Services and supports for young children with Down syndrome: parent and provider perspectives


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Abstract

Background As individuals with Down syndrome are living longer and more socially connected lives, early access to supports and services for their parents will ensure an optimal start and improved outcomes. The family's journey begins at the child's diagnosis, and cumulative experiences throughout infancy and childhood set the tone for a lifetime of decisions made by the family regarding services, supports and activities.

Methods This study utilized focus groups and interviews with seven nurses, five therapists, 25 service co-ordinators, and 10 English- and three Spanish-speaking parents to better understand family experiences and perceptions on accessing Down syndrome-related perinatal, infant and childhood services and supports.

Results Parents and providers reflected on key early life issues for children with Down syndrome and their families in five areas: prenatal diagnosis; perinatal care; medical and developmental services; care co-ordination and services; and social and community support.

Conclusions Systems of care are not consistently prepared to provide appropriate family-centred services to individuals with Down syndrome and their families. Individuals with disabilities require formal and informal supports from birth to achieve and maintain a high quality of life.

Introduction

The prevalence of Down syndrome (DS) in the USA is approximately 14 per 10 000 live births (Parker et al. 2010). Despite the availability of prenatal screening, many women do not participate and testing lacks sensitivity (Smith-Bindman et al. 2007; Benn et al. 2012) with the result that approximately 87.5% of DS diagnoses are postnatal (Skotko 2005a).

Despite an increase in life expectancy from 35 years in 1982 to 55 and older today (Barnhart & Connolly 2007), DS still presents a number of associated challenges. Medical costs for children 0–4 years with DS are 12–13 times higher than for those without DS, and higher still when the diagnosis includes congenital cardiac conditions (Boulet et al. 2008). Families are seeking early intervention, medical, and therapeutic services for their child; ideally, care for infants and children should occur within a continuous, co-ordinated and culturally effective system accessible for families and delivered by experienced healthcare professionals (American Academy of Pediatrics 2004). Although comprehensive multidisciplinary clinics care for children with specific conditions, few are tailored specifically to children with DS. Not every state has a DS clinic available and only one such clinic exists in the large state of Florida where this study was conducted.

The complexity of individual experiences within the framework of family, community and society across the lifespan is a key construct in the Life Course Model (Fine & Kotelchuck 2010); a framework increasingly embraced in public health policy and practice. The life course approach illustrates the interconnections and intricacies of health outcomes, particularly in explaining and addressing health disparities (Lu & Halfon 2003; Fine & Kotelchuck 2010). Cumulative contributions of biological, environmental and social stressors and supports over time promote or reduce health – a trajectory that
begins in-utero, continues throughout the lifespan, and to subsequent generations.

Specialized education and interventions can greatly benefit children with DS (Fidler & Nadel 2007; Davis 2008). Part C of the Individuals with Disabilities Education Act (IDEA) (US Department of Education, Office of Special Education and Rehabilitative Services n.d.) provides early intervention to eligible children ages 0–3; Part B of the statute provides special education services to children ages 3–21 years. These services are publicly supervised, provided free to families in natural environments (e.g. home or daycare) by qualified personnel, are individualized to meet the developmental needs of children with significant delays (U. S. Department of Education, Office of Special Education and Rehabilitative Services n.d.). Additionally, Children’s Medical Services (CMS), a Florida statewide network of physicians and healthcare, providers funded through Federal Title V legislation, assists with referral, care co-ordination, and a range of medical, therapeutic and supportive services for eligible children (by income and medical diagnosis) (http://www.cms-kids.com). Although additional community-based and private intervention services and supports exist (e.g. parenting and disability-specific support groups, recreation, therapy services), access is limited by geography, programme capacity, costs and lack of publicity. Data on enrolment in private or community services are not routinely examined nor systematically captured as they are in publicly funded services.

Levels of support for individuals with DS require regular examination and adjustment; family experiences throughout infancy and childhood set the tone for a lifetime of decisions and actions. Our purpose was to better understand services and supports most needed and accessed by families of children birth to age 3 who have DS, to identify gaps and barriers to accessing these services.

