

**Adoption of children with disabilities:  
An exploration of the issues for adoptive families**

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## Abstract

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This systematic literature review is an exploration of issues for adoptive families throughout the adoption process and into the various phases of the life of the adoptive family. Although there has been much recent research related to adoption, in general, very little adoption literature addresses the often unspoken needs of families who want to, or have adopted children with disabilities.

These families report lack of good preparation services, post adoption support, disability specific support, educational support and assistance with managing open adoptions. Children with significant emotional, physical, sensory or mental impairments represent an increased proportion of the population of children who have been adopted. This review of literature related to adoption and disability raises awareness of those involved in adoption processes and in education, of the needs of adoptive parents, which, in turn, will impact on the well being of families, and waiting and adopted children with disabilities.

Key words: adoption, adoptive parenting, post-adoption support, disability, special needs.

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The author would like to dedicate the paper to her husband, children and her children's first families.

Kia Ora.

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Since the 1960s adoption has moved from a focus on finding children for parents, to finding parents for children (Sclafani, 2004). With this shift in focus, to the best interest of the child, has come a permanency planning movement, special needs (SN) adoption movement and the emergence of SN adoptive parent support groups which are flourishing with the advent of social media. Legislation from the U.S. and from other countries in the late 1970s and 1980s began to make subsidies available for the adoption of children with SN. Eligibility requirements for prospective adoptive parents began to ease and agencies developed, dedicated to placing children with SN with families. Despite the increase in adoptions of children with SN, surprisingly little has been written about adoptive parents, generally, and even less in regards to the needs, health and well-being of adoptive parents of children with SN, specifically those children living with disabilities (Forbes & Dziegielewski, 2003; Freundlich, 2007; McKay, Ross & Goldberg, 2010; Reilly & Platz, 2003). The definition of SN varies from country to country and within different social services. It is used as an umbrella term to encompass a wide array of concerns and does not always include disability.

**Background**

*Disability in special needs adoption literature*

The term “special needs” (SN) can have different meanings in education, fostering, adoption and international adoption. Davenport (2006, p. 35) states that in the adoption world, “special needs” refers to children who have needs that are outside the ordinary and may

make parenting more challenging”. These needs can include older children, ethnic and racial minorities, sibling groups, those with histories of abuse, those with correctable physical or medical problems, permanent or chronic impairments or medical conditions, emotional or behavioural problems, functional limitations, developmental delays, premature birth or low birth weight and prenatal risk factors. In international adoption, “special needs” can cover a wider array of concerns. Children over the age of two, even with no health impairments, can be classified to have SN as they are considered more difficult to place in families and are likely to have developed attachment problems and developmental and social concerns that arise from institutionalisation. Children from developing countries may also be considered to have SN if they have minor health concerns which may be more difficult to address in their home countries due to lack of resources. In western domestic adoption, SN usually refers to children with intellectual and/or physical impairments (Gallinger, 2012).

In previous decades, when it was more stigmatising for unwed mothers to raise children, when contraception was less available, when abortion was less common, when children with significant disabilities were often institutionalised and when fewer programmes were available to financially assist prospective adoptive families, there was availability of white, healthy babies and little opportunity to adopt children with significant disabilities, who were considered to be “unadoptable”. Changing social factors, coupled with the increase in parts of the world in the competitive, domestic adoption of non-disabled children, even within developing countries, means there is an increase in the number of children who have impairments who are eligible for adoption internationally and domestically.

Rosenthal and Groze (1992) note that “children of various races, ages and backgrounds and often with significant emotional, physical or mental impairments comprise an increased proportion of the population of adopted children” (p. 1). There is a fair amount of research with a focus on “special needs adoption” but within this literature, few studies focus on disability or impairment (See Table 1). The purpose of this review is to identify research or gaps in research related to the adoption of children with impairments or disabilities and the needs of their adoptive families throughout the adoption process. It is not within the scope of this review to elaborate on the many unique facets of international adoption or fostering issues.

Perry and Henry (2009) indicate that common disabilities in children who are available for adoption include Down syndrome, cerebral palsy, spina bifida, intellectual disabilities, developmental delay, learning disabilities, special education needs and emotional and behavioural needs. The research reviewed here varies in its definition of disability and SN, but an effort is made to identify research involving disability, defined as impairment, activity limitation or participation restriction (WHO, 2013). Disability is “a complex phenomenon reflecting the interaction between features of a person’s body and features of the society in which he or she lives” (WHO, 2013).

Much of the literature found related to, disability and adoption uses a medical model view of disability and the language used can be disabling. WHO definitions of disability and impairment are utilised as this enables the use of a common language and has been the

language used in much of the reviewed literature. Effort has been taken here to avoid disabling language while describing the reviewed research.

### ***The process of adoption***

Adoption generally involves several phases: pre-adoption (consideration of adoption, formal preparation and approval and the waiting phase); matching; formal legal adoption processes; and post-adoption. Unique aspects of adoption in New Zealand (NZ) are mentioned here to provide context to the author's situation.

