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Parents' Dreams for Their Young Adults with Down syndrome: What Resources are Needed to Achieve Them?

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Parents' Dreams for Their Young Adults with Down syndrome: What Resources are Needed to Achieve Them?

by

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Dedication

To Cameron, my rock. You deserve this as much as I do. And to Mikey—may your dreams come true.

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I would like to thank all of the participating medical centers, clinics, and advocacy groups across the country for their willingness to support this vision. Without your support, this project would not have been possible. I would also like to express my sincere gratitude to my advisor Campbell Brasington and readers Vicki Vincent and Madeleine Will for your seemingly unending patience and valuable insight.

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In addition, I would like to thank all of the wonderful educators that have been instrumental over the years. Specifically, I would like to thank Janice Edwards and the faculty of the USC Genetic Counseling Program. Thank you so much for giving me this life-changing opportunity to fulfill my dream of becoming a genetic counselor.

Finally, I give thanks to God. To Him goes all the glory.

Abstract

This study sought to identify the goals parents have for their young adult sons and daughters with Down syndrome, the factors that help to achieve those goals, and parents' perceived barriers to successful attainment of those objectives. While many supports are readily available to youths with Down syndrome in primary and secondary school, many of these supports disappear as these individuals transition into adulthood. When combined with the inherent challenges of emerging adulthood, significant gaps in resources become evident for this population. In order to identify areas in need of improvement, this study surveyed 38 parents of post- and peri-transitional young adults aged 18 to 29. This sample population was drawn from a national advocacy group (National Down Syndrome Congress) and Down syndrome clinics across the nation. Participants completed a written or online survey in which they selected and ranked their goals, and described resources that are beneficial and are barriers to success. At the end of the written survey, participants were invited to take part in a semi-structured phone interview to expound on their experiences. 38 parents took the written survey and 13 took part in the phone interview.

Ultimately, many of the goals parents reported to be most important, including friendships, safety, paid employment, independent living, and access to healthcare, were amongst the least frequently achieved. A number of barriers, including lacking access to transportation, housing, and social options, were found to contribute to this disparity. In addition, this study replicated earlier reports, which indicated that protecting health, assuring safety and security in multiple realms, finding meaningful activities after high school, and establishing supportive social relationships were focuses of transitional youths with Intellectual Disability and their parents. Study participants also conceptualized new paradigms regarding independence and autonomy.

Keywords: Down syndrome, transition, adult, family, resources

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List of Abbreviations

ABLE	Achieving a Better Life Experience Act
DS	Down syndrome
ID	Intellectual Disability
IDEA	Intellectual Disability Education Act
IEP	Individualized Education Plan
NDSC	National Down Syndrome Congress
NDSS	National Down Syndrome Society

Chapter 1: Background

1.1 Down Syndrome

Down syndrome, or Trisomy 21, which has an incidence of about 1/830, is one of the most extensively studied genetic conditions. While there is great variability within this population, commonly occurring physical features, associated health problems, and cognitive characteristics have all been well defined. Many people with Down syndrome have specific and recognizable physical traits such as epicanthal folds, short stature, and brachycephaly. Infants and children with Down syndrome can also present with health problems like hypothyroidism, cardiovascular defects, hypotonia, obstructive sleep apnea, and gastrointestinal complications including Hirschsprung's disease and duodenal atresia (Steingass, Chicoine, McGuire, & Roizen, 2011). In addition to these childhood concerns, adults face somewhat different issues. These include an increased risk of developing hearing loss, vision problems, obesity, diabetes, seizures, and early-onset dementia (Desai, 1997; Pueschel, 1990; Smith, 2001; Steingass et al., 2011; Chicoine, McGuire, & Young, 1996). In spite of these health issues, advances in health care mean that, today, life expectancy for individuals with Trisomy 21 well exceeds 60 years (Stancliffe et al., 2012).

There is also significant variability in cognitive function among individuals with Down syndrome, and currently, it is unclear if this variability results mostly from environmental influences or individual genetic differences (Buckley, 2008). Common findings include deficits in expressive vocabulary, grammar and verbal short-term memory (Naess, Lyster, Hulme, & Melby-Lervag, 2011). While these cognitive differences may present challenges, people with Down syndrome often have strengths in social reasoning skills (Hippolyte, Iglesias, Van der Linden, & Barisnikov, 2010). In addition, people with Down syndrome are less likely to experience mental illness than others with intellectual disability. Behavioral problems are also less frequent in people with Down syndrome than with others diagnosed with intellectual disability (ID)—specifically, difficulties with aggressive, antisocial, or destructive behaviors are reported in a comparatively smaller percentage of individuals with Down syndrome (Hippolyte, et al., 2010).

People with Down syndrome are capable of living rich and fulfilling lives, and recent medical and social advances have likely increased the attainability of a high quality of life. Naturally, people who have Down syndrome enjoy many of the same activities as people with no chromosomal changes. Popular leisure activities amongst this group include socializing with friends, watching television, listening to music, reading magazines or books, and playing sports (Carr, 2008). Similar to many other youths, young people with Down syndrome are often captivated and influenced by television shows, movie stars, music, and other components of popular culture (Jobling, Moni, & Nolan, 2000). A study by Grantley, Brown, & Thornley, (2001) also found that many young people with Down syndrome, like their peers, are interested in employment, and can articulate their desires and job preferences. Jobling & Cuskelly (2002) found that, in their sample population of adults with Down syndrome who were working, 65% were placed in sheltered workshops, while only 23% were working in private enterprises.

Decreased private job opportunities, access to transportation, or relatively low independence may contribute to these numbers.

1.2 Needs of Affected Individuals

Because individuals with Down syndrome are at an increased risk for a number of associated health conditions, they often need more targeted medical care than persons without Down syndrome. The American Academy of Pediatrics has issued guidelines for the care of children with Down syndrome which include recommendations for opthalmologic, auditory, endocrine, cardiac, developmental, and gastrointestinal check-ups. In order to comprehensively monitor these potential health issues, several specialty clinics specializing in the care of people with Down syndrome have been created. In the United States, there are 58 centers—some of which specifically concentrate on adults, and some specialize in treating children and adolescents (NDSS, 2012b). Research suggests that these clinics can provide a detailed and targeted level of care that would be difficult for many primary care physicians to implement (Skotko, Davidson, & Weintraub, 2013).

In addition to medical needs, young adults with Down syndrome also have similar social desires as their same age unaffected peers, and friendships can be especially important in times of stress or change. As many people with Down syndrome are living longer lives and becoming more independent, these relationships can be an important source of support. However, making true friendships is a challenge for many people with Down syndrome. In fact, research suggests that, in comparison to typically developed peers, they often lack peer friendships (Jobling, Moni, & Nolan, 2000) and can have difficulty maintaining them outside of school (D’Haem, 2008). Unsurprisingly, emerging adults with Down syndrome are also interested in finding significant others. While few studies have explored romantic relationships amongst this group, preliminary studies suggest that many parents support their children having them (Camire, 2006).

1.3 Needs of the Family

While people with Down syndrome are in numerous ways the same as their typically developed peers, families of those with Down syndrome can still face significant challenges. In fact, parents of children with Down syndrome have been shown to report more stress than parents of typically developing children (Sanders & Morgan, 1997). This could occur because children with Down syndrome have significantly greater health needs than do typically developing children of the same age (Schieve, Boulet, Kogan, Van Naarden-Braun, & Boyle, 2011). Indeed, an analysis of the National Survey of Children with Special Health Care Needs revealed that children with Down syndrome experience more co-morbid conditions, face more significant family impacts, are less likely to have a medical home, and conversely, are more likely to have unmet needs than children with other special health care needs (McGrath, Stransky, Cooley, & Moeschler, 2011; Schieve et al., 2011). Nevertheless, families often show remarkable resilience and adaptability to challenging circumstances (Van Riper, 1999; King, et al, 2006). While some studies suggest higher rates of depression in these families, others emphasize their adaptability by citing positive changes within the family unit (King et al, 2006; Poehlmann, Clements, Abbeduto, & Farsad, 2005; Skotko, Levine, & Goldstein, 2011a). These articles, when combined with other data, suggest that the whole family structure can be altered in both positive and negative ways by a child with significant medical and developmental needs. Research by Barnett and Boyce (1995) supports this hypothesis. Their group found that allocation of family time differed from the average in parents of children with Down syndrome. These families "devoted more time to child care and less to social activities", and mothers spent less time earning money. These employment and financial issues were echoed by Schieve et al. (2011). Moreover, empiric evidence suggests an association between low socioeconomic status and trisomy 21 (resulting from nondisjunction in meiosis) (Hunter et al., 2013). While the etiology of this association is not known, this data suggests that, in general, mothers of individuals with Down syndrome may be more likely to experience financial disadvantages and other hardships. As a result of these influences, financial stressors could also be a source of anxiety for some families.

In spite of these pressures, some studies suggest that families with a child who has Down syndrome tend to experience less stress and have more harmonious family lives than families of children with other disabilities (Abbeduto et al., 2004; Hodapp, 2007). This trend could possibly be attributed to the relative lack of psychopathology amongst youngsters with a diagnosis of Down syndrome (Hodapp, 2007). The maturity level of mothers in this group may also play a role. Because of the association between Down syndrome and advanced maternal age, children with Down syndrome might often have more mature parents and stable home environments. At any rate, parents overwhelmingly report love for their child with Down syndrome, and do not regret having them (Skotko et al., 2011a). In fact, a significant portion of parents cite positive effects on the family unit, like learning flexibility, patience, and appreciation for differences (Skotko et al,, 2011a). Finally, siblings also report affection for and pride in their brothers and sisters with Down syndrome, and 88% of surveyed siblings even feel that they are better people because of their siblings (Skotko, Levine, & Goldstein, 2011b). These data suggest that while caring for loved ones with Down syndrome can in some ways be a different experience than raising a typically developing child, many families see it as a positive experience.

1.4 Available Support and Opportunities Throughout Childhood and Adulthood

Increasingly, the education and research communities are recognizing the unique challenges that many families in the Down syndrome community face. Within the educational system, there is policy in place which funds, regulates, and offers guidelines for the care of students with special needs. Under the Individuals with Disabilities Education Act (IDEA), children with Down syndrome have access to early intervention programs and Individual Education Programs (IEPs), and are placed in the least restrictive classroom environment (Noyes-Grosser et al., 2005). While adherence to the guidelines varies by location, these guidelines ensure that resources are available within the education system and promise at least a minimal level of care for children with special needs.

One of IDEA's focuses involves facilitating successful transition from the security of school to a more independent adult life—a challenging and nebulous course for most high school graduates with or without Down syndrome. The emergence of adulthood often brings with it many changes, including the roles, routines, and authority system of the family unit. While some young adults with Down syndrome continue to live in the home for some time, others transition into their own independent or semi-independent living arrangements. Nevertheless, the search for autonomy seems to be a common theme in this group. A study by Docherty and Reid (2009) found that parents often facilitate activities for their adult children and see themselves as "gatekeepers" of their transition and activities. Ultimately, however, parents felt that independence was natural and desirable for their children, and that evolution into a self-sufficient state was the ultimate goal.

