will transcribe their own interviews and contribute to the analysis and write-up of the data.

- All of the students contributing to this project will be actively involved in facilitating the proposed 'Research into policy and practice roundtables', including provision of support to youth with disabilities to enable their full participation. Further, all of the students involved in this project will be actively involved in communicating the results/emerging findings from this study. This includes contributing to the write-up of study findings, and oral presentations at local, provincial and national conferences.

### **C. Description of Recent Outputs**

The impetus for this research comes from (1) recent research undertaken by the Applicant in Canada, and (2) recent research by E. Emerson and G. Llewellyn in the United Kingdom and Australia.

#### *(1) Recent research undertaken by the Applicant*

Findings from three recent studies conducted by the Applicant and his research team suggest that children and youth with disabilities in Canada face profound social disadvantage.

**1a.** The first of these three studies investigated child welfare process and outcomes for children of parents with cognitive impairments, supported by a grant from the Alberta Centre for Child, Family and Community Research (ACCFRC). The method was secondary analysis of the 2003 Canadian Incidence Study of Reported Child Abuse and Neglect (CIS-2003). The CIS-2003 includes data on a multi-stage, stratified cluster sample of over 12,000 child maltreatment investigations across Canada. In this study the Applicant found that children and youth with disabilities are significantly over-represented in child maltreatment investigations in Canada (Feldman, McConnell & Aunos, in press; McConnell, Feldman, Aunos & Prasad, 2010; McConnell, Feldman, Aunos & Prasad, 2011). Indeed, based on an estimated population prevalence of 5%, *children with disabilities were found to be eight to ten times more likely than non-disabled children to be exposed to maltreatment.*

- The findings from this first study suggest that Canadian children and youth with disabilities are much more likely than their non-disabled peers to grow up in a family environment that is highly stressed, and potentially harmful to their well-being.

**1b.** The second of these three studies investigated parent support needs and family support service outcomes in Alberta. A total of 923 parent participants were recruited through 20 community-based family support service (FSS) providers in Alberta, Canada. Participants completed a survey, incorporating well-validated child, parent and family outcome measures, 8-12 weeks after utilising their FSS. Group interviews were also conducted with a total of 62 family support practitioners. The study found that most parents reported high levels of need satisfaction, and this was linked to lower levels of parenting stress and more positive parent-child interactions. In turn, lower levels of parenting stress and more positive parent-child interactions were linked to fewer child difficulties. However, outcomes for parents and families of children and youth with disabilities were less positive. *Parents and families of children and youth with disabilities reported the lowest levels of overall need satisfaction* (McConnell, Breitkreuz & Savage, 2010; McConnell, Breitkreuz & Savage, 2011; McConnell, Breitkreuz & Savage, forthcoming).

- The findings from this study suggest that although families of children and youth with disabilities are more likely to be highly stressed, these families are less likely than families with non-disabled children to receive or benefit from universal support services available in their community.

**1c.** The third study investigated work-family-care integration and out-of-home placement tendency in families with children with disabilities. This study, funded by a SSHRC standard grant (SSHRC ID: 410-2009-1134) involved a stratified (by child age-group) random sample of 538 families in Alberta. Primary parent-carers completed a comprehensive questionnaire annually for three years (2009-2011). In addition, in-depth interviews were conducted with approximately 100 parent-carers each year. [Interviews were completed by graduate students in the Master of Science (Occupational Therapy) program, University of Alberta. A total of 30 graduate students (10 per year) received training and gained experience in research interviewing, and the analysis and write-up of narrative data.]

Approximately 15% of the 538 families in this study were seriously considering or had taken steps to place their disabled child out-of-home. Family financial hardship and perceived social support predicted work-family-care integration, and this, in turn, accurately predicted out-of-home placement tendency. Over 50% of parent-carers reported having difficulty paying their bills and 20% expected that they would have to do without basic things over the coming months. Almost half of the parent-carers reported low levels of social support. Parent perceived social support and family financial hardship were also linked to the social participation of the children with disabilities. Notably, just 26% of the children and youth with disabilities were regularly involved in integrated sports or leisure activities, and almost half had no non-disabled friends at all. We are now in the process of writing up the findings from this important study. *A book based on this study is in preparation.*

- The early findings from this study suggest that many children and youth with disabilities are exposed to multiple and entrenched disadvantage. A substantial number face the prospect of growing up away from home and family.

## *(2) Recent research undertaken by E. Emerson and G. Llewellyn*

The findings from the Applicants three most recent studies highlight the need for a systematic investigation of the social inclusion/disadvantage and well-being of Canadian children and youth with disabilities. Over the past five years, international collaborators, E. Emerson and G. Llewellyn, have undertaken such systematic investigations in the United Kingdom and Australia. Employing a framework of indicators based on the United Nations Convention on the Rights of Persons with Disabilities, Emerson and Llewellyn have investigated the social inclusion and well-being of children and youth with disabilities utilising data from large longitudinal population/panel studies, including the Millennium Cohort Study in the United Kingdom, the Longitudinal Study of Australian Children, and the Household Income and Labour Dynamics in Australia (HILDA) Survey.

Their recent work suggests that despite social policy interventions in Australia and the United Kingdom over the last decade, the aspiration for disabled young people to become more socially included appears even further out of reach than previously, with a widening of the gap between the life conditions of disabled and non-disabled youth in five critical areas: living in a jobless household, being fully engaged in education or work, low economic resources and financial stress, and most worryingly, multiple disadvantage and entrenched multiple disadvantage (Emerson & Hatton, 2007; Emerson, Shahtahmasebi, Lancaster & Berridge, 2010; Llewellyn, Emerson, Honey & Kariuki, 2011; Shahtahmasebi, Emerson, Berridge & Lancaster, 2010). Further, their research findings suggest that disability-based disparities in subjective well-being (e.g., life satisfaction) are not 'essential', but are rather contingent on social disadvantage. Specifically, they report data indicating that when material/economic resources are adequate (i.e., low financial hardship) and social support and participation is high, no disability-based disparities in subjective well-being are found (Emerson, Honey, & Llewellyn, 2008; Emerson, Honey, Madden & Llewellyn, 2009; Emerson, Llewellyn, Honey & Kariuki, in press).