The one avenue for adopting within New Zealand (NZ) is through the government agency, Child, Youth and Family Services (CYFS). In NZ there is no targeted preparation or separate waiting pool for those open to adoption of children with disabilities. Unlike the UK, which legislates post-adoption assessment and support, and the US and Europe which have quality post-adoption programmes, pre-adoption service is the focus for CYFS (Gibbs, 2010).

Adoption is rare in NZ: "In the year ending June 2011, only 206 children were adopted in NZ courts. Most of these involved family members such as stepparent adoptions. An additional 238 overseas adoptions were completed in the same period" (CYFS, 2013). In 2012/2013 CYFS provided only 50 adoption reports in respect to non-relative domestic adoption. NZ offers only "baby-only adoptions" (Johnstone & Gibbs, 2010). Older children are likely to remain in foster care. There is no available evidence documenting how many adoptions involved children with disabilities. No recent identified NZ adoption research has a focus on disabled children.

Adoptive parents in NZ report a need for support and better communication from social, health, and educational services. These families need assessment, counselling, information, financial support, help with navigating open adoptions and therapeutic services. Finally, gaps in NZ research, such as the impact of adoption on families, need to be filled (Gibbs & Sherman, 2013).

### **Methods**

A systemic approach to identifying literature has been utilised with a 12-step process outlined by Kable, Pich and Maslin-Prothero (2012). Papers were obtained through the following databases; Discover (Massey University's Library Discovery Layer searches multiple databases, including Web of Science, Web of Knowledge and PsychInfo) and Scopus. Google Scholar was used extensively in early exploration of the topics, but was determined to be too imprecise to accurately identify specific numbers of articles that met the set criteria. Searches were conducted throughout 2013-2014 and updated in January 2015. Included are original research studies that were relevant to the needs of adoptive families in the adoption of children with disabilities. Scholarly, English language articles, published 2003-2015, available through Massey University in full-text were included in this review. Previously published systematic and literature reviews were excluded, as were any articles with a primary focus on fostering (rather than adoption), or unique aspects of SN international adoption.

The following search terms were used to search the databases with the titles, abstracts and key words and full text, in some instances, searched. Truncation was used to ensure all word variance was captured and thereby, no important research was excluded from consideration.

Keys words used were:

- Adoption
- Special needs
- Impairment
- Disability
- Adoptive parents
- Needs of adoptive parents
- Adoption support
- Open adoptions
- Family
- Post-adoption support
- Adoption preparation
- Parenting

Search words and their variations were narrowed to the following:

- Adoption
- Child
- Special needs
- Disability
- Adoptive parents
- Needs of adoptive parents

Table 1 provides an overview of the search process for each database. Key findings related to needs of adoptive parents of children with disabilities are summarised in Table 2. The search of the databases resulted in the retrieval of 17 relevant studies to be included in Table 2.

Studies were reviewed for their relevance to the research question: What are the needs of adoptive parents, throughout the process of adopting a child with disabilities?

## **Findings**

### *Characteristics of parents who adopt children with disabilities*

There is evidence that reasons for wanting to adopt are different for those who are open to children with disabilities and those who are not. Often infertile couples will seek non-disabled, young children to adopt. Parents open to adopting children with disabilities tend to have large families, and view themselves as successful, experienced and skilled parents (Weiss, 2011).

Despite there being unique motivations for adopting children with disabilities, families may find themselves just as surprised as a biological family would be, to be parenting a child with disabilities (Lindstrom, Voynow & Boyer, 2013). This can be because disabilities are often not identified until after the child has joined the family, or because an expectant mother, already matched to adoptive parents, unexpectedly gives birth to a child with disabilities, or potential adoptive parents are asked by adoption professionals to consider adopting a child with disabilities that they had not previously considered or thought they were able to handle.

Nelson (1985) describes five motivations for people to adopt children with SN: attachment to a child already known to them; availability; altruism; competence in their skills to raise such a child; and compatibility, perhaps with their family values and lifestyle. Nelson states that “the pool of prospective parents for special-needs children, then, has a stable core” (p. 85).

Reilly and Platz (2003) identified that a primary motivation to adopt children with SN is that parents had previously cared for the child through foster parenting. Other reasons cited included

wanting to expand the family, infertility, wanting a sibling for a child and having adopted the child's sibling (Vandivere, Malm & Radel, 2009).

Denby, Alford and Ayala (2011) explain that the characteristics of SN adoptive parents have changed to a more diverse pool, including single parents, same sex couples, minority parents and unmarried partners. Older parents and people with disabilities are also increasingly approved for adoption.

Despite mostly good outcomes being reported by SN adoptive families, and reports of enhanced and enriched family life with the addition of a child with disability (Lindstrom et al., 2013), in SN adoptions there is an increased rate of post-adoptive financial, medical, behavioural and legal problems and poorer parent-child relationships, which has caused disrupted and dissolved adoptions and heightened demand for pre-and post-adoptive services (Reilly & Platz, 2003; Tan, Major, Marn, Na & Jackson, 2015).

