

Working together in special needs parenting: An innovative research dissemination project

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Abstract: *Research findings are often inaccessible to those who need them and knowledge sharing between researchers, practitioners and community groups can be impeded by organizational, role and priority differences. This paper presents a university-community project designed to make research knowledge available to diverse users, facilitate their input, and build connections between diverse communities impacted by child disability. A team of Canadian researchers, social workers and community partners held workshops to discuss findings of a study on parenting adopted children with special needs and share research knowledge on advocacy for children with disabilities. Parents, service providers, professionals and organizations from disability and adoption communities met together in small mixed role groups to discuss the issues raised and identify priorities. Workshop material was captured to produce practical audio-visual and print documents, which were made available at no cost to all those who could use them. Formative and summative workshop evaluation concluded that project goals were achieved primarily because of ongoing community involvement and a respectful, open climate which encouraged sharing of expertise across roles and disciplines. Reflections of team members and community partners add data on the usefulness and challenges of this type of collaborative project.*

Keywords: *community research; parenting children with special needs; adoption*

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Introduction

Increasing numbers of adults, elders and children live with disabilities which directly affect their lives and options. Their rights have been recognized in international conventions and enshrined in some national constitutions but the struggle for respect, inclusion and equal access to resources is far from over. As societal responses vary worldwide with economic conditions and cultural attitudes to diversity, lack of social acceptance and inadequate support persist (Zavirsek, 2014). In many countries, conservative agendas have reduced access to publicly funded education, health and social services, further increasing the burden on families of those needing added support.

Parents of children with disabilities face multiple challenges. Despite differences in culture, socio-economic and disability situations, they face heavy demands, high costs, social exclusion and inequality in most societies as few provisions are made for children whose progress differs from the norm (Green, 2007; Dowling & Dolan, 2001). Many feel overwhelmed and isolated, yet they work to help their children manage while advocating relentlessly for services from multiple, complex systems. Some families whose children are doubly different can face even more complex challenges. Adoptive parents, for example, also have to deal with the child welfare system and their children often have an adverse past history or are racially different, as well as having disabilities.

Social workers and other professionals try to work together to help families of children with disabilities but are hampered by organization of services in separate silos. Many practitioners want to improve practice, learn new approaches or use research findings but heavy caseloads keep them away from activities outside direct service provision (Mosely & Tierney, 2005). Similarly, scholars who wish to engage in community research and dissemination find low recognition and funding of such activities get in the way of knowledge sharing (Allen-Meares et al, 2005). Finally, while consumer and community groups are keen to share their expertise and learn from professionals or researchers, survival concerns often take precedence over all else (Lee 2008). Despite the many challenges, a team of researchers, practitioners and parent group coordinators developed an innovative project on parenting children with special needs. Project goals were to share knowledge, get professional and community input, foster mutual learning and promote cross-role collaboration. This paper traces the team's journey from a small study of parenting adopted children with disabilities through planning and unfolding of the project on special needs parenting. Evaluation of the project and reflections on the experience are followed by some implications for practice and research.

Background: Parenting biological and adopted children with special needs

Parenting children with disabilities has been documented extensively, with early work focused on negative aspects of impairment or on the overwhelming role of structural barriers. Some theorists and consumers suggest neither approach fully captures the range of parenting experience (Beresford, 2002), as gender, ethnicity, socio-economic situation and culture interact with disability type to affect responses and options (Algood, Harris & Hong, 2013; Fazil et al, 2004). For example, mothers' primary caregiver role strongly flavours their experience (Home, 2012; Russell, 2003), while parents dealing with 'invisible' disabilities¹ can feel greater exclusion (Cronin, 2004), when behaviour that manifests unpredictably is misinterpreted by the public or professionals as willful disobedience or a sign of poor parenting (Kingston, 2007). This is only one of the many reasons professional-family partnerships long extolled in the literature (Seligman & Darling, 1997) remain more of an ideal than a reality.

