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Working with Special Needs Adoptive Parents: Insiders′ Perspectives on What Professionals Need to Know

Alice Home

Introduction

Parenting is one of the most difficult jobs in modern societies. Expectations placed upon parents remain high, even though family support has diminished in recent years. Despite this lessening support, it is assumed most adults will just become "competent" parents. Some adults learn informally from relatives but most formal support is limited to families in difficulty and those needing to do more than intuitive parenting, such as when children have disabilities (Kingston, 2007). Formal preparation rarely goes beyond pre-natal courses, except for groups considered at risk, such as young single parents and families previously involved with child protection. One exception is adoptive parents, who are required to take preparatory courses and often need to continue learning long after adoption finalization due to their unusually challenging family situations. This paper presents findings from a study of parenting adopted children with special needs stemming from disabilities, disorders, medical conditions or pre-natal substance exposure. After summarizing the theoretical backdrop and methods, we present and analyze our findings in the light of existing research and relevant theory and discuss implications for continuing learning.

Background and Context

Literature from several sources guided this study: disability theory, research on parenting children with disabilities, and studies on adoptive parenting. The study was grounded in the social relational disability framework (Thomas, 1999), which holds that the experience of people living with disability is influenced by both social barriers and the characteristics of specific disabilities. Research on families of special needs children notes that these families confront heavy demands and high costs yet receive little support, as modern societies make few provisions for children unable to progress at the expected pace (Green, 2007). These families face social exclusion and inequality in most life domains, given negative public attitudes to disability along with persistent material and social barriers (Dowling & Dolan, 2001). Parenting stress can be greater when children's disabilities are not readily apparent yet show up unpredictably in the form of behavioral or social difficulties (Dore & Roman, 2001). Lack of early visible signs in hidden disabilities such as Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD) and Fetal Alcohol Spectrum Disorder (FASD) can delay diagnosis and bring judgment (Dore & Roman, 2001). Relatives, the public and some professionals can misinterpret children's "inappropriate" behavior as willful disobedience or the result of poor parenting, leading to criticism and blame. In addition to resisting self-blame and helping their children, these parents have to "educate" those who lack understanding or knowledge (Kingston, 2007).

Raising these complex children means parents have to do a lot of learning. They need to become knowledgeable about their child's disabilities, available services and how to access them. They must modify family routines to accommodate the child's special needs and adapt parenting practices because usual intuitive methods do not work. As Segal's (2001) study concluded, "good enough mothering is not enough for these children…you cannot afford to just bumble through" (268). In the community, parents must advocate effectively to ensure their children's needs are met, even when rights are enshrined in laws and policies (Russell, 2003). Cost-cutting measures have restricted access to most public educational, health and social services in Canada and many other countries. As a result, services are often insufficient to meet need, especially outside major urban centers. Eligibility criteria such as family income, child age and type or severity of disability can further limit access to these vital

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supports (Home, 2012). For example, one mother received respite services for her autistic son but not for her child with severe ADHD, though she found the latter's needs more intense. Despite the ever-present risk of being labelled overprotective, mothers persist in the struggle to obtain what their children need. They "start as worriers and end as warriors" (Ryan & Runswick-Cole, 2008, p. 204).

Adopted children have unusually high rates of these disabilities (Simmel, Brooks, Barth & Hinshaw, 2001) and many are also affected by adverse past histories of abuse, neglect, trauma or multiple moves. These children present unique, complex challenges, even when parents were aware of certain special needs at placement (Foti-Gervais, 2005). Despite having taken pre-adoption courses, parents report feeling unprepared for behavioral and emotional problems that may emerge years later, often from unidentified hidden disabilities (Reilly & Platz, 2004). Though increasing numbers of these families seek help, post finalization support remains limited unless there is a serious risk of adoption breakdown (Perry & Henry 2009). This leaves parents on their own to get an accurate assessment and obtain needed resources, a quest often impeded by their child's limited medical and family history.

Although daunting challenges face parents of children with special needs, not all social work students learn enough about the issues facing these families. While programs may offer more disability electives than in the past, there is little evidence of broad-based commitment to and coverage of disability-related issues throughout curricula (Carter, Leslie & Engell, 2011). It is not clear that a majority of graduates are well-equipped to practice effectively with this population. Similarly, adoption-related issues get scant coverage in social work programs, leaving new workers without the specific knowledge to help parents of children whose special needs stem from traumatic and unstable past family experiences.

