

MONOGRAPH III

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

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FAIRE FACE AUX QUESTIONS DE CULTURE ET DE HANDICAP CHEZ LES ENFANTS ADOPTÉS AYANT DES BESOINS SPÉCIAUX

De plus en plus de familles adoptent des enfants d'origines culturelles ou raciales différentes des leurs. Tenir compte des besoins culturels de ces enfants représente un défi de taille quand ces derniers ont également des besoins spéciaux, tels ceux du handicap. Pour plusieurs parents, l'énergie passe à répondre aux besoins particuliers plus urgents de l'enfant, ce qui laisse peu de temps à développer chez lui une identité raciale ou une appartenance culturelle. Entre autres défis, mentionnons que pour certaines cultures, dont les autochtones, la « famille » englobe la communauté entière et pour d'autres, les croyances et tabous culturels entourant le handicap posent parfois problème. Les services existants manquent souvent de sensibilité culturelle. Rares sont ceux qui tiennent compte à la fois des questions d'adoption, de handicap et de culture ou de race. De même, la formation que doivent suivre des parents adoptifs traite la culture et les besoins spéciaux comme deux questions bien distinctes.

Alors, nous recommandons que soit obligatoire pour tout parent adoptif potentiel une formation qui traite conjointement de besoins spéciaux et d'enjeux raciaux ou culturels, ainsi que des services post-adoption pouvant aider avec l'un et l'autre de ces deux aspects. Des subventions et des services spécialisés sont requis. On pourrait en faciliter la création en formant des partenariats entre les secteurs de handicap, d'adoption et de communautés culturelles. Enfin, nous recommandons la mise sur pied d'une ligne d'urgence et d'écoute, d'un site Web multilingue, de groupes de soutien spécialisés, de même que de services de mentors culturels.

ADDRESSING CULTURE AND DISABILITY IN SPECIAL NEEDS ADOPTION: CHALLENGES AND STRATEGIES Rachel Warren® 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

MAIN ISSUES IN TRANSRACIAL AND CROSS-CULTURAL SPECIAL NEEDS ADOPTION

In recent years, there has been a dramatic increase in the number of families adopting children from different racial and cultural backgrounds through both domestic and international placements. Many of these children also have special needs arising from disabilities, prenatal risk factors, histories of institutionalization, and adverse social or economic backgrounds¹. A number of families facing long international wait times are adopting children with known medical conditions through "Waiting Child Programs". This shift towards special needs adoption has been accompanied by an increased reporting of post-adoption difficulties². Children growing up in multiracial families have cultural and racial identity needs that can add to the complex challenges they face in adoption. Parents must be prepared to address these unique identity needs as well as disability issues, as both aspects are crucial to the child's healthy development.

This monograph discusses the intersecting challenges of balancing culture and disability needs in special needs adoption, suggesting strategies for addressing both. A list of resources is offered as a guide for further learning.

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.

CULTURAL NEEDS BECOME SECONDARY TO DISABILITY

Not surprisingly, cultural needs in transracial and cross-cultural³ adoption often fall secondary to managing the child's more urgent and challenging behavioural, medical or learning needs. *Stakeholder* interviews reveal that parents without adequate support and respite in the post-adoption period can feel exhausted and unable to cope:

"I was phoning the agency crying, saying I don't want to give this kid back. I love her to death but we need sleep, we just need sleep." (Par 13)

Parents of special needs children are often left with little energy to engage in meaningful ways with their child's cultural or racial heritage. Maintaining cultural connections is more difficult when adopted children have developmental delays or disabilities which may be complex and not fully understood. Challenges with racial identity can add another layer of uncertainty regarding the nature of their special needs.

"Behaviours are really misunderstood. Trauma, FAS, neglect, abuse all have the same behaviour... we're trying to find out what's wrong with the child or what their special need is, often times it's misdiagnosed." (Par 14)

As children's urgent disability needs leave little time or energy left to address cultural needs, they may be missing opportunities to establish meaningful connections to their racial or cultural heritage.