In Canada and elsewhere, parent-led disability organizations demonstrated what empowered families could do to strengthen legal protection and community-based services for children with disabilities (Stienstra, 2012). Mothers in particular 'start as worriers and become warriors' (Ryan & Runswick-Cole, 2008, p.204), often expanding advocacy into the wider community. Parent advocacy influenced the focus of research, which is becoming more balanced with studies exploring how parents mobilize their strengths, agency and resilience. For example, one study found that while parents' meaning-making and response choices differed with culture, all wanted to be seen as knowledgeable and supported in their empowerment journey (Wilgosh & Scorgie, 2006). Other studies looked at which supports help and why. A finding across studies is that parent-led groups offer emotional support, opportunities to develop advocacy and empowerment, resource and information sharing as well as a sense of belonging (Law, King, Stewart & King, 2001; Singh et al, 1997).

As many parents of children with disabilities face social and economic challenges that increase the likelihood their children will be removed permanently (Romney, Litrownik, Newton & Lau, 2006), a disproportionate number of adopted children have disabilities (Simmel et al., 2001). Increasing numbers of adoptive parents are raising children with complex special needs which may not be fully known at placement. Parents adopting children from foster care may know about family history but not disabilities, while birth and family information is often unavailable on children adopted internationally. In both cases, uncovering the causes of behaviour difficulties is an essential but challenging first step to improving the situation and avoiding adoption breakdown before or after legalization. Chronic stress has increased the demand for post-adoption services, yet availability has not kept pace with need. (Reilly & Platz, 2004), Professionals, parent groups, service providers and policy-makers look to research for guidance but the few relevant studies tend to be from single regions of the United States. Findings must be nuanced for other social,

economic and political contexts such as in Canada, where provincial differences in laws, services, policies and practices affect both special needs and adoption issues. Usefulness of existing work is further hindered by lack of distinction between special needs stemming from bio-behavioural causes (disabilities, medical conditions or pre-natal substance exposure) and those reflecting environmental issues such as trauma, abuse, neglect or multiple moves (Wind, Brooks & Barth, 2007).

Origins of the dissemination project: A study of special needs adoptive parenting

As there was clearly a need for Canadian work encompassing both parent and professional perspectives across several regions, the researcher undertook a study to compare views of adoptive parents, practitioners and parent associations in two Canadian provinces. To avoid confusing special need types, this study focused on parenting children with disabilities, medical conditions or pre-natal substance exposure, including those with adverse histories only if a bio-behavioural issue had been identified by the time of the study. The child had to be aged 2-12 and living with the family for 1 to 4 years, to reduce the impact of transitional and developmental factors. The researcher chose a qualitative approach (Padgett, 1998) to allow depth in this exploratory study, using semi-structured interview guides to cover similar themes (challenges, supports, unmet needs and priorities) with all respondents.

Following ethics approval, recruitment was carried out via publicity from adoption councils, parent associations and agencies. A contrast sampling strategy (Patton, 2002) sought to map diversity while capturing themes that cut across different types of agencies, adoptions, family structures and cultures. The 26 participants, divided equally between British Columbia and Ontario, included 18 families, 3 parent associations and 5 social workers from domestic and international adoption agencies². There was some diversity in family composition, cultural and socioeconomic situation as well as path to adoption. The adopted children ranged in age and race/ethnicity and while they had various disability types, FASD, ADHD and mental health disorders predominated. A few had an adverse past history.

After participants had checked transcriptions, the data were subjected to thematic content analysis using a qualitative-interpretive approach. Findings showed that despite different roles, parents and professionals agreed on two main parenting challenges. The first was understanding and managing the child's special needs and their family impact. Parents felt unprepared for these challenges, perhaps due to not 'taking in' content of preparatory courses as workers suggested, or because of insufficient information on the child prior to placement. All stakeholders noted that understanding the nature of child difficulties was hampered by the range of disabilities that can be signaled by similar behaviours. When effects of prior history

and racial difference were added to the mix, understanding and dealing with the 'whole package' was even more complex. Even if special needs are fully known at placement, accepting and coping with lifelong disabilities was not easy as parents have to identify what works best with this child and adapt parenting strategies yet look after themselves if they wish to be a 'forever family' for the child.