Methods

Sampling and recruitment

Focus groups and interviews were conducted with parents and service providers to discuss their perceptions of formal and informal systems of care in Florida for infants and young children with DS. A purposive, convenience sample of parents of children ages 0–3 with DS and providers who serve this population were recruited through flyers distributed by local early intervention, therapy, and child care agencies, local support groups, email distribution lists, and at a statewide DS conference. Participants contacted the Primary Investigator (PI) via a telephone number on the flyer, were screened to determine eligibility for the study and provided their preferred time, day and location for the focus group or interview.

Procedures

Three focus groups were conducted with seven medical care manager nurses from CMS, 25 service co-ordinators from the Part C early intervention programme (Early Steps), and five physical, occupational and speech therapists. Four focus groups and two interviews with a total of 10 English- and three Spanish-speaking parents of children with DS were conducted at local libraries, Family Support and Resource Centers, workplaces, and at the statewide Florida DS conference. Participants were recruited until the sampling quota was met (one group of each provider type and two groups each of Spanish- and English-speaking parents) and theoretical saturation was reached. Focus groups with parents (two to five participants per session) and providers (5–25 participants per session) were conducted separately. Although the study was exempt by the USF Institutional Review Board, participants received a consent form (which was also read aloud), and provided verbal consent to participate. Signatures and personal identifiers were not collected on parent-completed demographic questionnaires. All focus groups and interviews were audio-recorded; attended by a facilitator, note-taker and one to two research team members assisting with child care. The Spanish groups and interview were facilitated by a native Spanish speaker. Parents and providers were asked about specific services and supports most needed, utilized, and helpful for families with infants with DS beginning at birth and services and supports parents have difficulty finding or accessing. Refreshments, child care, a small gift and an invitation to join an ongoing DS project Advisory Committee were provided to all participants; seven staff and nine parents signed up for the committee.

Analysis

Audio recordings were translated and transcribed in English by a researcher fluent in each participant’s primary language and all were reviewed for accuracy by a second team member. *Atlas.ti* qualitative software (http://www.atlasti.com) was used to code each transcript by a research team member and by the PI, independently, using *a priori* codes (corresponding with group/interview guide and research questions) and emerging codes. Discrepancies in coding were discussed by the research team until consensus was reached. Ultimately, 33 codes were identified and organized into a taxonomy describing
relationships between four key themes and several subthemes, as well as the factors influencing the family’s experience across the time span from the prenatal period through school age. Advisory committee members were invited to review the executive summary of findings and provide feedback; five responded and confirmed that the findings echoed their experiences.

Results

Participants (Tables 1 and 2) illuminated key issues from pregnancy through the child’s school-age years, with emphasis on infancy and early childhood, which have been organized into four major areas discussed below: Diagnosis and prenatal care; Services; Care co-ordination; and Social and community support. Parents rely heavily on prenatal care providers, paediatricians and specialty care providers to deliver diagnostic services and information during infancy and early childhood. According to both parents and providers, quality of life issues further emerge as the child grows: key issues include the availability of child care, school and recreational opportunities; long-term healthcare and education planning; and social and community supports.

Diagnosis and perinatal care

Prenatal screening experiences varied; several parents received negative blood serum and ultrasound screens, and therefore did not follow with an amniocentesis. Only three of 10 participating families reported receiving a DS diagnosis prenata tally, two of which reported pressure from their healthcare provider to terminate the pregnancy. Several participants reported utilization and satisfaction with genetic counselling; one nurse explained:

If they go for genetic counselling that’s where they have the choice to terminate or to continue the pregnancy. I don’t know the portion that terminates, I had a figure one

