



**SPECIAL NEEDS  
PARENTING**

**Working Together for Success**

MONOGRAPH I

# **WHAT'S GOING ON? DISENTANGLING CHILDREN'S DISABILITIES AND GETTING THE RIGHT SUPPORT**

BY ALICE HOME, MSW, PHD



## DÉMÊLER LES HANDICAPS D'UN ENFANT ET OBTENIR LES SOUTIENS NÉCESSAIRES

Plusieurs parents d'enfants ayant un handicap se sentent isolés et ne sont pas sûrs de la manière de s'y prendre. Cette monographie explique la difficulté d'obtenir une évaluation exacte des difficultés de l'enfant et d'accéder aux services appropriés. Elle propose aussi des possibilités de soutien et des stratégies utiles. Le nombre limité de services subventionnés et les listes d'attentes retardent le diagnostic, parfois difficile à établir vu la coexistence de plusieurs handicaps aux symptômes similaires, auxquels peuvent s'ajouter des enjeux d'attachement ou de trauma chez les enfants adoptés. Bon nombre de parents hésitent à chercher de l'aide, craignant le jugement que font certains professionnels. Le labyrinthe de services et les restrictions d'admissibilité font obstacle à l'obtention de services requis. Les parents ont besoin de soutien tant émotif que pratique pour continuer à exercer leur rôle exigeant. Ils peuvent en trouver chez d'autres qui vivent une situation semblable et en consultant les professionnels qui connaissent le handicap et qui ont une attitude d'ouverture. Certaines écoles et ressources communautaires sont prêtes à accommoder l'enfant dans ses besoins. Il est essentiel de sensibiliser le public et d'améliorer la formation professionnelle en matière de handicap et d'adoption. En travaillant ensemble, les parties concernées peuvent élaborer des stratégies afin d'obtenir le soutien financier et les services nécessaires à améliorer le sort des familles.

WHAT'S GOING ON? DISENTANGLING CHILDREN'S  
DISABILITIES AND GETTING THE RIGHT SUPPORT

Alice Home© 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

Families of children with special needs confront heavy demands and high costs yet receive limited support. As society makes few provisions for children unable to progress at the expected pace<sup>1</sup>, their parents face exclusion along with inequality in employment, income, leisure and quality of family life.<sup>2</sup> Isolated, overwhelmed or unsure how to get help, they struggle to avoid burnout and keep their families intact. Learning what they are dealing with is a difficult but essential first step in moving forward.

This monograph presents challenges in getting assessment and services, followed by useful supports, strategies and a resource list. It is for anyone dealing with children who may have physical, developmental, intellectual or emotional-behavioural disabilities, especially those not usually apparent. Hidden disabilities<sup>3</sup> show up unpredictably as social or behavioural difficulties, which can be misinterpreted as signs of disobedience or poor parenting. Despite their constant vigilance, advocacy and crisis management, parents are often blamed for children's difficulties<sup>4</sup>. Not surprisingly, presence of behaviour problems has greater impact and brings more parenting distress than disability type or severity.<sup>5</sup> As adopted children have high rates of these disabilities<sup>6</sup> sometimes along with adverse histories, this booklet includes some specific material for their families.

### 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 LEARNING WHAT'S GOING ON AND GETTING SUPPORT

### OBSTACLES TO FIGURING OUT WHAT'S GOING ON

Not all parents learn early on that their child has disabilities. If a child looks like others and seems to be developing normally, it may be years before they find out. Parents may not realize initially that problem behaviour can signal disability: *"it took me a while to get over the denial I now know I was in"* (PAR 8). Relatives uncomfortable with disability can discount problems as signs of passing stages like the "terrible two's", making it harder for parents to accept that they need to look for answers.

### GETTING A TIMELY ASSESSMENT

Once they do begin this quest, they run in the first hurdle. Rationed public services and extensive waiting lists bring long delays, except for families who have health benefits to cover costly private services. Once in the system, some parents find the right person who can help. Others encounter professionals who don't believe them or fail to take their concerns seriously (Group summaries, Oct 27, Nov 24). Several study participants felt their expertise was not respected and some felt blamed:

*"I was told it was my imagination. I was told I was exaggerating. I was told maybe I needed to calm down and be a better mother. I'm like 'you're kidding right? This is my fourth child!' "* (PAR 10)