While many parents want to work with their children to develop a self-sufficient lifestyle, it can be difficult to achieve. Fortunately, several mandated components of IDEA have been associated with positive goal attainment and improved post-transitional outcomes. Specifically, inclusion and transition programs have been shown to improve outcomes involving post-secondary school, employment, and education (National Secondary Transition Technical Assistance Center, 2010). In addition, other experiences have been associated with "desired" outcomes. For example, curricular life skills intervention has been associated with improved functional life skills (Alwell & Cobb, 2006), and vocational work, self-advocacy skills, and paid work experience have also been associated with improved employment outcomes (National Secondary Transition Technical Assistance Center, 2010). While this data offers practical evidence-based information about transition, further research on the relationships between extra-scholastic resources and the achievement of goals is still needed. In addition, these studies have pre-selected "desirable" outcomes instead of analyzing goals that the families themselves find valuable.

A survey undertaken at the 2000 NDSS (National Down Syndrome Society) convention did examine advocates' and parents' priorities and dreams for their loved ones with Down syndrome (Cohen, Nadel, & Madnick, 2002a). Priorities outlined by parents included postsecondary education, real job opportunities, and self-determination involving housing and money. Respondents also called for improvements in support involving budgeting, navigating employment services, and transition-planning.

In contrast to the childhood years, these available educational and vocational resources for post-secondary aged adults with Down syndrome are often insufficient (Cohen et al., 2002a). This often leaves family members and caregivers unable to provide optimal employment opportunities for their children during this crucial time. Fortunately, post-secondary school is now an option for some high school graduates with Down syndrome. Nationwide, there are over 50 such programs (Papay & Bambara, 2011). While training options for emerging adults with intellectual disability have existed since the 1970s, various separate, mixed, or individualized program models have since evolved (Papay & Bambara, 2011). Generally speaking, these programs are held on college campuses, and their curricula can be described as separate and transition-focused, dually-enrolled, or inclusive, respectively. These programs are operated mostly by local school districts (55.8%), outside organizations (17.3%), or the colleges themselves (42.3%) (Papay & Bambara, 2011). While school districts fund many of these programs, federal funding is limited and some pupils are responsible for their own tuition fees. However, some students can receive some federal financial aid grants and Work Study jobs, provided that they are involved in programs that are at least 50% inclusive (NDSS, 2012a). In addition, admissions criteria for some of these programs require that students be able to travel to school independently or complete prerequisite courses, which may not be possible for all youths with Down syndrome. Available classes in these programs include vocationally focused courses, health/fitness, lifeskills, “remedial” courses, computing, general academics, and the arts (Papay & Bambara, 2011).

1.5 Existing Research

While scientific literature clearly examines parents’ attitudes towards prenatal testing for Down syndrome as well as the healthcare of affected children, very little research focuses on young adults with Down syndrome. However, studies show that new parents are interested in the future, even very shortly after receiving a diagnosis of Down syndrome (Sheets, Best, Brasington, & Will, 2011). In addition, the existing research quantitatively describes many aspects of life after high school for young adults with intellectual disability (Alwell & Cobb, 2006; Bouck, 2012; Cobb & Alwell, 2009; National Secondary Transition Technical Assistance Center, 2010), but these do not separate Down syndrome from other conditions (in America) (Foley et al., 2013). The quantitative nature of these analyses also neglects deeper parental insight which could reveal less obvious themes. In the past, several studies have also analyzed the impact of specific practices and resources on outcomes seen in children with special needs (National Secondary Transition Technical Assistance Center, 2010). However, parents’ perceptions of the effects of these and other components have not been extensively gathered. As parents have the most intimate perspectives on family life, their thoughts and experiences are invaluable in any research aiming to determine which factors truly make an impact on their children. Moreover, there has been a call for more information on the life-span needs of families of persons with Down syndrome (Bouck, 2012; Hodapp, 2007). As the lifespan of the average person with Down syndrome increases, so does the need to address the care of and attention to this growing population.

1.6 Value in Genetic Counseling

Genetic counselors play many roles at different stages in the lives of parents of and people with Down syndrome. These roles range from balanced information-giving, diagnostics, decision facilitating, and psychosocial support in the prenatal setting to medical management, resource provision, and advocacy in the pediatric and adult arenas. Understanding motivators and experiences of this specific patient group is relevant in each of these areas. Specifically, while each family has unique desires and experiences, determining general trends in a specific population can still provide helpful information that can be used to anticipate common psychosocial concerns for adolescents, emerging adults, and their parents. In fact, determining underlying family motivators can help genetic counselors effectively utilize advanced empathy and build better rapport with patients (Veach, LeRoy, & Bartels, 2003). It follows that understanding what parents desire most for their adult children with Down syndrome could be a crucial component in effective psychosocial counseling. Defining parents' goals for their child's future is a primary step in facilitating their attainment, and determining why these dreams and goals change (or do not change) over time could provide valuable insight. The relative ages at which these changes occur might also reveal critical periods for this group—during which more support is often needed.

Finally, in addition to its obvious benefit in the pediatric realm, this topic is relevant in prenatal genetic counseling. Since parents are interested in their child's distant future (Sheets et al., 2011), views from parents of older children and adults will, no doubt, be valuable to new parents who are just beginning their lives with children who have a Down syndrome diagnosis.

1.7 Rationale of Current Study

While there is a preponderance of data surrounding prenatal diagnosis and care of children with Down syndrome, young adults with this condition remain underserved and under-researched. This study aimed to ameliorate this deficit by examining hopes and life goals described by families of young adults with Down syndrome, as well as their reported resources. Specifically, it utilized both quantitative and qualitative analyses to determine parents' aspirations and goals for their adult children and analyze how their dreams evolve over time. Trends reflecting changes in outcome appraisal/value were also used to examine the impacts of external factors on perceptions of the quality of their child's future. As a secondary objective, this study sought to examine the types of resources parents perceived to have the greatest impact on these desired outcomes. Moreover, by comparing parents' ideal resources with the supports that are truly available to these families, the study has identified specific resource deficits experienced by families in the Down syndrome community. Elucidating these needs may inform future decisions regarding allocation of funding and recommendations for future programs to aid children and young adults with Down syndrome. Particularly in the qualitative portion of the study, we focused on the reasons why parents feel these goals and desired resources are important and why their attitudes about them change (or don't change) over time.

Chapter 2:

Parents' Dreams for Their Young Adults with Down syndrome: What Resources are Needed to Achieve Them?[1]

2.1 Abstract

Abstract

This study sought to identify the goals parents have for their young adult sons and daughters with Down syndrome, the factors that help to achieve those goals, and parents' perceived barriers to successful attainment of those objectives. While many supports are readily available to youths with Down syndrome in primary and secondary school, many of these supports disappear as these individuals transition into adulthood. When combined with the inherent challenges of emerging adulthood, significant gaps in resources become evident for this population. In order to identify areas in need of improvement, this study surveyed parents of post- and peri-transitional young adults aged 18 to 29. This sample population was drawn from a national advocacy group (National Down Syndrome Congress) and Down syndrome clinics across the nation. Participants completed a written or online survey in which they selected and ranked their goals, and described resources that are beneficial and are barriers to success. At the end of the written survey, participants were invited to take part in a semi-structured phone interview

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to expound on their experiences. 38 parents took the written survey and 13 took part in the phone interview.

Ultimately, many of the goals parents reported to be most important, including friendships, safety, paid employment, independent living, and access to healthcare, were amongst the least frequently achieved. A number of barriers, including lacking access to transportation, housing, and social options, were found to contribute to this disparity. In addition, this study replicated earlier reports, which indicated that protecting health, assuring safety and security in multiple realms, finding meaningful activities after high school, and establishing supportive social relationships were focuses of transitional youths with intellectual disability and their parents. Study participants also conceptualized new paradigms regarding independence and autonomy.

Keywords: Down syndrome, transition, adult, family, resources

2.2 Introduction

Over their lifetimes, individuals with Down syndrome often face significant challenges. In addition to some degree of intellectual disability, a predisposition to develop early-onset dementia, and expressive language deficits, many people with DS must cope with a myriad of health issues—including cardiac problems, hypothyroidism, and gastrointestinal issues (Cohen et al., 2002b). Nevertheless, individuals with DS often live rich and fulfilling lives that include many of the same accomplishments that their typically developing peers strive for. However, many of these intrinsic challenges, when combined with additional external barriers, can render some goals and dreams difficult to achieve.

To help mitigate some of these obstacles, various policies have been put in place, which are designed to provide resources to children and youths with DS. Within the educational system, IDEA, or the Intellectual Disabilities Act, ensures that children with DS have access to early intervention and other services, including IEPs, or individual education plans, which are tailored to each child's individual needs (Noyes-Grosser et al., 2005). In addition, pediatric guidelines outline specific screening and healthcare recommendations for all children with Down syndrome (Bull, 2011). In contrast, fewer resources are often available to these families as youths leave the pediatric realm and transition into adulthood. While medical recommendations, educational resources, employment support, and other resources are available to some young adults with Down syndrome, access can be limited for many other individuals.

Using qualitative and quantitative analyses, our study sought to characterize the resources available to this group during and after this transition period. As parents are often primary care providers and are almost always actively involved in young adults' lives, we invited them to share their perspectives for this project. First, we established which goals were important to parents of emerging adults with DS. Our next aim was to characterize the effects of numerous resources on the achievement of these important goals. This data revealed barriers and areas of need for this population as well as which resources have proven valuable to then. In addition, parents shared their visions of the perfect future for their sons and daughters. This allowed us to come to a deeper understanding of what is truly important to these parents.

This information has relevance in the field of genetic counseling in various ways. Indeed, genetic counselors play various roles involving individuals with Down syndrome as well as their families. For example, prenatal genetic counselors facilitate screening, testing, and diagnosis of DS for expectant mothers. As a result, they are charged with the responsibility of providing accurate information concerning the spectrum of health concerns, lifespan needs, and abilities people with Down syndrome can have. For this reason, studies focusing on the accomplishments and challenges faced by adults with Down syndrome are crucial—patients often use information provided during this sensitive time to make pregnancy management, future reproductive, and major life decisions. The impacts of these initial meetings can be lasting and sometimes life-altering. In addition, pediatric genetic counselors often interact with children with Down syndrome and their families in a clinical setting for a number of years. During these interactions, counselors assist with patient intake and often respond to parents' inquiries. As patients grow older, parents may naturally have questions about available resources as well as future prospects for their children and youths with Down syndrome. While all individuals, of course, have unique strengths and challenges, projects designed to clarify the ranges of these possible future outcomes may provide helpful insight for patients in settings like these.

2.3 Materials & Methods

2.3.1 Participants.

The participant group consisted of parents of young adults with Down syndrome aged 18 to 29 were invited to participate in a written survey and an optional interview. A flier with an invitation to participate in a written or online survey through SurveyMonkey.com was given to Down syndrome clinics across the United States for distribution to families of their current patients. These clinics were accessed and invited via the Down Syndrome Medical Interest Group at DSMIG-usa.org. In addition, the flier was posted on the study section of the NDSC website. Patients without internet access were able to call and request packets, which included an invitation/introduction letter, a written survey, and a pre-paid return envelope.