MAIN ISSUES IN TRANSRACIAL AND CROSS-CULTURAL SPECIAL NEEDS ADOPTION

RACIAL IDENTITY IS COMPOUNDED BY BEHAVIOURAL AND LEARNING DIFFICULTIES

Identity loss is a major theme for children in transracial adoption, despite efforts by adoptive families and professionals to ensure cultural connections are maintained⁴. Special needs from disability can complicate, delay or prevent awareness of racial identity, impeding meaningful connection to culture. For example, some children with special needs have difficulty establishing healthy appropriate boundaries with same-race mentors. One *Stakeholder* study participant whose African-American child had anxiety issues explains how cultural and disability issues interacted in her family:

"You couldn't show him a commercial from Haiti [post-earthquake]. If he saw it he thought he was going to die, we were all going to die." (Par 10)

Children in transracial and cross-cultural adoption require specialized support from people knowledgeable about both culture and disability. The scarcity of such services makes obtaining the right support much more difficult.

CULTURAL DIFFERENCES IN THE MEANING OF 'FAMILY' AND 'DISABILITY'

Parents often enter the adoption process with the goal of creating a 'family' as defined by Euro-Western culture. This usually means parent/s and child/ren in a single household, with support from extended family and community members who are not directly responsible for child rearing. Parents who adopt cross-culturally need to understand the meaning of 'family' within their child's

socio-cultural context, which is now part of the adoptive family's shared reality. This issue emerged in both the *Stakeholder* study and workshop group discussions.

"It's about family...that's what we're all about. You don't own Aboriginal children. The community is a part of who they are." (Par 14)

Certain cultures have an expanded view of 'family' which includes the entire community, yet the adoption process does not take this into account. It is important for parents to recognize these lifelong ties do not terminate at the time of adoption.

"The definition of "family" extends beyond the nuclear family to include the whole community. The adopted child from these cultures becomes a member of the community, is embraced by all members, and everyone is responsible for caring for that child." (Group summary, Oct 27)

Parents adopting a child from Indigenous⁵ or other cultures with these beliefs need to be aware of the impact on both the child and his/her community of origin. This means honouring the continuing ties once the child legally joins the family, which can be challenging when parents are also trying to cope with complex disability needs. Other obstacles related to cultural history, taboos or beliefs may prevent families from seeking needed support. Indigenous parents can be influenced by residential school history, while immigrant families from some cultures may fear that disclosing disability will lead to community rejection or be met with government reprisals.

MAIN ISSUES IN TRANSRACIAL AND CROSS-CULTURAL SPECIAL NEEDS ADOPTION

"Parents can be hesitant to fight for or ask their rights to be respected...fearing authority, social stigma or that their children will be taken away. Some immigrant cultures put less emphasis on raising an autonomous individual than do Western cultures, preferring to keep the child in the family without asking for any external support." (Group summary, Oct 27)

Similarly, the concept of 'disability' is defined differently across cultures, often leading to cultural incompatibility between the child's needs and services provided.

Negative perceptions of disability that tend to dominate in Western medicine can increase stress and decrease parental satisfaction with a child's diagnosis of special needs⁶. Parents and professionals likewise bring their own preconceptions about disability based on dominant cultural beliefs⁷. Support services that are not culturally sensitive can target the child's deficits without considering different cultural beliefs and values regarding the meaning of disability. While these cross-cultural issues can add challenges, embracing a wider view of 'family' and 'disability' can provide adoptive parents with valuable insight, meaningful cultural connection and practical support.

CULTURE AND DISABILITY ARE SEPARATE SILOS IN ADOPTION PREPARATION AND SUPPORT

Not surprisingly, there is a direct relationship between adoption preparation, family adjustment, and success in special needs adoption⁸. Adequate and realistic preparation for adoption is a key indicator of success, as parents need to be ready for potential challenges they will face. However, adoption education programs tend to separate special

needs and transracial issues into two distinct components, and very little is offered on how to successfully address both. Consequently, parents often feel unprepared for emerging special needs as their child develops. This theme appeared repeatedly in *Stakeholder* interviews with families who had adopted cross-culturally or transracially.

"Nothing was done to prepare us for these children... they don't (say) there's no recourse, no support." (Par 11)

"It's not enough. They don't really focus on special needs either...you should be given more education to prepare yourself." (Par 18)

In these complex families facing both cultural and disability needs, parents face added challenges finding the right support in the post-adoption period. Services sensitive to adoption, culture and disability are virtually nonexistent.

