



STRENGTHS, WEAKNESSES, OPPORTUNITIES, AND THREATS FOR INDIVIDUALS WITH SPECIAL NEEDS: RECOMMENDATIONS FOR AN IMPROVED SYSTEM OF CARE

MICHAEL P. BRADY, PHD



Table of Contents

Data Collection Summary Table	3
Methods Used in the Community Needs Assessment	4
Data Collection & Analysis	4
Interviews	4
Focus Groups	5
Community Conversations	6
Surveys	6
Findings	7
Information and Referral	8
Assessment and Early Diagnosis	9
Service Shortages	10
Funding Streams	12
Transition Practices	14
Employment	15
Transportation Availability	17
Advocacy and Futures Planning	17
Recommendations for Services, Support, and an Improved System of Care	19
Hallmarks of a Comprehensive System of Care	19
Recommendations for Services and Support	22
Information and Referral	22
Assessment and Early Diagnosis	23
Service Shortages	23
Funding Streams	25
Transition Practices	26
Employment	27
Transportation Availability	28
Advocacy and Futures Planning	28
References	31
Appendix	33

Community Needs Assessment in Palm Beach County

Strengths, Weaknesses, Opportunities, and Threats for Individuals with Special Needs: Recommendations for an Improved System of Care

The Community Needs Assessment in Palm Beach County was conducted during the months of February through August of 2015. The project was funded by a grant from the Unicorn Children’s Foundation, Inc. to the Broward Regional Health Planning Council (BRHPC). BRHPC assembled a team of investigators who, in turn, conducted the data gathering and analysis activities resulting in this report. The intent of the Community Needs Assessment was to conduct a comprehensive analysis of the current service delivery systems for individuals with special needs in Palm Beach County.

To meet the goal of making the needs assessment as comprehensive as possible, an evaluation design was developed that included (a) multiple methods of data collection, (b) input from multiple groups of stakeholders, and that (c) represented the widest range of ages and disability characteristics of the community. Multiple investigators with expertise representing the ages and service delivery needs of the community participated, and these investigators used common data collection protocols so that the assessment methods would not bias the findings. A visual summary of the evaluation design is found in the Table below.

Data Collection Method	Children with Special Needs: Birth to 6 Years	School-aged Children with Special Needs	Adults with Special Needs
Interviews: Individuals with Special Needs		X	X
Interviews: Parents and Caregivers	X	X	X
Interviews: Providers	X	X	X
Focus Groups: Individuals with Special Needs		X	X
Focus Groups: Parents and Caregivers	X	X	
Focus Groups: Providers	X	X	X
Community Conversations: Individuals with Special Needs			X
Community Conversations: Parents and Caregivers	X	X	X
Community Conversations: Providers	X	X	X
Surveys: Individuals with Special Needs			X
Surveys: Parents and Caregivers	X	X	X

Methods Used in the Community Needs Assessment

Data Collection & Analysis

Four types of data collection activities were employed to gain information from community stakeholders. This included interviews, focus group meetings, community conversations, and an on-line survey.

Interviews. Individuals selected for individual and small group interviews were identified during focus groups, community conversations, or from referrals by others who were participating in the needs assessment activities. The individuals were asked to agree to be audio recorded, although none were disqualified if they were unwilling to be recorded. All individuals who were selected were assured of confidentiality of their input. As a token of appreciation, interview participants were offered \$25.00 gift cards from Target *for* completing the interviews. Interviewers for all groups used a “starter set” of questions to assure that all participants had the opportunity to address the same topics. Participants also had the opportunity to expand on their responses to these questions, and to address other topics. Interviews were conducted for the following groups:

- Students with disabilities in high school and college;
- Adults with disabilities in post-secondary transition programs;
- Adults with disabilities not in programs;
- Parents and caregivers of school-aged students with disabilities;
- Parents and caregivers of infants, toddlers, and other young children with disabilities;
- Parents and caregivers of adults with disabilities;
- Providers of services to school-aged youngsters;
- Providers of services to infants, toddlers, and other young children with disabilities;
- Providers of adult services.

A total of 87 individuals were interviewed. This included 39 individuals with disabilities, 28 parents and caregivers, and 20 providers. Individuals with disabilities ranged in age from 14 to 27 years for the students, and 19 to 63 years for other adults. Disability designations for this group included Intellectual Disability, Autism Spectrum Disorder, Down Syndrome, Epilepsy, Learning Disabilities, Cerebral Palsy, Bipolar Disorder, Post-Traumatic Stress Disorder, Hearing Impairments, Vision Impairments, mobility restrictions, and limited verbal communication.

Of the 28 parents and caregivers, parent and caregiver interviews included those of young children with Down Syndrome, Autism Spectrum Disorder, Physical Disabilities, PDD-NOS, and ADHD between the ages of 9 months to 5 years, as well as those of school-aged children, and adults aged 21 to 49 years. Of the 20 providers interviewed, They represented a wide range of public and private organizations including Early Learning Coalition, Children’s Services Council, Palm Beach County schools, Community Services of Palm Beach County, ARC, 211, CARD, Easter Seals, Gold Coast Down Syndrome, CHADD of the Palm Beaches, West Palm Beach Division of Blind Services, Palm Beach County Youth Services Department, and others.

Interviews were conducted in a variety of locations including a public library, a public school campus, on campus at FAU, at a charter school, and at several community job sites. Several parent interviews were conducted by telephone. Interview methods for several individuals with disabilities were modified to accommodate their communication preferences. For example some high school students supplied written responses to the questions, and others used electronic communication devices to respond to interview questions. Several of the adults with disabilities did not wish to be interviewed individually, so these individuals participated in small group interviews using a *round-robin* interview format. The majority of interviews were audio recorded, and summaries were made immediately following the interviews.