### ***Needs of prospective adoptive parents prior to adoption***

#### *Preparation.*

Adoptions of children with disabilities are generally thought to be successful, although Denby et al. (2011) cite a 15% disruption rate for adoptions of children with disabilities (compared to 11-13% generally). Research shows that more positive outcomes are linked to family preparedness, education, information and good relationships with adoption agencies (Denby et al., 2011).

There is little literature available on the needs of those considering or preparing for the adoption of a child with disabilities. Often there is no formalised assistance to families to consider what it means to adopt a child with disabilities. In NZ, for example, there is little or no discussion about disabilities in the one and only adoption preparation programme required for those seeking to adopt.

Preparation is essential in informing adoptive parents about a child's past, diagnoses and abilities, resources, and parenting and coping strategies (Molinari & Freeborn, 2006). Adoptive parents have found preparation programmes overemphasised negative aspects of raising a child with SN (Denby et al. 2011). Wind, Brooks and Barth reported that over half of the families in their study had not received general adoption preparation services, let alone any preparation to address SN or disability (2005).

Egbert and LaMont (2004) explored factors contributing to parents' preparation for SN adoption and found the most important factors related to parents feeling well prepared to adopt were the child's ability to attach well, good parent-agency relationship, shorter duration of the adoption and older age of parents. These researchers found that the best preparation for SN adoptive parenting was previous parenting experience.

Part of the process of preparing for adoption is the homestudy; the paperwork, assessments, interviews and home visits can be an extremely stressful time for families seeking approval to adopt. This is where the support of family and friends, and online support groups can be very helpful and Molinari and Freeborn (2006) have found this informal support to be a most crucial

factor in successful preparation. Forbes and Dziegielewski (2003) linked approval of family members directly to success of adoption.

Relationships with adoption professionals are formulated during this time and it is important for prospective adoptive families to be able to trust the adoption professionals and to have frequent contact during waiting periods, so hopeful parents do not feel they have been forgotten.

During times of preparation for the adoption of a child with a disability, community attitudes can have an impact on the family's decision making process. Saxton (2013) discusses how the idea of parenting a child with disability has recently been considered acceptable, even a pleasure. This is a result of decades of hard work by disability advocates, social media, raised awareness of the more positive realities of disability and community acceptance of people with disabilities, generally. However, discussion among adoptive parents in online discussion groups related to SN adoption often indicates that adopting parents often do not feel free to discuss their plans to adopt children with disabilities because of the negative feedback they tend to receive, or fear they will receive from family, friends and the wider community. Johnstone & Gibbs, (2010) noted that scrutiny of professionals, family and friends was disconcerting and undermining and prohibits help being sought. Therefore, counselling throughout the adoption process has been recommended to alleviate stress and enable hopeful parents to persevere through the sometimes complex and frustrating adoption process (Denby et al. 2011).

Denby et al. (2011) further identified that some adoptive parents strengthened their resolve to adopt children with disabilities even against the odds of skeptical family and friends, through the

lengthy approval process and when frustrations thwarted efforts. Concern for well-being of children likely to be passed over by others seemed to generate patience, tenacity and hope. This 2011 study showed most participants had support from family and friends throughout the adoption process. These families expressed confidence that they could cope with a myriad of problems, and viewed them as a challenge to help the child grow into a happy adult.

Denby et al. (2011) cite participants' expectations of the adoption process as being informed by research, prior adoption experiences and trust in adoption professionals. Many had misconceptions about the process and expected more structure and guidance along the way. Many cited negative experiences with adoption professionals. Delays in the process made some prospective adoptive parents feel neglected and frustrated by inefficiency within the system. Although many expressed a very high level of commitment to the process, some chose to discontinue the adoption process due to problems with the agency.

### *Matching*

Matching is usually the next step in the adoption process. This is where adoption professionals and sometimes birth families seek the most appropriate family for a child, matching what they know about a child to what they know about a family. Throughout the matching process potential adoptive parents may be required to be very specific about what kind of child they think best fits their family. Some adoptive parents and some, who have given up on the process, cite agencies' rigid placement parameters to be the biggest obstacle to successful adoption (Denby et al., 2011). Gibbs (2010) noted that some researchers have found that poor matching practices by adoption

professionals have contributed to adoption dissolutions in children with high needs. Hanna and McRoy (2011) found that adoption matching has moved from a practice that was to help maintain secrecy in adoption by matching physical traits of a child with an adoptive family, to trying to best meet the needs of the child, and some standardised matching tools might assist adoption professionals in selecting families for children.

The needs of adoptive families as they go through the preparation stages of adoption include: the need for emotional support from family, friends and adoption professionals; the need for quality information about the process and about the particular child they are adopting; and practical support from both informal and formal resources. Good preparation may strengthen the long term success of the adoption and family bonding.