Raising any child with special needs requires both resilience and societal support. Study participants agreed that getting adequate support was the other main challenge, given lack of timely access to publicly funded services in Canada coupled with the prohibitive cost of private options. As most adoptive parents of children with special needs do not get subsidies, only those with private insurance can afford essential supports such as respite, special camps and educational help. Marginalized due to difference and obliged to advocate constantly for their children's rights, parents found groups and peer associations to be the most critical source of support and this view was shared by professionals. Peer acceptance, strategies and resource ideas are especially crucial to adoptive parents due to concerns that seeking agency help could be viewed as their not being 'up to the job'. Indeed, while some parents got invaluable help from health, social service or education professionals, others' concerns were not taken seriously or it was implied their problems might be due to 'bad' parenting.

Moving forward: Development of a community dissemination project

This unique study evoked strong interest in disability and child welfare circles so the researcher was urged to make the findings known and seek broad input from those directly impacted by the issues. Canadian research support is usually limited to direct costs and scholarly dissemination but an unusual public outreach funding opportunity aimed at making research available in a timely, accessible way to those who can most benefit from it. Programme goals were to increase access to and use of research knowledge, facilitate multidirectional knowledge sharing and build relationships between researchers and users³. In keeping with a partnership approach, the researcher consulted five key informants (a social worker, an agency director, a parent association coordinator, a policy-maker and an adoption council board member) regarding the relevance of developing a knowledge-sharing proposal.

Those consulted agreed that despite working together informally, efforts to learn what is needed and what works best are hindered by lack of formal mechanisms to share work and connect to researchers. They were struck with the limited collaboration between child welfare and disability communities despite their many shared concerns. They thought it crucial to bring together parents, professionals and community groups in such diverse fields as education, health and social work

in small workshop settings to learn from each other and hear the findings, along with research knowledge on advocacy for children with disabilities. Finally, they suggested making selected material available for later use by parents, professionals and providers. The researcher formed a university-community team that combined a disability scholar, professionals from adoption councils and an agency and a parent association coordinator. The grant proposal set out four goals: disseminate research, build connections between disability and adoption communities, offer opportunities to discuss issues and provide input and lastly, make research material accessible for diverse users.

The project in action: ‘Working together for success in special needs parenting’

Once a dissemination grant had been awarded, the team developed a two phase plan to reach these goals. Workshops would be held in each region where the original study had taken place, then varied documents would be created and made widely accessible.

Phase one: Planning and carrying out regional workshops

The main activities for disseminating research knowledge, facilitating user group involvement and building connections were full day regional workshops in Victoria (Vancouver Island) and Ottawa, the latter teleconferenced to a Southwestern Ontario site with provision for live interaction. The common format featured morning research presentations, a networking lunch, theme-based discussion groups and a final plenary to share group summaries and action ideas. To ensure partner input, regional committees organized, facilitated and adapted the workshop format for local needs, supported by a researcher and a graduate assistant. Workshops were scheduled a month apart to allow for any adjustments.

To facilitate attendance, workshops were offered at no charge on a Saturday. Study participants had priority for the limited number of spaces with parents’ costs fully covered. To increase accessibility for minority Franco-Ontarians, all documents and handouts were available in French and bilingual discussion groups were offered in Ottawa. Regional teams generated invitation lists of parent and disability organizations, service providers, professionals and policy-makers in child welfare, social service, health, mental health and education. Each team prepared resource and information handouts and community organizations were asked to bring material for a display table. Parent groups were asked to facilitate informal lunch discussions in areas such as parenting children with FASD, in order to recognize and mobilize

different types of expertise while offering a range of mutual learning opportunities.

The Ontario workshop and teleconference attracted 32 participants. As post-workshop evaluations indicated high participant satisfaction, only minor adjustments were needed for the Victoria workshop. The morning programme featured a keynote address on findings of the adoptive special needs parenting study, followed by the disability scholar's presentation on advocacy for children with disabilities which outlined rationale, steps, strategies and challenges. After the community respondent's comments, participants networked informally over lunch or joined a designated lunch table. The afternoon began with small mixed role group discussions around themes emerging from study findings. Groups were set up around participant preferences while ensuring member diversity. To promote mutual understanding and learning, each group included at least one parent, one service provider or professional from disability, child welfare and other fields.