Table 1. Demographic characteristics of parent and family participants

<table>
<thead>
<tr>
<th>Parent role</th>
<th>n</th>
<th>Parent primary language</th>
<th>n</th>
<th>Parent age</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mothers</td>
<td>10</td>
<td>English</td>
<td>9</td>
<td>Age 31–40</td>
<td>5</td>
</tr>
<tr>
<td>Fathers</td>
<td>3</td>
<td>Spanish</td>
<td>4</td>
<td>&gt;40</td>
<td>8</td>
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<table>
<thead>
<tr>
<th>Race/ethnicity of parent</th>
<th>n</th>
<th>Parent-reported source of daily support</th>
<th>n</th>
<th>Parental access to transportation</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic White</td>
<td>8</td>
<td>Spouse</td>
<td>10</td>
<td>Yes</td>
<td>12</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>1</td>
<td>Other family member</td>
<td>0</td>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Hispanic</td>
<td>4</td>
<td>Friend</td>
<td>0</td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

| Child & family characteristics (n = 10 families) |

<table>
<thead>
<tr>
<th>Siblings in household</th>
<th>n</th>
<th>Child age</th>
<th>n</th>
<th>Child gender</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only child</td>
<td>2</td>
<td>4 years</td>
<td>2</td>
<td>Male</td>
<td>5</td>
</tr>
<tr>
<td>More than one child</td>
<td>8</td>
<td>3 years</td>
<td>0</td>
<td>Female</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 years</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>&lt;1 year</td>
<td>3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Programme enrolment</th>
<th>n</th>
<th>Family income</th>
<th>n</th>
<th>County of residence</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early steps</td>
<td>4</td>
<td>$15 001–$25 000</td>
<td>1</td>
<td>Hillsborough</td>
<td>7</td>
</tr>
<tr>
<td>CMS &amp; early steps</td>
<td>4</td>
<td>$25 001–$50 000</td>
<td>2</td>
<td>Duval</td>
<td>1</td>
</tr>
<tr>
<td>Neither programme</td>
<td>2</td>
<td>&gt;$50 000</td>
<td>7</td>
<td>Clay</td>
<td>1</td>
</tr>
</tbody>
</table>

CMS, Children’s Medical Services.

Table 2. Description of provider participants’ roles in caring for children with Down syndrome

<table>
<thead>
<tr>
<th>Provider role</th>
<th>Population served</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical care managers</td>
<td>Tri-county region, English/ Spanish, ages 0–21</td>
<td>7</td>
</tr>
<tr>
<td>Early intervention service co-ordinators</td>
<td>Tri-county region, English/ Spanish ages 0–3</td>
<td>25</td>
</tr>
<tr>
<td>Paediatric physical, occupational &amp; speech therapists</td>
<td>Hillsborough county, English/ Spanish, ages 0–18</td>
<td>5</td>
</tr>
</tbody>
</table>
time of 1/3 but that’s just a figure . . . Counselling could be very beneficial at that time and that might be an unmet need.

Many parents turned to the Internet as a convenient source of helpful information (particularly local and national DS organizations), as one parent described:

The doctor told me that there was a possibility my baby has DS. From that day I did my research on the internet and I was able to learn a lot from the [state DS] Association . . . everything I’ve learned on my own reading but I was very uncomfortable. I feel there are a lot of women who are ignorant.

The birth hospital experience was critical, as the setting for diagnosis and an initial entry point to informational, medical and therapy services. Families within the neonatal intensive care unit more often received information about programmes such as Part C through the discharge planning process. Unfortunately, timely access to accurate information about DS, available services and supports, and prognosis was lacking overall.

Among those who did receive information, resources came from various staff, including social workers, nurses and home visitors. Print information from the birth hospital/centre was often reported as incorrect and outdated; only a few parents received helpful information prepared and distributed by a local parent support group. For those with language barriers or without access to the Internet, finding information was even more difficult.

Services

Medical and therapeutic services utilized by families varied greatly, depending on the child’s needs, the presence and type of co-ordinating agency, the family’s awareness of service options, and insurance type. Both parents and providers agreed that early and intensive therapy services are essential for a young child with DS. While the ‘specialty clinic model’ was esteemed by several participants, there is no articulated comprehensive service delivery approach that is agreed upon among families and providers of children diagnosed with DS in Hillsborough County. Parents must grapple with conflicting recommendations among programmes and funding sources as they seek information from trusted providers, other parents and the Internet. One multidisciplinary health clinic was revered by several participants:

[They provide] sessions with speech therapy, occupational therapy, and physical therapy and they all know each other and speak to each other. You get one report and it helps you to better understand what you need.

