



SPECIAL NEEDS
PARENTING

Working Together for Success

MONOGRAPH II

ADVOCACY FOR CHILDREN WITH DISABILITIES: ISSUES AND STRATEGIES

BY IRENE CARTER, PHD, RSW



LA DÉFENSE DES INTÉRÊTS DES ENFANTS AYANT UN HANDICAP : ENJEUX ET STRATÉGIES

Ce processus consiste à travailler à défendre les intérêts d'une personne de façon efficace, progressive et structurée. Les parents l'entreprennent afin de contrer la discrimination que peuvent subir leurs enfants ayant un handicap et en vue d'augmenter l'accès aux services auxquels ils ont droit. Ce processus permet également aux parents de gagner en confiance, en connaissances, en espoir et en capacités. Lorsqu'ils agissent de concert avec d'autres parents, ils combattent l'isolement tout en augmentant leur sens d'empowerment. Ce processus est mieux gérable si on adopte une approche étape par étape. On commence en prenant le temps de comprendre les enjeux, afin de pouvoir déterminer ce dont on a besoin et choisir les cibles. On prévoit ensuite quand agir et quelle action entreprendre, en recueillant l'information pertinente pour influencer les décideurs. Enfin, on procède à la défense des intérêts, on évalue son action, on établit un suivi et on surveille la situation. En défendant les intérêts de leur enfant ayant un handicap, les parents contribuent au changement d'attitudes et à la promotion de meilleurs services pour les familles comme les leurs.

ADVOCACY FOR CHILDREN WITH DISABILITIES:
ISSUES AND STRATEGIES

Irene Carter© December 2013 Victoria, B.C.

INTRODUCTION TO THE MONOGRAPH SERIES SPECIAL NEEDS PARENTING: WORKING TOGETHER FOR SUCCESS

Raising a child with special needs brings challenges most families rarely face. Adoption complicates this difficult parenting, as these children often have unknown family histories/risks or an adverse past. Little Canadian research exists and while adoption and disability communities have concerns in common, they rarely work together.

This monograph/video series was created from two workshops held in Ottawa and Victoria in fall 2012. Social work researcher Alice Home conducted a study of stakeholders' views on parenting adopted children, whose special needs stem mainly from disabilities, disorders, medical conditions and risks related to prenatal substance exposure. Her interviews with 18 families, 3 parent associations and 5 social workers revealed main challenges, supports and unmet needs. A grant from Social Sciences and Humanities Research Council (SSHRC) enabled Dr. Home and her team to offer these workshops, ensuring parents and professionals in these communities had access to research findings, as well as a chance to provide input, share knowledge and build connections.

These short booklets, created from workshop research presentations, theme group discussion summaries and relevant literature aim to put research-based, practical information in the hands of parents and professionals. Two (What's Going On?, Advocacy) will be useful to many parents or professionals dealing with disability, while the third (Addressing culture and disability...) targets those in special needs adoptions. Each booklet discusses main challenges, suggests strategies for moving forward and offers a resource guide for further learning. We hope readers will find them both supportive and useful.

INTRODUCTION

Parents of children with disabilities have a history of grouping together to raise awareness about the needs of their children with disabilities. Engaging in advocacy can help individuals and families solve challenges at the personal level while working to improve support for all children with disabilities at the social level. In the process of striving to access needed services, parents become advocates for the recognition of their children's needs, as well as helping change social attitudes and develop improved social supports for persons with disabilities. Advocacy provides a step-by-step method for acting to resolve issues faced by children with disabilities.

ACKNOWLEDGEMENTS:

The project lead, Dr. Alice Home, thanks Social Sciences and Humanities Research Council for supporting this dissemination project and University of Ottawa for funding her *Stakeholder* study (2010-11). Core members of the project team are Dr. Irene Carter (University of Windsor) and Sandra Scarth (Adoption Council of Canada). The team thanks our three community partners (Adoption Council of Ontario, Canadian Coalition of Adoptive Families, Choices Adoption and Counseling) for their work organizing, hosting and publicizing the workshops. Rachel Warren was invaluable in her role as graduate research assistant throughout the project. This series would not have been possible without the workshop and study participants who shared their time, ideas, expertise and experiences.

MAIN ISSUES IN ADVOCACY

HISTORICAL INFLUENCE OF PARENTAL ADVOCACY FOR CHILDREN WITH DISABILITIES

Historically, parents of children with disabilities promoted the need for children with disabilities to access education, group homes, and employment preparation and training. The advocacy of mothers of people with intellectual disabilities resulted in the Canadian Association for Community Living (CACL), an early, continuing disability organization that introduced a plan of comprehensive, community-based services¹. In the 1970s and 1980s parents continued their advocacy in large disability movements and the rights of people with disabilities were included in the Canadian *Charter of Rights and Freedoms* (1982)². Presently, parents continue to question the quality of social supports provided for children with disabilities in both individual and socially collaborative ways, by addressing obstacles that their children face in achieving inclusion and accessibility.