The proposed study will build on these recent studies by McConnell, Emerson and Llewellyn. Firstly, it will determine the nature and level of social disadvantage faced by Canadian children and youth, *vis a vis*, their non-disabled peers, in 1994/5, 2000/01 and 2006/7. Second, this study will investigate the

influence of social disadvantage, in early and middle childhood, on the subjective well-being of adolescents with disabilities. Third, it represents a theoretical advance: The proposed study will investigate the potential mediating and moderating roles of parent workforce participation and family stress processes. Fourth, this study will enrich our understanding of the expectations and experiences of youth with disabilities: *their lives, their voices, their views*. This data is vital for developing policies and effective supports to promote the life chances and equalise opportunities for children and youth with disabilities living in Canada today.

## REFERENCES

- Emerson, E. & Hatton, C. (2007). Contribution of Socioeconomic Position to Health Inequalities of British Children and Adolescents with Intellectual Disabilities. *American Journal on Mental Retardation*, 112(2) 140–150.
- Emerson E., Honey A., Madden R., Llewellyn G. (2009). The Well-Being of Australian Adolescents and Young Adults with Self-Reported Long-Term Health Conditions, Impairments or Disabilities: 2001 and 2006. *Australian Journal of Social Issues*, 44(1), 37-53.
- Emerson, E., Honey, A. & Llewellyn, G. (2008). *The Well-Being and Aspirations of Australian Adolescents and Young Adults with a Long-term Health Condition, Disability or Impairment*. Retrieved Sept 1, 2010 from The Australian Research Alliance for Children & Youth (ARACY): <http://www.afdsr.org/publications/>
- Emerson, E., Llewellyn, G., Honey, A. & Kariuki, M. (in press). The lower well-being of young Australian adults with self-reported disability reflects their poorer living conditions rather than the presence of health conditions or impairments. *Australian & New Zealand Journal of Public Health*.
- Emerson, E., Shahtahmasebi, S. Lancaster, G. & Berridge, D. (2010). Poverty transitions among families supporting a child with intellectual disability. *Journal of Intellectual & Developmental Disability*, 35(4), 224-234.
- Feldman, M. McConnell, D. & Aunos, M. (in press). Parental cognitive impairment, mental health and child outcomes in a child protection population. *Journal of mental health research in Intellectual disabilities*.
- Llewellyn, G., Emerson, E., Honey, A. & Kariuki, M. (2011). *Left behind: Monitoring the social inclusion of young Australians with disabilities, 2011-2009. Policy briefing on social inclusion of young disabled Australians*. Australian Family and Disability Studies Research Collaboration, Faculty of Health Sciences, University of Sydney. ISBN 978-1-74210-245-0
- McConnell, D. Breitreuz, R. & Savage, A. (2011). Independent evaluation of the Triple P Positive Parenting Program in family support service settings. *Child & Family Social Work*, (in press) DOI:10.1111/j.1365-2206.2011.00771.x
- McConnell, D. Breitreuz, R. & Savage, A. (2010). From financial hardship to child difficulties: main and moderating effects of perceived social support. *Child: care, health and development*, 37(5), 679-91. DOI:10.1111/j.1365-2214.2010.01185.x
- McConnell, D., Breitreuz, R. & Savage, A. (in press). Parent needs and family support service outcomes in a Canadian sample. *Journal of Social Work*.
- McConnell, D., Feldman, M., Aunos, M. & Prasad, N. (2011). Parental cognitive impairment and child maltreatment in Canada. *Child Abuse & Neglect*, 35, 621– 632
- McConnell, D., Feldman, M., Aunos, M. & Prasad, N. (2010). Child Maltreatment Investigations Involving Parents with Cognitive Impairments in Canada. *Child Maltreatment*, 16(1), 21-32.
- Shahtahmasebi, S., Emerson, E., Berridge, D. & Lancaster, G. (2010). A longitudinal analysis of poverty among families supporting a child with a disability. *International Journal on Disability and Human Development*, 9(1), Pages 65–75.

Family name, Given name

McConnell, David

### Funds Requested from SSHRC

For each budget year, estimate as accurately as possible the research costs that you are asking SSHRC to fund through a grant. For each Personnel costs category, enter the number of individuals to be hired and specify the total amount required. For each of the other categories, enter the total amount required.

Personnel costs	Year 1		Year 2		Year 3		Year 4		Year 5	
	No.	Amount	No.	Amount	No.	Amount	No.	Amount	No.	Amount
<b>Student salaries and benefits/Stipends</b>										
Undergraduate										
Masters										
Doctorate	6	61,696	6	64,163	5	41,089	0	0	0	0
<b>Non-student salaries and benefits/Stipends</b>										
Postdoctoral										
Other	1	63,340	1	65,873	1	68,508	0	0	0	0
<b>Travel and subsistence costs</b>										
	Year 1		Year 2		Year 3		Year 4		Year 5	
<b>Applicant/Team member(s)</b>										
Canadian travel										
Foreign travel		6,000		6,000		6,000		0		0
<b>Students</b>										
Canadian travel		7,530		7,530		7,530		0		0
Foreign travel										
<b>Other expenses</b>										
Professional/Technical services										
Supplies										
<b>Non-disposable equipment</b>										
Computer hardware										
Other										
<b>Other expenses (specify)</b>										
Participant Honorarium		1,800		1,800		1,800		0		0
<b>Total</b>		140,366		145,366		124,927		0		0

## Budget Details & Justification

**Total Requested \$ 410,659**

---

### Personnel (\$364,669)

#### *Student stipends*

PhD student stipend, University of Alberta Graduate Research Assistantship (GRA award plus salary)