Even knowledgeable professionals can have difficulty making an accurate diagnosis as these disabilities often co-exist. ADHD rarely occurs alone, many children with FASD also have ADHD and disabilities such as these are often accompanied by mental health disorders<sup>7</sup>. As overlapping symptoms can look alike, such as when

## MAIN ISSUES IN LEARNING WHAT'S GOING ON AND GETTING SUPPORT

intense anxiety happens during transitions, different professionals can disagree on diagnosis (Group summaries, Oct 27, Nov 24). Some parents are slow to seek assessment as they worry about labeling but for many, diagnosis comes as a relief after months of doubt, worry and self-blame: *“No, this isn't normal, this isn't what you signed up for. I said ‘You mean it's not my fault - cause I have no patience?’”(PAR 10).*

Figuring it out is even more complex in **adopted children**, who may have been neglected, abused or moved many times. Some new parents think all will be fine if the child was young when placed with them but the lack of birth or genetic history can be problematic. Parents of a toddler who developed severe eating and breathing problems said they *“couldn't tell what's going on, you don't know what his brothers or cousins are like”* (PAR 6). Attachment and trauma issues can be part of the picture even in children placed as toddlers. Pre-adoption courses teach how to recognize and deal with this, as studies<sup>8</sup> show that with time and patience, *“the attachment piece is something you can work on and... eventually get through”* (AS 2). However, it can also be a red herring. The mother of a pre-schooler who had an unstructured upbringing found *“the behaviour related to his environment we were able to parent out of him”* (PAR 8) then learned he had severe ADHD. Similarly, the parents of an internationally-adopted toddler couldn't understand why their attachment techniques weren't working. The child was found to have FASD which had not picked up by doctors. The father noted: *“The books are black and white but with these children, the issues are not”* (PAR 1). A social worker summed up just how complex this puzzle can be:

*“Parents have to be detectives to figure out where these children's difficulties are coming from. If a child comes from an orphanage, is this behaviour because of FASD, attachment or sensory deprivation issues? So many children have self-soothing or self-stimulating behaviours, such as rocking...It's really a guessing game”* (AG 1)

### WHY IS GAINING ACCESS TO SERVICES SO DIFFICULT?

Having an accurate diagnosis can open doors but *“timely access to needed services is just not there”* (Group summaries, Oct 27, Nov 24). There are several reasons for this, starting with the resource cuts that delay assessment. As publicly funded supports are insufficient to meet the need, families face long waits for unevenly distributed services, along with eligibility restrictions by child age, family income, type or severity of disability. Existing services focus mainly on the child. As public resources continue to shrink, parents are being asked to carry much more responsibility yet are offered little support in their intense “24/7” work:

*“They never ask what I need - they all ask what my child needs then fail to follow through... What do the parents need in order to keep going? How are we going to be able to continue...if no one supports us?”* (PAR 10)

Caregivers themselves need care to avoid burn out or health problems. These parents can benefit from referral, counseling, contact with others in similar situations and especially **respite**, which helps families keep going and allows them to live a more “ordinary” life.<sup>9</sup> Even if they're eligible, however, parents get too little respite and even

## MAIN ISSUES IN LEARNING WHAT'S GOING ON AND GETTING SUPPORT

less help arranging it: *"We get \$200 a month which is the equivalent of 2 nights' respite. It's up to us to find the respite worker. There's no list, not everyone can cope. You can't have a teenager, they'll eat them up for supper."* (PAR 13). Some parents can't even face seeking these meager resources, as explained by a couple whose toddler had been sick for months:

***"Our family didn't understand the severity of it no matter how much we'd try. It was we were new parents and all new parents get exhausted... We were in survival mode. Like we really were. At the time we would not have had the energy to be able to go and find out if there was a respite service. We just wanted to sleep"*** (PAR 6)

Other obstacles include the complex maze of services, concerns about help-seeking and having to advocate constantly. Parents seeking services for children with multiple, complex disabilities find there is **no "one stop shopping"**. Though health, education, mental health and social services may be needed, these sectors are in separate silos with no road maps indicating what's available or how to find it. After spending hours searching, it is up to parents to act as their own case managers in coordinating different professionals and services (Group summaries, Oct 27, Nov 24).