Finally, social workers in a range of settings are expected to help parents learn new attitudes, strategies and skills either individually or in groups. As their professional education offers little adult learning content, many workers are unsure how to carry out this role in difficult situations. For example, adults who are obliged to undertake courses can feel threatened or powerless – two major barriers to learning. In addition, participants' lack of control over timing and content of courses is problematic, as adults learn best when they can influence content and see its immediate, practical relevance (MacKeracher 2004). The study presented in the following sections sheds light on why social workers need to continue learning about disability and adoption-specific issues. It also suggests why and how adult learning theory may be useful to strengthen their educative role.

Study Goals, Design and Method

Professionals, service providers, policy-makers and parents look for guidance on how to help special needs adoptive families but there is little recent research on this subject, particularly in Canada. Existing studies tend to explore one perspective (parent or professional) and are limited to a single region, despite differences in child welfare services, policies and practices. In an effort to fill these gaps, the author undertook a unique qualitative study exploring the views of three different stakeholder types (adoptive parents, social workers and parent associations) on special needs adoptive parenting. The study took place in the two Canadian provinces of British Columbia and Ontario. Given that existing research rarely distinguishes between special need types, this study focused specifically on parenting children with "bio-behavioral" needs (Wind, Brooks & Barth, 2007) stemming from disabilities, disorders, medical conditions and pre-natal substance exposure. Parents of children who had both an adverse past history and one of these diagnoses were eligible to participate. To reduce the impact of prior environment, transitional and developmental issues, children had to be aged 1 to 12 at the time of the study and living with the family from 1 to 4 years.

The study employed semi-structured interviews to allow exploration in some depth as well as comparison between the three stakeholder types. All interview guides focused on similar themes (parenting challenges, useful supports, unmet needs and priorities), with minor adaptations for each stakeholder type. After the researcher had obtained ethics approval, parent associations and agencies publicized the study on their websites. A contrast sampling strategy (Patton, 2010) enabled the researcher to map diversity of experience across different adoption types, family structures, adoptive and cultural situations, while a qualitative-interpretive design facilitated analysis of data by theme and identification of differences between stakeholders.

Participants included 18 families, 5 social workers and 3 parent associations, divided equally between British Columbia and Ontario. The collective experience of the social workers and associations covered both domestic (public, private) and international adoptions. Families varied in type, size, path to adoption, socioeconomic and ethnocultural background, while children ranged in age, race/ethnicity and sibling group status. They had diverse disabilities, conditions or disorders, with FASD, ADHD and mental health issues predominating. Some also had a difficult past history, such as an Aboriginal child with Asperger's, who had experienced abuse and multiple moves prior to being placed for adoption with his sibling group.

Findings: Learning Challenges Facing Parents

Despite differences in main role, region and adoption type/situation, all stakeholders agreed on the main challenges parents face in learning how to raise these children: preparing for this work, understanding and accepting the child's difference, reaching out for support/resources, adapting parenting strategies and learning advocacy. This paper presents these five key parental tasks separately for clarity. However, as similar challenges affect several of these tasks, the process should be viewed as a cyclical one with feedback loops. Sources of illustrative quotes are identified both by stakeholder type and interview number (such as Parent 11, Agency 2 and Association 3).

Preparing for Special Needs Adoptive Parenting

Adopting involves many unknowns, as medical and family histories may be either incomplete or inaccurate. Although some special needs may be known or suspected at placement, others may be unknown or not identified until later. Birth mothers may hesitate to share information that might restrict their child's chances of being adopted and some children adopted internationally are abandoned without birth or family medical history. For example, parents of a toddler were prepared for attachment issues because of her long stay in an Eastern European orphanage. As initial medical exams were satisfactory, however, they did not expect to learn she had FASD months after finalization.

Stakeholders in this study agreed that parents need sufficient and realistic preparation for this parenting journey so they will be ready to face potential challenges. Participants identified two types of preparation needed: pre-adoption education and full, accurate information on the child. Pre-adoption preparation required of all prospective adoptive parents tends to be fairly general, featuring standardized content covering different types of adoptions. Little detail is provided on specific topics because of limited course time. All stakeholders agreed these sessions were not sufficient but differed in their explanations. Parents focused on the overly general content, as well as on the mainly didactic way it is presented. "Nothing was done to prepare us for these children…they don't (say) there's no recourse, no support" (Parent 11) and "It's not enough. They don't really focus on special needs either" (Parent 18). An experienced foster parent related her experience: "I said to my husband, 'It's like lambs to the slaughter.' They didn't talk concretely about what FASD looks like and what you could be dealing with" (Parent 7).