ISSUES IN ADDRESSING DISCRIMINATION AND ACCESSIBILITY

Ongoing discrimination, the prejudging and negative treatment of people based on their characteristics, is sustained by attitudes experienced “in the areas of social assistance, health care, education, childcare, taxation, building codes, Aboriginal rights, immigration, development assistance, information technologies and housing”³. Parents are concerned about the discrimination their children with disabilities might face throughout childhood and into their adult years. A study participant noted that parents “*constantly need to fight for their rights – nothing is ever provided. You have to harass somebody.*” (PAR 18)

MAIN ISSUES IN ADVOCACY

Workshop participants noted it is important to “advocate for children ...learn more about advocacy” (Group summary, Oct 27) and “learn more about how to advocate.” (Group summary, Nov 24).

They are deeply concerned about stigma and limited accessibility in education but parents refuse “to give up on the school system”, determined to explore “a few more areas to look for help” (Group summary, Nov 24). One workshop participant pointed out:

“(they) have to go through the advocacy for their kids over and over and over again. They’re having to bare their souls, bare their children’s souls, and ask for help over and over and over again. I heard one woman say every September, she has to be at the school to start a new teacher.”⁴

Although education for persons with disabilities is improving, parents find they still need to pursue greater supports and accessibility for their disabled children. And they do, as shown by the words of another workshop participant who works “as a facilitator of a parent support group for parents of children with developmental/physical disabilities and am proactive in advocating for supportive services” (Oct 27, Group summary).

Parents that get together to form groups to advocate for their children face challenges. Many parent-led groups for children with disabilities need funds, staff, volunteers, and other resources to influence public policy as well as provide social support. As the Canadian government places limits on charitable organizations with a political purpose⁵, many members of struggling non-profit organizations are limited in the amount of advocacy they can do. Despite these challenges, parents

“get brave enough to contact and possibly join a support group” (Nov 24, Group summary) where they can “explore advocacy options.” (Nov 24, Group summary).

FRUSTRATIONS FACED BY PARENTS OF CHILDREN WITH DISABILITY

Parents experience significant stress when they receive a diagnosis of their child’s disability. They need to follow-up by acquiring services and support to help them adapt, meet their own and their children’s needs. The attitude of school professionals is particularly challenging for parents. In presenting their child’s learning needs, parents are often at odds with, and feel intimidated by, school personnel and experience. Asking professionals for help can be frustrating.⁶ Workshop participants emphasized that professionals need to “understand how adoptive parents are feeling” and their “struggles with the system” (Oct 27, Group summary). They identified barriers in parental advocacy, including a lack of knowledge and resources or drive to try new strategies. For many parents, going through the day-to-day struggles has more relevance than planning new advocacy skills. Developing them often depends on the amount of social support available.

WAYS FORWARD: DEVELOPING SUPPORT AND IMPLEMENTING STRATEGIES

This process involved developing personal and social support, as well as learning a step-by-step procedure to advocating. Study and workshop participants agreed that vital support comes from others parenting a child with a disability, Opportunities to meet can “*encourage sharing for parents,*” (Oct 27, Group summary) as sharing is “*therapeutic*” (Oct 27, Group summary). Many parents who gather together, formally or informally, experience a sense of hope that provides them with strength to face challenges and to develop their own problem-solving skills to deal with parenting a child with a disability. This sense of hope provides parents with the strength to believe they can change their environment. As individuals or part of a group, parents experience an increase in their self-esteem, and personal and social strength in improving their circumstances. When parents become empowered with knowledge about disability, their rights, and potential social support, they are better equipped to advocate for the services their child and family needs, personally and collectively.

Parents are encouraged to advocate collectively when they note that other parents are concerned about the effects of discrimination on their child and “*... are fighting the same fight*” (Oct 27, Group summary). Many parents spoke of the importance of “*information seeking and networking*” (Oct 27, Group summary). Together, they identify what services are lacking while providing support to other parents who may be unaware of their children’s rights, thereby influencing legislation and policy for children with disabilities. As a group, parental advocates develop a greater voice to address discrimination and influence organizations that provide needed services and support.

IMPLEMENTING ADVOCACY STRATEGIES

Parents participating in the workshops expressed the need to learn “*more about advocating along with [knowledge about the] many resources available out there.*” (Group summary, Nov 24). Parents are presented with opportunities, from diagnosis to adulthood, to advocate for their children with disabilities. Parents will face many issues about how their child’s needs are managed which offer opportunities for improving their child’s experience as s/he transitions through different stages of their life. Parents educate themselves, other parents and their children how to advocate for the services and accessibility to which they are entitled. Advocacy can provide the chance “*to build relationships with people in the community and the sense that things will change/improve*” (Oct 27, Group summary). It is important to note that each situation involving a person with a disability is somewhat different, and given the context, the most appropriate advocacy strategies will likely differ in intensity and variety.

