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	syndrome found that just one fourth of respondents received prenatal diagnosis, and less than half of families reported receiving family-centered care – needed information and, care coordination – in prenatal or birth settings.

ABSTRACT

Objective: To examine the experiences of parents or caregivers of children with Down syndrome related to prenatal care, the birth setting, primary and specialty care, and care coordination.

Design: Cross-sectional, mixed-methods study.

Setting: State of Florida.

Participants: Parents/primary caregivers (*N*=101) who spoke English or Spanish of children aged 0 to 18 years diagnosed with Down syndrome who were born in Florida.

Methods: Participants identified through snowball sampling completed an online version of the Family Experiences Survey. Analyses included descriptive statistics, Fisher's exact tests, and content analysis of the open-ended questions.

Results: Less than half of 101 respondents reported receipt of adequate information following diagnosis of Down syndrome during the prenatal period (n=18, 19.3%) or at the birth setting (n=35, 41.2%). Most respondents (range: 52.9% - 95.4%) reported that they received adequate time and specific information needed and that providers were sensitive to their feelings, values, and family customs during the prenatal period, at the birth setting, and during primary and specialty care. However, less than 60% of respondents (range: 19.3% - 59.1%) recalled that they received information about Down syndrome or helpful programs such as Children's Medical Services, Early Steps, or Healthy Start from prenatal care providers or at birth settings.

Conclusion: Our findings highlight the critical role that perinatal care providers play in establishing access to and utilization of specialty care services for neonates with Down syndrome and emphasize the need for family-centered care in prenatal and birth settings.

KEY WORDS: developmental disabilities, Down syndrome, family support

CALLOUTS:

1. Families of children with Down syndrome continue to face challenges in locating and accessing quality care and support.
2. The timing, process, and family-centeredness of provision of information and support upon diagnosis varied considerably; opportunities for improvement were indicated by most respondents.
3. By following a family-centered model of care, prenatal, postpartum, and pediatric health care providers can improve family participation in essential services.

Down syndrome is the most common chromosomal condition in the United States (Parker et al., 2010). Its prevalence in Florida is 13.0 per 10,000 live births, which is similar to the estimated, adjusted national prevalence of 14.2 per 10,000 live births in the United States (Mai et al., 2013). This equates to approximately 280 children born with Down syndrome in Florida each year (Florida Department of Health, 2011). Survival rates for patients with Down syndrome have improved during the past 20 years, and the one-year survival rate is 93% (Kucik, Shin, Siffel, Marengo, & Correa, 2013; Wang, Hu, Druschel, & Kirby, 2011). Individuals with Down syndrome are now living longer and fuller lives. Parents of children with Down syndrome reported overwhelmingly positive experiences, including love, pride, acceptance, and strong family relationships (Skotko, Levine, & Goldstein, 2011). However, these children may have medical comorbidities that span multiple body systems and lead to varying degrees of developmental delay. These challenges can affect a child’s ability to perform everyday activities and result in considerable time, emotional, and financial costs to families. The medical expenses that are accrued by the average child aged 0 to 4 years with Down syndrome are 12 to 13 times greater than those for a same-aged child without Down syndrome (Boulet, Molinari, Grosse, Honein, & Correa-Villasenor, 2008). Families of children with neurologic and intellectual disabilities often schedule between five and 10 medical or therapeutic appointments each week, while others are unable to access needed services because of gaps in resources and knowledge (McCabe, Hickey, & McCabe, 2011).

Down syndrome is typically identified either prenatally or in the early postpartum period (Jackson, Crider, Cragan, Rasmussen, & Olney, 2014). Because of elective terminations, it is difficult to estimate the percentage of infants who are diagnosed prenatally. Studies have shown that a family-centered approach to managing the screening and diagnosis processes during the perinatal period can lead to improvements in satisfaction and use of services, health outcomes, family functioning, and family impact/cost (Kuhlthau et al., 2011). In Florida, these services include free intervention and support through Early Steps (early intervention funded by Part C of the Individuals with Disabilities Education Improvement Act [2004]), Children’s Medical Services (network of health care providers and nurse care coordinators), and Healthy Start (home visiting programs). All of these are available statewide to support pregnant women and families with young children, including those with special needs such as Down syndrome.