Focus Groups. To generate participants for the focus groups, several invitations to participate were announced during the initial community conversations. Because the timing of the focus groups overlapped with the interviews, we also used a *snowball recruitment* technique where from referrals from others who were participating in the needs assessment activities helped us identify participants for the groups. Individuals who participated in the focus groups were informed that since these groups were open meetings, there was no assurance of confidentiality of their input, and certain no anonymity. Focus groups were coordinated by group leaders who made written notes of the topics. Like the interview participants, individuals who participated in the focus groups were offered \$25.00 gift cards from Target as a token of appreciation. Group leaders for all focus groups used a “starter set” of questions to assure that all participants had the opportunity to address the same topics. Participants in the focus groups also had the opportunity to expand on their responses to these questions, and to address other topics. Focus groups were organized for the following:

- Adults with disabilities in high school and post-secondary transition programs;
- Adults with disabilities not in programs;
- Parents and caregivers of school-aged students with disabilities;
- Parents and caregivers of infants, toddlers, and other young children with disabilities;
- Providers of services to school-aged youngsters;
- Providers of services to infants, toddlers, and other young children with disabilities;

A total of 11 focus group sessions were conducted, and 74 individuals participated. Focus groups for individuals with disabilities included (a) students and young adults aged 20-25 years old in a school-to-work transition program (all enrolled in or graduates of special diploma programs), (b) adults in college programs (including regular degree and non-degree programs), as well as (c) adults who did not receive employment or transition services. Disability designations for this group included Intellectual Disability, Autism Spectrum Disorder (with and without Intellectual Disability), Expressive Language Disorders, and Physical Disabilities. Parent focus groups included 27 participants representing young children and school-aged children. Finally, provider focus groups included 15 participants representing direct service and information and referral organizations who provide services across the lifespan and across a very broad range of disability characteristics. These agencies included ARC, CARD, Easter Seals, Children’s Services Council, Community Services of Palm Beach County, Early Learning Coalition, Palm Beach County schools, 211, and others.

Community Conversations. During the spring and early summer, monthly community conversations were held to solicit input from the broader community. Although these conversations were primarily attended by included providers and funders, family members, advocates, individuals with dual roles (e.g., parents who were also providers), and other people interested in the process and outcomes of the needs assessment also participated. These events provided opportunities for participants to give legislative updates, describe exemplary practices, identify new and on-going needs, brainstorm solutions and future directions, and more. Community conversations were held at United Way of Beach Peach County, and minutes of each event were taken and disseminated.

Although the community conversations continue, for the purposes of this report, the events conducted between January and June are included. During these six public conversations, 174 different people participated, representing 71 separate entities, as well as individual providers and community members. Attendance at the events ranged from 50 to 68 individuals.

Surveys. To extend the reach of the needs assessment further, three surveys were developed and posted on-line, and the public was invited to provide input by completing the surveys. Separate surveys were posted for (a) parents and caregivers, (b) providers, and (c) funders. [*For this report only results from the first two are included.*] Surveys were designed using multiple choice response formats, with selected items allowing for open ended responses. The survey for individuals with disabilities contained 34 items; the survey for parents and caregivers contained 37 items. Several items on both surveys contained embedded, follow-up questions so the actual number of possible responses was over 700. For both surveys the average response time for completing the survey was 25 minutes. Participants accessed the surveys through an on-line link to Survey Gizmo (<http://sgiz.mobi/s3/Individuals-with-Special-Needs-Survey> for the survey for individuals with disabilities; <http://sgiz.mobi/s3/Parents-Caregivers-Survey> for the Parent Survey). Each week the project director ran a summary analysis of the data and posted it to the project collection site. The FAU investigator responsible for the statistical analysis conducted the final analysis of all survey data through the end of July. That analysis is included in this report.

Regarding surveys from individuals with disabilities: A total of 277 individuals started the survey, however 134 completed enough of the survey to use in the analyses. Of the 134 surveys, 78 (59%) that were completed for the individual with a disability by a parent or caregiver, and 33 (25%) that were completed by the individual with a disability themselves. Teachers completed 10% of the surveys for the individual with a disability, and the other 6% were completed by others (e.g., a sibling). The average age of participants was 38.6 years (SD = 16.8) indicating a wide range of ages in this survey. The majority (75%) of the participants were female, and they had an average of 3.3 people living in their household (SD = 1.5). The average income was in the \$35,000-49,999 range. The relative high living status can also be seen by the 88% that indicate they have internet access in their home. The majority of participants were Caucasian (64%), followed by Hispanic (15%), and African American (13%). Asian, Native American and other races made up the remainder of participants. Participants' educational attainment indicated that 28% had not finished 12th grade, while 23% had a post graduate degree. Oddly 53% indicated they did not have a GED. It is unclear why the educational attainment questions did not represent normal distributions. It is likely that participants who took the survey themselves had a

significant amount of education (37% were college graduates) while many with lower levels of attainment had someone else complete the survey for them. (It could also be that some who completed the survey for the person with a disability, responded about *their own* education rather than the individual with a disability on some questions.)

Regarding surveys from parents and caregivers: A total of 427 started the survey, however 229 completed enough of the survey to use in the analyses. Of the 229 surveys, 76% were completed parents, 18%, were completed by a caregiver, and 6% were completed by someone else such as a sibling or grandparent. The average age of participants was 48; the individuals whose needs they referred to averaged 17.6 years. When parents and caregivers referred to children in particular, the average age of these children was 3.5 years (SD = 4.97), with many participants indicating that a disability diagnosis came at or before birth. Of the individuals whose needs the parents and caregivers referred to, 65% were male, they had an average of 3.5 people living in their household (SD = 1.5), and averaged 1.2 children with disabilities in their household. The average income was in the \$50,000-75,999 range. The majority of participants were Caucasian (67%), followed by Hispanic (14%), and African American (9%). Asian, Native American and other races made up the remainder of participants. Participants' religious preferences were mixed, with approximately 25% (each) indicating Jewish and Catholic, approximately 10% indicating Protestant, and the remainder having other or no religious preference. The most common disability diagnosed by this sample was Autism Spectrum Disorder (101) followed by ADD or ADHD (83), Intellectual Disabilities (78), mental health problems (48), behavioral or conduct disorders (44), medical and health concerns (41), Down Syndrome (identified separately from ID) (32), Epilepsy (28), Cerebral Palsy or other neuromuscular disorders (23), Asperger's Syndrome (23), PDD-NOS (21), visual impairments (17), Spina Bifida (13), and other conditions with less than 10 including Cystic Fibrosis, Muscular Dystrophy, and hearing impairments. [Because participants could check as many conditions as applied, the number of conditions identified equal more than 229). The majority of the persons with special needs attended school as their primary activity (63%), followed by attending a day program (13%), and staying home (12%). Only 8% were working full or part time, with the other 4% doing other activities. Parents and caregivers indicated that their child missed school, work, or their primary activity an average of 15 times in the previous year (SD = 46.6) indicating that many of them missed a very high number (some indicated 365), while others missed only a few times.