In planning advocacy, Richard Hoefler suggests the following steps:

1. Identify what is needed.
2. Determine the targets of advocacy or who can provide what is needed.
3. Assess when to act.
4. Understand what action is required to get what is needed.
5. Gather the appropriate information and incentives to influence decision makers.⁷

WAYS FORWARD: ADDRESSING CULTURE AND DISABILITY NEEDS IN ADOPTION

In applying the above steps in their child's early years, the parental advocate may identify needed support and services. As their child enters school, the parental advocate may conclude that the school principal is one of the targets that can secure their child's needed interventions or decide the best time to advocate is when their child's education plan or program is being developed. The parental advocate may act to ensure all professionals involved in implementing their child's services attend meetings concerning their child's needs. In this process, the parental advocate would gain knowledge and support from others to support their request for services, making recommendations such as the possibility of a pilot project involving the fulfillment of their child's needs.

One can employ advocacy as needed on a short- or long-term basis in varying degrees, when well prepared with knowledge along with effective communication and negotiation skills. Individual and group advocacy is helpful to everyone engaged in efforts to change legislated or agency policies. Disability advocates can work to revise existing or new policies, supported by research, and can collaborate with government personnel that promote the most successful community living arrangements and supports for persons with disabilities. The need for this approach was captured in the words of workshop participants who were interested in *"how to best advocate for special needs children/youth in adoptive families and awaiting permanent placement"* (Oct 27, Group summary). An advocate seldom works alone. Parents often find the *"enthusiasm is infectious"* (Oct 27, Group summary) in advocacy support groups. It is essential the advocate develop an effective support system so they can work as a group with policy makers in analyzing existing policies and seeking change.⁸

Advocacy can initially seem like a daunting task for a person with a disability, family, groups, or organizations. Initially, advocacy is best approached from a stage perspective, starting with getting involved and understanding the issue. During this stage advocates need to consider what they want and who can get it for them. During the middle stage of planning and advocating, they consider when and how they should act to attain long- and short-term goals. Lastly, advocates assess what action to take with the aim of improving the success of future advocacy efforts. The above steps will make advocacy manageable as well as rewarding in the development of empowerment at the individual or group level.⁹

Advocacy supports children with disabilities by addressing barriers they face in Canadian society. In attaining social inclusion, advocacy by parents, non-profit organizations or persons with disabilities helps to lessen the effects of stigma and discriminatory behavior and practices. Advocacy is an informed way to create further change and improved results in programs, policies, and legislation for supports for children with disabilities.

SELECTED RESOURCES FOR FURTHER LEARNING

NATIONAL/PROVINCIAL ORGANIZATIONS

Autism Canada

This national, volunteer led organization, provides treatment and resource information to families living with autism, and influences related health care and government policy.

P.O. Box 366
Bothwell, ON N0P 1C0
Telephone: 519-695-5858
info@autismcanada.org
www.bcadoption.com

Autism Ontario

Promotes acceptance and opportunities for all individuals with Autism Spectrum Disorders, and for the means to achieve quality of life as a respected member of society.

1179 King Street West, Suite 004
Toronto, ON M6K 3C5
Telephone: 416-246-9592
www.autismontario.com

Canadian Association for Community Living

CCAL is a family-based association assisting people with intellectual disabilities and their families. It focuses on advancing inclusion in their lives and communities.

Kinsmen Building, York University
4700 Keele Street
Toronto, ON M3J 1P3
Telephone: 416-661-9611
Email: info@cacl.ca
www.cacl.ca

Canadian Association of Paediatric Health Centres

This non-profit association of health care organizations aims at improving health care for Canadian children and youth. It advocates for national evidence-based delivery guidelines.

2141 Thurston Drive, Suite 104
Ottawa, Ontario K1G 6C9
Telephone: 613-738-4164
Email: info@caphc.org
www.nacac.org

Centre for ADHD Awareness, Canada

Takes a leadership role in all areas that affect people with ADHD, including education, health, support, employment, regulatory bodies and resources.

3950 14th Ave, Ste 604
Markham, ON L3R 0A9
Telephone: 416-637-8584
Email: erin.cozad@caddac.ca
www.caddac.ca/cms/page.php?2

Council of Canadians with Disabilities

A national human rights organization of people with disabilities working for an inclusive and accessible Canada.

926-294 Portage Avenue
Winnipeg, MB R3C 0B9
Telephone: 204-947-0303
Email: ccd@ccdonline.ca
www.ccdonline.ca/en

ARTICLES AND WEBSITES

Pacey, M. (n. d.)

Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder Among Aboriginal Canadians: Knowledge Gaps

www.nccah-ccnsa.ca/docs/nccah%20reports/NCCAH_FASDII_report.pdf

Wilson, A. (2013)

A Social Work Student's Developing Understanding of Fetal Alcohol Spectrum Disorder from Medical and Social Perspectives and Implications for Practice

First Peoples Child and Family Review, 8(1), 25-39
www.journals.sfu.ca/fpcfr/index.php/FPCFR

Duquette, C., Stodel, E., Fullarton, S., & Karras Hagglund. (2012)
Educational Advocacy Among Adoptive Parents of Adolescents with Fetal Alcohol Spectrum Disorder

International Journal of Inclusive Education 16 (11), 1203-1221

Prince, M. (2004)

Canadian Disability policy: Still A Hit-And-Miss Affair

The Canadian Journal of Sociology, 29(1), 59-82

Learning Disabilities Association of Canada (LDAC)

The national voice for persons with learning disabilities and those who support them, enabling individuals with LD to function as citizens with equitable opportunities. www.ldac-taac.ca

The National Educational Association of Disabled Students (NEASD)

A consumer organization, working to encourage self-empowerment of post-secondary students with disabilities. www.neads.ca/en/about

SELECTED RESOURCES FOR FURTHER LEARNING

BOOKS & AUDIOVISUALS FOR PARENTS

Fiedler, C., Simpson, R., & Clark, D. (2007). *Parents and Families of Children with Disabilities: Effective School-based Support services*. Pearson Education Canada, Ltd.: Toronto, ON

O'Brien, M., & Daggett, J. A. (2006). *Beyond The Autism Diagnosis: A Professional's Guide to Helping Families*. Paul H. Brooks Publishing Company: Baltimore, MD.

Brown, I. (2011). *The Boy in the Moon: A Father's Journey to Understand His Extraordinary Son*. St. Martin's Press: New York, NY

TV Ontario
Everything You Wanted to Know...About Special Needs
www.tvoparents.tv.o.org/special/parenting-child-special-needs

BOOKS & AUDIOVISUALS FOR CHILDREN

Canadian Centre for Disability Studies (2011). *New ways of looking at disability across the curriculum, Raising awareness: A toolkit for all middle years educators and Disability, development and diversity: People with disabilities in Canada and around the world*. This project aims to increase the knowledge of students on issues facing people with disabilities and encourage positive changes in perceptions and attitudes toward disability, through an instructional workbook and video.
www.disabilitystudies.ca/ddd-home

Reiff, H. (2007). *Self-advocacy Skills for Students with Learning Disabilities: Making It Happen In College And Beyond. A Resource For Students, Parents, and Guidance Counselors*. Dude Publishing: Port Chester, NY

No Pity and Positively Autistic
Two videos on The Autism Acceptance Project website
www.taaproject.com

REFERENCES

- ¹ Stienstra, D. (2012). *About Canada: Disability Rights*. Fernwood Publishing, Halifax, NS.
- ² Canadian Charter of Rights and Freedoms. (1982). The Constitution Act, 1982, being Schedule B to the Canada Act 1982 (U.K.), 1982, c. 11.
- ³ Stienstra, D. (2012). *About Canada: Disability Rights*. Fernwood Publishing, Halifax, NS.
- ⁴ Home, A. (August 2013). *Ways Forward*, Chapter 4 in Video Series *Special Needs Parenting: Working Together for Success*.
www.adoption.ca/special-needs-parenting
- ⁵ Canada Revenue Agency. (2013). *Political Activities*. Retrieved from www.cra-arc.gc.ca/chrts-gvng/chrts/plcy/cps/cps-022-eng.html#N1038D
- ⁶ Trainor, A. (2010). Diverse approaches to parent advocacy during special education home-school interactions: Identification and use of cultural and social capital. *Remedial and Special Education* 31, 1, 34-47.
- ⁷ WHOefer, R. (2012). *Advocacy Practice for Social Justice* (2nd. Ed.). Chicago, IL: Lyceum Books
- ⁸ Jansson, B. (2011). *Becoming an Effective Policy Advocate*. 4th Ed. (pp. 2 to 33). Pacific Grove, CA: Thomson Learning.
- ⁹ Hoefer, R. (2012). *Advocacy Practice for Social Justice* (2nd. Ed.). Chicago, IL: Lyceum Books.



SPECIAL NEEDS PARENTING

Working Together for Success

This is **number two** in a series of three monographs.
Other monographs in this series include:



MONOGRAPH I

WHAT'S GOING ON?:

DISENTANGLING CHILDREN'S DISABILITIES
AND GETTING THE RIGHT SUPPORT



MONOGRAPH III

ADDRESSING CULTURE AND DISABILITY
IN SPECIAL NEEDS ADOPTION:
CHALLENGES AND STRATEGIES