Unfortunately, its location in Northeast Florida makes access difficult for most parents across the state. Providers also stressed the importance of early access to this type of comprehensive care:

. . . from a therapy standpoint, usually the child gets referred for a motor therapy which is OT or PT first . . . They’re accessing . . . more medically based services in the first year because they are trying to resolve any cardiac issues, compounding issues, getting them stable . . . Sometimes I’ll see kids with the diagnosis and they haven’t had PT or OT for the first 12 to 16 months . . . therapy becomes changing instead of intervening.

Parents relied on family practitioners or paediatricians to assist with care co-ordination for specialty care services, including: cardiology, ear nose and throat, vision, hearing and urology. Participants described the limited insurance coverage for therapy services, limited information about available resources, and inflexible service schedules. Medicaid-covered services and provider availability were limited, nurse care co-ordinators lamented:

If your family is over the income, then you not going to get SSI [Social Security benefits] anyway, but you still qualify for the Agency for Persons with Disabilities [APD] . . . and the 8,000 other people that are waiting to be put on the list . . . you are going to be on that list for about 10 years.

Families with private insurance also struggled to cover therapy costs for their child:

We had [insurance] copays to pay but you know that twice a week $50 dollars each time . . . it adds up.

Part C was identified as a gap filler for services; however, parents and providers acknowledged the tension around the limited services offered through Part C versus those services recommended and accessed through private pay:

[Part C] actually wanted to cut her therapy. I had an early interventionist and she came to my home and at that point [Part C] said that was all she needed. It was the paediatrician who told me that Medicaid covered all therapies. They just offer you the basic . . . There’s a spectrum, but there are certain things that are a given with all Downs. I shouldn’t have to fight for those services. . . . Not being knowledgeable you don’t know what to fight for . . .
Care co-ordination and service systems

Services appeared scattered, unco-ordinated and difficult to find, and communication among providers and between providers and parents was inconsistent, unco-ordinated or non-existent. Poor co-ordination of services was noted by therapists:

One big problem in our area; and it is across the board with Downs, there is no group that can work together

and by parents:

Our co-ordinator changed almost monthly . . . to build a relationship with someone and then they’re gone and then it takes months for the other person to call you back . . . getting a response from them was just a huge challenge.

When children with DS require a full schedule of care and services, employment can be difficult to maintain:

I can’t get a job since our child has so many hospital visits. Today I came here, tomorrow I have an appointment with the audiologist, and later we have an appointment with [the doctor].

These scheduling demands impact family life, as observed by one parent:

I have to say why I’m not going out to many other networking or support groups because you’re busy, especially he was five weeks early so . . . you’re going to doctors a lot more than the average child; you know your way around the hospital pretty good. . .

Social and community support

The impact of the child’s diagnosis on the primary and extended family was substantial. Several examples were given by providers and parents who didn’t immediately accept or share the diagnosis:

We didn’t tell anyone for a year . . . until she got older and started to look a little more like Downs.

Societal acceptance of DS was perceived as improving by some providers; one nurse noted:

People are more comfortable with Downs . . . we have actors with DS now . . . most of the kids that have Downs are in the Special Olympics . . . a lot of things that have brought Downs to the forefront.

For most parents, finding others familiar with DS was difficult, particularly for those with language and transportation barriers.

Parents weren’t always aware of the available childcare or educational options. There is a scarcity of welcoming, high-quality, and affordable child care and respite:

Child care is ridiculous when you have Down syndrome. I had a hard time when he was younger finding a safe place for him . . . child care for a child with special needs is a joke. And most places that get the FTE dollars, they’ll be glad to take them but the care is sometimes . . . mediocre.

Furthermore, the anticipated transition to preschool and school-age services was expressed as a bewildering process by parents. As aptly described by one parent:

When a child is in the category of 0–3, everybody’s there everything’s there for you. [Part C] . . . doctors . . . support groups are there; the day that they become three years old and one day you lose the [Part C] arena you’re on your own basically . . . you’re fighting the school system . . . when they were a baby everything came to you.