Findings from the Community Needs Assessment

There were numerous findings generated from the Community Needs Assessment that crossed the participant groups, and related to populations of people with special needs across the lifespan and across disability characteristics. Many of these findings were inter-related (such as a service might be difficult to become eligible to receive; finding available providers is difficult once a person becomes eligible; and then finding a way to receive funding for this service). The findings revealed that Palm Beach County citizens identified *strengths, weaknesses, opportunities* for growth, and *threats* to individuals and systems. The findings are presented in eight categories, with recognition that these categories have some degree of overlap. Categories include:

- Information and Referral
- Assessment and Early Diagnosis
- Service Shortages

- Funding Streams
- Transition Practices
- Employment
- Transportation Availability
- Advocacy and Futures Planning

Information and Referral (I&R) practices in Palm Beach County vary across ages and disability characteristics, but are largely driven by the age of the individual with special needs. Families of young children frequently seek out services through Early Steps or sometimes, private early childhood providers. These private providers include VPK providers, preschools, and pediatricians). This tendency is simultaneously both a strength and a weakness. The *strength* of age being a driver for Information and Referral is that families report that they get to know the “major players” germane to their family member with special needs at the same time they arrange for services. A *weakness* was reported as families not being able to identify I&R providers as their family members transition from one set of age-related services (e.g., school services) to another (e.g., adult services). Some agencies (e.g., Division of Blind Services) serve individuals from Birth through the lifespan. The school system is another example of a major stakeholder and provider who provides continuous services for many years. These agencies have an *opportunity* to play a central role as an Information and Referral provider as well as a service provider.

Families and providers both reported that easy, language-friendly, and accessible Information and Referral services benefit families by helping them avoid the myriad shopping, referral, and intake anxieties. Providers who showed particular *strengths* in this included 211 and Child Find. For infants in particular, NICU personnel were helpful and supportive, and as babies grew into toddlers and preschoolers, Early Intervention providers typically provided family service coordinators who were reported to be extremely helpful when guiding families to navigating systems. *Threats* and obstacles occurred when coordination across organizations was unreliable. For example families reported that Early Steps does not always refer or coordinate with parent and family groups such as Gold Coast Down Syndrome, and hospital staff frequently did not provide referral information beyond purely medical services.

Three specific I&R *threats* were reported for school-aged students, and for students preparing for transition to adulthood. First, families identified the need for early and specific information for their children with lower incidence disabilities (including severe intellectual disabilities, psychiatric disorders, hearing and vision impairments), and for specific types of service needs (such as behavior therapy, mental health services; information about leisure and recreation activities). Second, both parents and providers identified the need to better serve unique I&R needs of specific cultural and ethnic populations, as well as groups in hard-to-serve geographic areas. Third, parents and providers identified the need to activate a stronger I&R system for students preparing to exit the school system. Because no single agency coordinates information and services for adults with special needs, I&R needs grow exponentially the closer students get to graduation. Finding information regarding employment, adult living, medical services, and more is a major and very complex obstacle to the transition to adulthood.

One finding reported frequently was the role that many parents play in seeking out information on their own. It was reported by parents and providers that many parents learn about providers primarily through word of mouth. As one provider observed: *There is a lot of 'human capital' in the parents movement.* Some providers and organizations collect and post satisfaction data so parents and caregivers can make informed decision about their services (e.g., 211, NAMI, CILO, Palm Tran). However, parents also report that the need to constantly search for information is exhausting. Where the internet has assisted many families to find information, families noted that it is easy to *over use* the internet: *I can spend hours looking and tracking things –I need to spend more time with my child.* This presents an interesting opportunity for some providers to help parents reach out and support other parents. A positive example of this was reported at Renaissance Learning Academy: At the beginning of the year, they host a resource fair at night for parents; providers attend so parents have an opportunity to talk directly to the providers and collect information about potential future relationships with these providers. A second positive practice was identified as The Family Café Conference for parents and providers. Described as the State's largest and best, this disability resource fair provides workshops, information tables, displays by state and federal agencies, and practical examples of specialized diets, vehicles, and other accommodations for and by people with significant disabilities. A third positive practice is seen in the effort by the Palm Beach County Youth Symposium to develop a television show on channel 20 that features programs about specific services, and brings others to talk about services. The show is intended to run regularly across the entire county, so families will know about services and how to get involved.

Assessment and Early Diagnosis. One *strength* noted regarding assessment and diagnostic services for young children is that Child Find screening and evaluations for 3-5 year olds have been greatly streamlined so the process is completed much faster than in the past. In addition, there are many example of good collaboration between programs who provide assessments (and intervention programs) for young children programs (for example, Early Steps and First Steps). However, early diagnostic services were consistently reported as a *weakness* for youngsters with certain disability designations. For example, a lack of system capacity was reported in Early Steps for assessment batteries appropriate for diagnosing Autism Spectrum Disorders. Difficulty in making an early diagnosis results in many children receiving a diagnosis as developmentally delayed, thus missing out on more robust services for young children with ASD. This *weakness* reportedly applied to young children with emotional and behavioral disorders as well. Failure to identify in children's preschool years pose a *threat* to obtaining appropriate services which, in turn, results in strengthening of challenging behavior and mental health concerns. Also, independent assessments have become difficult to obtain because many private psychologists have waiting lists. The result is that children who do not receive early diagnosis, followed by robust interventions, get removed from more inclusive school environments and are removed to more restrictive environments. This led nearly three quarters of the survey sample to identify assessment needs as a priority. Fortunately, many service organizations in the county identify earlier diagnosis for ASD and ADHD as an *opportunity* for providers. Both CSC and Child Find are actively trying to increase the availability of developmental screenings.

The obstacles and *threats* to receiving disability-specific assessments and diagnostic services follows many children throughout their school years. To pursue specialized educational services beyond the school system, comprehensive assessments are needed for a range of low incidence

disabilities. These assessments are difficult to administer, particularly when they extend beyond the typical academic realm. Many families not able to afford the comprehensive evaluations that will allow their children to access services outside of the school district. The interviews with adults who wrestled with emotional and behavioral disorders reported that their mental illnesses were not diagnosed until they were out of school. All of them completed high school, and some admitted that they “just barely” did so. None of these individuals received special education services during their school years. For these individuals, the lack of a comprehensive system of evaluations resulting in early diagnosis and treatment resulted in a *threat* to meaningful educational preparation for adulthood. This, in turn, set them up for life threatening disabilities as adults, with repeated job failures, living situation failures, and continuous struggles in their family lives. Only one of the people in the group remained married throughout their struggle to understand mental illness.

As adults, the findings indicated a *weakness* in assessing students’ abilities to succeed in post-secondary education. If secondary students do not leave the school district with recent and specific assessments regarding their need for academic and other accommodations in college, they might not receive them if they attend college. Re-evaluations to get accommodations at the college level is not done by the school district, so students must carry their assessment reports with them, or pay for private evaluations if they attend college. If parents can’t afford private evaluations, students do not get them, and thus are not eligible to receive accommodations in college.

Services Shortages. Regardless of their “roles” participants reported a great many unmet needs for individuals with special needs in Palm Beach County. Gaps in services were identified for specific, individual services, as well as for an overall system of services, with shortages attributed to insurance coverage gaps, transportation issues, and sometimes the geography or location of the service.