"Parents would like to see more groups for their children, but cultural groups for adopted kids are often not developmentally appropriate for special needs children." (Group summary, Nov 24)

"We [need] a list of people and resources that you can go to...in my case having a black child puts me in a whole different group because I also have the race thing." (Par 10)

Inadequate preparation and support for both issues, combined with parental grief over the loss of the 'expected' child, can create significant strain for these families.

WAYS FORWARD: ADDRESSING CULTURE AND DISABILITY NEEDS IN ADOPTION

Responses from both the *Stakeholder* study and workshop discussions suggest some ways that agencies can enhance support to families in transracial and cross-cultural special needs adoption. These are highlighted below.

- Ensure adequate preparation for adoption by establishing:
 - Standardized, mandatory pre-adoption training in special needs and transracial/cross-cultural adoption issues for all prospective adoptive parents. As every adoption involves risk, all parents should be prepared adequately.
 - Post-adoption education on managing special needs and supporting identity development for children in transracial or cross-cultural adoption across their lifetime.
- Provide immediate support in the post-adoption period by offering:
 - Specialized services and subsidies through new partnerships between disability, child welfare and cultural groups. Collaborative efforts between these distinct communities can help to increase the availability of culturally-relevant disability support services for families, such as respite care offered by culturally appropriate caregivers.
 - 24 hour peer support and emergency respite line, where parents with relevant experience can offer immediate emotional and practical support, with assurance that further formal or professional help is available as needed.

- Offer ongoing information and resources to families by creating:
 - A **single website** (with multi-lingual content) for adoptive parents of children with special needs, featuring resources such as government services, adoptive families' blogs and contact information. This would link families, help reduce isolation and ease access to information. This site could include a list of culturally-competent adoption professionals, as well as an interactive forum to connect adopted children, youth and adults.
 - Cultural mentors and peer support groups during adoption preparation to link parents together before they adopt, to help prepare prospective parents while offering support on ways to maintain cultural connections.

SELECTED RESOURCES FOR FURTHER LEARNING

NATIONAL/PROVINCIAL ORGANIZATIONS

Adoption Council of Canada

As umbrella organization for adoption in Canada, ACC offers a variety of services and support for all adoptive families.

416-2249 Carling Ave Ottawa, ON K2B 7E9 Telephone: 613-235-0344 E-mail: info@adoption.ca www.adoption.ca

Adoption Council of Ontario

A non-profit agency providing outreach, support and education to all adoptees, adoptive parents, prospective adoptive parents, birth families and professionals in Ontario.

36 Eglington Ave West, Suite 202 Toronto, Ontario M4R 1A1 Telephone: 1-877-ADOPT-20 Email: info@adoption.on.ca www.adoption.on.ca

Adoptive Families Association of BC

Support, advice and adoption education to families in transracial and special needs adoption in BC.

200 - 7342 Winston Street Burnaby, BC, V5A 2H1 Telephone: 604-320-7330 Toll-free: 1-877-236-7807 www.bcadoption.com

Caring for First Nations Children Society

A BC agency offering Indigenous online training program, cultural planning support, training for professionals working with Indigenous children, and Indigenous youth mentorship.

664 Granderson Road Victoria, BC V9B 2R8 Telephone: 250-391-0007 Email: info@cfncs.com www.cfncs.com

North American Council on Adoptable Children

Focuses on waiting children and families who adopt them in USA and Canada through advocacy, education, adoption support, and leadership development.

970 Raymond Avenue, Ste 106 St. Paul, MN 55114 Telephone: 651-644-3036 E-mail: info@nacac.org www.nacac.org

Ontario Federation of Indian Friendship Centres

A province-wide organization promoting education and cultural awareness.

219 Front Street East Toronto, ON M5A 1E8 Telephone: 416-956-7575 Email: info@ofifc.org www.ofifc.org

WEBSITES AND ARTICLES

Growing Up in a Multiracial Family: My Concept of Self

www.bcadoption.com/articles.asp?pageid=38&Offset=75&AK=ShowAll&HC=1&AD=63

The Adoption Counselor for adoptive families and professionals

- Brenda McCreight

www.theadoptioncounselor.com/Transracial/Transcultural Parenting, NACAC

www.nacac.org/postadopt/transracial.html

Transracial and Transcultural Adoption, US Department of Health & Human Services

www.childwelfare.gov/pubs/f_trans.cfm

BOOKS & AUDIOVISUALS FOR PARENTS

Adoptive Families Association of British Columbia (1999)

Raising Healthy Multiracial Adoptive Families:

A Question and Answer Guide for Adoptive Parents

This guide is designed to answer questions and offer support to address the unique challenges of raising children in multiracial families.