**Reluctance to seek help** is a stumbling block for many, as society expects families to cope with little outside help. Despite their unusually stressful situations, parents worry that help-seeking will be interpreted as a sign of inadequacy.<sup>10</sup> It takes courage to overcome this concern, rooted in public judgement of "inappropriate" child behaviour and attitudes of some professionals. Adoptive parents feel this even

more: *"there's so much judgement and stigma. Like I felt at one treatment resource they thought 'she's not really yours - there's going to be differences and maybe you're just not accepting'"* (PAR 11).

As a result of the scrutiny they face, adoptive parents will *"try every other outlet... before going back to the agency"* (AS 2) because *"you're very careful...about how much bad stuff you're going to share"* (PAR 1). Needing to appear perfect was identified as a major barrier in several recent studies.<sup>11</sup> These parents face added challenges as funded post-adoption services are not built in unless a child's needs are known prior to finalization and a service agreement established. Furthermore, financial support ends once a foster child is adopted, which has been likened to having medication cut off overnight.<sup>12</sup> Adoption subsidies are few and target certain groups, making it prohibitive for most parents to afford services their children need. Those who manage to get funding have to fight to maintain it. Finally, these parents struggle to find professionals who are sensitive to both disability and adoption issues (Group summaries, Oct 27, Nov 24).

While participants emphasized parenting challenges, they also identified supports that can help. The two most important were contact with similar families and certain professionals, along with wrap-around approaches.

# SUPPORTS AND STRATEGIES FOR MOVING FORWARD

## MEETING OTHER PARENTS FACING SIMILAR ISSUES

Participants agreed on how crucial it is for these isolated parents to get understanding, practical help and comradeship from peers informally or through groups and associations:

*“...we had meetings. We had on-line chats...families all visit each other and we share war stories ...but we know we will be confidential...I think other parents that are going through what you're going through is probably what's most helpful”* (PAR 14)

*“I felt like our family just blossomed...we have our supports in place and not only for ourselves. Our children know they're not the only adoptive family with special needs and of different races”* (PAR 15)

While peer groups can be one of the strongest supports, they are not available in all areas and can be precarious.<sup>13</sup> With few resources and led by parents facing their own family challenges, these groups can fall apart if no professionals are involved (Group summary, Oct 27).

## KNOWLEDGEABLE, RESPECTFUL PROFESSIONALS AND WRAP AROUND APPROACHES

Many parents talked about the pivotal part played by a certain professional, irrespective of specific role or sector. What stood out was the person's understanding and knowledge of disability and his/her willingness to work in partnership with the family. Examples were a pediatrician who was *“really committed to this and really honest with us”* (PAR 5), teachers who understood kids that learn differently and social workers who provided help beyond what they strictly had to do. Sometimes, an entire school or program was on board, doing everything

possible to accommodate or integrate the child, special needs and all. Private special camps, recreation programs and schools were useful if some costs were subsidized.

Finally, a few parents had excellent experiences with approaches that focused on how to best meet the child's multiple needs, rather than on what each service or professional could provide. This child-centered approach stood out in stark contrast to the usual maze.

## PRIORITIES FOR MOVING FORWARD

**Raising public awareness** of these families' situations is an essential first step to reducing isolation, increasing understanding and support. **Strategies** include capturing media interest and finding engaging ways of combating stigma.

**Mandatory disability and adoption content** must be a part of all professional education in health care, social work, mental health and education. **Strategies** include suggesting learning material and creative use of human resources, such as bringing parents into the classroom. Rewarding professionals for continuing their education in these areas is a way to encourage them to update their knowledge.

Social workers and associations should consider ways to normalize disability at the pre-adoption stage despite concerns about scaring potential parents. Honest, upbeat presentations by experienced parents show that it **is** possible to deal with the inevitable challenges. Pre-adoption courses need to communicate the impact of special needs on individuals and couples (AG 2), to help potential parents see that it is essential to look after their own needs (Group summary, Nov 24). Some parents are so eager to get a

## SUPPORTS AND STRATEGIES FOR MOVING FORWARD

child that such information “*doesn't really sink in - it's all coming at the wrong time*” (AG 4). Parents need low cost opportunities to continue learning once the child has arrived.