### ***Needs of adoptive parents post-placement***

#### *Post placement Support*

The meaning of adoption can change over time for the child, birth family and adoptive family. Unique needs related to disability must be addressed over time. Support may be needed at various times for all involved.

Berry, Propp and Martens, (2007) identified that at 12 months post-placement, the best predictor of family intactness was the quality of adoption agency support. This is evidence that formal adoption support services should include post-placement support and should last longer than six

or 12 months. Anderson (2005) found that regardless of time since placement, even after 16 years, families reported similar needs for agency support.

The trend toward more adoptions of children with disabilities has brought along an increased rate of post-adoptive problems and even disruptions (Reilly & Platz, 2004). And Reilly & Platz (2003, 2004) identified that agencies must promote and provide a wide range of post-adoption services and these must be provided by those knowledgeable of the needs of SN families.

Forbes & Dziegielewski (2003) identified three types of post-adoption services important to mothers with children with disabilities; educational, clinical and material. Mothers reported that lack of information from their adoption agency was one of the most prevalent sources of adoption stress; families not receiving financial subsidies were at higher risk of adoption disruption; and finding clinical specialists who understood adoption issues was difficult.

McKay and Ross (2010) conducted interviews with newly adoptive parents to investigate the transition to parenthood. A finding unique to adoptive parenting is the anxiety of new parents related to feelings that they should be perfect parents and held to a higher parenting standard as they were chosen to raise this child. Parents also feared the child could be removed during the probationary period. Adoptive parents experienced stress due to lack of needed parenting knowledge, because of the often suddenness and unpredictability of adoption; in some NZ adoptions, for example, a child may be placed with a family with just 48 hours' notice. Parents may suddenly be thrown into school systems, health systems and in the case of children with disabilities, therapy programmes and hospital systems. McKay and Ross also reported that

adoptive parents reported feelings of isolation, due to them being older parents, likely to be living away from extended family and because of the lack of adoption support groups.

Parents reported pressure to be constantly happy and grateful for their parenting role, feeling they could not complain or seek support from friends and family when experiencing difficulties (McKay & Ross, 2010). These researchers also found that some factors helped in the transition to adoptive parenthood; achieving the long-sought goal of becoming a parent, seeing children develop and achieve milestones, and accessing supports, particularly from those who share the adoption experience. As important as these supports are from other adoptive families, it appears to be more difficult to find this support when the adoption is domestic rather than international. This is likely because international adopting families share common experiences of culture, language and travel, and may find it easier to make contact with each other (Gibbs, 2010).

Other researchers also identified that adoptive families sought each other for support and that this informal support was preferred to professional support, with which adoptive parents have cited many difficulties (Gibbs, 2010; Johnstone & Gibbs, 2010; Molinari & Freeborn, 2006). Gilkes and Capstick (2008) evaluated a programme that utilised adoptive parents as trained mentors for those in the early stages of adoption, and found it to be positively effective.

Baskin, Rhody, Schoolmeesters and Ellingson. (2011) also found that SN adoptive parents, who were able to give support to couples with similar needs as their own, found encouragement and support themselves. These researchers provided interventions to SN adoptive families that addressed depression, marital satisfaction and forgiveness. Adoptive parents struggled to forgive

birth families, in instances when maltreatment occurred; they experienced rage at the child welfare system due to lack of support, lack of information and inexperienced, critical case managers, and these parents needed to find a way to forgive grandparents who may have welcomed biological children but not adoptive children. Forgiveness had widespread benefits to entire families by helping to resolve past hurts, reduce depression and improve marriage satisfaction and family functioning. Marital distress was also found in SN adoptive families and couples were encouraged to make time for themselves and to increase awareness of their spouse's needs.

A shared reading programme for SN adoptive families, piloted by Faver and Alanis (2012) demonstrated that agencies can offer post-adoption support and provide a venue for peer support among adoptive families, with creative, effective programmes. Families read stories that elicited feelings about adoption and family issues; results demonstrated enhanced empathy and family communication.

Reilly & Platz (2004) reported that the most frequently reported post-adoption service needs for SN families were financial, medical and dental subsidies. Unmet service needs included counselling, informal supports, financial supports, respite care and in-home supports, such as babysitting.

Therapeutic intensive adoption preservation services, offered in some parts of the world, have been highly valued (Zosky, Howard, Smith, Howard & Shelvin, 2005) and criticised only in that parents wished these services could be expanded to include respite care and mentoring. These

home-based therapeutic services can address grief and attachment, and can identify issues related to the adoption of children with SN. Positive behavior change in children has been reported with these services when traditional counselling has not.

Ryan, Nelson and Siebert (2009) identified that both parents and adoption professionals shared similar views about needed post-placement services. These included the need for support group development, expanded financial support and improved training and information.