Cogen, P. (2008)

Parenting Your Internationally Adopted Child

Harvard Common Press

Offers advice on how families can effectively address the unique issues of internationally adopted children from placement through the teen years.

Coughlin, A. & Abramowitz, C. (2004)

Cross-cultural Adoption:

How to Answer Questions From Family, Friends and Community

LifeLine Press

A guide for parents on how to handle questions about cross-cultural adoption.

Simon, R. & Altstein, H (2000)

Adoption Across Borders:

Serving the Children in Transracial and Intercountry Adoption

Rowman & Littlefield

Provides a summary of research findings in transracial and intercountry adoption.

SELECTED RESOURCES FOR FURTHER LEARNING

BOOKS & AUDIOVISUALS FOR PARENTS continued...

Spalding, D. (2006)

Roots, Wings and Other Things: A Mother's True Story of Transracial Adoption
Rain Publishing

A book about raising a multiracial family that "works" in Canada.

BOOKS & AUDIOVISUALS FOR CHILDREN

Kissinger, K. & Krutein, W. (2002)

All The Colors We Are: The Story of How We Get Our Skin Color

Redleaf Press

Helps young children sort through the often confusing information they learn about skin colour, helping them to develop racial identity.

Lester, J. (2008)

Let's Talk About Race

Harper Collins Publisher

Discusses how racial identity affects the way we view one another.

Parr, T. (2007)

We Belong Together

Little, Brown Books for Young Readers

Explores the many ways that families can come together

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- ² Reilly, T. & Platz, L. (2004). Post-adoption service needs of families with special needs children. *Journal of Social Service Research*, 30(4), 51-67.
- ³ Transracial adoption refers to parents (usually European/Caucasian) forming families with children born into a different racial or ethnic group. Crosscultural adoption includes parents of one racial group who adopt racially similar children from a different cultural background (McCroy (1989); McRoy, R. & Grape, H., (1999). Skin color in transracial and inracial adoptive placements: Implications for special needs adoption. *Child Welfare*, 78, 673-692.
- ⁴ Carrière, J. (2007). Promising practice for maintaining identities in First Nations adoption. First Peoples Child and Family Review, 3(1), 46-64; Carrière, J. (2008). You should know that I trust you ...Cultural planning, Aboriginal children and adoption. Ministry of Children and Family Development; Carrière, J. (2010). You should know that I trust you...Phase 2. School of Social Work, University of Victoria, Victoria BC; Riley, D. & Singer, E. (2008). Red flags: Is it adoption or something else? The Center for Adoption Support and Education Fact Sheet 10. Burtonsville, Maryland.
- ⁵ The term "Indigenous", used to describe First Nation, Métis and Inuit people, has been chosen to reflect the history of colonialism and oppression enacted upon the First Peoples of Canada. The term Aboriginal will only be used in direct citations from other sources.
- ⁶ Carteledge, G., Kea, C., & Simmons-Reed, E. (2002). Serving culturally diverse children with serious disturbance and their families. *Journal of Child Family Studies*, 11(1), 113-126.
- Wilgosh, L. & Scorgie, K. (2006). Theoretical model for conceptualizing cross-cultural applications and intervention strategies for parents of children with disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 3(4), 211-218.
- ⁸ Groze, V. (1995). A 1- and 2- year follow-up study of adoptive families and special needs children. *Children and Youth Services Review*, 18, 57-82; Molinari, D. & Freeborn, D. (2006). Social support needs of families adopting special needs children. *Journal of Psychosocial Nursing*, 44(4), 28-34; Perry, C. & Henry, M. (2009). Family and professional considerations for adoptive parents of children with special needs. *Marriage and Family Review*, 45(5), 538-565.



This is **number three** 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 II

ADVOCACY FOR CHILDREN WITH DISABILITIES:

ISSUES AND STRATEGIES