Several measures were taken to create the climate of safety and mutual respect needed for full engagement. Participants were identified by first name only and group members signed an information sheet on confidentiality which assured them that non-identifying group summaries would be sent to them for verification. Team members, research assistants and community partners facilitated the groups and then summarized main points in the closing plenary. Workshops ended with recommendations for action, completion of evaluation forms and verification if participants could be contacted later by an independent evaluator. Those who wished to remain connected circulated an e-mail list. The Victoria workshop was adapted in two ways: plenaries and presentations were filmed for later use and participants choosing the 'culture and disability' theme group signed ethics consents to allow the facilitator to use the material in her graduate research. They had been advised of this beforehand and were offered other group options.

Edited summaries were verified by members of each group and then distributed to all workshop participants prior to thematic analysis. Issues and priorities that emerged from several groups and regions included lack of timely access to services, the constant need to advocate and 'educate', inadequate preparation, long-term support and gaps in addressing both culture and disability. Priorities were educating professionals and the community on both special needs and adoption, advocating for adequate resources for families and ensuring full, accurate information was easily accessible. Working together across roles/regions was considered essential, in order to 'act with a common voice'.

Phase 2: Creating varied documents for wide distribution

The project shifted focus in the second year to the final goal of making research material accessible for flexible use by diverse users. The plan was to create well-researched, practical documents for parents, professionals/providers and

organizations seeking information on disability and/or special needs adoption issues. Audio-visual documents would be created from filmed workshop content and written plenary summaries, while short monographs authored by team members would focus on selected themes. Some documents would be translated into French to increase accessibility.

A production manager experienced in health and social issues coordinated all work and wrote/directed the videos. To add interest, short interviews were filmed with five workshop participants: a parent, a policy-maker, a practitioner and coordinators of a disability organization and an adoptive parent association. The writer-director proposed four thematic video 'chapters', each blending presentation and interview content. The series included a project introduction ('Working together across boundaries') a chapter on study findings, one on steps and strategies in advocacy and a final video on ways forward. Core team members and the research assistant worked closely with the director to do this work⁴. The project lead and writer-director prepared a 'paper edit' content for each video, which was revised based on team feedback. The writer-director prepared a series introduction and description of each chapter, which was translated into French along with the video on study findings. Mindful of the need to 'educate' the social work education community, the team presented its project and final video at a national conference of social work educators, supervisors and students⁵.

The video series was designed to promote awareness of special needs parenting issues and decrease parent isolation. As these short videos could not deal with issues in depth or direct viewers to resources, the team planned short monographs on three themes. Two targeted anyone helping children with special needs: one discussed disentangling disabilities and getting the right support, the other dealt with advocacy for children with disabilities. The third, based on the research assistant's graduate project, covered the critical, virtually unexplored area of culture and disability in special needs adoption.

To promote series consistency while balancing information and accessibility, all monographs were written in a clear, concise style following the same outline. Each began with a series introduction and French summary, followed by a monograph introduction, core content on main issues, supports and strategies. Each ended with a guide to further learning such as websites, organizations and documents. The writers drew core content from research literature, the study findings and workshop summaries, illustrating main points with quotes. Other team members provided feedback on drafts, imagining how an exhausted parent or overworked professional might respond to this work. A graphic designer prepared final web and print versions, incorporating measures to enhance accessibility for readers with disabilities. The documents could be viewed and downloaded free of charge via links on the adoption council's website, with a limited number of hard copies distributed to key organizations and individuals likely to use these documents or well placed to implement action strategies.

The project in retrospect: Results and reflections

Two methods were used to collect data on how well this project achieved its goals and why. As the workshops were the principal means to achieve the first three goals, an independent evaluator assessed their perceived impact. Relevance of the video and monographs in relation to the fourth goal was evaluated informally through analytics on use along with community feedback. Team members' observations and reflections provided added data.