From the perspective of adoption professionals Dhimi, Mandel and Sothmann (2007) identified barriers to providing post-placement supports, which match up well with barriers identified by parents in earlier studies. Despite the helpfulness of post-adoption services, they found low usage and recommended that these must be specifically targeted to individual family needs and must be informal and initiated by agencies to increase uptake, especially because families may not know that services exist or that they are eligible. They also found that professionals felt there was a need to assist families in navigating open adoptions.

McKay & Ross (2011) also examined the perspectives of professionals regarding barriers to post-placement supports. They indicated that it is quite impossible for hopeful parents to prepare for the adoption of a child, especially one with a disability, as adoption can occur suddenly and adoptive parents are not likely to know about the age, disability, background or needs of the child until just before they come to live with the family. They found parents were unwilling or hesitant to seek support and that there was a lack of community resources for support. The need

for support groups was often unmet and there was a lack of recognition of post-adoption depression.

When an older, disabled child is adopted, the family may find tremendous support from the school the child enrolls in. These may be the first professionals to share with new parents the joy and frustrations of caring for and educating this child. Although school staff may not realise their role, they can become important providers of post-adoption support to the entire family.

Post-adoption support is not available worldwide, but where it is offered, some innovative programmes effectively improve parenting satisfaction and relationships for adoptive families. It has been clearly identified that important post-adoption supports include information, counselling throughout the process and beyond, financial supports, and the most consistently mentioned unmet need was for support from other adoptive families. Adoption professionals could assist with the formulation of peer support groups for families that are involved in adoption. Subgroups of adoptive families with children living with disabilities could have much to offer in the way of support.

#### *Relationships with birth families.*

Open adoptions are on the increase and are thought to be in the best interest of the child.

“Among adoptive parents are those who wish to maintain some level of openness because of a view that openness benefits their adoptive child, adds richness to their family’s life, enhances their ability to obtain much needed information (e.g. medical), and satisfies their own curiosity

about their child's origins" (Brabender & Fallon, 2013, p. 17). Both adoptive and birth families may need assistance in navigating the complexities of open adoption.

Sellick (2007) describes the challenges in promoting support services and assistance for birth families before and after adoptions in England and Wales. Quality counselling, self-help groups, mentoring and legal assistance for birth families are desperately needed. These services seldom are offered and when offered are not often taken up by birth families, as they report frustration and anger with agencies that were associated with the adoption of their child. Higgins (2011) identified that needs of birth families included ongoing counselling, trauma counselling, education for health professionals, and increased information. One noted practice in the UK was of an adoption professional who contacted birth and adoptive families to inquire about well-being and about post-adoption contact between families. The professional was then prepared to meet with, support, negotiate and mediate to facilitate an open adoption that is in the best interest of the child (Sellick, 2007).

Open adoptions are complex and there is very little information available to assist families to have successful, healthy relationships between adoptive and first families. Add disability to the mix and there is little or no available information; there are no recent studies found that relate specifically to managing an open adoptions when the child lives with disability. And "adoption telling", or disclosing to a child about their past may be more challenging when disability was the primary reason for them being placed for adoption.

*Disability specific support.*

Adoption strain is a family stressor (Sanchez-Sandoval & Palacios (2012) and as difficult as parenting a child with disabilities can be, adoptive parents are, with adequate support, generally well equipped for the job and generally satisfied with their parenting skills.

Denby et al. (2011) identified that as adoptive parents may have chosen to adopt a child with disabilities, they may not have experienced the shock, despair and depression that may engulf families who give birth to a child with a disability. Forbes and Dziegielewski (2003), Molinari and Freeborn (2006) and Perry and Henry (2009), however, identified that SN adoptive parents commonly experienced adoption grief, shock, denial, depression, bewilderment, numbness, rage, multiple losses, guilt, bitterness, feelings of failure, self-blame, anger, roller coaster emotions, confusion about competence, adoption isolation, post-traumatic stress, fear, hopelessness, distress and guilt, physical signs of stress and despair, all related to parenting children with SN. Parenting children with disabilities can be difficult and the stigma of adoptive motherhood can compound difficulties (Forbes & Dziegielewski, 2003). These researchers report that the dominant society view is that adoptive motherhood is inferior and messages confirming this can be subtle, yet constant.

Molinari and Freeborn (2006) identified adoptive parents who, despite problem-focused coping skills, may never feel fully prepared for the stress of parenting a child with disabilities. One mother spoke of parenting a SN child, after enjoying adoption preparation training, “But you can’t understand at that point what it means for your life. You think love will make all the difference” (p. 32).

Reilly & Platz (2003) found that adoptive families reported that adoption agencies underreported the seriousness of the child's problems, and that agencies must provide special training on the developmental needs of medically fragile and substance-exposed children. They also noted that barriers to getting post-adoption services included not knowing where to go and believing that "people who were supposed to help did not understand their problems" (p. 799).