Numerous participants in the needs assessment reported that there were service *strengths* throughout Palm Beach County. Typically, these *strengths* targeted particular agencies and practices. For example, the Children’s Services Council and United Way received high praise for their special needs equipment fund for individuals 18 yrs and older whose equipment requests have been denied by insurance. CILO was identified as an organization who has been successful in reducing or eliminating a waiting list for services, and the Palm Beach Habilitation Center was identified as one of the very few agencies to provide housing options for retirees with cognitive and physical disabilities. Palm Beach County Youth Services provides a 3-month residential treatment facility for youth 11 to 16 years old with behavioral needs, youth and family counseling programs, parent education and mental health counseling programs, youth violence program, summer camp, and summer food programs. Other than an initial registration fee, these services are free. Each of these examples were cited as positive practices in the county.

There were other examples of service *strengths* as well. Many families reported that school services for students with disabilities have improved, and the district employs many fine professional educators. The county has also attracted numerous charter and private schools, and some of these meet children’s needs. Also, there is an increasing trend for parents to successfully transfer their children from public to other public, private to public, public to private, and public

to charter schools when the initial school was not a good match for their children. It was unclear whether this flexibility was due to a system intervention or simply evolved by default, but the impact on students and families was considered a strength. In post-secondary schools a *strength* was identified as the academic accommodations (exams, note taking, papers) for academic classes that are increasingly provided at colleges and universities.

Weaknesses in county services were many and varied. There were numerous examples provided of families that relocated to south Florida to be nearer to families, only to discover services like job coaches, housing, health care, and employment services here were severely limited or did not exist for them. Housing was repeatedly identified as a service gap and a central *weakness* in the county. Although housing options that include behavioral therapy or support, and housing for special needs populations who are dually diagnosed (DD with Alzheimer's; DD with Dementia; DD with health care) were identified as a major gap in services, many participants reported that *any* affordable housing options are limited. Housing options for individuals who need more support for executive function (e.g., daily organization, life planning), and housing for people who need behavior or psychiatric support are rare. When housing options exist they are frequently limited to group homes, with focus on daily living skills for adults with intellectual disabilities. As a result, a very large proportion of participants lived with their aging parents and family members.

Another *weakness* involved the paucity of respite. Respite services lessen the need for full-time housing alternatives but must be available, reliable, and provided by individuals who have been screened and trained. Respite can be provided either in-home or out-of-home. Few agencies deliver respite services, and fewer deliver screening and training for special needs in-home sitters. The notable exceptions were the ARC and UCP, however requests for their respite services overwhelm their ability to meet the demands. Several parents of young children and school-aged children noted that although getting through the school days is manageable for families, weekends and summers can put a family in crisis, and few weekend residential services are available. Also, nearly half of the survey sample reported a need for afterschool care. Like the scarcity of housing options overall, respite services for nonverbal children, and those with complex needs, is greatly needed and least available.

Service gaps were also identified for a range of other individual services. This included speech and language therapy, socialization opportunities and social skills training, cognitive and other services for individuals with TBI, and counseling and other support for parents of children with severe behavioral difficulties; and mental health services. The highest need identified in the surveys was for dental care, although the majority of respondents also reported that these needs were being met. Surprisingly, several participants reported that there are still access issues for people with mobility issues. This includes ramps, ramp locations, and bathrooms that accommodate wheelchairs. Several providers and funders identified that the gap in these and other individual services had a negative impact on many individuals and families, this pointed to a broader *weakness* – the absence of a robust and reliable system of support that integrates services for individuals with special needs in the county.

Numerous *opportunities* were identified for improving services. Given the awareness of the gaps in individual services, along with the awareness by providers and funders of the lack of a strong

system of support, there are *opportunities* for both micro-level and macro-level approaches to creating and delivering services. An example of micro-level delivery involves *opportunities* for growth in recreational, leisure, and mental health services. Organizations and individual professionals find willing and grateful recipients of services, and some geographic areas of the county are wide open for providers. Some participants reported that the trend toward privatization in vocational rehabilitation could provide job placement and employment opportunities that have not existed in some parts of the county. Services provided for other populations with needs (such as elderly citizens in the county) are potentially a models for narrowing the gap in services. For example, many models of independent and assisted living exist in the county for elderly adults without disabilities; these models and facilities (and the organizations who support them) could be partially replicated, and their service experiences might have helpful implications for individuals with special needs. Finally, a macro-level approach to services is seen in an initiative by PBC Youth Services. This agency serves children 6-22, and the Highridge Family Center focuses on 11-16 year olds, with a newly created program that brings various youth programs (e.g., residential treatment services, youth and family counseling) under one umbrella. Other services include youth and family counseling and education. These programs provide services particularly for those with mental and behavioral health needs. To reduce the service gap in the western part of the county, the agency has opened an office in the Glades. Although this initiative is still developing, it has the *opportunity* to help other organizations re-think their service approaches.

The *threats* and obstacles to a strong array of services were varied. Funding was identified as a common threat, and this is described further in a separate section. The common issue of paperwork obstacles touched everything from obtaining bus passes to making medical appointments, and this was addressed by all of the participant groups. Most participants required some level of support in filling out paperwork required by employers, local/state agencies, medical providers, funding agencies, job coaches, and others. Students and adults with special needs frequently identified the impact of “paperwork fails” including missed appointments, lost services, and generally, missed opportunities for services. Simple issues for adults without disabilities became crises for some participants; for example one individual who was struggling to keep his slot in a group home asked what he should do when he had difficulty handling money and paying bills. Another asked how she should respond to things she received in the mail.

Most participants identified the *threats* to one’s quality of life posed by the ever-present waiting lists for services, and by inconsistent policies on using Medicaid Waiver and Medicaid to pay for services. Other *threats* involved personnel shortages. For example, the large turnover of psychiatrists results in long periods of time with certain medical and mental health service shortages, and low wages and large waitlists are known to cause “burn-out” in support coordinators and other professionals. The impact of personnel shortages and “being spread too thin” was described by providers from Therapeutic Recreation; by their own admissions the programs don’t happen in the southern part of the county due to the staffing obstacles. Within and outside of the school system, many providers are not familiar with assistive technology and AAC devices. This becomes an obstacle to individuals who rely on these devices to skillfully use them for communication, mobility, and movement support.

Funding Streams are closely related to the delivery of services, since funding exists solely to support services for individuals with special needs. However, findings related to funding stream are described in this section so that readers can differentiate the actual services from the means used by consumers to obtain these services. The central finding involving funding streams is that they are unstable and unpredictable.