- 1 PhD student (A. Savage) @ 24 months + COLA\* = (\$23,706 yr 1; \$24,654 yr 2) = \$48,360
- 5 PhD students (C. Dube, E. Hyun, S. Cherrier, L. Hahn, L. Pacheco) @ 4 months/year x 3 years  
GRA = \$7,598 p/a + COLA\* x 5 students (\$37,990 yr 1; \$39,509 yr 2; 41,089 yr 3) = \$118,588

\*COLA = 4% p/a

#### *Trust administrator*

Project Coordinator/Trust Administrator (Level 2b): 1 x 0.6FTE (+ COLA & benefits) = \$63,340 yr 1;  
\$65,873 yr 2; 68,508 yr 3 = \$ 197,721

### Travel and associated costs for interviews (\$22,590)

- Urban - 60 youth interviews x 3 waves of data collection @ 45km/interview @ \$0.46/km = \$3,726
- 3 round trips to Calgary x 3 waves @ 590km/trip @ \$0.46/km = \$2,442
  - (Calgary) accommodation (3 trips x 3 nights x 3 waves) @ \$140/night = \$3,780
  - (Calgary) per diem (3 trips x 4 days x 3 waves) @ \$45/day = \$1,620
- Rural - 30 youth interviews x 3 waves of data collection @ 150km/interview @ \$0.46/km = \$6,210
- 2 overnight round trips to rural sites x 3 waves @ 700km/trip @ \$0.46/km = \$1,932
  - (Rural Sites) accommodation (2 trips x 3 nights x 3 waves) @ \$100/night = \$1,800
  - (Rural Sites) per diem (2 trips x 4 days x 3 waves) @ \$45/day = \$1,080

### Travel for international collaborators (\$18,000)

- Air - Sydney, Australia/Edmonton, Canada: Round (Llewellyn) 1 trip/year x 3 years = \$6,900  
- Lancaster, England/Edmonton, Canada: Round (Emerson) 1 trip/year x 3 years = \$4,500  
Accommodation - 2 (Llewellyn & Emerson) x 1 week x 3 trips = \$6,600

### Honorarium (\$5,400)

90 participants (Study component 2) x 3yrs @ \$20.00 (gift card) = \$5,400

### Hosting (\$0.00)

*The cost of hosting the 'Research into Policy and Practice' Roundtables (venue hire, catering, parking) is covered by a cash contribution from the Faculty of Rehabilitation Medicine, University of Alberta.*

Graduate Research Assistantships (2012-2015). Six higher degree (PhD) students will receive research training and actively contribute to this project. One student, Ms. Amber Savage will be employed for two years on a renewable GRA and will contribute to Component 1, analysis of the NLSCY data. Five other doctoral students (C Dube, E Hyun, L Pacheco, L Hahn, S Cherrier) will receive one GRA in each year of the study. Each will conduct up to three interviews (one per year) with 15-20 youth with disabilities, and will transcribe most of their own interviews. All will participate, as full members of the research team, in regular planning and progress meetings.

Trust administrator/project coordinator (2012-2015). A trust administrator (0.6FTE) is required for the duration of the project. The trust administrator will be responsible for the day to day management/coordination of the project. Duties will include liaising with research team members (including the international collaborators and graduate students contributing to the project); arranging/coordinating team meetings and research roundtables; maintaining an up-to-date research reference library; managing the recruitment of participants for Component 2; responding to any parent-carer or youth enquiries about the project; implementing participant 'retention' strategies; contributing to interview transcription; maintaining project databases; contributing to the analysis of Component 1 and Component 2 data; and, contributing to the write-up of plain English summaries (for participants) and scholarly journal articles.

Travel for data collection: A total of \$22,590 is requested to cover travel (mileage) and related costs associated with conducting 90 x 3 interviews with youth with disabilities in urban and rural Alberta.

Travel for Collaboration: A total of \$18,000 is requested to cover travel (flights) and accommodation expenses for international team meetings. E Emerson and G Llewellyn will travel to Edmonton for team meetings and to contribute to the graduate student training and planned research roundtables.

Honorarium: Interview participants will receive an honorarium of \$20.00 (gift card) after each interview. This is to acknowledge the contribution the youth make to this important project.





Family name, Given name

McConnell, David

**Suggested Assessors** - List up to 3 Canadian or foreign specialists whom SSHRC may ask to assess your proposal. List keywords that best describe the assessor's areas of research expertise. Please refer to the Suggested Assessors section of the detailed instructions for more information on conflicts of interest.

Family name <b>Griffiths</b>		Given name <b>Dorothy</b>		Initials	Title <b>Professor</b>
Org. code	Full organization name <b>Brock University</b>		Keywords <b>Human Rights of Persons with Intellectual Disabilities</b>		
Department/Division name <b>Faculty of Social Sciences</b>			Address <b>Brock University Child and Youth Studies South Block, Room 438</b>		
Country code		Area code	Number	Extension	City/Municipality
Telephone number		1	905	688-5550	4069
Fax number		Country <b>CANADA</b>			
E-mail <b>griffith@brocku.ca</b>					
Family name <b>Tossebro</b>		Given name <b>Jan</b>		Initials	Title <b>Professor</b>
Org. code	Full organization name <b>Norwegian University of Science and Technology</b>		Keywords <b>Services and social reforms; Disability; childhood and families; Special education Integration and normalisation; Living conditions</b>		
Department/Division name <b>Dept. of Social Work and Health Science</b>			Address <b>NTNU, Dragvoll block 11, level 5, room 11 543 Trondheim</b>		
Country code		Area code	Number	Extension	City/Municipality
Telephone number		47	73	59 17 20	
Fax number		Country <b>NORWAY</b>			
E-mail <b>jant@svt.ntnu.no</b>					
Family name		Given name		Initials	Title
Org. code	Full organization name		Keywords		
Department/Division name			Address		
Country code		Area code	Number	Extension	City/Municipality
Telephone number					
Fax number		Country			
E-mail					

Personal information will be stored in the Personal Information Bank for the appropriate program.