Providers, who had experience with children with DS of all ages, also discussed the challenges in finding appropriate preschool and elementary school settings that met both the educational and therapeutic needs for both the child and family. Advocacy (by parents, professionals and self-advocates) continues to be essential from birth and as children age; one therapist conducted a presentation on DS in a mainstream classroom:

They don’t want the kids in the class because they are different; they get made fun of. But if they understand it, you can empower them and make them advocates.’

Discussion

We identified key experiences, transitions and supports for families of children with DS from the perspectives of parents and providers. Parents require services and supports that address short and long-term needs and goals. Consistent with McCabe and colleagues (2011), we found that the family, community and system-level interactions, from pregnancy through early childhood impact the timeliness and quality of services a family receives, and ultimately transitions throughout the school years into adulthood. From the beginning, follow-up and management is central to keeping the promise of newborn screening (Centers for Disease Control and Prevention 2011), so
the diagnosis of DS is only helpful in the context of connection to services and supports which relies on the provision of clear information on DS, its causes and expectations (Skotko 2005b). The availability of non-invasive prenatal testing for DS could result in higher rates of early diagnosis, requiring corresponding improvements in counselling, support and referral (Benn et al. 2012).

Today, greater inclusion and integration have become expectations among families with children with DS (Schalock 2004). Studies show that many parents and siblings of children with DS report positive impacts within their family; comparatively higher levels of successful coping, family harmony and closeness, and lower of maternal stress have been found in families with DS compared with other disabilities (Hodapp 2007; Skotko et al. 2011a,b). While parents in our study expressed both positive and negative experiences, they identified important amendable challenges related to the inaccessibility of reliable information about DS and available services; a lack of sensitivity, knowledge and care co-ordination among providers; and an ongoing need for formal and informal support systems.

The onset, duration, cost and quality of medical and therapeutic services for children with DS varied. Previous research on children with special healthcare needs found that children with DS faced multiple barriers when seeking genetic counselling (McGrath et al. 2009). Gaps in funding within the private healthcare system and state-managed programmes continue to result in disparities in access to family-centred primary and specialty care (Kuhlthau et al. 2011; McCabe et al. 2011; Tait 2011). Continuity between multiple providers and parents works best if the service delivery model is tailored to the child’s medical needs as well as a broader definition of health that includes activities of daily living and social participation at home, in school and in the community (Committee on Evaluation of Children’s Health & National Research Council 2004; Miller et al. 2009,p.9).

Both parents and providers emphasized that early and intensive therapy (e.g. physical, occupational, speech and feeding) is essential for many children with DS; as recommended by guidelines put forth by the American Academy of Pediatrics (Bull and the Committee on Genetics 2011). However, services seem to depend on family knowledge, resources and advocacy, and responsiveness and flexibility on the part of the service systems and providers. McGrath et al. (2011) found that adequate insurance coverage, medical home and receipt of co-ordinated medical care improve access to supports and services for children with DS. Unlike nations with universal healthcare systems, the USA does not guarantee a full range of publicly funded healthcare services. Children with DS are more likely to have unmet healthcare needs than other children with special healthcare needs, particularly for those who have low income or are uninsured (McGrath et al. 2011; Nelson et al. 2011). Publicly insured (Medicaid) services and providers are limited; families with Medicaid or whose insurance status fluctuates struggle to cover as many as 5–10 therapy services per week (McCabe et al. 2011). Despite IDEA’s intent to fill in gaps in early intervention and care co-ordination, Part C faces fiscal and practical challenges in meeting families’ needs (Florida Developmental Disabilities Council n.d.; OPPAGA 2006). Provider shortages increase the likelihood that parents opt out of Part C or supplement with private services. Although 70% of parent participants had a family income of over $50 000/year and private health insurance, their barriers were consistent with those of uninsured parents.