In addition to these programs, parents or caregivers of children with Down syndrome may access numerous other medical or developmental services; coordination of these services relies on communication between the primary care provider and specialty care services and access to and facilitation of services and supports. Despite some focus on Down syndrome in research studies, advocacy, and the media, families of children with Down syndrome may not receive as much public attention as families of children with other health care conditions (Bull & the Committee on Genetics, 2011).

Families should be able to receive appropriate information and referrals to services before or shortly after birth in a manner that is consistent, timely, and family-centered. Parents need up-to-date general information about their children's diagnoses as well as specific information about their child's health status, treatment, and services available. However, families of children with Down syndrome face challenges in locating and accessing care even with the substantial improvements in awareness, specialty care, education, and family support offered through the Individuals with Disabilities Education Improvement Act (2004) and the Americans with Disabilities Act (1990).

< CALLOUT 1 >

The goal of family-centered care is to provide the highest quality of care within a service plan tailored to the patient and family. Family-centered planning evolves from the collaborative efforts of the patient's family and an interdisciplinary team of health care professionals. Since 1987, the inclusion of this model has been encouraged by the U.S. Surgeon General and endorsed as an objective for children with special healthcare needs by the Maternal and Child Health Bureau (Kuhlthau et al., 2011). Several aspects of family-centered care, including cultural awareness, a nonjudgmental approach, honesty, and open communication, make it the ideal approach to caring for a child with a special health care need (Kuo, et al., 2012Families of children with Down syndrome who receive family-centered care are more likely to improve in overall psychological health, seek help from health care providers, and experience a high level of satisfaction with the care their children receive (Kuhlthau et al., 2011). The purpose of our study was to examine the experiences of parents or caregivers of children with Down syndrome related to prenatal care, the birth setting, primary and specialty care, and care coordination.

Methods

Design

We used survey methods in this cross-sectional exploratory study to examine families' experiences in receiving family-centered care for their infants with Down syndrome. The principles of family-centered care (dignity and respect, information sharing, participation, and collaboration) guided the structure of the survey, with particular focus on its application during prenatal care, birth setting experiences, and care coordination.

Setting and Sample

The target population of the survey included any parent or primary caregiver who spoke English or Spanish of a child from 0 to18 years of age born with Down syndrome in Florida.

Measures

The Family Experiences Survey evolved from focus groups conducted in 2011 with 50 Florida parents, therapists, nurses, and service coordinators for children with Down syndrome ages 0 to 3 years; these groups identified areas of strengths and the need for formal and informal services and supports (Marshall, Tanner, Kozyr, & Kirby, 2015). Focus group participants emphasized the importance of sensitive and informative prenatal care and early intervention as primary influencers on their expectations for their children's prognoses. This survey was developed to gather additional information, including quality and satisfaction with prenatal care, birth setting experiences, and care coordination using family-centered care as a guiding framework.

The Family Experiences Survey content is based, in part, on similar studies in which researchers used surveys and other methodologies to examine the experiences of families and caregivers of children with Down syndrome or other disabilities (Nolan, Orlando, & Liptak, 2007; Thomas et al., 2011). The 95-question survey includes sections on prenatal, birth setting, and postpartum primary and specialty care; family stress and support; child care and education experiences; community participation; transition; and demographics. In this study, we focused on family-centered services during the perinatal period (questions related to prenatal, postpartum, and early childhood primary and specialty care sections of the survey). Because family-centered care includes sensitive and timely communication, information sharing, and interactions, we selected particular variables aligned with respondents' perceptions of access and quality of care and information across settings and providers. Most questions were rated on a Likert scale or were multiple choice, and some were open-ended; comment boxes were also included. This bilingual, English and Spanish, survey was offered in paper format and online through Qualtrics software (Qualtrics, Provo, UT). Because the survey was developed by the research team, its reliability and validity have not been tested. However, a 19-member advisory committee consisting of parents, service providers, and community members reviewed the survey for appropriate language and items, relevance, accuracy, readability, and ease of use before dissemination. We examined family-centered prenatal care, birth setting, and pediatric care by asking parents about access to care (primary and specialty services), provision of clear and accurate information (general information about Down syndrome and a separate question asking about specific information needed for the child's care), provider sensitivity, and overall satisfaction.