Application WEB

Do not photocopy this page.

Internal use	CID (if known)
120827	191312

**Identification**  
Only the information in the Name section will be made available to selection committee members and external assessors. Citizenship and Statistical and Administrative Information will be used by SSHRC for administrative and statistical purposes only. Filling out the statistical and Administrative Information section is optional.

<b>Name</b>			
Family name	Given name	Initials	Title
McConnell	David		Dr.

**Citizenship** - Applicants and co-applicants must indicate their citizenship status by checking and answering the applicable questions.

Citizenship status	<input type="radio"/> Canadian	<input type="radio"/> Permanent resident since (yyyy/mm/dd)	<input checked="" type="radio"/> Other (country)	Have you applied for permanent residency?
			<u>AUSTRALIA</u>	<input checked="" type="radio"/> Yes <input type="radio"/> No

**Statistical and Administrative Information**

Birth year	Gender	Permanent postal code in Canada (i.e. K2P1G4)	Correspondence language	Previous contact with SSHRC? (i.e. applicant, assessor, etc.)
1971	<input type="radio"/> F <input checked="" type="radio"/> M	T6R2S6	<input checked="" type="radio"/> English <input type="radio"/> French	<input checked="" type="radio"/> Yes <input type="radio"/> No

Full name used during previous contact, if different from above

**Contact Information**  
The following information will help us to contact you more rapidly. Secondary information will not be released by SSHRC without your express consent.

Primary telephone number				Secondary telephone number			
Country code	Area code	Number	Extension	Country code	Area code	Number	Extension
1	780	4927475		1	780	7575514	
Primary fax number				Secondary fax number			
Country code	Area code	Number	Extension	Country code	Area code	Number	Extension
Primary E-mail <b>David.McConnell@ualberta.ca</b>							
Secondary E-mail							

Personal information will be stored in the Personal Information Bank for the appropriate program.

**Checked**  
Web CV  
2011/10/11

Identification

**PROTECTED B WHEN COMPLETED**

**Do not photocopy this page.**

Family name, Given name

McConnell, David

<b>Current Address</b> Use only if you are not affiliated with a department at a Canadian university. (If you are affiliated with a department at a Canadian university, the department's mailing address will be used.) If you wish to use another address, specify it under the Correspondence Address.			<b>Correspondence Address</b> Complete this section if you wish your correspondence to be sent to an address other than your current address.		
Address			Address		
City/Municipality	Prov. / State	Postal/Zip code	City/Municipality	Prov. / State	Postal/Zip code
Country CANADA			Country		
<b>Temporary Address</b> If providing a temporary address, phone number and/or E-mail, ensure that you enter the effective dates.			<b>Permanent Address in CANADA</b>		
Address			Address		
City/Municipality	Prov./ State		City/Municipality	Prov./ State	Postal/Zip code
Country			Country		
Start date (yyyy/mm/dd)	End date (yyyy/mm/dd)	Temporary telephone/fax number			
		Country code	Area code	Number	Extension
Temporary E-mail					

**Do not photocopy this page.**

Family name, Given name

McConnell, David

### Research Expertise (optional)

The information provided in this section refers to your own research expertise, not to a research proposal. Filling out the following 4 sections is optional. This page will not be seen by selection committee members and external assessors. This section will be used for planning and evaluating programs, producing statistics, and selecting external assessors and committee members.

#### Areas of Research

Indicate and rank up to 3 areas of research that best correspond to your research interests as well as areas where your research interests would apply. Duplicate entries are not permitted.

Rank	Code	Area
1	200	Family
2	350	Social development and welfare
3	260	Law and justice

#### Temporal Periods

If applicable, indicate up to 2 historical periods covered by your research interests.

From				To			
Year				Year			
		BC	AD			BC	AD
_____		<input type="radio"/>	<input type="radio"/>	_____		<input type="radio"/>	<input type="radio"/>
_____		<input type="radio"/>	<input type="radio"/>	_____		<input type="radio"/>	<input type="radio"/>

#### Geographical Regions

If applicable, indicate and rank up to 3 geographical regions covered by your research interests. Duplicate entries are not permitted.

Rank	Code	Region
1		
2		
3		

#### Countries

If applicable, indicate and rank up to 5 countries covered by your research interests. Duplicate entries are not permitted.

Rank	Code	Countries	Prov./ State
1			
2			
3			
4			
5			

Family name, Given name

McConnell, David

## Curriculum Vitae

### Language Proficiency

	Read	Write	Speak	Comprehend aurally	Other languages
English	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
French	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

### Work Experience

List the positions, academic and non-academic, you have held beginning with the current position and all previous positions in reverse chronological order, based on the start year.

Current position		Start date (yyyy/mm)
Full Professor		2010/6
Org. code	Full organization name	
1480111	University of Alberta	
Department/Division name		
Occupational Therapy		
Position type	<input checked="" type="radio"/> Tenured <input type="radio"/> Non-tenure <input type="radio"/> Tenure-track <input type="radio"/> Non-academic	Employment status
		<input checked="" type="radio"/> Full-time <input type="radio"/> Part-time <input type="radio"/> Non-salaried <input type="radio"/> Leave of absence
Position	Start date (yyyy/mm)	End date (yyyy/mm)
Associate Professor	2007/1	2010/6
Org. code	Full organization name	
1480111	University of Alberta	
Department/Division name		
Occupational Therapy		
Position	Start date (yyyy/mm)	End date (yyyy/mm)
Senior Lecturer	2004/9	2006/9
Org. code	Full organization name	
9661102	University of Sydney	
Department/division name		
Faculty of Health Sciences		
Position	Start date (yyyy/mm)	End date (yyyy/mm)
Visiting Scholar	2003/9	2003/9
Org. code	Full organization name	
9121135	University of Sheffield	
Department/Division name		
Sociological Studies		

Personal information will be stored in the Personal Information Bank for the appropriate program.