2.3.2 Research methods and statistical analysis. Quantitative analyses were performed on data collected through the survey using Microsoft Office Excel 2013 software and Statistical Package for Social Sciences (SPSS), version 22.0. Surveys contained a questionnaire with nine ranking, Likert scale, and open-ended questions. Refer to Appendix A. for the complete survey.

Participants who agreed to be contacted for qualitative analysis participated in structured telephone interview, which asked them to expound upon some of the closed ended questions that were covered in the online or hard copy survey. The information gleaned from this portion of the study was analyzed for themes using Grounded Theory methods.

Since this project was somewhat exploratory, descriptive statistics, such as frequencies and percentages, were used to assess trends in nominal portions of the study, such as importance rankings of goals, top 3 goals, achieved goals, and categorical responses to open-ended questions. Fisher's exact test was utilized to examine associations between demographic data and these nominal survey responses as well as between nominal and ordinal (ranked) survey responses.

This study was approved by the Institutional Review Board of the Office of Research Compliance, University of South Carolina, Columbia, in September, 2013.

2.4 Results

2.4.1 Quantitative analysis.

2.4.1.1 Demographics. Of the original 61 study participants who responded to the invitation, 38 met all requirements and completed the survey. Table 2.1 outlines the demographic characteristics of the subjects. Parents also answered demographic information about their young adult sons and daughters with Down syndrome. See Table 2.2 for demographic information concerning subjects' young adult children with DS.

2.4.1.2 Importance of goals for young adults. Parents were asked to rate the importance of 17 specific goals using a Likert scale*: 5 = Highest importance; 4 = High importance; 3 = Medium importance; 2 = Low importance; 1 = Lowest importance.* In descending order, goals including *Safety, Access to healthcare, Friendships, Personal living skills, Self-advocacy, Leisure activities, Mental health, Paid employment,* and *Financial security* had rankings above "High Importance." Miscellaneous "*Other*" goals and *Supervision/assistance with daily activities* were both ranked "High Importance," while *Independence-related skills* (paying bills, using a calendar, keeping appointments, buying groceries), *Independent living* (outside of the parents' home), *Marriage and romantic relationships,* and *Post-secondary* (after high school) *education* were ranked between "*High Importance*" and *"Medium Importance."* See Table 2.3 for specific ratings.

Table 2.1

Parent Demographic Descriptions

Age of Parent		***Number (n)***	***Percentage (%)***	**Parent Marriage**		***Number (n)***	***Percentage (%)***	**Average Household**		***Number (n)***	***Percentage (%)***
	25 to 34	0	0.00%		Single/Never Married	0	0%		$0-$24,999	*0*	*0%*
	35 to 44	3	7.90%		Married	35	92%		$25,000-$49,999	1	3%
	45 to 54	20	52.60%		Widowed	1	3%		$50,000-$74,999	8	22%
	55 to 64	13	34.20%		Separated	0	0%		$75,000-$99,999	3	8%
	65 to 74	2	5.30%		Divorced	2	5%		$100,000-$124,999	9	25%
	75 or older	0	0.00%		Remarried	0	0%		$125,000-$149,999	4	11%
					With a Partner	0	0%		$150,000-$174,999	2	6%
Parent Education		0	0%						$175,000-$199,999	3	8%
	Less than high	2	5%	**Parent Ethnicity**					$200,000 and up	6	17%
	High school	5	13%		Asian	1	3%				
	Some college	5	13%		Black	1	3%	**Gender of Parent**			
	Associate degree	15	40%		Hispanic	1	3%		Female	37	97%
	Bachelor degree	11	29%		Native American	1	3%		Male	1	3%
	Graduate degree				White	37	97%				
					Other	0	0%				

Table 2.2

Young Adult Demographic Information

Age of Young Adult	***Number*** *(n)*	***Percentage*** *(%)*	**Residential Status of Young Adult**	***Number*** *(n)*	***Percentage*** *(%)*	**Ethnicity of Young Adult**	***Number*** *(n)*	***Percentage*** *(%)*
Less than 20	14	37%	With his/her parents	29	76%	Asian	2	5%
20-21	9	24%	With his/her spouse/partner	0	0%	Black	1	3%
22-23	3	8%	With a family member who is not a parent	1	3%	Hispanic	2	5%
24-25	5	13%	With a friend	0	0%	Native American	1	3%
26-27	3	8%	Alone	1	3%	White	36	95%
28-29	4	11%	In a residential school or boarding school other than a college	2	5%	Other (please specify)	0	0%
			In a college dorm	2	5%			
Education Level of Young Adult			In a group home or other supervised living arrangement	1	3%	**Gender of Young Adult**		
Less than high	16	42%	In a medical or mental	0	0%	Female	24	63%
High school degree or	14	37%	Other (please specify)	2	5%	Male	14	37%
Some college but no degree	8	21%						
Associate degree	0	0%						
Bachelor degree	0	0%						
Graduate degree	0	0%						

2.4.1.3 Top 3 goals for young adults. Study participants also chose their top three most important goals from a list of the same 17 goals. The goals that most frequently fell into the top three categories were *Friendships*, *Safety*, *Paid employment, Independent living,* and *Access to healthcare*, respectively. Goals following closely behind these top selections include *Personal living skills, Independence-related skills,* and *Financial security*.

Associations between goal selection and demographic data were also examined. Using Fisher's Exact Test, age of the young adults was not found to be significantly associated with goal selection. In addition, young adult residential category was not associated with selection of the top two most important goals (also using Fisher's Exact Test). See Table 2.4 for total frequencies, and Appendix B. for specific counts of first, second, and third goals.

2.4.1.4 Achievement of goals. Next, subjects shared how close their children were to achieving these top three goals using a Likert scale: *5 = My child has achieved this goal, 4 = Very close, 3 = About halfway, 2 = Not very close, and 1 = Not close at all*. On average, parents reported ratings of 3.27, 3.3, 3.57 for goals 1, 2, and 3, respectively. Table 2.5 delineates specific response frequencies.

To examine associations between goal achievement level and demographic data, Fisher's Exact Test was utilized. No demographic characteristics were found to be significantly associated with the achievement status of goals.

Table 2.3

Goal Ratings

Answer Options	Rating Average	Answer Options	Rating Average
Safety	4.89	Other	4
Access to healthcare	4.74	Supervision/assistance with daily activities	4
Friendships	4.71	Independence-related skills (paying bills, using a calendar, keeping appointments, buying groceries)	3.97
Personal living skills (for example, hygiene/bathing, dressing, and eating)	4.53	Independent living (outside of the parents' home)	3.81
Self-advocacy skills (being able to decide and stand up for his/her opinions or to voice his/her preferences)	4.35	Marriage and romantic relationships	3.38
Leisure activities (hobbies)	4.32	Post-secondary (after high school) education	3.32
Mental health	4.19	Unpaid employment (volunteer work)	2.72
Paid employment (competitive employment in the community)	4.19	Sheltered work (in a "workshop")	1.59
Financial security (enough money to cover living expenses)	4.16		

Goal Ratings (5=Highest importance; 4=High importance; 3=Medium importance; 2=Low importance; 1=Lowest importance)

Table 2.4

Most Important Goals

Goal	Frequency (n)	Goal	Frequency (n)
Friendships	16	Mental health	4
Safety	15	Marriage	2
Paid employment	13	Other	2
Independent living	10	Leisure	1
Access to healthcare	10	Supervision	1
Personal living skills	8	Sheltered workshops	1
Independence-related skills	6	Unpaid employment	0
Financial Security	6	Post-secondary	0
Self-advocacy	4		

Table 2.5

Achievement Level of Most Important Goals

Answer Options	Not close at all	Not very close	About halfway	Very close	My child has achieved this goal	Rating Average
The most important goal?	2	7	12	11	5	3.27
The second most important goal?	2	6	13	11	5	3.3
The third most important goal?	2	4	9	15	7	3.57

Goal Ratings (5=Highest importance; 4=High importance; 3=Medium importance; 2=Low importance; 1=Lowest importance)

Parents were also asked to check which goals were achieved. See Table 2.6 for an outline of these results

2.4.1.5 Family quality of life survey. In the Family Quality of Life Survey, parents ranked their satisfaction with multiple quality of life measures using a Likert scale: *5 = Very Satisfied, 4 = Satisfied, 3 = Neither, 2 = Dissatisfied, and 1 = Very Dissatisfied.* Averages of these responses were tabulated, and can be referenced in Table 2.7. Overall, quality of life was high for most participants, with average ratings ranging from 3.46-4.77.

2.4.2. Qualitative analysis

2.4.2.1 Written results. In addition to quantitative analyses, parents were asked to provide answers to open-ended questions about helpful resources, missing resources, and dreams for their sons and daughters. Qualitative analysis using Grounded Theory methods resulted in the following Themes:

Helpful resources. Answers to the prompt "*What resources/supports have helped you/ your child to achieve these goals?*" fell into several themes. The most commonly mentioned themes were *Family advocacy and community support*, *School resources, Local and national organizations,* and *Government assistance,* with 26, 14, 12, and 11 instances in which parents cited them as beneficial, respectively.

Insufficient resources. Parents were also asked, "*What resources/support do you still need to help achieve these goals? In other words, what missing resources are preventing your child from succeeding?*" The most frequently listed missing resources fell into three themes: *Training, Social support,* and *Transportation.* These themes had 11, 7, and 6 mentions, respectively.