Because of skewed responses toward the extremes and to improve interpretability of findings, several key ordinal variables originally measured on a 5-point Likert scale were dichotomized. For example, participant satisfaction with prenatal care was assessed by the question, “How would you rate your experience in receiving prenatal care?” Responses were dichotomized as satisfied (*excellent* or *good*) or unsatisfied (*neutral*, *poor*, or *very poor*). Experiences with prenatal care at the birth setting and with the primary pediatric care provider were assessed by the adequacy of time spent with the family, timely provision of specific information needed during the visit, and sensitivity of the provider to feelings, family values, and customs. Responses to these questions were dichotomized into satisfied (*sometimes*, *rarely*, or *never*) and unsatisfied (*usually* or *always*). The receipt of adequate care coordination was assessed by the question, “How often do you receive help in arranging/coordinating care for your child?” Responses were dichotomized as inadequate care (*sometimes*, *rarely*, or *never*) or adequate care (*usually* or *always*). Quality of information was categorized into helpful (*somewhat helpful* and *very helpful*) and not helpful. The survey also included open-ended comment boxes following several questions that allowed respondents to provide further detail about their experiences and a final survey question for additional comments.

Procedures

Because Florida is the fourth most populous state and has many diverse and transient populations, recruitment for this study was a challenge. It is estimated that 280 children are born with Down syndrome in Florida annually (Florida Department of Health, 2011), and enrollment in various programs and groups varies by region and age of child. In 2012, we disseminated surveys to more than 100 businesses, non-profit agencies, local support groups, service providers, and additional support and advocacy groups across the state for families of children with Down syndrome that we identified through the Internet, resource guides, and Facebook. Our goal was to reach families from various regions and age groups from among and estimated 5,000 children under age 18 living in Florida. Strong community support and engagement from governmental and community programs, such as Children's Medical Services and Early Steps, were key to facilitating access to parents of children with Down syndrome. Active Down syndrome support groups and social networking sites also agreed to disseminate paper and online copies of both survey language versions. Reminders were sent weekly for 2 months then monthly for 10 months. Snowball sampling (forwarded from one provider or family to another) was employed as a low-cost means to identify previously unknown providers. Because of online distribution and snowball sampling, we were unable to determine the response rates accurately.

The lead author's institutional review board reviewed this study and considered it minimal risk and exempt. However, informed consent was obtained (signature waived as no personal identifiers were collected) and confidentiality and data security protections were followed.

Analysis

We computed descriptive statistics, including frequencies and percentages for prenatal care, birth setting, primary pediatric care, and specialty care services and experiences. We used Fisher's exact test to examine the relationship between timing of diagnosis (prenatal period and birth setting) and enrollment in early intervention (Children's Medical Services, Early Steps, and Healthy Start). Quantitative analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC). Native Spanish-speaking research staff from Puerto Rico and Venezuela translated open-ended Spanish comments into English. All qualitative data from open-ended responses were compiled and reviewed with the quantitative questions and results rather than analyzed separately. Open-ended responses were primarily used to enrich the results from the quantitative survey and to add more detail and context to our findings.

Results

We collected 154 surveys (139 English and 15 Spanish; 12 paper and 142 online) from parents or caregivers of children with Down syndrome from February 2012 through January 2013. The final sample consisted of 101 respondents (97 who responded in English and four who responded Spanish) after 29 respondents with children who exceeded our age limit (≤ 18 years), one who was not the parent/primary caregiver, and 23 surveys with missing values on multiple scales were excluded. Surveys were collected throughout the state of Florida, but most were returned from Hillsborough, Palm Beach, and Orange counties. Most respondents were mothers of the children with Down syndrome and were born in the United States, 35 years of age or older, White non-Hispanic, married/partnered, fluent in English, and had at least college degrees and private insurance (Table 1).