Workshops were evaluated formally using two procedures: a participant feedback sheet completed at the workshop and telephone interviews with a cross-section of attendees three months later. To ensure neutrality and quality, an independent evaluator designed and supervised post-workshop feedback and personally carried out the summative evaluation. The 2-page feedback sheet aimed at assessing participants' perceptions of short-term outcomes, including both fixed response and qualitative items. Attendees were asked what stood out most, what they learned, most liked and planned to use, as well as which aspects were most and least useful. The 87% total response included all Ontario attendees and over two-thirds of those in British Columbia. Results were similar for both workshops. Fifty-seven percent considered the workshops excellent overall, with presentation clarity and small group discussions most highly rated. Participants noted a sense of community and liked the diversity of those attending, which offered everyone the rare opportunity to connect with both professionals and parents. They appreciated the open climate which promoted sharing of experiences and ideas, as well as the balanced, organized presentation of information. Main areas of learning included knowledge about children with disabilities and existing supports, similarities between biological and adoptive parents' experience and the enormous need for respite. Participants hoped to use advocacy strategies, engage in peer networks, increase support for and better connect families as well as share what they'd learned.

Some of these initial impressions were echoed in the qualitative interviews conducted several months later. The 15 respondents, drawn evenly from the two regions, included 4 parents, 3 dual role parent-professionals and 8 service providers or professionals working for diverse organizations in the fields of disability, addictions, child mental health and adoption. Interview questions asked what stood out and what was learned, any changes made in family or professional work, actions taken and obstacles to acting. Overall trends were identified as were differences by role and region.

Respondents agreed workshops had afforded a unique opportunity to meet and share with a diverse group in a respectful, open climate. As explained by a parent/professional:

[It] recognized all stakeholders' expertise equally as experts in their own right and allowed people to speak freely...Service providers need to hear that parents know

their needs ... it provided space for parents' perspectives to be validated and their expertise honoured.

Another added 'I really felt validated. I wasn't alone. I felt acknowledged and respected'. A professional found it invigorating that 'people were there because of their commitment to help the children in their care' while another was impressed by 'the strength and resiliency of adoptive parents with special needs children'. Some respondents were struck by how many parents have negative experiences with providers or professionals. Others realized how difficult it is for parents to find out about these uncoordinated services:

the information isn't easily available or accessible. There needs to be a one-stop shop for parents of children with special needs. The organizations are competing for resources instead of working together.

Respondents reported learning that in the current climate of fiscal restraint and reduced services, both advocacy skills and peer support are needed. A final important outcome was normalizing parents' experiences and reducing their isolation. As one parent put it, they learned 'we weren't the worst parents in the world because we can't find help for our child'.

Respondents shared workshop information with colleagues and families. Some took action or made changes, such as 'linking families with each other' as 'it is one of the most important gifts you can give an adoptive family'. Several parents overcame time and energy constraints to get involved in peer support activities. A single mother attended an adoptive families' camp which was 'great for me and my boys. All the kids at the camp may have special needs, but everyone fit in'. Another found a parallel parent-child group: 'the single most helpful thing has been to have our girls get together as a group while the parents are having their support group'. A group coordinator referred some parents to a counsellor specialized in adoption, which prompted them to find the time, energy and resources to get the help they needed.

Some parents applied new advocacy strategies in dealing with schools:

I keep the meeting on track and focus on the specific things that I want for my kids. We're so used to waiting for professionals to make suggestions. The workshop was a good reminder that we know what we want for our kids and can ask for that

Advocacy action was more common among parents and it focused on helping the child. For professionals, advocacy was more complex as it was located at the systems level. One professional found 'the workshop reinforced that the advocacy group that I joined... is on the right track. Many of the strategies suggested... are things we have been doing and recommending'. However, some efforts were constrained by agency mandate and budget: 'Our hands are tied; we don't do individual, case

by case advocacy'. Another lamented 'there isn't much wiggle room in the funding guidelines'. Other actions by professionals included setting up FASD training for parents in response to findings indicating the need for this and for post-adoption preservation programmes. In response to issues raised at the workshop, other professionals made information more transparent and linked department websites. Some agencies decided to offer more information in the post-adoption stage and to remind parents that internationally adopted children often have special needs, even if the latter are not obvious at placement.