Table 2.6

Achieved Goals

Answer Options (Goals)	Response Percent	Response Frequency	Answer Options (Goals)	Response Percent	Response Frequency
Leisure activities (hobbies)	66.70%	24	Safety	25.00%	9
Personal living skills (for example, hygiene/bathing, dressing, and eating)	63.90%	23	Self-advocacy skills (being able to decide and stand up for his/her opinions or to voice his/her preferences)	16.70%	6
Access to healthcare	61.10%	22	Independent living (outside of the parents' home)	13.90%	5
Friendships	55.60%	20	Financial security (enough money to cover living expenses)	13.90%	5
Supervision/assistance with daily activities	50.00%	18	Sheltered work (in a "workshop")	5.60%	2
Unpaid employment (volunteer work)	47.20%	17	Independence-related skills (paying bills, using a calendar, keeping appointments, buying groceries)	5.60%	2
Mental health	30.60%	11	Other (please specify)	5.60%	2
Paid employment (competitive employment in the community)	27.80%	10	Marriage and romantic relationships	2.80%	1
Post-secondary (after high school) education	27.80%	10			

Table 2.7

Family Quality of Life Survey

Answer Options	**Rating Average**	**Answer Options**	**Rating Average**	**Answer Options**	**Rating Average**
My family enjoys spending time together.	4.69	Our family solves problems together.	4.17	Adults in my family have time to take care of the individual needs of every child.	4.03
My family members help my child with Down syndrome learn to be independent.	4.4	My family members support each other to accomplish goals.	4.34	My family gets dental care when needed.	4.74
My family has the support we need to relieve stress.	4.03	My family members show that they love and care for each other.	4.66	My family feels safe at home, work, school, and in our neighborhood.	4.77
My family members have friends or others who provide support.	4.2	My family has outside help available to us to take care of special needs of all family members.	3.46	My family member with Down syndrome has support to accomplish goals at school or at workplace.	3.91
My family members help my child with Down syndrome with schoolwork and activities.	3.82	Adults in our family teach my child with Down syndrome to make good decisions.	4.4	My family member with Down syndrome has support to accomplish goals at home.	4.51
My family members have transportation to get to the places they need to be.	4.14	My family gets medical care when needed.	4.66	My family member with Down syndrome has support to make friends.	3.83
My family members talk openly with each other.	4.2	My family has a way to take care of our expenses.	4.54	My family has good relationships with the service providers who provide services and support to our family member with Down syndrome.	3.97
My family members teach my child with Down syndrome how to get along with others.	4.29	Adults in my family know other people in my child with Down syndrome's life (friends, teachers, etc.).	4.23		
My family members have some time to pursue our own interests.	4.38	My family is able to handle life's ups and downs.	4.43		

(5=Very Satisfied, 4=Satisfied, 3=Neither, 2=Dissatisfied, and 1=Very Dissatisfied)

Resources needed for long-term maintenance of goals. Responses to the prompt "*What resources/supports would you/ your child need to maintain these goals long-term?*"

were grouped into these themes: *training (n = 10), funding (n = 9), housing (n = 7),* and *transportation (n = 7).*

Dreams about the future. When parents were asked "*What are your dreams or goals for your child's future?*" Their responses could be grouped into a few key themes, including *Employment, Friends, Independent living,* and *Health.* Parents emphasized employment *(n = 18),* friends *(n = 15),* independent living *(n = 14),* and health *(n = 10).*

2.4.2.2. Phone interviews. At the end of the survey, participants were asked to include their contact information if they wished to participate in a phone interview. Of the 38 survey participants, 13 were available for interviews, during which they discussed their dreams, goals, and resources in greater depth. Several common themes emerged from this qualitative data including *barriers to success, beneficial resources, dreams for the future*, *dreams over time,* and *other advice for fellow parents*.

Barriers to success. Comments within this theme fell into two subthemes: insufficient resources and other intangible barriers.

- *Insufficient resources*

In the interviews, parents described several missing resources that hinder the achievement of goals and successful outcomes. One of the most commonly cited missing resources was adequate housing options. Specifically, several parents expressed a desire for more options that provide a degree of individual autonomy and facilitate supported independence.

- *If [name] lived in an apartment where she was just supervised, she can make a lot more choices about what she ate, what she felt like doing, rather than being told. So I think it's just like another step in independence for her. You know, to live there and to be able to run out of clothes because, you know, she didn't do her laundry. And then to think of and have a natural consequence of life. Life would be able to teach her a whole lot more if she could achieve the next level up of independence.*
- *If she has a good day, she will do great and do all of these safety precautions that she needs to do with cooking and maybe follow an easy recipe. But if there's a day when she didn't get the sleep she needed and doesn't feel well, that can go through the window. So she needs personnel that [will] help and oversee it a little bit. Don't be on top of her and watching every move—but can judge [what she needs] a little bit.*
- *My goal is to eventually find small apartment complexes that have 24 hour emergency services but basically the adult is living on their own and responsible for themselves to the best of their abilities, but the help is there if they need it --whether it's help with paying their bills or finding transportation.*

In addition, some parents said that ideal living situations are often unaffordable for families.

- *What's available to him right now as far as housing is pretty pitiful --as far as just being a group home, unless you do a "for pay" scenario. The normal person can't afford spending $50,000-$100,000 a year depending on how nice of an environment.*

Parents also expressed a desire for more available living arrangements that promote social opportunities.

- *When he was in college his friends were always around him and they were always getting together to watch this TV show or go to that birthday party. He doesn't have that accessibility to other friends like that-- that are living independently and living close to each other. And I think it's because not that many people live in their own apartment. They're either in group homes or with their parents. So they can't just say "you want to come over John? Come on over." So we want them to have a place on their own where they can arrange their own things.*
- *Before she went away to school she… she did try after high school going to a day program. She lasted maybe nine months and then got really bored there. I think the problem with most of the group things that they have for people with disabilities is that they are all age ranges. So it goes from 18 to 80. And she doesn't want to spend her day with 80-year-olds.*

Some parents also felt that the available housing options do not provide safe or reliable environments.

- *If the government would…. they are giving out the Social Security and that's fine. But they don't put in place the kind of homes, other than basically nursing homes or people that aren't looking out for him properly…. and you run into the same scenario as a nursing home. You look at the type of people that are taking care of these people in nursing homes and it's horrific. Basically we are in the same boat. It just that we are younger and we can watch what's going on.*

Other insufficient resources include continuing education. Some parents simply felt that there were not enough postsecondary programs for young adults with ID.

- *…and then continuing educational activities [are a problem]. When we started Beyond Academics there were only two or three post secondary programs that I knew about. Now they are starting to crop up all over the place and I think that's great. So I think that's very exciting.*

Other parents expressed a need for more financial support for college.

- *I wish there had been more financial support for college. We bumbled into a scholarship, but at a major university the situation is $25,000. There are probably ways to figure it out if you haven't graduated…if they let you still be in high school if you go to the university and use special ed dollars along with Medicaid but they wouldn't let her graduate late. So we couldn't access special ed dollars.*

Finally, participants also desired continuing education for young adults who are not "high functioning."

- *I mean, my daughter still doesn't read and it's hard to figure out what she needs to be able to learn to read. I mean, there is a point where she did pretty good.. At least kindergarten, first grade level. But then that suddenly stopped and it's not because of her abilities, it's more because everything else that's going on and how we are teaching. I would love to see continuous education…I mean, some colleges try to start some groups but mostly they are looking at life skills—you know, why not? But usually they include people with intellectual disability that can read a little bit. But there is really nothing much for the other groups that still struggle with reading.*
- *I don't think there is enough, let's see, facilities or programs, not necessarily day care, but when kids get a certain age over 12 you don't really have any place for them to go if you are a full-time worker and parent….So, just her being home by herself is not something we would want to do for a long period of time even all day during the summer time....I guess I meant that after high school that's basically it. I guess college programs or… I don't necessarily mean like government programs… that I think more so of just what is available for them after high school. So different available things that they could possibly do in areas that they like. You know, things that they like to do. There's just not much available after high school for them to do.*

Another absent resource that participants commented on was transportation. Particularly, parents felt that transport was necessary to maintain fulfilling friendships and avoid depression.

- *…transportation for social events—for going to the movies and Special Olympics. Unless you live on a public bus line, the specialized services don't do it. They'll transport you to a doctor's office, for grocery shopping, but the movies? No. For people who are in a more financially limited situation, the social life goes away. And you get into issues with depression and other problems.*
- *I sometimes worry about depression a little. Because she's, um, a little more high functioning than others so she kind of gets it. It's not like a typical kid that can get in the car and drive where their friends are. Most of her friends are dependent on somebody else bringing them or taking them where they need to go.*

Insufficient transportation also had a negative impact on the independence and employability of young adults with Down syndrome. One mom said, *"I could take her up a level of independence if I could let her use public transportation. But there's none."*

- *Sometimes the paratransit bus gets them an hour and a half after pickup time. So then you are an hour and a half late for work. So those are the big stumbling blocks for people with cognitive disabilities. It's slowing getting better but it's not fast enough.*

Available transportation resources are also not always safe.

- *Yeah I think a huge resource for our kids is safe transportation. [Name] would never be driving . And the bus—[name] probably could do it but for me that's one of the places where I'm too overprotective. You know some people get off at the same place at the same time every day and there are predators who look for that.*
- *The one job she had that she did enjoy was at a AAA baseball stadium in the summer. But transportation was a big issue because it was nighttime. Transportation is tough. To me it's not safe for her here. Up where she goes to school, it's fine. But not where we live.*

Parents also shared their concerns about the lack of opportunities for social interaction amongst young adults.

- *I've joined up with groups on here try to find activities for her and they are just not there. She does dance once a month and that is just not enough for her. But I think friendships …someone she can call and go to the movies with…she is missing that now.*
- *She does use Medicaid funds to hang out socially but it's not like a set "Hey, I know my friends are going to be somewhere". It's not very well organized. So I feel like that could be a lot stronger.*

Several parents hoped to see an increase in available employment and consistent job supports for young adults with Down syndrome.

- *And finding those programs is pretty easy within the system, but again some of these programs—once they get you your first job, they're pretty much done with you. You've achieved the goal and it's not to keep achieving that goal.*
- *She is an office assistant three days a week. He [her boss] is a really good guy. His platform last year was to find more jobs for people with disability and he hired [name] and she's been there for a year and a half now. But he has a four-year term so when that's up we will have to make sure we can find her other employment—which is not easy to do. Not a lot of employment available for people with disabilities.*

Some participants also called for more focused group activities in which individuals meet to share in a common experience or interest.

- *I would love it if they had something—a craft day twice a month. Something like that, that where different people can come together with different interests and sit next to each other and learn crocheting or knitting or anything like that.*
- *And we are trying to find a cooking class and we've had no success so far. You know, things like that. Because I think she would enjoy it—learning basic cooking in a group environment with other people that have the same interest.*

Another missing resource cited by parents was inclusive programs or opportunities.

- *There [are] a lot of “dayhab” settings but again he doesn't like to be around other special needs people believe it or not. It’s hard to put him in these because he is not going to be happy there. Some kids are happy there that he is not one that likes to be continually just around special needs people.*
- *They say that they are not different or that they are not treated different but it is different because a 19-year-old child with a disability can't do the same as a 19-year-old with nothing… I mean I guess just more involvement with them. Because a lot of kids with special needs learn from what they see, or mimic what they see. If they are in an environment with all just special needs kids they don't really have a chance to advance.*

Health services were also difficult to access for some parents and their sons and daughters.

- *…having gyms like the YMCA and different centers help families with the cost because our kids do need to be active, and they already have challenges because of their disability. Health problems are going to arise if they don't get enough exercise.*
- *Unfortunately when you turn 21 you can no longer attend a Children's Hospital. So finding adult health care for her has been difficult. It took me 18 months to find a family physician that would take her on….and then it was hard because when you're in a Children's Hospital all the*

specialists were there. So when you get to the adult (indiscernible), there is nothing like that.

-Intangible Barriers

In addition, parents of young adults with Down syndrome reported that their children faced barriers that were unrelated to specific resources. One of these barriers was the attitudes of others. Parents felt that misconceptions have been barriers to safety and employment.