Social workers and associations, however, focused on parents not being open to learning or not ready to learn during preparatory courses. They noted that the non-voluntary nature of parent training can get in the way, especially when participants are "so bound and determined they want a child" … they don't get how difficult it's going to be" (Agency 2). In part, this important information is "all coming at the wrong time" (Agency 4) before the child arrives, so potential parents have difficulty connecting to and integrating the material. In addition, some parents think it won't happen to them or are convinced all will be fine if the child is adopted at a young age, as they do not understand the potential for unknown disorders of genetic or prenatal origin.

Later preparatory components include the individual home study and the worker's presentation of a particular child. The latter was seen as problematic by all stakeholders. Social workers were concerned that parents do not have all the tools to decide whether or not to commit to a specific child. Both parents and professionals agreed that incomplete or inaccurate information made it difficult to get a realistic picture of what to expect and the possible family impact. Many parents suggested that workers may withhold crucial information about the child, fearful of scaring off families that are willing to provide a permanent home. Workers, however, emphasized that full, accurate information is often just not available to share with parents.

Understanding and Accepting the Child's Special Needs

All stakeholders noted the critical importance and difficulty of understanding the nature of the child's special needs and accepting what this means for them. However, a number of barriers can stand in the way.. First, it is not easy for any parent to accept that his or her child has a disability, especially if the latter was not evident at a young age. As one mother put it: "it took me a while to get over the denial I now know I was in" (Parent 8). Accepting that something is not right can be more difficult if well-meaning relatives discount problems as signs of passing stages like the terrible twos. Another obstacle occurs if parents, prepared for attachment issues that may resolve over time, have difficulty accepting the permanent impact of some disabilities and mental health disorders: "FAS is lifelong…it's not necessarily going to get better if it's pre-existing and there's no cure" (Association 2). Accepting the child as he or she is also means understanding the profound impact this will have on family life and realizing that both the child and family need support.

Once parents accept the child's behavior or development is atypical, they embark on the long journey of getting an accurate assessment. This is complicated by the relative scarcity of publicly funded services in most parts of Canada and other countries, which bring long delays for families unable to do it privately due to lack of extra health insurance. Once in the assessment process, parents can encounter professionals who fail to take their concerns seriously: "he's disintegrating in front of me and the doctors are saying, 'Oh you're a first-time Mom.' I'm like, 'there's something wrong' " (Parent 6). When children have hidden disabilities, parents can even be 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!' " (Parent 10).

Some parents see the very procurement of an assessment as a double-edged sword., Many families are understandably reluctant to see their child labelled because of stigma facing people with disabilities, yet a diagnosis is needed to obtain services. An accurate diagnosis can even come as a relief after months of worry, self-doubt and frustration: "'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?'" (Parent 10). Figuring out what is going on is difficult even for knowledgeable professionals, as these disabilities often co-occur. In young adopted children, there can be many different explanations, as noted by this social worker:

> "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 behavior because of FASD, attachment or sensory deprivation issues? So many of these children have self-soothing or self-stimulating behaviors such as rocking… It's really a guessing game" (Agency 1).

Reaching Out and Obtaining the Right Supports

By the time parents have an accurate assessment and have come to terms with their child's differences, they are usually veterans in negotiating a complex maze of services. Many may have become more resilient in the face of community or professional indifference and some have developed new advocacy skills. Parents need all this for the next step of reaching out and securing what the child and family need to order to succeed. While a diagnosis can open doors to services, it does not guarantee they will be accessible in a timely way. Parents still face the challenge of obtaining affordable resources in complex systems with separate silos for education, social services, health and mental health. Without case managers, this is a major roadblock for the many parents whose children have multiple disabilities often combined with other special needs. Finally, there seems to be an assumption that if the child gets help, the family will be just fine. Services are focused almost exclusively on the child, despite parents' need for long term support if they are to persist in their demanding caregiving role. As one mother put it: "They never ask what I need – they all ask what my child needs then fail to follow through" (Parent 10).

For adoptive parents concerned about judgment, just reaching out for help can be an additional obstacle. These parents feel they need to appear perfect so they "will try every other outlet... before going back to agency" (Association 2). As one parent put it "You're very careful…about how much bad stuff you're going to share" (Parent 1). Those who do seek support from the adoption agency often find workers very helpful, even though post-adoption support is rarely part of their mandate. However, community attitudes can also be problematic: "There's so much judgment 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'" (Parent 11).