Quantitative

Prenatal care. Among the 93 respondents who reported that they received prenatal care, 23.7% received diagnoses of Down syndrome prenatally, and 95.7% were satisfied with the overall quality of that care. Of the respondents who received diagnoses of Down syndrome prenatally, 59.1% received information about Early Steps, 50% received information about Healthy Start, and 45.5% received information about Children's Medical Services (Figure 1). The results showed that families that received prenatal diagnoses were more likely to receive information on these programs; however, these differences were not statistically significant ($p>0.05$, Figure 1). Among respondents who received prenatal care, most reported adequate time with provider (n=76, 81.7%); specific information (n=77, 82.8%); and provider sensitivity to their feelings (n=66, 71.0%), family values, and customs during the prenatal period (n=68, 73.1%). Only 19.3% (n=18) reported that they received information on Down syndrome from their prenatal care providers (Table 2). Most of these 18 respondents (n=14, 77.8%) found the information they received to be helpful. When asked about the type of information they most wanted from their prenatal care providers, respondents indicated that they wanted information about available services (73.1%), how to contact other families with the same or similar conditions (64.5%), common related health conditions (54.8%), prognosis (53.8%), risk of recurrence (29.0%), prevalence (24.7%), and causes and prevention (15.1%; data not shown).

Birth setting experiences. Of the 85 respondents who had data for birth settings, 72.9% reported that their children were diagnosed with Down syndrome at these settings. Nurses (21.2%) acted as the primary conduits of information at the birth setting, followed by physicians (12.9%), and geneticists (7.1%). Among respondents who received diagnoses of Down syndrome at birth settings, the highest percentage (48.4%) received information about Early Steps, followed by Healthy Start (Figure 1). Most respondents reported that they received specific information needed, and had providers who spent adequate time and were sensitive to their feelings, family values, and customs. However, just 41% of the respondents reported that they received information on Down syndrome at the birth setting(Table 2).The quality of information received at birth settings varied, and only 40% of respondents rated the information as *very helpful*.

< CALLOUT 2 >

Primary care provider and specialty care. Of the 66 respondents who reported that they had medical homes/consistent primary care providers, 94% indicated that their providers were knowledgeable about Down syndrome (Table 2). Most respondents reported that they received adequate time (92.4%), specific information (80.3%), and sensitivity to their feelings (95.4%) from their providers. All respondents reported use of a variety of Down syndrome-related specialty care services. The most common were physical therapy (96.0%), speech therapy (95.1%), and cardiology (86.1%). More than half of respondents' children received more than three services within the first six months of life, and more than two-thirds of respondents' children received at least three services within the first year of life (data not shown).

Care coordination More than half of respondents (58.4%) reported that they received adequate care coordination. Most respondents (88.0%) reported satisfaction with the communication between their children's health care providers and other providers. Likewise, 77.3% of respondents expressed satisfaction with the communication that occurred between their children's healthcare providers and the school, early intervention programs, child care providers, or vocational education or rehabilitation programs (data not shown). However, 53.3% of the respondents had to cut back on work hours or quit their jobs altogether to care for their children.

Qualitative

Prenatal care. Respondents reported that they received good prenatal care and support during the prenatal period. A mother of a 6-year remarked, “Thankfully, our physicians took more than enough time to meet with us, answer questions, and support us.” Another respondent noted the following:

> We had the best OB/GYN & perinatologist; you could tell they cared about us and our unborn child. We had some complications, and while they were being cautious, I felt like I was their only patient because they always made time for us.

However, prenatal care experiences also included strong pressure to terminate the pregnancy. A mother of a four-year-old reported:

> The doctor recommended that I get an abortion. They even set up an appointment [*sic*] for one. I left that doctor and went to see a high-risk specialist. He also recommended that I get an abortion. He said that I didn't want to raise a child "like that."

Respondents also reported receipt of information of inconsistent quality and the desire for more information:

> The information we received was not all that useful regarding the diagnosis. For the most part, we were left to our own devices to find information. It would have been extremely helpful to at least have received a sheet with websites and/or information about local support services.