- *Well I guess the safety issue. The big thing is he's alone when he's at the community college, so I think the barriers are other people's understanding of people with disabilities. You can't put the kids in a bubble, but there is inherent danger in having a cognitive disability in public.*
- *…how do I convince employers that with just a little bit of effort on their part they will have a very good employee? I think getting the word out about that is the main thing because our kids want more than people think. And until they have an opportunity to prove it to people – to the world – it's a shame that they have to prove themselves all the time too.*

Other barriers cited by parents included inadequate transition assistance from school programs.

- *Our transition program that [name] is in through our school district does unpaid work experience and not the paid. They have a 2% success rate in placing students in paid employment by the time they are out of* *the program, and they don't really seem to have….be concerned with researching why it's 2% or doing any better than that….they don't support community college classes. And my son has taken some community college classes without their support-- some he's passed, some failed. . So you know actually supporting the person's individualized goals would be very critical.*

- *In transition meetings, the transition person came and I said that I would love for [name]—she's in an early childhood classroom right now—for her to be a teachers aide. And I said, "I'd love for her to have a job within the school district." And they said "Well she will have to apply." Okay, she can apply but who can make that actually happen?*

The final barrier that parents reported involved financial regulations. Specifically, loss of entitlements including SSI disability and Medicaid/Medicare can occur if financial assets are in excess of $2000.

- *And then, there was the implications of social security and you know you can't live and pay,…you know, we have to pay a share. If we paid for her then that was gifting and she wouldn't get any of her benefits.*
- *Obviously he's getting Social Security and he can only make a certain amount. And I don't see him being able to live independently on… without the Social Security. So as far as the job, yes we would like for him to be gainfully employed to where he is self-sufficient but I don't see that as a possibility. It's a tough one. Your hands are kind of tied by the*

> *system, and the system doesn't seem to be working in favor of making children independent or helping them achieve that goal. It's a catch-22.*

Beneficial resources. In the phone interviews, parents also shared their experiences with beneficial resources. Key sub-themes within this category were helpful resources and other positive influences.

-Helpful resources

Several parents felt that educational resources were beneficial for their young adults—particularly in relation to independence skills.

- *She's also learning a lot about music and living an independent life. It's a vocational school and they work on all independence skills but they do a lot of music. It's a two year certificate program and you can do extended learning community. So they have kids that live in a house, some that have an apartment, some that live with another family, some that live independently and go to school.*

Inclusive experiences were also said to have positive influences in these young adults lives. They were lauded in a number of ways: particularly, they provided motivation, helped them build confidence, and improved communication skills. One mom said, *"If I raised [name] with just people with disabilities, her speech wouldn't be how it is, communication, and social skills wouldn't be where they are,"* while another said that being included in "regular" classrooms *"has been very beneficial because I think that she feels like she belongs."*

- *If he was in a segregated classrooms and nobody… he certainly would not do what he's doing at the community college. And would not have the leisure activities in the hobbies that he has.*
- *But she was probably mostly included in education. So that's maybe why she has similar goals. I feel like there were some classes in high school (like career days and college visits and all of that) that she wasn't included in, and so I took her to the community college myself.*

Case-workers and life/job coaches were also reported to play positive roles in employment outcomes.

- *The community rehab organization provided job coaching because the employer-- you know they don't just let you…they don't want a mom calling like "Hey what time does she need to do this?" They wanted a point of contact to make their life easier.*
- *He gets supported employment through [Easterfield] so he has a worker that picks him up at his apartment and takes them to work. And that's helped him expand his role.*

Government assistance, specifically Medicaid waivers, has provided families with resources necessary to obtain employment and learn independence skills.

- *He lives in his own apartment that he has and the Medicaid waiver program gives him so many hours of help a day to meet goals. So he has somebody that comes in the morning and makes sure he does the hygiene and things he needs to do. And they take him grocery shopping* *and do some community activities that he's involved in and things like that. It's just a number of hours a day so it's not like putting somebody in a group home and going to the day program. He sets his own schedule and just as somebody come in to help and if needed. They're supposed to help him meet goals. He's got a gas stove so they help him learn to use the gas stove. And they help make sure he gets his groceries and that he takes care of his apartment things like that.*

- *This state is moving forward with this Medicaid program and trying to offer all kids with disabilities some independence...It has provided job coaches where they can have someone teach them the job and stay with them until they are independent in their job.*

Transportation reportedly enabled young adults to become more independent, maintain employment, and go to school.

- *I mean, I can do some of the transportation, but I would never be able to do all. Without having transportation support, she wouldn't be able to go to her job all the time. It just gives her some power to go where she wants to go—with or without me.*

Finally, participants commented that several private organizations had been factors in their child's successes in independence, health, confidence, and relationships.

- *We are very involved in Special Olympics and [name] has taken some of their leadership training courses. And it has been very beneficial for her. She now is one of their speakers. When they have requests for athletes to* *speak in front of audiences, she is one of their speakers. She will go out and talk to a crowd of 300 with no qualms. She is very confident in that area...They need to be healthy, they need to be confident in themselves (which they are doing that too). And they need to form friendships, which …it's a wonderful organization because they are with people of the same—the same as them.*

- *And they meet once a week in a public location and read a book out loud to each other. And that the club is just amazed all of us because we get facilitators who train, who had no background with special needs, who just absolutely fall in love with their book clubs and don't quit after two years. And then the kids, they get to see their friends.*

Finally, access to good healthcare was credited with allowing young adults to pursue other things, like education and leisure activities.

- *Close access to a children's hospital has done two things. [Accessing healthcare] costs time and money. Having a good quality children's hospital allowed us to really access specialists when we needed and sometimes preemptively. Many trips to the specialists were really more "Let's rule out something," rather than address an issue. And it gave us a chance to talk to really experienced medical professionals to get the right care quickly. And from that standpoint I felt that our son really benefited because he wasn't dealing with illness in addition to disability....I felt that because we had that and because we had really good health insurance, that was one thing that we didn't have to worry* *about we could really spend our time focusing on academics, life skills, and fun. You know he got to participate in things like Boy Scouts and sports.*

Other positive influences. While some parents had negative experiences with their local schools, others felt that primary and secondary educational organizations were an asset.

- *We happen to live in a district that was very good-- very willing to implement IDEA the way it was intended and in all there were places where we would occasionally disagree, we work together as a team to discuss why we disagreed and come to some kind of alignment of the team and the process worked well for us. And because of that because it was a very collaborative effort we had good educators and good therapists.*

Other participants cited their own proactive actions and positive attitudes as factors in their child's successes.

- *I want to say that I've been doing transition since kindergarten. I've been trying on purpose to start saying "What do you want to be when you grow up?" And saying "That's great but you have to graduate from high school or…third grade, right now." So I just started thinking that the teachers need to know that she plans to own a home and work. I got those on her IEP early and so they would keep carrying forward. I* *wanted everybody to know so that for planning they can see that it was in there.*

- *All those things she learned at home. She is smart and capable and we have always treated her to expect her to be able to do something. She has to prove to us that she can't before we say no. Whereas the outside world expects nothing of her. So I would say most of it came from within family.*

Dreams for the future. Several subthemes emerged from the phone interview participants' descriptions of dreams for their sons and daughters. These subthemes included romantic relationships, friendships, independent living, employment, and general independence.

Several parents hoped their children would have a future that involving a significant other. This was often a goal for the young adults themselves as well—"[*Name]'s goal is to get married. So he had a girlfriend for many years and they wanted to get married but her parents wouldn't let her."*

- *I think in [name]'s perfect future he would have… perhaps some kind of life partner. With one in 800 there's not a lot of other girls or other people for him to be around. At the NDSC a lot of people end up meeting boyfriends and girlfriends there, which is great, but then they are four states away.*

The desire for lasting friendships was also a frequently mentioned dream. A participant shared that the *"…vision now for [her] daughter is that she has her own circle of support, her own friends, and that she would live the way she wants to live.*

- *She would live with her friends in an apartment --probably in a small town. I would love to see her stay in [town] and stay affiliated with the school. That's what they are trying to build up to there. People will stay there and have a social life there…and they will have some unity. So that's what I would like to see. I'd like for her to stay there and make a life with her friends.*

Independent living, specifically in apartment settings, was also important to parents.

But I think if she wanted to get married and live out like in an apartment type setting I would be all for it because she wants it for herself. So I think continued working. And if she could ideally be out an apartment that's supervised.

- *We often talk about it. So I think of the family we are pretty aligned in terms of all having a unified vision. He would like to live in an apartment. He often talks about wanting to live with friends initially and then also living with his girlfriend.*

In addition, some degree of independence from parents was a focus amongst participants.

- *If something were to happen to me I would want to know that she would be able to kind of take care herself. And knowing what's right and what's wrong. I don't think she will ever really live alone, but just be able to function to the best of her ability without her parents.*
- *Because what if I'm unavailable or I'm gone? I need her to continue without me. That's my current focus. She has to replace me as much as possible—she needs to replace my advocacy herself as much as possible.*

Some parents would like their sons and daughters to be employed in the future, sharing that their child's perfect future would include *"…a job he liked in a supportive environment,"* or "*a paying job that at least help support her."*

Other parents' visions included an advocate for their loved ones.

- *And make sure that we have a good strong group or someone who will look after him after we are gone….somebody that just able to help manage his money, his time …can get him to where he needs to be in taking care of himself. More just training and working.*

Dreams over time. When asked if their dreams and goals for their children changed with time, parents shared varying viewpoints. These can be categorized into several subthemes: *insignificant change to dreams over time, growing awareness of limitations,* and *expanding the vision.*

Some study participants reported that their dreams for their sons and daughters have remained unchanged as they grew into adulthood. For example, one parent reported that "*the goals have always been the same. You know, as long as those things were what she wanted…and they are. She wants to be out and about on her own.*"

Other parents shared that some goals have been more difficult to achieve than they initially predicted.

- *I don't know if the vision has changed but the awareness of the limitations gets more real...It's just the awareness that the path is different the older you get. So when they are little, it's a little bit different. But when they're older it takes a lot more support.*
- *Yeah we thought growing up that since she did so well in school that she would be able to work full-time and support herself. That goal was little overoptimistic. Stamina wise there's no way could work a 37.5 or 40 hour work week. And then I think we were a little naïve in thinking she could be independent at an earlier age. She's pretty independent in the house but it is safe and it set up for her. So I think it would take a lot more on our part to find independent living for her that would make her as comfortable as she is in her own home.*
- *No—she is a very blessed child and she's capable, so she's been able to do a lot. The friendship thing has just been a killer in the last 3 years maintaining the relationships she developed early on. And having moved, which I thought would be better for us.*

- *Our whole outlook on it from childhood is that he's just like everybody else-- it will be fine. And really that was the easy part. Now the hard part is once he's older and… what are we going to do with him? Is he going to be able to live a long healthy life like is used to doing? I wish we had thought more about when he was younger.*

Finally, some parents found that their sons and daughters have been able to achieve more than they initially thought possible.