Finally, those committed to improving the lives of these children and their families need to **work together across disciplinary and role boundaries** to press for needed changes. Using their combined expertise backed by solid research, parent associations, professionals, service providers and researchers can develop strategies to influence decision-makers who control spending priorities. Economic arguments can be used to show long-term savings of timely access to diagnosis and suitable services. For example, early FASD diagnosis and services can reduce mental illness and justice system involvement that is so costly on both personal and societal levels.<sup>14</sup> Similarly, “*keeping (adoptive) families together ...by offering the needed support will save the system money in the long run*” (Ag 4) and “*we know that children do better in adoptive than in foster homes yet the money goes to foster parents*” (AG 5). As workshop participants pointed out, (Oct 27), we can't ask people to adopt these complex children unless they can count on post-adoptive financial support and services.

Children with special needs and their families face more than enough challenges. The least we can do is provide the support they need to succeed.

## RESOURCES FOR FURTHER LEARNING ON DISABILITY AND ON SPECIAL NEEDS ADOPTION

**ADOPTION COUNCIL OF CANADA**  
Email: [info@adoption.ca](mailto:info@adoption.ca)  
[www.adoption.ca](http://www.adoption.ca)

**ADOPTION COUNCIL OF ONTARIO**  
Toll-free: 1-877-AD OPT-20  
Email: [info@adoption.on.ca](mailto:info@adoption.on.ca)  
[www.adoption.on.ca](http://www.adoption.on.ca)

**ADOPTIVE FAMILIES ASSOCIATION OF BC**  
Toll-free: 1-877-236-7807  
[www.bcadoption.com](http://www.bcadoption.com)

**CANADA ADOPTS**  
Lists adoptive parent support groups.  
[www.canadaadopts.com/canada/resources\\_groups.shtml](http://www.canadaadopts.com/canada/resources_groups.shtml)

**CANADIAN YOUTH MENTAL HEALTH INFORMATION NETWORK**  
Information for young people, families and professionals.  
[www.cymhin.ca](http://www.cymhin.ca)

**CENTRE FOR ADHD AWARENESS CANADA**  
Wide-ranging resource on ADHD  
Telephone: 416-637-8584  
Email: [erin.cozad@caddac.ca](mailto:erin.cozad@caddac.ca)  
[www.caddac.ca](http://www.caddac.ca)

**CHADD CANADA**  
Support and education for people with ADHD, families and professionals.  
E-mail: [chaddcanada@hotmail.com](mailto:chaddcanada@hotmail.com)  
In BC: [chadvan@vcn.bc.ca](mailto:chadvan@vcn.bc.ca)  
[www.chaddcanada.org](http://www.chaddcanada.org)

**CHILDREN'S MENTAL HEALTH ONTARIO**  
Enhancing services for children, youth and families  
[www.kidsmentalhealth.ca](http://www.kidsmentalhealth.ca)

**FASLINK**  
Information for people with FASD, parents, professionals  
[www.faslink.org](http://www.faslink.org)

**FASD SUPPORT GROUPS**  
In BC  
[www.mcf.gov.bc.ca/fasd/kw\\_support.htm](http://www.mcf.gov.bc.ca/fasd/kw_support.htm)  
In Ontario  
[www.fasdontario.ca/cms/resources/support-groups](http://www.fasdontario.ca/cms/resources/support-groups)

**LEARNING DISABILITIES ASSOCIATION**  
And provincial chapters for support and information on LD and ADHD.  
[www.ldac-acta.ca](http://www.ldac-acta.ca)

**NORTH AMERICAN COUNCIL ON ADOPTABLE CHILDREN**  
E-mail: [info@nacac.org](mailto:info@nacac.org)  
[www.nacac.org](http://www.nacac.org)

**THE AUTISM SOCIETY OF CANADA**  
And its provincial chapters.  
Toll-Free: 1-866-476-8440  
[www.autismsocietycanada.ca](http://www.autismsocietycanada.ca)

# SELECTED RESOURCES FOR FURTHER LEARNING

## BOOKS & DOCUMENTS FOR PARENTS

**BARKLEY, R. A. (2013)**

*Taking Charge of ADHD: The Authoritative Guide for Parents*  
The Guilford Press

**HEALTHY GENERATIONS FAMILY SUPPORT PROGRAM (2008)**

*Picture This: Life as a Parent of Children with FASD*

18m 36s. Can be viewed at [www.citizenshift.org/picture-this](http://www.citizenshift.org/picture-this)

**KINGSTON, A. (2007)**

*Mothering Special Needs: A Different Maternal Journey*

London: UK, Jessica Kingsley Publishers

Discusses raising a child with disabilities, through interviews with mothers of children with ASD, ADHD and Down Syndrome.