Web CV

Family name, Given name

McConnell, David

**Work Experience (cont'd)**

Position		Start date (yyyy/mm)	End date (yyyy/mm)
Executive Director		2002/9	2006/9
Org. code	Full organization name		
9661102	University of Sydney		
Department/Division name			
Australian Family and Disability Studies Research Collaboration			
Position		Start date (yyyy/mm)	End date (yyyy/mm)
Postdoctoral fellow or associate		2002/9	2004/9
Org. code	Full organization name		
9661102	University of Sydney		
Department/Division name			
Faculty of Health Sciences			
Position		Start date (yyyy/mm)	End date (yyyy/mm)
Research Assistant		1996/9	2001/9
Org. code	Full organization name		
9661102	University of Sydney		
Department/Division name			
Faculty of Health Sciences			
Position		Start date (yyyy/mm)	End date (yyyy/mm)
Research Assistant		1996/9	1998/9
Org. code	Full organization name		
9661102	University of Sydney		
Department/Division name			
Faculty of Medicine			
Position		Start date (yyyy/mm)	End date (yyyy/mm)
Research Assistant		1993/1	1995/12
Org. code	Full organization name		
9661102	University of Sydney		
Department/Division name			
Faculty of Health Sciences			

Family name, Given name

McConnell, David

**Work Experience (cont'd)**

Position		Start date (yyyy/mm)	End date (yyyy/mm)
Occupational therapist		1993/1	1993/12
Org. code	Full organization name		
1	Blacktown Hospital		
Department/Division name			
Bungarribee House (Psychiatry)			
Position		Start date (yyyy/mm)	End date (yyyy/mm)
Org. code	Full organization name		
Department/Division name			
Position		Start date (yyyy/mm)	End date (yyyy/mm)
Org. code	Full organization name		
Department/Division name			
Position		Start date (yyyy/mm)	End date (yyyy/mm)
Org. code	Full organization name		
Department/Division name			
Position		Start date (yyyy/mm)	End date (yyyy/mm)
Org. code	Full organization name		
Department/Division name			



<b>Academic Background</b>				
List up to 5 degrees, beginning with the highest degree first and all others in reverse chronological order, based on the start date.				
Degree type	Degree name	Start date (yyyy/mm)	Expected date (yyyy/mm)	Awarded date (yyyy/mm)
Doctorate	PhD	1997/07		2001/12
Disc. code	Discipline			Did SSHRC support enable you to get this degree?
99999	Applied Health and Social Sciences			<input type="radio"/> Yes <input checked="" type="radio"/> No
Org. code	Organization			
9661102	University of Sydney			
Country <b>AUSTRALIA</b>				
Degree type	Degree name	Start date (yyyy/mm)	Expected date (yyyy/mm)	Awarded date (yyyy/mm)
BA Hon.	BAppSc (OT) Honours Class 1	1989/03		1992/12
Disc. code	Discipline			Did SSHRC support enable you to get this degree?
99999	Occupational Therapy			<input type="radio"/> Yes <input checked="" type="radio"/> No
Org. code	Organization			
9661102	University of Sydney			
Country <b>AUSTRALIA</b>				
Degree type	Degree name	Start date (yyyy/mm)	Expected date (yyyy/mm)	Awarded date (yyyy/mm)
Disc. code	Discipline			Did SSHRC support enable you to get this degree?
				<input type="radio"/> Yes <input type="radio"/> No
Org. code	Organization			
Country				
Degree type	Degree name	Start date (yyyy/mm)	Expected date (yyyy/mm)	Awarded date (yyyy/mm)
Disc. code	Discipline			Did SSHRC support enable you to get this degree?
				<input type="radio"/> Yes <input type="radio"/> No
Org. code	Organization			
Country				
Degree type	Degree name	Start date (yyyy/mm)	Expected date (yyyy/mm)	Awarded date (yyyy/mm)
Disc. code	Discipline			Did SSHRC support enable you to get this degree?
				<input type="radio"/> Yes <input type="radio"/> No
Org. code	Organization			
Country				

Family name, Given name

McConnell, David

### Credentials

List up to 6 licences, professional designations, awards and distinctions you have received and feel would be the most pertinent to the adjudication of your application. List them in reverse chronological order, based on the year awarded.

Category	Name	Source or Country	Duration (Months)	Value / Year awarded
Honorary Position	Chair, SIRG Parenting	International Assoc. Scientific Study of Intellectual Disabili	36	\$0 2010
Honorary Position	Research Affiliate, Glenrose Rehabilitation Hospit	CANADA	48	\$0 2008
Professional Designation	ACOT Registered/licensed Occupational Therapist	CANADA	60	\$0 2007
Honorary Position	Honorary Professor, University of Sydney	AUSTRALIA	54	\$0 2007
Postdoctoral Fellowship	Australian Research Council Postdoctoral Fellowshi	AUSTRALIA	36	\$240,000 2001
Graduate Scholarship	Australian Postgraduate Award	AUSTRALIA	36	\$66,000 1997

### Research Expertise

The information provided in this section refers to your own research expertise, not to a research proposal.

#### Keywords

List keywords that best describe your areas of research expertise. Separate keywords with a semicolon.

Developmental disability; family care; parenting; child welfare; social determinants

### Disciplines

Indicate and rank up to 5 disciplines that best correspond to your research interests. Duplicate entries are not permitted.

Rank	Code	Discipline	If Other, specify
1	63202	Children, Family	
2	63408	Social Relations	
3	63214	Welfare State	
4	63416	Health Systems and Society	
5	63208	Social Policy, Planning and Social Prevention	

Family name, Given name

McConnell, David

### Funded Research

List up to 8 grants or contracts you have received from SSHRC or other sources. List them in reverse chronological order, based on the year awarded. If you are not the applicant (principal investigator), specify that persons' name.