- *I think it's become more detailed. Back when he was in elementary school, the way the vision was articulated (and that was certainly before he could really articulate it himself), his dad and I always thought that we'd like him to be a taxpayer. We'd like him to have a job and pay taxes (laughs). And we had always hoped that he would live semi-independently but in elementary school we didn't really know. The older he got we realized that he really is a very independent person.*
- *So I think my goals raised for him and his became more reasonable. You know, when he was born 29 years ago there was no way I would ever imagine he would be living in the apartment, having become a college graduate and wanting to get married.…If we followed the path that we were given by the school is putting him in a segregated classroom that really believing he can only do "what people with IQ of 46-50 could do," that is what he would be doing. But we knew he was capable of more. And he showed us he was.*

Miscellaneous observations. Several miscellaneous themes also emerged from the interviews. These included *criticisms of group homes, a new definition of independence, and "a life like mine".*

Throughout several discussion topics, many parents shared unsolicited criticisms of sheltered workshops/group homes. These comments were often related to the lack of autonomy and independence in these settings.

- *We mostly have group homes—I think they are run, for the most part, very poorly and they are lumping people together that might not actually want to live together (which I don't think is a good idea.).*
- *…they go out to the Day activity Center, they go out to sheltered workshops, they go to other work opportunities they have, but most of the time they work part day and they go to the day activity center for the rest. And they cannot go back to their home and just be there. So we are looking for something where she can continue following her own schedule.*
- *There is still a lot of the sheltered workshop thinking in this area and they should just slowly move towards independent living and what the individual wants. It's more for people…*

Parents also challenged traditional definitions of independence.

- *Independent living— I don't mean that it's done without support. I mean, supports should be there that she needs, to have to go for independent living. So right now we are looking but I don't mean that she necessarily* *has to live alone. I think it will be something that would be just a trial and error to see where she's more comfortable. And realizing that she won't do everything by herself and that that isn't what independence means. But that she has the support she needs and that she has the right to decide how.*

- *…at school, they want to hover and give her 24-7 "para" support. But in the real world, we don't have adult support for her 24-7. She has supervision, but she does a lot of stuff. But she has to have her freedom to be happy.*

Finally, participants noted that their sons and daughters are ultimately not so different from their same-aged peers.

- *[We tried] Special Olympics activities where all the kids had disabilities and we tried to…we went to soccer and to cheerleading. And both times she said "I don't want to do this. Why are we here?" Because she noticed that everybody had a disability. And they took me a long time to realize that, you know, we as people without disabilities don't look for programs just to be around people with disabilities. We want to be around all kinds of people. And she felt exactly the same way.*
- *Independent living—I just feel like it gives a person self-esteem. I mean really… more freedom than they would have living at home with their parents-- more rights, more responsibility. So it's more… It will be more like that phrase that is going around Virginia: "A life like mine, a*

life like yours." You know, it's more realistic. From what I can see, I believe she will have more independence.

- *To me life is about making choices. And the more control I can give her in life and over her life, the more satisfied she would be …just as a human being.*

2.5 Discussion

This purpose of this study was twofold. Using quantitative analyses, it first sought to determine which goals parents felt were important aims for their young adult sons and daughters with Down syndrome and whether or not these goals are being achieved. Through qualitative analyses, the study also determined which barriers, including lacking resources, present challenges to the achievement of these goals. In addition to these barriers, participants outlined which resources have been helpful for these emerging adults. When taken together, these data reveal the impacts of different supports as well as areas of need for this population.

2.5.1 Importance of goals. Overall, subjects ranked vast majority of proposed goals highly (equal to or above "*High importance*) in this study. It is apparent that for participants in our sample, a diagnosis of Down syndrome does not preclude them from having a variety of desires and aspirations for their sons and daughters, including safety, access to healthcare, friendships, personal living skills, self advocacy skills, leisure activities, mental health, paid employment, financial security, supervision, and miscellaneous other goals.

Of the goals that fell into these top three categories, friendships, safety, paid employment, independent living, and access to healthcare were listed the most frequently. Because safety and access to healthcare are fairly basic needs and paid employment fulfills a financial requirement, several of these goals can be thought of as largely pragmatic choices, making them predictable “top” selections. Interestingly, parents valued the less concrete goals of friendship and independent living as highly as or even higher than some of these practical needs. It is likely that parents simply see these goals as contributors to personal fulfillment and happiness—desires all parents have for their children. In addition, these results were consistent with previous analyses of post transitional goals for emerging adults with Intellectual Disability (ID). A study involving 64 youths with ID and their parents, found that “protecting health, assuring safety and security in multiple realms, finding meaningful activities after high school, and establishing supportive social relationships” were key objectives in their sample (Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012). These goals are also similar to priorities listed by parents at the NDSS meeting in 2000, which included real job opportunities and self-determination involving housing and money. One contrasting result, however, was the absence of postsecondary education from the list of highest ranking goals in this study—a goal that was prioritized at the NDSS. It is possible that reduced access to or awareness of postsecondary education options within our sample population account for this difference.

2.5.2 Goal achievement and focus of transition efforts. While parents on average reported that their children were in an intermediate stage in the goal achievement process, the analysis of achieved goals revealed that many of the highly ranked objectives remain largely unattained. Financial security, mental health, safety, independent living, and paid employment are amongst these infrequently achieved goals. Subsequently, these categories likely denote significant areas of challenge for this group. Moreover, they represent areas especially in need of increased focus during and after completion of the transition process. For instance, increased efforts on the part of secondary school programs to facilitate and secure paid employment, continued physician awareness of and attention to warning signs of mental health issues like depression, early-onset cognitive decline, and preemptive counseling regarding the predisposition for these concerns could all increase the likelihood that young adults accomplish these objectives.

2.5.3 Barriers and their impacts on goal achievement. In discussions involving these barriers to success, two resource categories in particular were reported to affect many different aspects of young adult life and success: transportation and housing. Throughout qualitative components of the study, participants emphasized the varied and far-reaching negative effects limited access to transportation has on their sons and daughters opportunities to succeed. Undoubtedly, many young adults with Down syndrome do not have adequate access to this resource. While paratransit is available for some individuals, it is often unreliable, unsafe, and limited—both in terms of available times and locations. As several parents noted, this can make maintaining employment, meeting friends, and general independence challenging, at best. Moreover, in addition to the impacts listed by parents in this sample, other evidence shows that transportation plays a role in the physical activity of individuals with ID as well (Temple). Likewise, the relative lack of semi-independent housing for individuals with DS hinders young adults from achieving many of the top ranked goals in this study. Specifically, parents noted that there are few independent living settings with supports and proximity to peers. Available housing options typically only offer extremes, which consist of completely unsupported apartments or “sheltered” scenarios that allow little to no personal autonomy. As a result, many individuals who are not ready for total independence are forced to remain with a parent or other relative.

The implications of these disparities are vast. Many individuals with DS already face challenges with which the general population does not have to contend, including major health problems and some degree of intellectual disability. As a result, deficiencies of resources that are available to the general population (i.e. independent travel options and the adequate housing opportunities) only widen barriers to success by adding to these existing challenges. These inadequacies also raise the possibility that existing data regarding ranges of ability for individuals with Down syndrome is negatively biased. While individual abilities obviously vary, it is possible that compensating for these disparities could result in a general increase in goal realization, as well as a greater understanding of the true potential many young adults with Down syndrome have. Solutions to these disparities may require policy changes and allocation of more funding to these areas.

Parents also reported that a dearth of social opportunities poses a major setback for their young adults, citing a lack of various kinds of social prospects, including hobby-centered interest groups, dances and parties for young adults with ID, and inclusive activities. While this barrier has a narrower spectrum of effect, the goal it does influence was the most frequent top tier goal for parents—friendship. Friendships may be easily established for many people with Down syndrome, but various limitations can render them difficult to maintain after the completion of secondary school. For example, same-aged peers with ID often live far away, cannot travel, or are simply few in number. In addition, typically developing friends in this age group are often becoming increasingly engaged with postsecondary education, work, getting married, and having children—experiences which many emerging adults with DS unfortunately do not always share. As a result, opportunities for social interaction outside of work are rare for many individuals with DS. This was an especially emotionally distressing topic for several mothers, who felt that loneliness was leading to depression in their sons and daughters. While the exact association with depression is unclear, people with Down syndrome often undoubtedly already possess multiple risk factors known to increase the risk of clinical depression, including differences in neuroanatomy, reduced serotonin, and prevalent somatic disorders (Walker, 2011). Social isolation, when combined with these predispositions, is indeed concerning. As environmental factors like these are known to play a role in the manifestation of depression, barriers to friendship may be considered contributing factors in the development of legitimate mental health concerns in this population. While it is tempting to trivialize "fun" things like social activities by giving them lower priority, these issues are real and significant to families in this population. Specifically, one could argue that issues affecting psychiatric concerns merit increased attention from publically funded sources, both in terms of monetary assistance and event organization. While there is obviously no instantaneous solution to this problem, professionals involved with youths during transition should ideally preemptively disseminate information about *local* resources and private organizations that offer community activities to families. As medical professionals also share responsibility in the care of these individuals, they should remain cognizant of the predisposition for certain mental health concerns.

While access to healthcare was often reportedly achieved, study participants did note some barriers to optimal care. Deficient communication between specialties, a predicament one mother faced, is reflective of the relative rarity and uptake of Adult Down syndrome clinics. While several of these clinics are available across the United States, not all families have local access to them. As these clinics involve physicians from multiple disciplines which specialize in treating Down syndrome and provide "one-stop," streamlined care, barriers like inadequate communication between medical specialties could be alleviated by local access to them. In addition, more primary care physicians are needed to manage individuals with DS. Again, one family found that locating physicians who were willing to treat individuals with DS was a significant challenge. Like their pediatric counterparts, adults with DS are at increased risk for several comorbid conditions (Smith, 2001). For these individuals, a competent primary care physician who coordinates specialist care and manages screening for these known comorbidities as well as age and gender-based health checks is crucial. Missing regular checks with a primary care physician may mean that some of these serious health and psychiatric issues go undetected and untreated.

While postsecondary education was not a highly ranked goal, several parents did note lacking resources with regard to scholastic opportunities for this age group. While a number of study participants felt that postsecondary education was lacking, their definitions of continuing education were varied. Some parents called for more programs with traditional college structures, while others pointed out the absence of continuing education for nonreading students. In fact, some of these "lower functioning" young adults reportedly lost skills after they completed secondary school. Consequently, this represents an area in need of further development. Without adequate postsecondary programs, a crucial opportunity to help emerging adults achieve their maximum potentials remains unrealized.

2.5.4 Other barriers. In addition to these specific resource deficiencies, miscellaneous barriers were also reported. Unfortunately, misconceptions about Down syndrome continue to make it more difficult for young adults with Down syndrome to meet their goals. Societal misconceptions were reportedly impactful for two highly ranked goals (safety and employment). Specifically, the participants felt that some potential employers still harbor pessimistic or disparaging attitudes about the abilities of people with Down syndrome. Emerging adults subsequently face greater challenges to employment than their typically developing peers do.