Family-centred care must occur at the individual, organizational and environmental levels (Kuhlthau et al. 2011). Unfortunately, some healthcare practitioners fail to identify the particular medical needs of a child with DS, described as ‘diagnostic overshadowing’, which leads to unresolved medical issues (Minnes & Steiner 2009). Families navigate multiple medical and therapy services, with high case manager turnover, and are frequently alone in co-ordinating their child’s care (Lindeke et al. 2002; Nolan et al. 2007). The USA utilizes a primary care provider model for well-child care, while nine of 10 developed nations in one study regarded well-child care as a co-ordinated effort among multiple providers; this lack of care co-ordination in the USA results in preventable health consequences (Kuo et al. 2006; McCabe et al. 2011).

As in other studies, we found that parents had to reduce hours or stop working to manage their child’s care (Rogers & Hogan 2003; Phelps et al. 2012). Adequate access to childcare and respite would help families maintain employment and its associated income and insurance benefits to cover health costs (Rogers & Hogan 2003). Additionally, child behaviour issues compromised enrolment in child care; behavioural problems among children with DS are lower than among children with many other developmental disorders, but higher than typically developing siblings or peers (Dykens 2007). Despite a slow trend towards inclusion, children with intellectual disabilities are still less likely to spend time at school with peers in a general education setting (Turnbull et al. 2010) or in community recreational programmes which offer important social and health benefits, such as obesity prevention (Menear 2007).

While our study results are not fully generalizable, participants in this exploratory study encompassed considerable depth and breadth of experience, including the perspectives of fathers, Spanish-speaking families, nurse care managers, therapists and
service co-ordinators. Participants were self-selected and were recruited from intervention and therapy programmes, support groups and other community settings; therefore these parents may differ from those who may be less connected to services. Responses may have been subject to recall or social desirability bias. Although our parent participants were older and had higher income than the general population, the participants’ comments reflected a wide range of experiences. Providers with therapy, nursing and social work backgrounds offered additional insight from working families of children with DS of all ages and from working within larger systems of care. This study informed development of a statewide survey to accommodate a larger and more diverse sample of parents, including geographically and demographically under-represented groups.

Conclusion

Adapting systems of care for individuals with DS to a lifecourse framework is an ongoing process. The journey for parents begins with diagnosis, prenatally or at birth, and early interactions set the tone for the family’s experience while also serving as critical gateways to medical and developmental services. Co-ordinated system should provide the best of medical and developmental care, information and family support throughout the lifespan (Shin et al. 2009; McGrath et al. 2011). To start, recommendations for clinical management of DS, such as those published by Bull and the Committee on Genetics (2011), should be widely disseminated among providers and parents, along with specific information about the local sources of services and supports recommended in the protocol. The National Down Syndrome Society (http://www.ndss.org/) offers interactive maps to help parents find affiliated groups and supports in their area. This study provided the impetus for development of a resource guide which was disseminated throughout Florida and also a listing of resources included on a DS fact sheet developed with our state birth defects registry (http://www.floridahealth.gov/). Our ongoing research examines improvements to information dissemination in Florida hospitals for parents of children born with DS. We recommend expansion of multidisciplinary specialty clinics and co-located services (e.g. child care and on-site therapy) which have shown to improve care for families of children with DS (Skotko et al. 2013). Finally, identifying and addressing gaps in insurance coverage, underserved geographic areas and populations will help to ensure that fewer families fall through the cracks.

As widespread funding for services and supports may be a more difficult goal to obtain in part because of the US policy trend towards privatization and free-market healthcare system (Kuo et al. 2006), changes in public policy supporting quality of life for individuals with disabilities throughout the lifespan will require targeted efforts and collaboration by consumers and advocates, educators and practitioners, programme administrators, policy makers, researchers and evaluators (Schalock et al. 2002; Bittles et al. 2006, p. 1; McManus & Rogers 2011).

Key messages

- Improved family-centred care, co-ordination and transition support would increase efficacy, utilization and parent satisfaction with perinatal, paediatric and community services.
- Parents and providers described family, community and system-level interactions impacting services and supports for infants and young children with DS and their families.
- The life course approach, which recognizes critical periods, multiple influences and a long-term orientation, is a useful framework in supporting families of children with DS.

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References