Reactive Attachment Disorder (RAD) can theoretically be identified in children who have been adopted at any age, and is more likely to be found in those adopted after age one (Wimmer, Vonk & Bordnick (2009). Very little research can be identified about the effectiveness of attachment therapies and how other disabilities can impact on such therapies. This is an area of adoption research that needs serious attention, as the impacts of RAD on a family can be devastating. Therapy has been viewed positively by adoptive mothers of children with RAD and it has been found to assist in family preservation (Wimmer, Vonk & Reeves, 2009). Yet the combined impact of RAD and other disabilities is unknown.

Adoptive families need disability specific support. Adoption professionals could work to ensure that parents are as prepared as possible, with as much child and disability specific information that can be obtained. Professionals can try to help adoptive families to manage the stigma and discrimination from family, workplace and school that is attached to both disability and adoption.

### ***Ethical adoption processes***

There is a long history of worldwide injustices in adoption practices (Higgins, 2011; Howell, 2006; Wilson, Lordon & Mullender, 2004). It is important to understand the losses experienced by all members of the adoption triad and to ensure ethical adoption practices are followed. Susan Smith's (2006) document on safeguarding the rights and well-being of birthparents can keep all parties informed and aware. Despite the many critiques about adoption in general, little criticism is found related to domestic adoption of children with disabilities and little mention of disability is made in Smith's 2006 report. Although in her expose of the adoption industry, Joyce (2013) states "there are signs that special-needs adoptions may constitute the next wave of adoption corruption" and "no category of adoptions, even the most seemingly heroic, is exempt from commercialization" (p240).

Adoption professionals can assist families by ensuring them that all due care is taken to protect all parties and that ethical processes have been followed. Adoptive families need to know that birth families have made legal, informed, careful and thorough decisions and have been supported in their decision-making.

### ***Parenting issues unique to adoptive families living with disability***

Hussey (2011) identified that in the long-term life of families, adopted children with disabilities in his study were vulnerable to depression and fears of abandonment as a result of early multiple losses and disruptions in care-giving. Hussey warns adoption professionals and adoptive parents and educators that maltreatment is likely to be more common than is actually documented, and effects of early abuse or neglect may not emerge for years. Therefore, long-term assistance to

help parents adjust expectations, understand emerging child needs and to seek appropriate help is needed. Hussey states that post-adoption supports should include long-term educational supports, mental health supports and mood and substance disorder monitoring and supports.

Marriage disruption and dissatisfaction can accompany the strains of both adoption and disability (Baskin et al., 2011; Forbes & Dziegielewski, 2003). Therefore, adoptive families could benefit from having access to counselling, not just during the adoption process but for the long-term life of the family. Adoption professionals could advise families that disability and adoption related stress can emerge over the years and professionals can try to ensure that supports are available.

Parents who have adopted children with disabilities have demonstrated tenacity, patience, tolerance (Gibbs, 2010) and perseverance and have much to offer others who want to follow the same path. Denby et al. (2011) have suggested that adoptive parents could act as advocates, mentors, ombudsmen and mediators, working on behalf of children, with families, agencies, courts, grievance committees and hiring boards. To be able to use that hard-earned knowledge and experience to benefit others can be rewarding.

There is much research available related to adoption. There is a substantial amount of adoption research related to children with special needs. But little research, information and support exists when that special need is disability. The intersection of adoption and disability can have effects on families that produce stress and the need for support and much of those needs go unmet.

### **Recommendations for supporting adoptive families and for research**

Leung, Erich and Kanenberg (2005) demonstrated that families who have adopted children with disabilities have higher needs for strong support networks. Yet little research is available reflecting the uniqueness of adoptions of children whose SN are medical, physical or developmental disabilities. Adoption professionals can improve adoption preparation programmes so they address disability specific information, parental expectations and recognition that the intersection of adoption and disability can involve facing discrimination, grief, anger, and stress on family and marriages. Post-adoption support should include facilitation of peer support, long term counselling and access to professionals who understand both disability and adoption issues faced by families.

Risk for negative adoption outcomes have been clearly linked to some SN categories (sibling groups, older children, children with histories of maltreatment, ethnic and racial minorities, severe emotional and behavioural problems, and multiple previous placements). Literature linking adoption outcomes to physical, developmental or medical impairment/disability is sparse. Information related to infant adoption of children with disabilities is virtually nonexistent.

The research identified for review here includes primarily a range of small scale and survey based approaches conducted in the U.S. (See Table 2). Within this research SN and disability has been defined inconsistently, and mostly through a medical model of disability lens (Bunt, 2014). . Larger scale studies are needed, throughout the world, which involve diverse family situations, in order to better identify the needs of adoptive families with children living with impairments. A social model of disability lens could better inform such research, by defining disability as social oppression and exclusion and could challenge assumptions of medical models

(Saxton, 2013). A more positive view of disability identity and adoption could also be taken to balance the focus on stressful aspects of adoption highlighted in the literature found for this review. Research could strive to assist social model practitioners develop positive practice strategies.

Research questions related to adoption and disability that have yet to be explored include:

- What is the impact of disability, both positive and negative, on adopted children, birth families, adoptive families, schools and communities?
- What are the benefits and disadvantages of open adoption when the child is living with disability?
- For adopted disabled children are there fewer or unique attachment concerns?