Where *strengths* related to funding streams exist, they involve the predictability of funding, and the access to services that follow. State funding for autism support has been increasing and has been fairly accessible, and this should be considered a *strength*, however funding for other services and supports, and for other disabilities, is notoriously low and results in waiting lists that might be years-long. In Palm Beach County, early childhood services has strong funding support from Children’s Services Council (also a *strength*), but CSC support across the ages is thin or absent. Participants reported that funding for ABA, physical therapy, and occupational therapy, are services that are most easily accessible; most are satisfied with private services and grateful for Medicaid and Medicaid Waiver. Some funders have begun to link support to providers to consumer satisfaction as a condition of continued funding and future contract (such as recent Palm Tran Connections contracts). This has added a degree of accountability to providers, and was reported as a *strength* by many.

Weaknesses involving funding stream are many, and they are complex. One weakness involves restrictions on - and inconsistencies regarding - who will pay for what. Not all private providers accept Medicare or Medicaid Part D, a primary funding source for many services. Other services many or may not been accepted by private insurance companies. Also, there are inconsistencies across counties regarding what services (e.g., transportation) will be paid by Medicare. This has led to on-going battles as families and individuals with disabilities who might find services have to battle for a way to fund them. One parent indicated spending “thousands upon thousands upon thousands” of dollars for private services. A second *weakness* related to funding is the resulting delay in services caused by unreliable funding streams. Nearly every organization and provider has had to devote energies to dealing with waiting lists. Getting on “the list” was a recurring theme across all categories of participants. Parents devoted enormous energy to trying to figure out what “category of need” they have to document to receive different types of services. They frequently spoke of trying to figure out how many years in advance they had to sign up, knowing that their children’s needs will change in the meantime. As one provider said, parents have to “know your list and get on it early.” Families reported that the Medicaid Waiver wait list is years long to qualify. Others noted that the wait list for APD high school to adult transition services is over 10 years long, so parents needed to know to sign their children up early. Florida’s Agency for Persons with Disabilities has approximately 20,000 people on the wait list; this equates to approximately 10 years for someone needing services. Some participants learned that if a family is in crisis (such as with the death of parents; court placement; or the child is in danger) then some courts will provide services sooner.

Because the gap in services and the funding streams that support services have such complex challenges, *opportunities* do exist for improvement. During the community conversations in particular, participants exchanged information about state legislators who were most knowledgeable about regulatory solutions to make system wide changes. Other participants represented organizations who provide a broad array of services, and this was identified as a

potential *opportunity* to create or advocate for funding streams that supported less restrictive, more comprehensive services. A variety of providers and funders reported that the funding stream challenges served as an *opportunity* and should be viewed as the impetus for convening future working groups focused on the creation of manageable funding streams.

Threats and obstacles involving funding have resulted in huge increases in behavioral and mental health needs going unserved. One threat was linked to diagnostic services; the difficulty in obtaining a diagnosis of autism prevents families from using insurance to fund certain therapies. Also, Medicaid reimbursement is so low that some private providers do not accept it. For young children and school-aged children whose diagnostic evaluations do not result in identified disabilities, these children typically do not receive services even though they demonstrate genuine difficulties. This was most frequently reported for children 3 to 5 years with behavior disorders and self-regulation problems, and often results in them being excluded from the class or preschool on a daily, weekly, and sometimes permanent basis. Without an identified disability, some private child care settings view “kicking the child out” as a viable option. Providers identified a common *threat* for stabilizing funding streams was the ever changing role of state funding. Florida operates in a legislative and regulatory environment in which the priority for social services has waned in recent years. The impact on VR, APD, and Medicare, for example, has been dramatic. Some organizations and providers now exist on their grant writing expertise alone as a means of generating funds to deliver services. This shift in priorities has been a major *threat* to supporting Floridians with special needs who rely on services funded by these agencies.

Finally, a number of *threats* to a healthy system of care for Palm Beach County were based on timing and geography. The timing *threats* involved the limited grants and financial support for summer programs, resulting in few summer opportunities for school-aged and younger children, although Palm Beach County Youth Services Department offered summer camp scholarships and summer food programs. Geographic *threats* included the challenges inherent in delivering services in a county the size of Palm Beach, and trying to assure distribution of services to areas with unmet needs. One example of this was the difficulty in providing VR services across the county. Ironically, some providers identified *threats* and obstacles such as publicity, or getting information out about their services out to people in different regions of the county. From their perspective, marketing, outreach, and public awareness was as significant a barrier as the actual geographic characteristics of the county. Cumulatively these barriers create challenges to creating and operating a system based on collaboration among agencies, consistency of services, and accountability of all services provided.

Transition Practices. A *strength* of the transition efforts in Palm Beach County is seen in the efforts between Early Intervention and the school district. Transition planning is initiated at the first meeting of the family with EI providers, and is revisited as children approach their 3rd birthday. There are some options under way that could add *strength* to transition practices for adults with disabilities to post-secondary education as well, although these were only briefly discussed by parents and providers.

There were *weaknesses* identified in transition practices distributed across all age groups. Although transition in Early Intervention was identified as a strength, there were challenges with

transition planning and services from ESE Preschool services to Kindergarten. One challenge involved a shortage of qualified evaluation specialists and psychologists to evaluate children prior to Kindergarten so these children could be accurately identified, and their educational needs planned for as they entered Kindergarten. This is particularly important given the changes underway in contemporary Kindergarten. Participants noted that today's Kindergarten is expected to provide an academic curriculum, replete with a curriculum scope and sequence, and frequent performance assessments of children. In most ESE pre-K environments the focus is on school adjustment, learning through play, learning to share, and telling stories to promote vocabulary development. Children transitioning from these settings to Kindergarten face a disconnect when expected to participate in an academic curriculum, sit for long periods of time, work independently, and demonstrate self-control. This transition is frequently not planned for. Another transition *weakness* involves preparation of school-aged children for post-school life. In previous years, transition preparation often included community-based instruction for students in middle school years and beyond. That is, transition preparation was elevated to a curriculum function. Currently there is little opportunity for community-based instruction for middle schoolers, and participants noted that even secondary students receive only minimal exposure. Employment and other transition preparation has been replaced by a stricter focus on academic instruction. For older students this makes their transition success much less predictable, and transition to services in adulthood, once away from the school system, was reported to be haphazard.

There are state legislative changes that will affect school to post-school transition, and it is not clear whether these changes hold *opportunities* to improvements for students and young adults. Until recently students on a Special Diploma track in school often had IEPs and accompanying instruction with a transition focus toward employment or higher education. With the state move away from the Special Diploma, there could be *opportunities* or *threats* to transition planning. Nationally, replacing Special Diploma options with more academic requirements have often had the unintended consequence of diminishing transition planning and preparation for students most in need of this programming (Brady et al, 2014; Goodman et al, 2011). However, in Palm Beach County, this shift could be an *opportunity* to institute transition planning for all secondary students (not just those with disabilities) as a universal part of the general education curriculum.