Team members' reflections

Team members were asked to reflect on their observations several months after the workshops had taken place. Several were struck with the mutual learning that can occur when people sharing a common commitment meet in a safe, open, respectful climate. When parents and professionals from varying sectors listened to each other, they deepened understanding of others' perspective, discovered some frustrations were shared and realized that working together might build bridges to further collaboration. The researchers were impressed by participants' willingness to engage and learn, as well as noting that prioritizing community dissemination increased the practical usefulness of their work. For all, this unique project proved a worthwhile learning experience, despite frustrations from time zone and work situation differences.

The adoption council representative was disappointed at limited progress over the past decade in post-adoption support, subsidy provision and parent preparation. The group discussions reiterated for her the importance of developing peer support early in preparatory courses and providing professional support to parent groups. The support group coordinator agreed, as she could draw only on her parenting expertise when trying to respond to the increasingly urgent needs of parents raising adopted children with disabilities. Finally, the research assistant found the workshop helped break down silos by linking professionals and providers from such diverse sectors.

Feedback on monographs and videos

The launchings of the video series and monographs, accompanied by bilingual press releases, resulted in national radio interviews with team members and a parent study participant. These interviews brought the content to life while attracting listeners' attention to the documents. The printed monograph series and press release with the link for on-line access was sent to a wide range of organizations across the country. The recipients included provincial adoption organizations, government departments, child health and mental health organizations, adoption clinics and foundations,

disability associations, special education representatives, Indigenous health and child welfare organizations, schools of social work and university libraries. The documents were also sent to some disability organizations overseas.

One limitation on wide use of these documents is that on-line access had to be channelled through one website, that of the national adoption council. While that organization has a wide network and efforts were made to promote use by disability organizations, parents not involved in adoption might not check this website. Another limitation is the lack of a systematic mechanism to assess use and relevance of these documents, other than a request to submit feedback. Web analytics suggest the monographs are being used more than the videos, perhaps because of their specific, practical, hands-on content. Informal feedback suggests the combined series are being used by adoptive parent associations, some disability organizations, social work and disability studies programmes, as well as adoption agencies offering parent courses and staff development. One agency director found the documents professional, informative and important, given the scarcity of relevant resources.

Conclusions and implications

This unique project showed that by taking an innovative approach to dissemination, researchers are able to make their work accessible to parents, practitioners and community groups working to improve the situation of children with special needs. Through the slow process of ongoing consultation and feedback, it was possible to build trust between those in different roles and sectors and foster mutual learning. Results of workshop evaluation and feedback on documents suggest that this labour-intensive project was successful in achieving its goals.

However, making research accessible and sharing knowledge in ways that cross role and disciplinary boundaries remains challenging. Different roles, obligations and organizational priorities made effective teamwork difficult, despite all members' high commitment to this project. It appears that obstacles to research translation reported a decade ago have changed little (Allen-Meares et al 2005), at least in Canada. Another research utilization initiative evaluation found supervisors unsure of their ability to make practice-relevant findings available to front-line workers, who in turn lacked time to use the material (Shera & Dill 2012).

Nevertheless, social work programmes committed to making a difference in the community need to resist university pressures for highly visible results, continuing to promote collaborative approaches to research. This is particularly important in the special needs area, as there is little evidence of broad-based coverage of disability issues in social work education (Carter, Leslie & Angell 2011). The struggle for full acceptance and inclusion of children with special needs and their families will be a long one. Only by pooling our differing types of knowledge and expertise can we progress.

Notes

- 1 Examples include Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD) and Fetal Alcohol Spectrum Disorder (FASD)
- 2 Directors of two associations were social workers. These data were analyzed together due to small numbers.
- 3 The 'Connexions' stream of Social Sciences and Humanities Research Council of Canada awarded a dissemination grant to the team in 2012. The research team gratefully acknowledges the support of SSHRC, without which this project would not have been possible. The original study was supported by a research development grant from University of Ottawa.
- 4 Community partners in this project contributed as well. An example is the parent association which found suitable photos to include as a backdrop in the video.
- 5 This panel presentation took place at the annual conference of the Canadian Association for Social Work Education in Victoria BC in June 2013.

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