Families who adopt disabled children have been found to be committed, tenacious, tolerant, skilled at managing stress, patient and committed. They have also been found to experience stress and frustrations, grief, depression and rage attached to adoption that is seldom acknowledged. Adoptive parents with disabled children share the needs of all parents, parents of children with disabilities and adoptive parents. They may hesitate to seek help as they perceive this as a failure. Finding appropriate services can be a challenge. The unmet support needs of these parents with disabled children, from society, family, health and education systems, adoption professionals and informal support groups can result in stress and sometimes even disrupted adoptions.

However, adoption practices appear to be making a positive change, better serving the needs of disabled children and their adoptive families (Bunt 2014). The large majority of adoptive families with disabled children report loving, successful relationships, yet this largely unexplored area of their needs has yet to identify the best way for these families to stay supported and strong, particularly in the long-term life of the child and the family.

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Insert Tables 1 and 2 about here

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Table 1 Search Results 2003-2015

Data Base:	<b>Discover</b> (searches multiple databases including Web of Knowledge, Web of Science and PsychInfo)  (full text search)		<b>Scopus</b>  (all field search)	
Search terms	# retrieved	Table 2 article ID	# retrieved	Table 2 article ID
adopt* child*	19188		19852	
adopt* child* "special needs"	160	1, 2,3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17	54	1, 2, 4, 6,8, 10, 12, 13, 14, 15, 16
adopt* child* "special needs" disabilit*	73	3, 4, 12,	10	
adopt* child* "special needs" disabilit* "adoptive parents"	3	3, 4	(6)	17
adopt* child* "special needs" disabilit* "adoptive parents" "needs of adoptive parents"	0 (3)	1,2	1 (2)	2
"needs of adoptive parents"	7 (16)	2, 7	2 (2)	2
"needs of adoptive parents" disabilit*	0 (8)	1,2	1 (3)	2 2

Table 2

## Summary Table of Articles. Adoption, Disability, Needs of Adoptive Parents

	Authors, year, country	Method/design	Sample size and special needs (SN) and disability defined	Comments/key findings related to needs of adoptive parents of children living with disabilities
1	Faver & Alanis 2012 USA	Evaluative survey of pilot reading programme	8 families including 14 parents, 17 children with histories of abuse or neglect; some had physical, mental or emotional disabilities	Aim was to foster empathy and facilitate communication in adoptive families with a shared reading programme. The programme assisted with parent-child interactions, supported parents and helped parents see adoption experience from child's perspective. Stories can be used with adoptive families to help address challenging emotional issues.
2	McKay & Ross 2010 Canada	Thematic analysis of pilot project exploring transition to adoptive parenthood	8 interviews with 9 newly placed adoptive parents  SN not defined; disability not specifically mentioned	Adoptive parents of SN children cite unmet needs for support from extended family, parenting groups appropriate to adoptive families. Challenges to transition to parenthood included fear and anxiety, lack of information and isolation/lack of support. Facilitators included overcoming challenges, positive parenting experiences and support.

3	Hussey 2012  USA	Case file reviews  Mixed retrospective/prospective design	362 SN adopted children files reviewed in one Ohio agency  SN included emotional, behavioural, communication disorders, developmental delay	Adoptive parents need to be aware of child's previous losses and be aware of the child's vulnerability to depression, anniversary reactions and ongoing fears of abandonment. Parents and social workers need to be aware that patterns of maltreatment are more common than documented. Early and ongoing monitoring of mood and substance abuse disorders needed for many SN adopted children. Post adoption support should include educational and mental health supports.
4	Denby, Alford & Ayala 2011  USA	Qualitative inquiry involving interviews	9 families; 17 parents  SN defined to include disability.	Adoptive parents' motivations, expectations, sense of preparedness and experience with agencies, adoption workers and training programmes were similar whether or not adoptions were completed. Successful adoptions were linked to supportive adoption workers, family and friends, personal counselling and support groups.
5	Molinari & Freeborn 2006  USA	Grounded theory approach to analyzing interviews of SN adoptive families on social support needs	20 SN adoptive families interviewed about problems with professional health care providers; 5 health care providers also interviewed.  SN defined to include mental health and physical disorders.	SN adoptive families prefer informal social supports over professional care and find providers lacking in knowledge of adoption issues, family dynamics and health issues. Parents delay seeking supports until crises arise and are not aware of available resources. Recommendations are for an interdisciplinary primary prevention approach to support that involves a care plan, mentoring, educational support, case management and prevention counseling.