Birth setting experiences. Though the quantitative results showed that the providers were sensitive to the feelings of respondents, some commented on the insensitive manner in which the diagnosis was delivered to them: "Deliverance of diagnosis very poor. Didn't have good bed side manner and told other family before father who was out of room." Another respondent commented, "I was told my daughter had DS while I was still being stitched up. They could have waited 'till I was at least in a hospital bed." A similar experience was echoed by another respondent: "Doctor walked in and said 'Well you knew there would be a chance she would have Downs and shrugged her shoulders and walked out of the room."

Some respondents reported that they searched searching the internet for information on Down syndrome after they received insensitive care or uninformative information. Others expressed that a sensitive physician and adequate information helped them to locate and acquire appropriate services and support. Many respondents complimented the nurses but criticized physicians and outdated resources:

> The nurses in the NICU were amazing. The doctors left a lot to be desired. The nurses allowed me to mourn and allowed me to fall in love with the baby. They gave me time, and space, and courage, and support. The docs gave diagnosis and prognosis, usually negative. (Mother of 13-year-old)

> I remember the pictures more than the information. I saw a lot of cute babies, infants, adolescents, and they look very capable and typical to me. So the pictures gave me at [sic] another perspective of what having my son with Down syndrome was going to be. One of them was a girl playing the violin. (Mother of 8-year-old)

Some respondents received information from providers that was negative or obsolete:

> Some of the information was outdated. There are many inspirational stories involving children and adults with Down syndrome. Many pamphlets and booklets should be updated. It would also be beneficial for the hospital to have a list of parents they could call to provide support to new parents should they need it. (Mother of a 2-year-old)

Primary care provider and specialty care. Most respondents reported that their primary care providers were helpful and knowledgeable, though open-ended responses alluded to some searching switching providers before finding a knowledgeable provider. A mother of a six-year-old remarked, “We drive 45 minutes to see our doctor. She is very patient with my daughter and she is knowledgeable about Down syndrome, so it is worth the drive.” Another respondent (mother of a 5-year-old) described the excellent care provided by her child’s pediatrician:

> My pediatrician was the one who provided us with info on Early Start/Early Steps programs. She was an excellent source of specialists (ENT, ophthalmologist and pulmonologist and gastro) when we needed them at the time. And they were more than

> qualified with special needs kids. We were treated no different, if not probably treated better on all occasions we went for our check-ups.

However, one respondent (mother of a 16-year-old) noted variability among providers regarding knowledge about Down syndrome and sensitivity: “The first pediatrician was completely unknowledgeable. She actually called my daughter a mongoloid! Of course, I did not continue to see her. After we switched to a new pediatrician, everything has been great.” In open-ended comments, nine respondents indicated that they changed providers and rated their current providers as more helpful than the previous ones.

Care coordination. Respondents noted the difficulty in balancing care coordination with work, financial struggles (e.g., Medicaid coverage, therapy costs), and inflexible care regimens that put a strain on their careers:

> Cannot pursue career due to lack of quality, affordable child care for my special needs son. Very, very limited, to near non-existent child care available for elementary and middle school age special needs children. Have had to stop work entirely at times; have to cut hours during summers. Very difficult.

Respondents shared their overall perspectives on balancing the rewards and challenges of caring for their children with Down syndrome:

> I expressed incidents that have happened to me and the reason for answering this survey is with the intention to be taken into account to prevent events that hopefully will not happen to more people. Having children with special needs, I can tell you now, is the most beautiful experience in the world – it is an appreciation of life itself and that ability that one does not imagine to have within to continue in the face of adversity, and that love that flows from you before them. Incredible. Before, everything was “confusion,

> frustration," as I did not have the opportunity or they did not have the capacity to inform me during my pregnancy nor at birth [about Down syndrome]. (Mother of 1-year- old translated from Spanish to English.]

Discussion

While most respondents in our study had positive experiences, our findings suggest opportunities for improvement in family-centered prenatal counseling and support, birth setting care, and primary and specialty care coordination. Though providers were sensitive to their feelings, family values, and customs, some respondents reported lack of sensitivity when providers delivered diagnoses of Down syndrome prenatally or at the birth setting. Even though health care providers need to communicate the diagnosis clearly and in a timely manner in busy clinical settings, it is essential to do so with compassion (Lemacks, Fowles, Mateus, & Thomas, 2013).