Org. code	Full name of funding organization	Year awarded (yyyy)	Total amount (CAN\$)
1	Alberta Centre for Child, Family & Community Research	2011	\$100,000
Role	Applicant		Completion status <input type="checkbox"/> Complete
Project title	Ameliorating psychosocial risk among mothers with intellectual disabilities and their children		
Applicant's family name		Applicant's given name	Initials
Org. code	Full name of funding organization	Year awarded (yyyy)	Total amount (CAN\$)
1	World Universities Network (WUN)	2010	\$16,000
Role	Collaborator		Completion status <input type="checkbox"/> Complete
Project title	Health & wellbeing indicators for disabled children and youth.		
Applicant's family name		Applicant's given name	Initials
McConnell		David	B
Org. code	Full name of funding organization	Year awarded (yyyy)	Total amount (CAN\$)
3010325	Social Sciences and Humanities Research Council of Canada	2009	\$199,604
Role	Applicant		Completion status <input checked="" type="checkbox"/> Complete
Project title	Sustainable family care for children with severe or profound disabilities		
Applicant's family name		Applicant's given name	Initials
McConnell		David	B
Org. code	Full name of funding organization	Year awarded (yyyy)	Total amount (CAN\$)
1	Alberta Centre for Child, Family and Community Research	2008	\$150,000
Role	Applicant		Completion status <input checked="" type="checkbox"/> Complete
Project title	Integrating Triple P into Parent Link Centre Services		
Applicant's family name		Applicant's given name	Initials
McConnell		David	B

Family name, Given name

McConnell, David

**Funded Research (cont'd)**

Org. code 1	Full name of funding organization Alberta Centre for Child, Family and Community Research	Year awarded (yyyy) 2007	Total amount (CAN\$) \$40,000
Role Applicant		Completion status <input checked="" type="checkbox"/> Complete	
Project title Child welfare process and outcomes for children of parents with cognitive impairment			
Applicant's family name McConnell		Applicant's given name David	
Initials B			
Org. code 1	Full name of funding organization Australian Research Council (SSHRC equivalent)	Year awarded (yyyy) 2005	Total amount (CAN\$) \$414,000
Role Applicant		Completion status <input checked="" type="checkbox"/> Complete	
Project title Maintaining family-based placements for children and young people with disabilities			
Applicant's family name McConnell		Applicant's given name David	
Initials B			
Org. code 1	Full name of funding organization Australian government, Stronger Families and Communities Strategy	Year awarded (yyyy) 2004	Total amount (CAN\$) \$2,800,000
Role Co-applicant		Completion status <input checked="" type="checkbox"/> Complete	
Project title Healthy Start: A national strategy for children of parents with intellectual disability.			
Applicant's family name McConnell		Applicant's given name David	
Initials B			
Org. code 1	Full name of funding organization Australian Research Council (SSHRC equivalent)	Year awarded (yyyy) 2003	Total amount (CAN\$) \$330,000
Role Applicant		Completion status <input checked="" type="checkbox"/> Complete	
Project title Human service workers and parents with disabilities: Working cooperatively in the best interests of the child			
Applicant's family name McConnell		Applicant's given name David	
Initials B			

## **RESEARCH CONTRIBUTIONS (2006-2011)**

*David McConnell, PhD, Professor, Faculty of Rehabilitation medicine, University of Alberta*

### **Edited Book**

1. Llewellyn, G., Traustadottir, R., **McConnell, D.** & Sigurjonsdottir, H.B. (2010). *Parents with Intellectual Disabilities: Past, present and futures* (271 pages). West Sussex: Wiley-Blackwell.

### **Sole author book**

2. McConnell, D. (2009). *Disability and Discrimination in the child welfare system* (184 pages). Saarbrücken: VDM Verlag Publishing Inc.

### **Book chapters**

3. Llewellyn, G., Traustadottir, R., McConnell, D. & Sigurjonsdottir, H.B. (2010). Introduction. In G. Llewellyn, R. Traustadottir, D. McConnell & H.B. Sigurjonsdottir, (Eds.), *Parents with Intellectual Disabilities: Past, present and futures* (pp.1-14). West Sussex: Wiley-Blackwell.
4. Llewellyn, G. & McConnell, D. (2010). Looking back on their own upbringing. In G. Llewellyn, R. Traustadottir, D. McConnell & H.B. Sigurjonsdottir, (Eds.), *Parents with Intellectual Disabilities: Past, present and futures* (pp.33-47). West Sussex: Wiley-Blackwell.
5. McConnell D & Sigurjónsdóttir H (2010). Caught in the child protection net (pp. 171-188). In G. Llewellyn, R. Traustadottir, D. McConnell & H. Sigurjónsdóttir (Eds.), *Parents with intellectual disabilities: past, present and future*. Oxford: Wiley-Blackwell.
6. McConnell, D & Llewellyn, G. (2010). Supporting mothers' community participation. In G. Llewellyn, R. Traustadottir, D. McConnell & H.B. Sigurjonsdottir, (Eds.), *Parents with Intellectual Disabilities: Past, present and futures* (pp.205-223). West Sussex: Wiley-Blackwell.
7. McConnell, D., Llewellyn, G., Traustadottir, R., & Sigurjonsdottir, H.B. (2010). Conclusion: Taking stock and looking to the future. In G. Llewellyn, R. Traustadottir, D. McConnell & H.B. Sigurjonsdottir, (Eds.), *Parents with Intellectual Disabilities: Past, present and futures* (pp.241-262). West Sussex: Wiley-Blackwell.
8. Llewellyn, G. & McConnell, D. (2010). You have to prove yourself all the time: people with learning disability parenting. In G Grant, P Goward, M Richardson, P Ramcharan (Eds.), *Learning Disability: A life cycle approach to valuing people* (2nd Edition). Open University Press.