6	Reilly & Platz 2004  USA	Survey research exploring post-adoptive service needs	249 SN adoptive families; 373 children with emotional, behavioural, developmental and/or medical problems	Most cited needs of SN adoptive families included financial, medical and dental subsidies. Unmet needs included counseling, in-home supports. Financial, legal and social work support linked to higher parental satisfaction. Unmet needs linked to poorer perceived quality of relationship.
7	Egbert & LaMont 2004  USA	Survey research exploring perceived preparation of SN adoption.  Mixed method retrospective study	368 SN adoptive parents completed surveys.  SN not defined to specifically include disability	Factors were identified that were linked to parents' perceived preparation for adoption of children with SN. Most highly correlated factors included child's level of difficulty attaching, parents' overall relationship with agency, duration of the adoption and parent ages at adoption. Low levels of feeling prepared were related to numerous placements prior to adoption, known abuse and neglect histories, difficulty attaching to parents and known emotional and behavioural concerns during adoption. Parenting experience was the best preparation for SN adoption.
8	Wind, Brooks & Barth 2005  USA	Comparative factor analysis of adoption preparation services for SN vs. typical adoptive families	1219 survey respondents. 13% had adopted disabled children. SN defined to include medical/physical disability, emotional-behavioural problems, pre-natal drug exposure	31% of families who adopted children with disabilities/behavior/emotional problems or prenatal exposure risks reported having received general preparation services. Preparation programmes must target long term needs of children to improve expectations, reduce stress and improve adoption satisfaction.
9	Forbes & Dziegielewski 2003  USA	Intensive interviews	14 SN adoptive mothers  SN defined to include emotional, physical or mental disability	16 challenges identified, related to social, health, emotional, family, financial and child behavioural issues. Post adoption support could increase adoption satisfaction and decrease disruptions.

10	Berry, Propp & Martens 2007 USA	Case data analysis of factors that predict family preservation in adoption	445 children in 99 families. SN defined to include learning, developmental, behavioural, emotional disability	At 6 months post-placement best predictors of family preservation were child's initial reason for placement. At 12 months, characteristics of adoption services was best predictor.
11	Anderson 2005 USA	Descriptive study of parents and children in post-adoptive families	182 participants from 97 families from one agency  SN includes mental, physical and medical health	All adoptive families, regardless of time since placement, reported similar needs for support. When social workers addressed child's special needs, overall child well-being and attachment can be increased, likelihood of disruption will decrease. No significant differences found between responses of mothers and fathers.
12	Reilly & Platz 2003 USA	Survey research exploring factors related to positive SN adoption outcomes	249 special needs adoptive families; 373 children with emotional, behavioural, developmental and/or medical problems	Many problems of SN children were found to manifest themselves years after placement, therefore, post adoption support must be ongoing. Many reported not receiving enough information and that seriousness of problems are underreported by adoption agencies. The more appropriate parental expectations were, the more positive the adoption outcomes. The fewer behavior problems of the child, the greater parenting satisfaction.
13	Hanna & McRoy 2011 USA	Overview of tools used in adoption matching	7 measures reviewed  SN defined to include emotional, behavioural, mental health, physical and cognitive needs	Adoption matching has moved from a goal of secrecy in adoption (matching child to family traits) to a goal of permanency for child and family preservation. Some objective tools may help in family selection.

14	Leung, Erich & Kanenberg 2005  USA	Convenience sampling data set analysis comparing gay/lesbian, heterosexual and SN adoption family functioning	86 adoptive parents and 117 of their adopted children participated in assessment measures measuring family function  SN included physical, learning, intellectual and psychiatric disabilities	No negative effects found by gay/lesbian headed families. Higher levels of family functioning were found with younger and non-disabled child adoptions. Professionals should place children as early as possible; sibling adoptions must be accompanied by strong post-adoption and financial supports. Disabled children require stronger family support.
15	Baskin, Rhody, Schoolmeesters & Elingson 2011  USA	Comparative study of educational group intervention with measures of forgiveness, marital satisfaction and depression	112 SN adoptive parents; 54 from a treatment group that received immediate intervention and 58 from a comparison group that received delayed treatment SN defined to include emotional, physical or mental disability	Both groups showed similar gains that were maintained over 3.5 months. Interventions in forgiveness, marital satisfaction and depression prevention had positive effects on adoptive families.
16	Sanchez-Sandoval & Palacios (2012)  Spain	Examination of stress factors in adoption	156 families of domestically adopted adolescents completed questionnaires.  SN included physical, psychological and sensorial needs	Correlates of stress in adoptive parents include characteristics of child, parent and family and supported resources used. Stress was higher in sibling group adoptions and when mothers had poor affect-communication scores. More professional intervention was related to higher stress. Parents had positive views of their parenting and have the capacity to cope with adoption strain.

17	Ryan, Nelson & Siebert 2009  USA	Concept mapping, mixed method exploration of facilitators and barriers to delivering post-placement services	33 adoption professionals completed telephone interviews  SN defined to include medical, developmental, behavioural and emotional problems	Researchers identified new barriers to post-placement support that include difficulties in transferring adoption paperwork when families move. Another barrier is parents trying to appear perfect and competent and fearing negative consequences, unawareness of services, high adoption worker turnover. Professionals' views matched views of adoptive parents regarding post-placement services.
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