Screening programs can be further improved with the inclusion of education for parents and long-term follow-up (Bull & the Committee on Genetics, 2011). The importance of family-centered care cannot be overstated. Family-centered prenatal care should consist of early and regular appointments, provision of clear and accurate information about testing options and recommendations, and information on risks and results delivered tactfully, in the family's primary language, by a consistent and sensitive provider. Family-centered prenatal care can result in early recognition/diagnosis, faster linkage to services, and greater family satisfaction and participation in services (Kuhlthau et al., 2011). Receiving an accurate prenatal diagnosis of Down syndrome can help parents find services and support before birth. A positive birth experience and receipt of resources in the birth setting can help parents enroll in early intervention programs and support groups.

Most of our respondents accessed at least three Down syndrome related specialty care services within the first 6 months of their children’s lives. Arranging for authorization and payment for these services and coordinating appointments can be a tremendous challenge for families. In Florida, Children’s Medical Services evaluates and provides medical care and support for children with special health care needs, Healthy Start provides home visiting services and supports to pregnant women and parents of infants with a variety of perinatal and social risk factors, and Early Steps provides services through a comprehensive team of professionals to support infants and toddlers with developmental delays. The system of intake and referral to these resources is in place in birth settings; however, only 46% to 59% of respondents who received prenatal diagnoses and 37 to 48% of those who received diagnoses at birth settings could recall receiving information about these programs. Thus, there is a need to improve linkage for family support and early intervention services for families of children with Down syndrome, especially among infants diagnosed at birth settings.

Finally, parents need to have accurate, comprehensive, and timely information about Down syndrome and available resources. Fewer than half of the respondents received information about Down syndrome at the birth setting, and this lack of information dissemination was most pronounced during the prenatal period. The American Academy of Pediatrics indicated that to provide newborns with optimal care, communication and co-management are necessary within the birth setting (Burke, Liptak, & Council on Childrend with Disabilities, 2011). In one study on Down syndrome, mothers preferred to receive the diagnosis from familiar physicians, particularly those who were present during prenatal care (Glynn, Saya, & Halliday, 2012). These same mothers also wanted receive such news within 24 hours of birth if they were medically stable. Moreover, it is important to inform the families of children with birth defects about health care professionals, such as genetic counselors, who are available to discuss their children's conditions (Glynn et al., 2012). Several open-ended comments from respondents in our study indicated that a sensitive and informative provider is a critical determinant to guide parents to seek out and access services and support for their children.

Receipt of specialty care and early intervention may optimize developmental outcomes for children with intellectual disabilities such as Down syndrome (Bull & the Committee on Genetics, 2011). Children with Down syndrome use numerous specialty care services, often early in infancy. Respondents in our study reported that their children received from 2 to 5 or more appointments weekly. Therefore, family-centered care and care coordination are essential for locating, accessing, and managing many services and supports tailored to each family's needs and expectations (Miller et al., 2009). A primary care provider who is knowledgeable about Down syndrome can provide optimal care for the child, support and information for parents, and assist in care coordination (Bull & the Committee on Genetics, 2011). Only 65% of respondents in our study reported that their children had medical homes. Those who did sought out providers who were knowledgeable about Down syndrome and found the care to be family-centered. The presence of a primary care provider within a medical home, along with continuous medical insurance coverage, may lead to earlier and more consistent care. The primary care provider can also support care coordination, which may reduce parental stress; decrease the necessity of reducing work hours; and lead to earlier, more comprehensive and effective medical, education, and therapy services (Burns et al., 2010). Parent and family characteristics and socioeconomic factors may affect utilization, satisfaction, and type of services received. Family-centered care should begin during prenatal care, continue throughout diagnosis, and include all aspects of the family's experience, as it will help the family cope with the information that they are receiving.

(American Academy of Pediatrics: Committee on Genetics, 2001; Phelps, Pinter, Lollar, Medlen, & Bethell, 2012). Guidance to health care providers (Sheets et al., 2011; Van Cleve & Cohen, 2006) urges physicians to address the health care needs of children and adolescents with Down syndrome and to support their families throughout the lifespan. Supporting parents in their roles as clients, drivers, and co-providers of services for their children can improve the quality and level of care coordination among providers and better manage existing and future health care services for their child (Miller et al., 2009).