The *threat* most commonly discussed involved the shortage of personnel with expertise in transition planning. Within the school system, there are not enough transition specialists to promote a focus on instruction that yields more efficient transition to adulthood. Individual teachers are provided mixed messages regarding the need to align their instruction to the academic curriculum, and simultaneously incorporate individual transition goals into students' IEPs. And for students who do exit the school system ready for employment or post-secondary education, there are few program options available. County colleges and universities provide supports and accommodations for individuals in regular degree programs, and participants identified this as a strength. However other college and university options that prepare people for supported employment, supported living, and enhanced community access have not been available.

Employment. Two examples of employment *strengths* stood out during the needs assessment. First, a positive practice of a private employer was identified as All-Tag, a

manufacturer of electronic surveillance products in Boca Raton. This light manufacturing business produces security devices to help protect retailers from shoplifting. All-Tag is not a human services agency, but was identified for its employment practices and hiring record for adults with special needs. A second *strength* was development in hiring and training job coaches by two organizations (Goodwill and Palm Beach Habilitation Center). Since job coaches are central to successful job preparation, placement, and retention for many individuals with special needs, providers sometimes include on-site job coaches as a central part of their employment services. These two organizations received praise by people with disabilities as well as other providers for their expertise in job coaching.

Participants reported four types of *weaknesses* involving employment. First, there is a significant need for competitive employment options. Many human services professionals have increased their attention on supported employment as a positive alternative to both unemployment and sheltered employment. However, a common sentiment among many individuals with special needs was that they were searching for opportunities to enter competitive work environments with adults who do not have disabilities. Currently, there is not a strong focus in Palm Beach County on competitive employment. For adults who would prefer supported employment, a second *weakness* was reported: there is a distinct lack of supported employment settings, and job coaches to increase the likelihood of employees' success there. A third *weakness* was reported as the lack of variety in employment options. Some participants reported that many individuals with special needs are slotted for employment opportunities limited to custodial work, food service, and related fields. These options are limited, and frequently do not match the interests and strengths of future employees. Finally, as reported in the section on Transition Practices, a fourth *weakness* was the inconsistent attention paid to transition of secondary students into the post-secondary adult services world. The three employment service needs reported in the survey (training, placement, and paid employment opportunities) met the needs of less than 50% of participants; the three services were highly correlated with one another (r ranges from .79 to .90) indicating that participants who expressed a need for one of the services also express a need for the other two.

Parents and providers reported that an unrealized *opportunity* to increase employment is the creation of microenterprises for individuals with disabilities. The development of microenterprises as an employability solution has made gains nationally, and much closer to home, as a vocational training option in Miami Dade County Public Schools. Microenterprises are typically home-based operations, and require vocational skill, as well as general business acumen. Although microenterprises could isolate some individuals, it is a positive employment *opportunity* for others. A second *opportunity* was reported for post-secondary educational institutions and other organizations who target employability services. Participants reported that opportunities exist for training and certificate programs specifically targeted to local employment needs. In addition, *opportunities* exist to increase employment supports for employers and other agencies. For example, an effort to increase the pool of job coaches in the county would lessen the need for employers to provide this training, and would allow them to increase their focus on hiring and supporting employees with special needs. And, training *opportunities* for job coaches would create better job coaches. Increased salaries for job coaches, based on their training, would attract additional applicants for job coach positions. A job coach initiative would create an *opportunity* for a coordinating agency to train, support, and evaluate job coaches.

A *threat* reported previously for most other services, the wait list, is a major obstacle for employment services as well. Parents recommended that others apply for VR services at least 2 years before students exit high school, although even an early application is no guarantee of consistent service. The wait for employment services, coupled with the restricted options for employment, can be seen in the survey results. Of the individuals with disabilities who responded to the survey, 31% were unemployed, and 47% worked less than 10 hours per week. (These Palm Beach County data are consistent with national studies.) Of those who did have paid employment, they worked an average of 21 hours per week (SD = 21). Thus, the threats identified by participants are reflected in actual employment patterns in the county.

Transportation Availability. The needs assessment resulted in mixed findings on issues involving the availability of transportation. Interestingly, transportation is a service often cited as lacking in South Florida; 41% survey respondents identified transportation as a need, and 65% indicated this service was being used. (Note: few data were reported on satisfaction with the service.) Because transportation access has not been predictable the Florida Developmental Disabilities Council conducted a feasibility study examining options which are published in their report (FDDC and The Able Trust, 2010). Also, it became obvious that individuals with special need and their families used a wide variety of transportation methods to access services and to life their daily lives, and this flexibility and ingenuity was a clear *strength* among the respondents. Some participants reported using public transportation and ride share arrangements, while others relied on family members. Some used a bus pass that allows them to use any Palm Beach County public transportation including regular buses, trolleys, and Palm Tran connections. Others took multiple forms of public transportation each day, often changing buses two or three times to get to their jobs. Still others drove themselves to work and appointments, or relied on friends and family members for transportation. Some described using bicycles for transportation, although this was identified as an obvious *weakness* when weather conditions resulted in missing work and creating safety hazards.

Because agencies and service providers are dispersed throughout the county, and are not always near the persons who need them, transportation issues reflect the same *weaknesses* and *threats* found in the section of the distribution of services. Because providers cannot deliver a full array of services in some geographic areas of the county, individuals living in those regions must travel to the services, and there are *weaknesses* associated with this. Transportation across the county was reported to be problematic. This was made more complicated because Palm Tran is not a Medicaid Waiver service, so those funds cannot be used to purchase as in Broward and Miami Dade Counties.

With the recent intervention literature showing the utility of portable electronic devices as transportation aids, there is an *opportunity* for providers and others to explore this technology in our region. Four of the participants in the needs assessment used mini-iPads to navigate the transportation system. These iPads were pre-loaded with transportation apps, and managed by the transition program. In addition, one of the providers recently completed an empirical investigation on the use of iPads for transportation safety training.

Advocacy and Futures Planning. Advocacy and futures planning has been cited in many needs assessments as areas in which finding services has been difficult. In the Palm Beach County needs assessment, advocacy, futures planning, and legal services had the lowest ratio of “needs being met” (i.e., only 29% agreed that their needs were being met). In spite of this, none of the parents indicated that they belonged to any advocacy or similar support groups, with the main barrier attributed to a lack of time to be involved. Participants identified two areas of need when discussing advocacy and futures planning: guardianship issues for people who need a variety of interventions (including bio-medical intervention), and financial planning and money issues (including managing assets).

