

SUMMARY of MAIN SURVEY FINDINGS

“Supporting Special Needs Adoptive Families” Survey

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Regardless of path to adoption, increasing numbers of parents find their children have special needs which bring persistent post-adoption difficulties. This summary presents main findings from a new Canadian survey on challenges of raising younger adopted children with certain special needs, along with most helpful supports. It follows up on a recent study of parenting adopted children aged 1-12 with disorders, disabilities, medical conditions and/or prenatal substance exposure carried out by Dr. Alice Home (University of Ottawa). Findings from interviews with 26 parents, professionals and service-providers in BC and Ontario revealed pressing concerns that Dr. Home shared with the community through workshops and a video/monograph seriesⁱⁱ. The Adoption Council of Canada (ACC) undertook this survey in the same regions to learn how a large sample of these stakeholders saw similar issues, as well as to identify ways forward. Results from 167 respondents highlighted the need for more funded post-adoption services, support for caregivers as well as greater public and professional understanding.

The online survey questionnaire designed by the researchers included open and closed (fixed response) questions developed from the original study findings. Most of the 167 respondents completing the survey lived in BC but nearly 30% were from Ontarioⁱⁱⁱ. Fifty-three percent were adoptive parents while the remainder were professionals or service providers, most of whom were social workers in public (52%) or international/private (23%) adoptions. Nearly 1/5 were both professionals and adoptive parents. The families varied in size and structure but two-thirds were raising one or two children and one-fifth were headed by a single parent. Nearly half were fostering or raising birth children as well as those they had adopted. The vast majority of adoptions were public. Most of the 157 adopted children had been in the home 3-4 years and two thirds were now school-aged. Over 80% had been prenatally exposed to drugs or alcohol. Special needs were diverse but certain “invisible” disabilities predominated: Attention Deficit Hyperactivity Disorder (57%), anxiety & mood disorders (50%), Fetal Alcohol Spectrum Disorder (48%) and learning disabilities (39%). Most children had either several disabilities or additional special needs reflecting adverse past history (multiple moves, abuse, neglect), racial/cultural difference or being placed with siblings.

FINDINGS ON MAIN CHALLENGES AND SUPPORTS

All respondents were asked to describe the most difficult challenges encountered at home or in their work with families. A similar question asked about most helpful supports. Subsequent questions asked respondents to rate (on a 1-4 scale) importance of specific challenges and supports identified in the interview study. Comparing responses to these different question types helped make key challenges and supports stand out clearly. Quantitative and qualitative findings were similar. They are presented together in this summary and supported by quotes.

TOP CHALLENGES

Challenge items were put in order of percent choosing “very important”, then items referring to similar challenge were combined. The two **highest ranked challenges together** rated very important by **57%** of respondents while the third and fourth were so identified in nearly half.

- **Lack of timely access to needed resources** and constantly having to advocate for them (66%). Families face restricted eligibility or long wait lists for publicly funded services. Over half have difficulty just finding out what is available.
- **Inadequate post-adoption services and financial support** (48%). Subsidies are rarely available to pay for costly professional and special resources, while respite care is severely limited. One parent noted *“My children’s needs will be lifelong but I have no access to services or financial support”*.
- **Insufficient care for caregivers** and the profound family impact of children’s special needs (52%). Inadequate support coupled with daily management of complex behaviour issues affects parents’ ability to cope and persevere: *“Families tell me it’s hard to have no break from the child’s difficult behaviour...[yet} they have to find it within themselves to stick it out, ride the wave...and still hang in”*.
- **Lack of public and professional understanding** of these adopted children and their families (46%). *“Parents have to constantly “educate” everyone around them about adoption, attachment and their child’s special needs”*. As their concerns are often met with judgment or not taken seriously, parents struggle with *“finding professionals that understand these unique issues and being able to afford them”*.

A professional summed up these challenges as lack of *“ready access to support programs for themselves and children that are affordable and respectful of the adoptive parents”*. Other important challenges were delays in learning the nature of children’s special needs (41%), impact on family finances (37%) and inadequate preparation for this parenting (36%).

MOST HELPFUL SUPPORTS

Respondents identified specific supports **not** available in their area, then rated helpfulness of any used on a 1-4 scale. Those responses were grouped into “helpful” and “less helpful”. Results are presented in descending order by percent rating each item “helpful”.

A respondent characterized useful supports as “those *that were free, had short wait lists and you could access as needed throughout the child’s growing years*”. However, several seen as most helpful were **unavailable** to at least one-quarter of respondents: adoption subsidies (30%) respite care (27%) and disability support groups (26%). The first two support groupings below were rated helpful by 75% of respondents using them. They included:

- Having access to **knowledgeable health and other professionals** (75%) who are competent in special needs and/or adoption issues. This most cited item in the open question boiled down to “*having experts and supports available when we need them*”.
- Three practical supports were helpful to three-quarters: **adoption subsidies** (79%), **financial support** (77%) and **respite care** (74%). While mentioned less often in open responses, they were clearly of great value to those able to access them. As one parent put it: “*Respite funding from post-adoption assistance is a life saver*”.
- Disability or adoption **parent support groups and peer associations** were rated helpful by 63% of those using them and mentioned second in the open question. As a service provider noted: “*We link a family with others who then become their support. They ‘understand’ when other family and friends do not always ‘get it’*”.
- **Specific agencies or programs** offering trained staff and activities for children with special needs was helpful for 65%. Examples include special camps, recreation, playgroups and culturally-based Aboriginal services. Regular community resources that were able to accommodate these children were helpful as well.

PRIORITIES FOR ACTION AND RESEARCH

Three main themes emerged from an open question on most urgent **action priorities**. They included:

- **Post-adoption services and financial support** (36% of responses). One parent stated it poignantly: “*Had we had adequate support we would not have had to disrupt our adoption. Five people would not have had to go through that intense trauma*”.

- **Greater access to publicly funded services** (20% of responses): *“There is never enough money, enough people or enough time”*.
- **Educating professionals and the public** about adoption and disability issues (20%). As noted by a professional, there is an urgent need for *“ongoing post adoption support which sees and treats parents as a valuable member of the team”*.
- **Other** priorities included realistic preparation of parents and children, coordination and continuity of services, support with transition, case management and certain specific special needs or adoption issues.

Finally, respondents highlighted three **avenues for further research**, listed here in order of importance:

1. **Identify factors differentiating successful** from unsuccessful adoptions, in terms of outcomes for child, family and society.
2. **Compare economic and social outcomes** when children with special needs are adopted *with* built-in supports **VS** when similar children remain in foster care.
3. **Examine impact** of specific disability and/or adoption issues on children and families and identify best practices.

NEXT STEPS

A more complete report will be available in early 2015. It will present further information on background and methodology as well as more details on findings, including differences between respondent groups.

ⁱ Dr. Home acted as methodology consultant for survey design and analysis, as well as writing this summary for ACC.

ⁱⁱ These tools are accessible at no charge on the ACC website. The dissemination project was supported by a grant from Social Sciences and Humanities Research Council of Canada awarded to Alice Home and her team: Irene Carter (University of Windsor) and Sandra Scarth (ACC). Three community partners also participated: Adoption Council of Ontario, Canadian Coalition of Adoptive Families and Choices Adoption and Counselling.

ⁱⁱⁱ This figure also includes a few respondents living elsewhere.