< CALLOUT 3 >

Strengths and Limitations

One strength of our sample is that since it included parents of children who were 0-17 years of age at the time of the study (birth cohorts from 1995 to 2012), thus we can provide insights on parental care encounters with healthcare providers over a number of years. The variety of counties from which respondents originated – including over 30 birth hospitals – helped us gain a broader perspective on the regional differences in availability of services and supports in Florida. For instance, while a multidisciplinary health clinic for children with Down syndrome exists in Florida's northeast Duval County, no other similar clinics were found in the state. Parents who travel from throughout the state to this clinic may only visit once or twice per year.

Our study was limited by a small sample size despite persistent efforts to distribute surveys electronically and in-person through professional and social networks. We were not able to draw conclusions from this study regarding Spanish-speaking families' experiences because of the limited number of responses (15). Responses from individuals with children older than 10 years could have been affected by recall bias and practices may have changed over time.

Moreover, although not an objective of our study, smaller sample sizes for specific age groups limited our ability to have the statistical power necessary to investigate differences in the quality of family-centered perinatal services over time. Snowball sampling may have also contributed to homogeneity in the sample. Several respondents were recruited through Down syndrome support groups and intervention providers, which may impact the generalizability of results. The sample may also have been impacted by participant recruitment through community/social networks along with those who have available internet access. Funding constraints precluded our ability to effectively market the survey, or to explore other more costly survey media (e.g., paper); as such, families who were not connected to online networks are underrepresented in our study. Since factors associated with access to online networks may also be associated with care experiences, this further reduces the generalizability of our findings. Finally, some modifications to the Family Experiences Survey are needed for future projects. It will be helpful to collect information on the child's sex to examine possible differences in enrollment patterns and access to services, and the window for first receipt of specialty care and services should extend well beyond the birth to 36 months age range currently designated in the survey.

Implications for Practice

Family-centered care during the prenatal period, at the birth setting, and during the provision of primary and specialty care and coordination services may enable parents/caregivers of children with Down syndrome to overcome challenges. Accurate and timely information about Down syndrome and available resources should be component of family-centered care for these families. This model of care may also be used to guide the provision of diagnosis, information, and linkage to resources to improve family satisfaction and participation in essential services.

Conclusion

This exploratory study enabled us to take a snapshot of the experiences of families of children with Down syndrome across the state of Florida. The inclusion of open-ended questions in this bilingual survey provided the opportunity for respondents to share personal stories, struggles, and successes in their own words and to supplement and clarify the quantitative results from close-ended questions. Next steps include expanding the survey geographically and demographically, adapting the survey to other congenital anomalies and conditions, and validating the survey design. Because survey respondents were mostly older and wealthier White parents and caregivers of children with Down syndrome, in future research we will use recruitment methods and venues to capture the experiences of underrepresented subgroups who have children with Down syndrome. As shared by respondents in our study, timely diagnosis and referral to services, overlaid with clear and sensitive communication and information provision, greatly assist parents in accessing and coordinating the care that will help their children reach their fullest potential.

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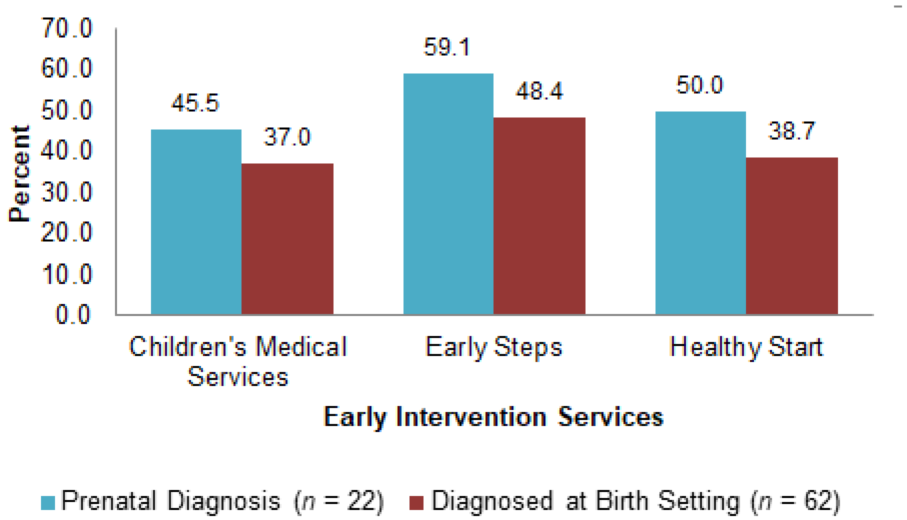