As adoption subsidies are rarely built in, these parents have to learn to advocate to get their child's needs met in publicly funded educational and health systems as well as in the community. They need to advocate constantly, both to obtain services to which the child is entitled and to make sure systems follow through with legally mandated accommodations for their special needs. This often means "educating" social workers, teachers and health professionals who did not get enough training on disability or adoption. Even more frustrating is the need to do this every school year and every time a child starts using a new community resource. This adds to the already heavy burden these parents face in their family lives, as exemplified by one mother's dealings with a teacher:

> "He can't sit still during circle time so we can institute all the sticker charts you want, he's just going to feel like a failure. You're asking him to do something he can't do"...Having to educate others about his needs so they're being proactive vs. punitive because with his disabilities, he looks like he's trying to be defiant or not cooperative. (Parent 11).

Parent study participants were clear, however, that if some professionals were an impediment, those who were caring and competent played a pivotal role in supporting both child and family. No one type of professional stood out. What made a difference was a particular person's understanding, knowledge of disability and willingness to work in partnership with the family. Examples were a pediatrician who was "really committed to this and really honest with us" (Parent 5), teachers who understood children who learn differently and social workers who provided help beyond what they were strictly required to do.

Discussion and Implications

This study suggests that the stress of parenting these complex children arises not only from unpredictable child behavior but also from lack of knowledge and understanding. Our findings confirm the conclusions of others (Foti-Gervais, 2005) that parents require thorough, realistic preparation for adopting a child with special needs if they are to make an informed choice and be fully equipped to face the challenges. Despite growing agreement on this need, however, pre-adoption preparation remains uneven. Some agencies and regions adapt the mandated content and delivery by inviting experienced parents as speakers, which gives participants a realistic, practical sense of what to expect. When this potentially troubling information comes from peers "in the trenches" rather than from workers with decisional power, parents feel less threatened, as well as more able to take it in and reflect on its meaning for them. Some agencies are experimenting with creative ways to provide mandated content and facilitate its integration. For example, some build in time for peer discussion in small groups, which can enhance participant engagement and help them connect new learning with past experience. Other agencies provide greater flexibility in content delivery, thereby accommodating learners' different styles and situations (MacKeracher, 2004). Other options to explore include offering separate sessions for specific subgroups .An example would be to expose childless parents to simulation activities and films showing the daily reality of families living with different disabilities.

However, even the most realistic preparation will not be effective without building in "situated" learning opportunities after placement, as few families can fully understand the challenges they will face until after the child arrives (Forbes & Dziegielewski, 2003). Regular "booster" sessions would allow parents to revisit and integrate preparatory content into their day-to-day experience of parenting this particular child. Ensuring contact with peers in similar situations could increase support and reduce parent concerns about needing to appear perfect, making it easier to seek help in a timely way

This study showed clearly, however, that it is not only parents who need to continue learning. For many study participants, the most difficult challenges came not from the child's special needs but from others' lack of awareness, knowledge and understanding. While parent support groups provided invaluable support, as did professionals with strong disability knowledge, many parents reported not being taken seriously and some even got blamed. The findings of this study point to the need for continuing education in the community. For example, low-cost short workshops could be offered to a range of service providers, focusing on child disability and its impact on families as well as on intervention and accommodation strategies.

It is clear that disability content must be strengthened in both initial and continuing professional education to ensure that professionals understand and support these parents. Offering solid adult learning and group work content would better equip new graduates to think creatively about adapting parenting courses to specific needs of families struggling to raise children with complex disabilities, Content on a range of issues of concern to these families should be built into obligatory courses, along with strategies to increase societal and professional support.

It will take time before such changes are fully implemented, but parents and children need knowledgeable social workers now. We urge social work programs and professional associations to offer continuing professional education on disability and its family impact, and ensure that this knowledge acquisition is formally recognized. Consulting parents and disability support groups on content and delivery of such courses would recognize their expertise while enhancing professionals' learning. Many of these associations have developed creative tools for increasing awareness of the issues and how to address them. Partnering would make maximum use of the resources of parent organizations, disability communities, social work programs and professional associations.

Parenting children with special needs means learning every day how to face and overcome new challenges. These parents are performing an essential service, not only for their children but also for society. All parents raising children with disabilities deserve the support of knowledgeable social workers who can understand their situation and help advocate to improve it.

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