### **Selected Monographs**

9. McConnell, D., Feldman, M., Aunos, M., & Prasad, N. (2010). *Child welfare process and outcomes: caregiver cognitive impairment*. University of Alberta. ISBN 978-1-55195-262-8.
10. McConnell, D., Breitzkreuz, R., Savage, A., & Hamilton, A. (2010). *Supported parenting: Integrating "Triple P" into Parent Link Centres*. University of Alberta. ISBN 978-1-55195-268-0

### **Refereed Journal Articles**

11. McConnell, D., Breitzkreuz, R. & Savage, A. (in press). Parent needs and family support service outcomes in a Canadian sample. *American Journal of Social Work*.
12. Feldman, M., McConnell, D. & Aunos, M. (in press). Parental cognitive impairment, mental health and child outcomes in a child protection population. *Journal of Mental Health Research in Intellectual Disabilities*.
13. Breitzkreuz, R., McConnell, D., Savage, A. & Hamilton, A. (2011). Integrating Triple P into Existing Family Support Services: A Case Study on Program Implementation. *Prevention Science*, Advance online publication. doi: 10.1007/s11121-011-0233-6
14. Mayes, R., Llewellyn, G. & McConnell, D. (2011). "That's who I choose to be": The mother identity for women with intellectual disabilities. *Women's Studies International Forum*, 34(2), 112-120.

15. McConnell, D., Breitzkreuz, R. and Savage, A. (2011). Independent evaluation of the Triple P Positive Parenting Program in family support service settings. *Child & Family Social Work*, Advance online publication doi:10.1111/j.1365-2206.2011.00771.x
16. McConnell, D., Feldman, M., Aunos, M. & Prasad, N. (2011). Parental cognitive impairment and child maltreatment in Canada. *Child Abuse & Neglect*, 35, 621– 632
17. McConnell, D., Feldman, M., Aunos, M. & Prasad, N. (2011). Child maltreatment investigations involving parents with cognitive impairments in Canada. *Child Maltreatment*, 16(1), 21-32.
18. Westad, C. & McConnell, D. (2011). Child welfare involvement of mothers with mental health issues. *Community Mental Health Journal*, Advance online publication.doi: 10.1007/s10597-011-9374-0
19. Hill, A., McConnell, D. & Mayes, R. (2010). Transition to independent accommodation for adults with schizophrenia. *Psychiatric Rehabilitation*, 33 (3), 228-231.
20. Llewellyn, G., Bundy, A., Mayes, R., McConnell, D., Emerson, E., Bretnall, J (2010). Development and psychometric properties of the Family Life Interview. *Journal of Applied Research in Intellectual Disabilities*, 23, 52-62.
21. Llewellyn, G., McConnell, D., Gething, L., Cant, R., & Kendig, H. (2010). Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample. *Research in Developmental Disabilities*, 31, 1176-1186.
22. Lovat, A., Mayes R., McConnell, D., & Clemson, L. (2010). Family caregivers' perceptions of hospital-based allied health services post-Stroke: Use of the Measure of Processes of Care to investigate processes of care. *Australian Occupational Therapy Journal*, 57(3):167-73.
23. Mill, A., McConnell, D. & Mayes, R. (2010). Negotiating autonomy within the family: The experiences of young adults with intellectual disabilities. *British Journal of learning Disabilities*,38, 194-200.
24. McConnell, D. Breitzkreuz, R. & Savage, A. (2010). From financial hardship to child difficulties: main and moderating effects of perceived social support. *Child: care, health and development*, 37(5), 679-91.
25. Mill, A., Mayes, R. & McConnell, D. (2009). Negotiating autonomy within the family: the experiences of young adults with intellectual disabilities. *British Journal of Learning Disabilities*, 38, 194–200.
26. McConnell, D., Llewellyn, G., Dalziel, A., Laidlaw K., & Hindmarsh, G. (2009). Strengthening the social relationships of mothers with learning difficulties. *British Journal of Learning Disabilities*, 37, 66-75.
27. Grace, R., Llewellyn, G., Wedgewood, N., Fenech, M., & McConnell, D. (2008). Far from ideal: Everyday experiences of parents and teachers negotiating an inclusive early childhood experience in an Australian context. *Topics in Early Childhood Special Education*, 28 (1), 18-30.
28. Llewellyn, G., Mayes, R., & McConnell, D. (2008). Editorial. Towards acceptance and inclusion of people with intellectual disability as parents. *Journal of Applied Research in Intellectual Disability*, 21, 293-295.
29. Mayes, R., Llewellyn, G., & McConnell, D. (2008). Active negotiation: Mothers with intellectual disabilities creating their social support networks. *Journal of Applied Research in Intellectual Disability*, 21, 341-350.
30. McConnell, D. (2008). Parents labeled with intellectual disability: position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disability*,21, 296-307.

31. McConnell, D., Matthews, J., Llewellyn G., Mildon, R., & Hindmarsh, G. (2008). Healthy Start. A national strategy for children of parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 5 (3), 194-202.
32. McConnell, D., Mayes, R., Llewellyn, G. (2008). Prepartum distress in women with intellectual disabilities. *Journal of Intellectual and Developmental Disability*, 33 (2), 177-183.
33. McConnell, D., Mayes, R., Llewellyn, G. (2008). Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *Journal of Intellectual Disability Research*, 52, 529-535.
34. Booth, T., McConnell, D., & Booth, W. (2006). Temporal discrimination and parents with learning difficulties in the child protection system. *British Journal of Social Work*, 36 (6), 997-1015.
35. McConnell, D., & Llewellyn, G. (2006). Health of mothers of school-age children with disabilities. *Australian and New Zealand Journal of Public Health*, 30 (6), 572-4.
36. McConnell, D., Llewellyn, G. & Ferronato, L. (2006). Context contingent decision-making in child protection practice. *International Journal of Social Welfare*, 15, 230-239.