Figure 1. Participant Receipt of Information about Early Intervention Services by Time of Diagnosis

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Table 1: Sociodemographic Characteristics of Family Experiences Survey Respondents, Florida (*N* = 101)

Characteristic	*n* (%)
Role	
Mother	93 (92.1)
Father	6 (5.9)
Other	2 (2.0)
Missing	0 (0.0)
Age (years)	
Under 30	5 (4.9)
30 – 34	9 (8.9)
35 or older	84 (83.2)
Missing	3 (3.0)
Race/Ethnicity	
White non-Hispanic	72 (71.3)
Black non-Hispanic	3 (3.0)
Hispanic	12 (11.9)
Other	12 (11.9)
Missing	2 (2.0)
Education	
High School and Less	13 (12.9)
Some College	15 (14.8)
College Degree or Beyond	69 (68.3)
Missing	4 (4.0)
Marital Status	
Married/Partnered	88 (87.0)
Single/Divorced/Widowed	11 (11.0)
Missing	2 (2.0)
Annual Household Income	
$25,000 and under	14 (13.9)
$25,001 – $50,000	20 (19.8)
$50,001 – $75,000	17 (16.8)
Over $75,000	45 (44.5)
Missing	5 (5.0)
Type of Health Insurance	
Private Insurance	64 (63.4)
Public Insurance	31 (30.7)
Other	3 (3.0)
None	3 (3.0)
Missing	0 (0.0)

Place of Birth	
Born in the United States	87 (86.1)
Born Outside of the United States	11 (10.9)
Missing	3 (3.0)
English Proficiency	
Fluent	93 (92.1)
Somewhat Fluent	3 (3.0)
Not Fluent	1 (1.0)
Missing	4 (4.0)
Child Age (years)	
0-4	41 (40.6)
5-11	38 (37.6)
12-17	22 (21.8)
Missing	0 (0.0)

Note. Percentages may not add up to 100% due to rounding.

Table 2: Experiences of Family Experiences Survey Respondents, Florida (*N* =101)

Characteristic	Prenatal Care *N* = 93	Birth Setting *N* = 85	Primary Pediatric Care *N* = 66
	n (%)	*n* (%)	*n* (%)
Received Down syndrome information (brochure, information sheet, or book)			NA
Yes	18 (19.3)	35 (41.2)	
No	70 (75.3)	46 (54.1)	
Missing	5 (5.4)	4 (4.7)	
Adequate Provider-Patient Time			
Yes	76 (81.7)	53 (62.3)	61 (92.4)
No	13 (14.0)	26 (30.6)	5 (7.6)
Missing	4 (4.3)	6 (7.1)	0 (0.0)
Received Specific Information from Provider			
Yes	77 (82.8)	45 (52.9)	53 (80.3)
No	11 (11.8)	32 (37.7)	13 (19.7)
Missing	5 (5.4)	8 (9.4)	0 (0.0)
Provider Sensitive to Feelings			
Yes	66 (71.0)	45 (52.9)	63 (95.4)
No	22 (23.7)	36 (42.3)	3 (4.6)
Missing	5 (5.4)	4 (4.7)	0 (0.0)
Provider Sensitive to Family Values and Customs			
Yes	68 (73.1)	45 (52.9)	61 (92.4)
No	19 (20.4)	36 (42.3)	1 (1.5)
Missing	6 (6.5)	4 (4.7)	4 (6.1)
Familiarity of primary care provider with Down syndrome	Not available	Not available	
Knowledgeable			62 (94.0)
Not knowledgeable			2 (3.0)
Missing			2 (3.0)

Note. Percentages may not add up to 100% due to rounding.