**MCCREIGHT, B. (2012)**

*Healing From Hazardous Parenting*

HarperCollins Publishers.

For parents raising children and youth with extremely challenging behaviours.

**TORONTO FASD Coordinating Network (2008)**

*Fetal Alcohol Spectrum Disorders (FASD)* [www.eMentalHealth.ca](http://www.eMentalHealth.ca)  
[www.torontocas.ca/wp-content/uploads/2008/09/FASD.pdf](http://www.torontocas.ca/wp-content/uploads/2008/09/FASD.pdf)

**PHELAN, T. W. (2010)**

*1-2-3 Magic (series)*

DVDs, CDs, videos and books offering practical strategies to manage difficult behaviour in preschool & preteen children. [www.parentmagic.com](http://www.parentmagic.com)

## BOOKS & AUDIOVISUALS FOR CHILDREN

**BOBULA, K. and BOBULA, J. (n.d.).**

*We Are Powerful Series*

Wilberry Productions

For children with various disorders, syndromes and disabilities.

**VINCENT, Annick (2010)**

*My Brain Needs Glasses*

Montreal, QC. Quebecor

Helps young people with ADHD and families understand the disorder and how to manage it. User-friendly for persons with ADHD. Disponible en français.

The version for adults (My Brain Still Needs Glasses) is useful as well.

## REFERENCES

- 1 Green, S. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*. (64): 150-163
- 2 Dowling, M. & L. Dolan (2001). Families and children with disabilities: Inequalities and the social model. *Disability and Society*. 16, (1), 21-35.
- 3 Examples are ADHD (Attention Deficit Hyperactivity Disorder), ASD (Autism Spectrum Disorder), and FASD (Fetal Alcohol Spectrum Disorder).
- 4 Russell, F. (2003). The expectations of parents of disabled children. *British Journal of Special Education*, v 30 (3), 144-149; Morrissette, P. (2001) Fetal alcohol syndrome: Parental experiences and the role of family counsellors. *The Qualitative Report*. 6 (2), 1-16.
- 5 Dore, G. & S. Romans (2001). Impact of bipolar affective disorder on family and partners *Journal of Affective Disorders*. 67 (1-3), 147-158.;
- 6 Simmel, C. Brooks, D. Barth, R. & Hinshaw, S. (2001). Externalizing symptomatology among adoptive youth: Prevalence and preadoption risk factors. *Journal of Abnormal Child Psychology*. 29 (1), 57-69.
- 7 CADDAC. Diagnosing ADHD. [www.caddac.ca/cms/page.php?53](http://www.caddac.ca/cms/page.php?53)
- 8 Breen, C. & Burns, L. (2012) Improving services to families affected by FASD. Sydney, Australia. Foundation for Alcohol Research & Education. [www.fare.org.au/wp-content/uploads/2011/07/Improving-services-for-Families-affected-by-FASD.pdf](http://www.fare.org.au/wp-content/uploads/2011/07/Improving-services-for-Families-affected-by-FASD.pdf)
- 8 Sobraska, J. (2013) "The big three: Attachment, trauma and executive function". Presentation at the 39th NACAC conference. Toronto, Ont. Aug 9, 2013.
- 9 Harper, A., Taylor Dyches, T., Harper, J., Olsen Roper, S., South, M. (2013) Respite care, marital quality and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*.
- 10 Kingston, A. (2007). *Mothering special needs: A different maternal journey*. London, Jessica Kingsley Publishers.
- 11 Ryan, S., Jeanen, J, Nelson, N, Siebert, C. (2009). Examining the facilitators and barriers faced by adoptive professionals delivering post-placement services. *Children and Youth Services Review*. 31(5), 584-593.
- 12 Festinger, L. (2002). After adoption: Dissolution or permanence? *Child Welfare League of America*. 81 (3), 515-533.
- 13 Home, A. (in press). Research with and about groups: Overcoming obstacles to creativity and solidarity. In Roy, V., Berteau, G. & S. Genest Dufault (Eds.) *Strengthening social solidarity through group work: Research and creative practice*. London (UK): Whiting & Birch.
- 14 Streissguth, A., et al (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics*. 25, 228-238.



# SPECIAL NEEDS PARENTING

**Working Together for Success**

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



## MONOGRAPH II

**ADVOCACY FOR CHILDREN WITH DISABILITIES:  
ISSUES AND STRATEGIES**



## MONOGRAPH III

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