***Other refereed contributions (selected from last six years)***

37. McConnell, D., Feldman, M., & Aunos, M. (2010). Parents with intellectual disabilities and child maltreatment in Canada. *Journal of Applied research in Intellectual Disabilities*, 23, 461.
38. McConnell, D., & Llewellyn, G. (2010) Building systems capacity to support children of parents with intellectual disabilities in Australia. *Journal of Applied research in Intellectual Disabilities*, 23, 461.
39. Wade, C., Mildon, R., Llewellyn, G., McConnell, D., & Hindmarsh, G. (2010). Healthy Start: Evaluation and future directions. *Journal of Applied research in Intellectual Disabilities*, 23, 461.
40. McConnell, D., Llewellyn, G., & Hindmarsh, G. (2008). Strengthening social relationships of mothers with intellectual disabilities. *Journal of Intellectual Disability Research*, 52 (8&9), 721.
41. McConnell, D., Feldman, M., & Aunos, M. (2008). Child welfare investigation outcomes for parents with cognitive impairment and their children in Canada. *Journal of Intellectual Disability Research*, 52 (8&9), 722.

**OTHER RESEARCH CONTRIBUTIONS (KNOWLEDGE TRANSLATION)**

*Building systems capacity to support parents with intellectual disabilities and promote a healthy start to life for their young children (see article 31 above).* I am co-principal investigator of *Healthy Start*, a world-first trial of a national strategy ([www.healthystart.net.au](http://www.healthystart.net.au)), funded by the Australian government (\$5million+ over 6 years), to mobilize knowledge from research and build systems capacity to support parents with intellectual disability and promote a healthy start to life for their young children. In brief, the strategy involves the development of local leaders and practitioner networks in addition to dissemination of knowledge and innovation to support evidence based practice. Innovative, cross-disciplinary and inter-sectoral practitioner networks are at the heart of this capacity building strategy. These networks or ‘learning hubs’ bridge the gap between research knowledge and practitioner knowledge as a basis for planning and coordinating local service development. A total of sixty-nine learning hubs have been established, with hubs in every Australian state and territory. These hubs now involve more than 400 organisations and over 900 practitioners. The *Healthy Start* strategy has invested knowledge and resources in these learning hubs. All have access to the information rich-website. This website has recorded more than 250,000 sessions to date. In addition, knowledge has been invested through a graduate level unit of study on parents with intellectual disabilities completed by hub leaders; and, the dissemination of two evidence-based parenting programs, involving workshop training of over 500 practitioners Australia-wide. Local learning hubs are now implementing a range of innovative plans to build capacity to support parents with intellectual disabilities and their young children in their own local areas, bringing together knowledge from research with knowledge of local area needs.

## **MOST SIGNIFICANT RESEARCH CONTRIBUTION**

*Uncovering discrimination experienced by parents with disabilities and their children in child and youth protection practice and court proceedings (see articles 2, 5, 16, 17, 34 & 36 above).* I initially conducted a large-scale audit of court records and found that parents with disabilities are fifteen to twenty times more likely than non-disabled parents to have their children taken away. I was then the first to apply critical theory and ethnographic methods to the study of child protection and court processes. My research revealed how court outcomes were all too often driven by fear and ignorance of disability rather than hard evidence. I found that children's court proceedings were a one-sided contest in which parents with disabilities were side-lined and denied a genuine hearing. Furthermore, I showed how the fate of children was more often determined through 'hidden' deals driven by system imperatives, than careful deliberation over what is in their best interests. My work has had an impact in Australia and elsewhere, on legislation, practice and research. In Australia my findings led to the insertion of a clause in the Children and Young Persons (Care and Protection) Act (2002) specifying that parents cannot be presumed incompetent on the basis of disability or poverty *per se*. My findings that these parents are treated more harshly and their children more often removed have also given impetus to a review of children's services in two parliamentary inquiries. In addition my empirical work has been taken up by disability rights advocacy organisations that have prioritised justice for parents with disabilities and their children. My theoretical work has forged a new understanding of the complex interaction between prejudicial beliefs, statutory decision-making, the privileging of 'expert' knowledge and system imperatives that drive this discrimination. Widespread dissemination of this work has resulted in replication by University of Sheffield researchers in the United Kingdom. *Most recently, I have expanded my research into child welfare process and outcomes to Canada, where I have analysed the Canadian Incidence Study of Reported Child Abuse and Neglect.* In addition, my research was extensively cited in a petition to the US Supreme Court for a Writ of Certiorari on the question of whether Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12132, applies to termination of parental rights proceedings initiated by state agencies and prosecuted in state courts.

## **CONTRIBUTIONS TO TRAINING**

I am 10 years post-doc so I have had limited opportunities to formally supervise higher degree research students through to completion. Notwithstanding, I have supervised/co-supervised three doctoral students (primary supervisor S Isbel, co-supervisor R Mayes & C Jarrett) and four Bachelors Honours research students (S Dougherty, A Hill, A Mill, A Lovat) through to successful and timely completion of their theses. I am currently primary supervisor for six doctoral students (L Pacheco, A Savage, E Hyun, L Hahn, C Dube, S Cherrier), and one Masters (thesis) student (M Parrakel). I am co-supervising two others (W Intaprasert & C Cocchio). I have created many other opportunities for students and graduates from a range of disciplines (social work, psychology, sociology, occupational therapy) to receive research training and mentoring in an intellectually vibrant team setting through my collaborative research program in Australia and in Canada (see [www.ualberta.fdsa.ca](http://www.ualberta.fdsa.ca)), known as the Family and Disability Studies Initiative (FDSI). Several individuals who contributed to the FDSI over the last 10 years including, for example, R. Dunn (Macquarie University) and M. Maple (University of New England), have gone on to establish successful careers in research and scholarship. Most recently, 30 graduate students in the Masters in Rehabilitation Science program gained valuable research training and experience as members of the 'interview team' for my SSHRC funded study, "Sustainable family care for children with disabilities". Many of these students reported that this was one of the most valuable learning experiences of their lives.