Parents who cited poor transition planning as a barrier reported differing levels of scholastic involvement in this process. Indeed, studies suggest that adherence to IDEA's tenets varies between regions (Landmark). An extreme example involved a school's refusal to record an individual's goals on his IEP in an attempt to avoid addressing them. While policies designed to increase positive post-transitional outcomes are currently in place, it is ultimately the responsibility of individual education programs to implement them.

The final barrier involves regulations which limit the monetary resources that can be accumulated whilst remaining eligible for Supplemental Security Income (SSI) or Medicaid funds. This posed a financial dilemma for several families in our sample. However, the ABLE Act, which was introduced in February of 2013, would ensure that "A beneficiary will not lose eligibility for Medicaid based on the assets held in the ABLE account." In addition, SSI benefits would be available until the ABLE account contains $100,000. These regulations would ameliorate some of the stressors associated with the previous scenario, in which benefits (for some parents) would be lost after the accumulation of $2000. Another important component of the ABLE act is the list of qualified expenditures. These include housing, transportation, employment support, health and wellness, and a limited number of miscellaneous expenses are covered by this law. As many of the central goals in this study fall under one of these categories, this act would represent a positive step towards goal achievement.

2.5.5 Beneficial resources. The next portion of qualitative analyses focused on resources that have been beneficial for young adults with DS. In contrast to the previously outlined barriers, some parents reported that several resources have helped their sons and daughters realize their goals. One of these resources was education—both post-secondary and secondary. Improvements in independence-related skills, in particular, were felt to be the result of access to high-quality school programs. In addition, inclusive experiences, both within the contexts of education and recreational activities, facilitated the beneficial outcomes of confidence, improved communication skills, and motivation. Not only did inclusive opportunities have positive results, but several mothers noted that their sons and daughters strongly preferred to be included with the general population. Case-workers and job coaches also provided noteworthy support to our sample population. Specifically, maintenance of paid employment was made possible by these workers. As this was another highly-ranked goal, the importance of these supports cannot be underestimated. Most frequently, government funding provided the monetary resources needed to access these coaches. Unsurprisingly, transportation was also listed as a beneficial resource for those who had access to it. Access to transportation was reported to have a positive influence on the achievement of the same goals that a *lack* of transportation hindered—including employment, independence, and education. Finally, several private organizations were thought of as beneficial supports to study participants. As these organizations vary in focus, their benefits differed widely. Of course, organizations like The Special Olympics were reported to increase activity amongst members—but parents also cited the added benefit of networking for these groups. Other interest-based groups were reported to build friendships as well as confidence in young adults. Local organizations were also good sources of information for families, as were national advocacy organizations. Interestingly, local support groups were infrequently mentioned in discussions involving beneficial resources. This could be the case because, as some participants pointed out, many parents of adults transition into supportive roles within these groups as they become mentors for younger parents. While parents in this study seemed to view this as a positive and fulfilling experience, they did not necessarily feel that their own leadership roles were beneficial resources for their own adult sons and daughters.

It is imperative to note these areas of benefit for two reasons. First, they offer evidence that supports do have positive outcomes for this group. It is true that, like the general population, people with Down syndrome represent a spectrum of varying abilities, strengths, and talents. However, stereotypes that people with DS can never live independently, cannot maintain a “real” job, or even that they will never become literate, are still perpetuated through misinformation and prejudice. Many of these stereotypes are still present in healthcare settings, and can lead to inaccurate descriptions of the future implications involved with a diagnosis of Down syndrome. In contrast, this study demonstrates that, when the necessary supports are present (and even sometimes without them), many young adults with Down syndrome are capable of achieving feats that have even taken their parents by surprise. It is important to make future parents aware that, while not all individuals are this "high functioning," many are able to accomplish goals like those proposed in this project. Second, this data offers evidence which reinforces the value of allocating funding and resources to these needed areas. While continued improvement is needed in many of these fields, it is clear that advancements have already been made and can be associated with specific positive outcomes.

2.5.6 Dreams. For this segment of the participant interviews, parents were asked to share their "perfect visions" of the future for their sons and daughters. While the dreams varied, of course, the ultimate aim of these dreams was happiness in the future for the young adults. Accordingly, these dreams reflect concepts that parents perceived to contribute to their sons' and daughters' well-being and overall quality of life. Interestingly our study found that there were some differences between parents' goals and these "dreams" for their young adults. While goals were thought of as at least remotely achievable objectives, "dreams" contained some elements that were ideal, but may be difficult to attain. These elements were not ranked highly in the "Top Three Goals" section or reported to be frequently achieved. Specifically, marriage and romantic relationships were major focuses in the ideal futures of young adults. Parents often noted that this dream was significant to them because it was important their sons and daughters—something they hoped for and often discussed. Unfortunately, existing studies show low rates of marriage (roughly 2%) for people with Down syndrome (Zhu, et al., 2014). While the sample size was small, this study found similar results. For this dream, parents cited many of the same hindrances which acted as barriers to friendship maintenance—transportation, low numbers of available individuals, and few social activities to meet others in this peer group. As a result, the same resources that would improve access to friends would be helpful in this case as well.

In contrast with marriage, some themes in this portion of the study were unsurprising, given the previously outlined topics. Independent living was one such theme. Again, many parents shared a dream involving a living scenario in which individual choice is encouraged, but assistance is available when needed. This ideal housing situation would also facilitate friendships by allowing peers to be in close proximity with one another. Parents' dreams also consistently involved employment (another highly ranked goal) because of the potential positive influences it could have on their sons and daughters. Many parents felt that jobs make young adults feel fulfilled, productive, and active.

Ultimately, many of parents' dreams were based on concerns about their children's futures without them. While they often did list specific dreams within this context (independent living, employment), a general theme of maximizing one's independence was also apparent in their descriptions. Understandably, most parents simply want their young adults to be happy and able to function on their own, to the best of their abilities. Alternatively, one parent specifically hoped that her young adult would always have an advocate who could compensate in areas in which her son was not always able to achieve complete independence. This person would ensure that her child's rights were always protected and that her needs would be met.

2.5.7 Dreams over time. While overall themes involving future visions converged on a few concepts, participants' descriptions of the evolution of dreams over time varied greatly. Several factors appeared to have affected dreams as the years passed. A number of parents, who found that dreams were more difficult to achieve than they initially estimated, noted that the scarcity of post-transitional supports was astonishing and unexpected. As some parents pointed out, these challenges are magnified by the fact that some personal limitations can become more apparent as individuals emerge into adulthood. Again, these accounts are evidence of the need for expansion in terms of the resources available to post-transitional youths.

In contrast, parents whose dreams and expectations expanded over time cited prior perceptions as influential factors in their estimations. Early on, many parents were told exactly what their children "could and could not accomplish"—estimations made based solely on the diagnosis of Down syndrome or on the results of an IQ test. Unfortunately, these estimations failed to take individual differences into account, which initially caused some parents to limit their expectations. However, parents in this sample felt that, once they allowed young adults to set their own boundaries, they were frequently surprised by their capabilities. These experiences highlight the importance of unbiased, balanced descriptions of Down syndrome when health professionals, like genetic counselors, share a new prenatal or postnatal diagnosis. Not only do these interactions influence family adjustment to the diagnosis of DS as well as their views of the immediate future—whether positively or negatively—but as this study demonstrates, information given in these cases can have lasting effects for years afterwards.

2.5.8 Miscellaneous observations. One noteworthy finding was that several unexpected themes emerged, unprompted, over the course of the interviews. For example, throughout discussions involving several topics, subjects brought forth several criticisms of the "sheltered workshop" system. These critiques mostly centered on the lack of autonomy that is often associated with these arrangements. While some aspects of structured systems like these were seen in a favorable light, parents noted that homes with entirely predetermined schedules removed some opportunities for individual choice—a basic right that, to them, all people deserve. Indeed, of all of the proposed goals, sheltered work was the only category that was overwhelmingly felt to carry the "lowest importance." This low ranking confirms these qualitative analyses which suggest that parents have critiques of this concept.

Another important observation was parents' new definitions of independence. They described this concept throughout discussions involving housing, transportation, employment, and various other topics. To many of the study participants, "independence" did not mean living entirely without help on one's own. Instead, independence meant retaining autonomy whilst working to the best of one's ability—receiving assistance only when needed.

The final theme in our study concisely describes the essence of our study results. Throughout the study, parents described "a life like yours." Essentially (and unsurprisingly), parents want their sons and daughters to have lives that are similar to those of their same-aged peers. This study offers evidence that young adults with Down syndrome have many of the same goals, needs, and desires as typically developing individuals in their age group. Unfortunately however, young adults with DS face challenges that others do not have to face. These challenges can be intrinsic—for example, health issues—as well as external, including a lack of transportation, distance from friends, and negative social attitudes. As a result, it is imperative that advocates across all disciplines endeavor to identify and ameliorate these obstacles.

2.5.9 Limitations. Admittedly, this sample population represents a fairly homogenous demographic, especially in terms of gender and (high) education. In consequence, this project is inherently subject to some biases. This sample also may represent an especially "active" group, as many members were recruited through national advocacy organizations (NDSC). As a result, they may collectively expect or aim for more than most parents in the Down syndrome community. In addition, this group may have resources to find and access more opportunities such as assisted living, post secondary education, and transportation—all of which require financial support.

In addition, many of the emerging young adults described in this study represent a fairly "high functioning" group. It is important to note that this is not necessarily reflective of all people with Down syndrome. However, it is crucial that awareness regarding the existence of individuals like those referenced in this study—public speakers, musicians, actors, and college graduates—is encouraged amongst medical professionals, educators, and the general population. A better understanding of the strengths and accomplishments of young adults like these can potentially help facilitate the elimination of stigmas and misconceptions involving people with Down syndrome.

2.5.10 Future Directions. This study established a basis for a number of future analyses. In particular, similarly designed investigations using less biased populations could provide insights that this study may have overlooked. For example, because all but one study participant was female, a project analyzing difference between maternal and paternal goals would possibly provide perspectives that this study could not ascertain. Future studies could also aim to draw from larger and more diverse ethnic, educational, and socioeconomic backgrounds in order to reduce bias.

In addition, future studies could involve parents of older adults with Down syndrome. This group is likely facing unique challenges that were not outlined in this study.

Chapter 3: Conclusions

Our findings indicate that, while some individuals with Down syndrome are accomplishing a number of things, many of parents most desired goals for their young adult sons and daughters with Down syndrome are largely going unachieved. While dreams by nature differ from goals, many of the same resources would help increase their realizations. Unfortunately, a number of these resources are currently insufficient. As a result, practice implications for genetic counselors and other health professionals, educators, and government liaisons include increased assistance with transition planning and increased awareness of appropriate referrals and post-transitional recommendations. Moreover, policy changes are needed to facilitate increased rates of success for members of this population.

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Appendix A – Participant Materials

Dear Participant,

Please write, check, or circle your answers on the attached survey questionnaire. Once you have finished, place the survey in the envelope included in this packet and mail this envelope to us. There is no need to purchase stamps or address the envelope, as we have already paid for postage and included our return address. Thank you for taking this survey!

Sincerely,
Julianna Baker

Parents' dreams for their young adults with Down syndrome: what resources are needed to achieve them?