In spite of the unmet needs, the needs assessment identified several *strengths* regarding advocacy and futures planning. First, a variety of services were identified and are available. For example, Levine Family Services provides futures planning services to help parents of individuals with disabilities set up trusts or other legal services for their adult children before they experience a life crisis. They also assist families deal with crises that they are unprepared for. They receive referrals from 211 in Palm Beach and Treasure Coast, NAMI, and home health agencies, and are well known within elder services circles. Alpert Jewish Children and Family Services is a second organization that provides futures planning services. Another *strength* is the availability of private attorneys in the county with expertise in “special needs” legal matters. These special needs attorneys frequently provide pro-bono legal services; others provide services for a limited number of families (e.g., 2-3) for about \$1,000 (the typical legal package is about \$2,500 to \$3,000). One respondent reported provide pro-bono legal services to 13 families (equating to approximately \$39,000 in legal services).

As with all other services discussed by participants, there are *weaknesses* as well. Unlike some disability groups, there are few champions and advocates for people with mental health challenges. Where disability-specific services and organizations have become popular in some disability circles, that phenomenon does not serve this population well. Participants with mental health challenges reported on-going needs for advocacy for these individuals. A second *weakness* was reported as a paucity of legal services for elder adults with disabilities. Although many elder issues parallel disability issues, there are unique circumstances when these two areas of special needs are combined. Discussions involving advocacy also included a *weakness* in finding advocates to assist with pragmatics during times of crisis. For example, some adults with special needs identified a specific need for someone to assist with storm and hurricane preparations, and to advocate for people with health care needs after a storm. These issues included medicine management, shelter access, assistance with shutters and generators, and technology needs during and after a hurricane. A fourth *weakness* involved the need for Spanish and Creole speaking advocates and financial planners.

Participants identified several *opportunities* for providers to increase their scope of advocacy services. South Tech Academy teaches students to self-advocate. This includes developing transition goals that promote learning how to self-advocate, increasing involvement in all of their meetings, etc. Other providers might increase their effectiveness by including self-advocacy strategies as one of their services. Two other organizations that are effective in advocating for individuals with special needs are Lost and Found and Project Lifesaver. Both organizations are integral in helping families who deal with elopement and wandering, but serve different

populations. Participants identified *opportunities* for these organization to increase their effectiveness and reach by forming closer ties and collaboration. A third opportunity exists by bringing the school system into closer alignment with providers who provide advocacy, information, and referral. Participants reported that information about provider services needs to begin in elementary school. For example students and their families should be able to gain useful contact information (about respite, in-home care, etc.) from Florida’s Agency for Persons with Disabilities and other local organizations, but typically ESE contacts in elementary schools have only minimal information and awareness about these services. Simply providing this information to teachers and ESE contacts would improve parents’ knowledge about the system of care.

The *threat* in Palm Beach County regarding advocacy and futures planning was described as failing to empower families, and enabling providers to spin their wheels instead of improving our system of care. As one provider described, “Futures planning needs to focus on social capital of individuals with disabilities.” Social capital relies on informed individuals, families, providers, and funders. The absence of accessible advocacy and futures planning services is an obstacle to an effective and efficient system of care.

Recommendations for Services, Support, and an Improved System of Care

The 2015 Community Needs Assessment in Palm Beach County generated findings that were both surprising and predicted. Using a variety of data collection and analysis strategies, and gathering input from a variety of stakeholders, the SWOT analysis identified positive practices, as well as compelling needs for improvement. These findings lead to a series of recommendations for services and supports. For recommendations to have greater impact, however, they must exist within a context, lest they simply become a menu of ideas without a plan for implementation. A context for recommendations emerging from the Community Needs Assessment involves embedding the various findings into the broader system of care in Palm Beach County.

Hallmarks of a Comprehensive System of Care

Numerous system of care models exist that have resulted in improvements in services and supports for individuals with special needs and their families. Two recent reports provide guidance when strengthening an existing system of care. The Lucile Packard Foundation for Children’s Health (2012) identified six areas for attention when improving a system of care model:

1. Changes across time occur in the needs and experiences of individuals with special needs and their families;
2. Resource needs and their availability within the community are constantly changing;
3. Perspective on these resources (i.e., how individuals and families gain access and interact with available resources) is as real as actual access to the resources;

4. There is friction within every system (i.e., increasing difficulties obtaining services as the urgency of people's needs change);
5. Patterns of interaction between families and service providers are diverse and ever changing; and
6. Hope serves as the energy source which fuels family motivation and determination for a better future.

System interventions that devote energy to each of these areas have the greatest probability of making robust changes to the system, and having an impact of the community members most in need of support. In a related report, the Association of Maternal and Child Health Programs and the Lucile Packard Foundation for Children's Health (National Consensus..., 2014) identified evolving national standards that address both structures and processes of an effective system of care for individuals with special needs. Identified as system outcomes, these standards included:

1. Family Professional Partnerships: Families will partner in decision making at all levels, and will be satisfied with the services they receive;
2. Medical Home: Children with special needs will receive family-centered, coordinated, comprehensive, and continuous care within a medical home;
3. Insurance and Financing: Families will have adequate private and/or public insurance and financing to pay for the services they need;
4. Early and Continuous Screening and Referral: Children will be screened early and continuously for special needs;
5. Easy to Use Services and Supports: Services will be organized so that families can use them easily, including individual and family-centered care coordination;
6. Transition to Adulthood: Youth with special needs will receive the services necessary to transition to all aspects of adult life, including adult health care, work, and independence;
7. Cultural Competence: All children with special needs and their families will receive care that is culturally and linguistically appropriate, and that attends to racial, ethnic, religious, and language domains.

Each of these outcomes were linked to research or best practices in the literature, and each included a range of specific service and practice implications. Although both reports targeted health care needs (including a strong link to medical services), both provide a manageable perspective of what a *comprehensive* system of care looks like for a county such as Palm Beach.

Given the parameters of what a comprehensive system of care would look like, a reasonable question is whether such systems of care actually exist. Three models can be considered that address this. A model with relevance for Palm Beach County can be seen in the California

example (Association of Maternal and Child Health Programs, 2009). Given its size and population diversity, creating a system of care in California faces many challenges. However the California model incorporated two recommendations that strengthened this system. First, system planners targeted coordinated care as a central tenet of the system. The second recommendation was to designate initiatives that were more comprehensive than many medical models of care, and that included focused attention on mental health needs. Like other states, the California model incorporates recommendations for a commitment to coordination of services, partnerships (private and public providers), family involvement, service improvements, and diversified funding. A second model with relevance to Palm Beach County comes from an unlikely source given the demographics of the state. In Vermont, a system of care exists that targets sources of funding as a key element in making a coordinated system of care accessible to families (Vermont Family Network, undated). System advocates in Vermont point out that individuals with special needs often access several different health-related services, each with different eligibility requirements, different means of access, and different funding options. Since the health care system is difficult to navigate and access, especially for children with special health care needs, many families discover that trying to access and fund services can become a full time job. System advocates place funding (and ways to navigate the nuances of funding) as the centerpiece, by providing basic information on health insurance, information on the medical home model, and increased family use of a special needs trust as three tools for accessing care needed by children with special needs.