Demographic Information:

What is your age?
_____25-34
_____35-44
_____45-54
_____55-64
_____65-74
_____75+

What is your gender (Male or Female)? _______________

What is your highest level of schooling?
_______________ some high school
_______________ finished high school or GED
_______________ some college education
_______________ Associate's Degree
_______________ Bachelor's Degree
_______________ College beyond Bachelor's degree

What is your income level?

________________Less than $25,000
________________$25,000 to $49,999
________________$50,000 to $74,999
________________$75,000 to $100,000
________________More than $100,000

What is your ethnicity?
____ Asian
____ Black
____ Hispanic
____ Native American
____ White
____ Other (please specify): ____

What is your current marital status? (Please check one)
☐ Single/Never Married ☐ Married ☐ Widowed ☐ Separated
☐ Divorced ☐ Remarried ☐ With a Partner

What is the age of your child who has Down syndrome? _________________

What is the gender of your child with Down syndrome (Male or Female)?______________________

What is your child with Down syndrome's highest level of schooling?

________________ currently in high school

________________ finished high school or GED

________________ received a high school certificate

________________ attending a postsecondary (college) education program

________________ finished postsecondary (college) education program

What is the ethnicity of your child with Down syndrome?

____ Asian

____ Black

____ Hispanic

____ Native American

____ White

____ Other (please specify): _________________

Where does your child with Down syndrome live?

a) With his/her parents
b) With his/her spouse/partner
c) With a family member who is not a parent
d) With a friend
e) Alone
f) In a residential school or boarding school other than a college
g) In a college dorm
h) In a group home or other supervised living arrangement
i) In a medical or mental health facility
j) Other (please specify) ____

Survey

1) In your opinion, please rate the level of importance of the following goals for your child. (Circle the best option):

a. Sheltered work (in a "workshop")

Lowest importance low importance medium importance high importance highest importance

b. Unpaid employment (volunteer work)

Lowest importance low importance medium importance high importance highest importance

c. Paid employment (competitive employment in the community)

Lowest importance low importance medium importance high importance highest importance

d. Personal living skills (for example, hygiene/bathing, dressing, and eating)

Lowest importance low importance medium importance high importance highest importance

e. Independence skills (paying bills, using a calendar, keeping appointments, buying groceries)

Lowest importance low importance medium importance high importance highest importance

f. Independent living (outside of the parents' home)

Lowest importance low importance medium importance high importance highest importance

g. Financial security (enough money to cover living expenses)

Lowest importance low importance medium importance high importance highest importance

h. Friendships

Lowest importance low importance medium importance high importance highest importance

i. Marriage and romantic relationships

Lowest importance low importance medium importance high importance highest importance

j. Leisure activities (hobbies)

Lowest importance low importance medium importance high importance highest importance

k. Access to healthcare

Lowest importance low importance medium importance high importance highest importance

l. Post-secondary (after high school) education

Lowest importance low importance medium importance high importance highest importance

m. Self-advocacy skills (being able to decide and stand up for his/her opinions or to voice his/her preferences)

Lowest importance low importance medium importance high importance highest importance

n. Safety

Lowest importance low importance medium importance high importance highest importance

o. Supervision/assistance with daily activities

Lowest importance   low importance   medium importance   high importance   highest importance

p. Mental health

Lowest importance   low importance   medium importance   high importance   highest importance

q. Other. Please list: ___________________________

Lowest importance   low importance   medium importance   high importance   highest importance

2) In your opinion, what are the top 3 most important goals?

3) How close do you feel your child is to achieving:

a. The most important goal?

Not close at all   Not very close   About halfway   Very close   My child has achieved this goal

b. The second most important goal?

Not close at all   Not very close   About halfway   Very close   My child has achieved this goal

c. The third most important goal?

Not close at all   Not very close   About halfway   Very close   My child has achieved this goal

4) Which goals do you feel your child has achieved? Check all that apply.

☐ Sheltered work (in a “workshop”)

☐ Unpaid employment (volunteer work)

☐ Paid employment (competitive employment in the community)

☐ Personal living skills (for example, hygiene/bathing, dressing, and eating)

☐ Independence-related skills (paying bills, using a calendar, keeping appointments, buying groceries)

☐ Independent living (outside of the parents’ home)

☐ Financial security (enough money to cover living expenses)

☐ Friendships

☐ Marriage and romantic relationships

☐ Leisure activities (hobbies)

☐ Access to healthcare

☐ Post-secondary (after high school) education

☐ Self-advocacy skills (being able to decide and stand up for his/her opinions or to voice his/her preferences)

☐ Safety

☐ Supervision/assistance with daily activities

☐ Mental health

☐ Other. Please list: ____________________________

Comments:

5) What resources/supports have helped you/ your child to achieve these goals? For example: transportation, training programs, national advocacy groups, government programs, financial aid, support from family and friends, or health services.

6) What resources/support do you still need to help achieve these goals? In other words, what missing resources are preventing your child from succeeding?

7) What resources/supports would you/ your child need to *maintain* these goals long-term?

8) What are your dreams or goals for your child’s future?

9) Have your dreams/goals for your child changed over time? If so, which ones changed, and why?

The next part of the survey is about how you feel about your life together as a family. We will use what we learn from families to inform policy makers and service providers for children and families. Your "family" may include many people – mother, father, partners, children, aunts, uncles, grandparents, etc.

For this survey, please consider your family as those people
-Who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and
-Who support and care for each other on a regular basis.

For this survey, please DO NOT think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.

The items below are things that hundreds of families have said are important for a good family quality of life. We want to know how Satisfied you are with these things in your family. Please check the boxes on the following pages that reflect your level of satisfaction with each item.

☐ Checking the first square means you are very dissatisfied.
☐ Checking the fifth square means you are very satisfied.

Thank you so much for sharing your opinion with us!

How satisfied are you that…
(Please circle one)

1. My family enjoys spending time together.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

2. My family members help my child with Down syndrome learn to be independent.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

3. My family has the support we need to relieve stress.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

4. My family members have friends or others who provide support.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

5. My family members help my child with Down syndrome with schoolwork and activities.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

6. My family members have transportation to get to the places they need to be.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

7. My family members talk openly with each other.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

8. My family members teach my child with Down syndrome how to get along with others.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

9. My family members have some time to pursue our own interests.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

10. Our family solves problems together.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

11. My family members support each other to accomplish goals.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

12. My family members show that they love and care for each other.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

13. My family has outside help available to us to take care of special needs of all family members.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

14. Adults in our family teach my child with Down syndrome to make good decisions.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

15. My family gets medical care when needed.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

16. My family has a way to take care of our expenses.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

17. Adults in my family know other people in my child with Down syndrome’s life (friends, teachers, etc.).
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

18. My family is able to handle life’s ups and downs.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

19. Adults in my family have time to take care of the individual needs of every child.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

20. My family gets dental care when needed.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

21. My family feels safe at home, work, school, and in our neighborhood.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

22. My family member with Down syndrome has support to accomplish goals at school or at his/her workplace.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

23. My family member with Down syndrome has support to accomplish goals at home.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

24. My family member with Down syndrome has support to make friends.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

25. My family has good relationships with the service providers who provide services and support to our family member with Down syndrome.
Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

10) Thank you for completing my survey! My study has an optional second part, which is a phone interview. The purpose of the interview is to learn more about your goals for your child

and resources available to you. If you wish to participate in the phone interview at a later date, please leave your:

a. First name (this tells us who to ask for):

b. Phone number:

c. The best day of the week to call:

d. The best time of day to call:

Informed Consent: Hello, my name is Julianna, and I am a student at the University of South Carolina School of Medicine. I am performing a study called “Parents’ dreams for their young adults with Down syndrome: what resources are needed to achieve them?” Thank you for completing the survey, which was the first part of my study! In the survey, you indicated that you were willing to participate in a phone interview, during which we will discuss your goals and dreams for your son or daughter in more depth. Do you still wish to participate in the phone interview portion of this study? Is this a convenient time to talk? If you choose to answer the questions in this interview, you are agreeing to participate in this study. Your survey will be linked to this interview, so I have your survey responses at hand in case you don’t remember the exact answers. The interview is voluntary, and if you do not wish to answer a particular question, you are not required to do so. You may choose to stop the interview at any time. Before we begin, do you have any questions?

Phone Interview

1) In the previous survey, your top 3 more important goals for your child were ___________. Are there any that you would change? What made you choose these?

2) Of the ideal supports/resources for achieving your goals for your child ("you listed ___________"), how have/would these supports help to achieve your goal?
3) What resources for achieving your goals for your child do you feel were not available or lacking?
4) Of these missing supports you listed, how would they help you to achieve your goals ?
5) In your opinion, what barriers have prevented your child from achieving these goals? For example, has a lack of resources or a policy prevented your child from realizing your dreams for him/her?
6) In your opinion, what supports have helped your child achieve his/her goals?
7) For those whose goals for their child change over time: can you talk more about what made your goals change over time.
    a. *Please share your vision of what your child's perfect future would look like.*
    b. *Has this changed over time? For example, did you have the same long term goals when your child was younger as you do now? If yes, what made them change? If no, which ones were the most important to you? Which ones did you set aside or change as your child became older?*

UNIVERSITY OF
SOUTH CAROLINA
School of Medicine

You are invited!

The University of South Carolina is conducting a study focusing on **parents' dreams and goals for their 18-29 year old children with Down syndrome**.

We created this study in order to learn **what these dreams are** and **what resources have helped or would help to reach them**.

This research involves a survey, which can be completed through the following link: https://www.surveymonkey.com/s/goalsanddreams. If you do not have internet access, please feel free to call me at 903-388-3960, and I will mail a written packet to you.

To complete this survey, you must be a **parent of an 18-29 year old young adult with Down syndrome**. If you have any questions about this research, you may contact either myself or my faculty advisor, Victoria Vincent, MS, CGC, using the contact information below.

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Appendix B- Supplemental Data

Table B.1

Top Three Goals

Goal 1

Goal	Frequency	Percent (%)
14	8	24.2
6	5	15.2
8	5	15.2
3	4	12.1
4	4	12.1
5	2	6.1
13	2	6.1
7	1	3
9	1	3
17	1	3

Goal 2

Goal	Frequency	Percent (%)
3	7	21.2
11	6	18.2
14	6	18.2
6	4	12.1
4	3	9.1
8	3	9.1
5	2	6.1
1	1	3
9	1	3

Goal 3

Goal	Frequency	Percent
8	8	24.2
7	5	15.2
11	4	12.1
16	4	12.1
3	2	6.1
5	2	6.1
13	2	6.1
4	1	3
6	1	3
10	1	3
14	1	3
15	1	3
17	1	3

Key			
Sheltered workshops	1	Leisure	10
Unpaid employment	2	Access to healthcare	11
Paid employment	3	Post-secondary	12
Personal living skills	4	Self-advocacy	13
Independence-related skills	5	Safety	14
Independent living	6	Supervision	15

Financial security	7	Mental health	16
Friendships	8	Other	17
Marriage	9		