Closer to home, many of the system of care recommendations resulting from the 2004-2005 community needs assessment in Broward County (Brady & Wood, 2005) have value for Palm Beach County as well. Sponsored by the Broward County Children's Services Council, the Broward Regional Health Planning Council conducted a comprehensive needs assessment, with recommendations for system improvement, and a business plan to guide these improvements. Although the Broward needs assessment was more limited in scope than the one in Palm Beach County (it primarily targeted children, and the context involved their health care needs), many of the Broward findings were also discovered in the Palm Beach County findings. As important, given that a decade has passed since the system of care recommendations were proposed, Palm Beach County providers can examine the Broward experience when looking to improve their own system of care.

The recommendations for the Broward system of care were based on a Medical Home Model of Care (frequently called a Medical Home). This model is designed to help families navigate the various systems of primary medical care, and studies have reported positive findings involving family satisfaction, continuity of care, and child outcomes (Christakis, Wright, Zimmerman, Bassett & Connell, 2003). Although the Medical Home model is rooted in *medical* care, with pediatricians playing a key role, it is becoming an evolving practice as a model for a *comprehensive* system of care as well. The system of care in Palm Beach County, like Broward County and many other communities in the United States, is composed of a complex and baffling array of services, providers, and funding sources. Accessing the system is difficult and confusing, with different eligibility and funding requirements for different types of services. Information changes constantly, as do the providers and organizations who deliver services. As important, there is no single source of information for services and supports for individuals with special needs. Most examples of the Medical Home model of care incorporate the national

standards (National Consensus..., 2014) as well as the Packard Foundation standards described previously (Lucile Packard Foundation for Children’s Health, 2012). Implementing an effective, efficient, coordinated, and comprehensive system of care in Palm Beach County would yield improvements in:

- Timely and appropriate entry into a system of care;
- Staying in care and receiving services as needs change over the lifespan;
- Continuous access to funding streams to pay for services; and
- Continuous measurement leading to improvement in services and the system of care.

Recommendations for Services and Support

As noted in the section on Findings, the Community Needs Assessment identified service needs that were broad in scope and compelling in need. Recommendations within an improved system of care are presented based on the eight categories of findings, with a reminder that the categories have a degree of overlap.

Information and Referral (I&R). A single point of entry should be established that supports easy access to information on services and referrals for services for parents, caregivers, providers, and individuals with special needs. In a Medical Home model with children, this point of entry will center with the pediatrician. However, in a comprehensive system of care, with individuals accessing the system at any point in the lifespan, “single point of entry” will mean that the entry door will exist through medical, educational, rehabilitation, social service, and other organizations. That is, basic information and referrals must be accessible in schools, from medical professionals, in therapy clinics, from housing agencies, and elsewhere. Because dissemination of I&R is dispersed, a single core agency (such as Children’s Services Council of Palm Beach County) should take the lead in developing and distributing I&R materials.

The existence of a lead agency responsible for developing and updating I&R materials, combined with an expectation that all provider organizations disseminate the materials and information, will establish a “*No Wrong Door*” entry into the Palm Beach County system of care. A *no wrong door* single source I&R system means that every family and provider in Palm Beach County will have accurate and up-to-date information immediately available. Because I&R is not discipline-specific, health, education, and social service providers will share common knowledge germane to family members with disabilities. This is increasingly important in regions with service provider shortages, and where providers have overlapping responsibilities (e.g., Florida Diagnostic and Learning Resource Services, hospitals, social service agencies). I&R will not be idiosyncratic to specific providers or organizations, disability categories, or age groups. The lead agency in the I&R system (e.g., Children’s Services Council) could establish a single entry system by contracting out for the development and maintenance of a Palm Beach County I&R portal with basic information on health, education, and social services, and with links to provider directories and websites. A county-wide rollout of the portal will require information dissemination via billboards, TV spots, radio announcements, churches and temples, more visible Child Find activities, and training for personnel who work in the 211 system. Materials must be available in the written languages used in the county (e.g., Spanish, Haitian-Creole), and with various platforms and formats (e.g., braille, large print, TDD/TTY, audio).

In summary, the single point of entry will require the establishment of a lead agency to develop and distribute a comprehensive I&R system, and dissemination of those materials will be a core function of providers who serve individuals with special needs in the county, regardless of their discipline or organization.

Assessment and Early Diagnosis. To reduce the gap in providing diagnostic assessments, particularly diagnosis leading to early eligibility decisions, a county-wide effort is needed to improve developmental screening, diagnosis, and referral across disciplines. Cross-disciplinary assessment has long been considered a best practice in early intervention, but is less common as children get older and enter adulthood. Arena assessments that incorporate the expertise from multiple disciplines, and non-technical screenings can be administered by a host of providers (and even some paraprofessionals) if they are trained and receive periodic updates and skill assessments by specialists. The Children’s Services Council of Palm Beach County has a long and positive history of promoting services for young children, and could serve as the lead agency to develop partnerships with FDLRS and institutions of higher education in the county to establish an initiative to prepare clusters of providers skilled in administering developmental screenings. A larger cadre of providers with these skills would reduce the wait list for other eligibility and in-depth assessments by addressing the simpler screening functions, and freeing up diagnosticians for more specialized assessments. These screening providers could evaluate risk for developmental problems, identify high risk children who need more in-depth assessments, administer family ecological and environmental assessments, administer vocational preference and skill assessments for school-aged children and adults, and identify needs for family education and services.

Improving assessments in a comprehensive system of care is not limited to young children, however. The same coordination of effort is needed to increase access to meaningful assessments for individuals (including adults) with behavioral and mental health challenges, and other low incidence disabilities. Again, CSC is best positioned to serve as the lead agency to establish a network of providers and individuals with expertise in low incidence assessments. Expertise from psychologists, social workers, special educators, mental health counselors, disability support professionals at colleges, both public and private, exists in the county. However, these assessments are complex and time consuming, and professionals with this expertise rarely practice these assessment functions unless they operate with a system that enables them to predict future referrals. As the primary funding source for screening and assessment of young children in the county, CSC could coordinate an “assessment clinic without walls” that would increase capacity in Palm Beach County to provide timely specialized assessments.

To implement the recommendations to improve assessment and early diagnostic services, the plan will need personnel capable of coordinating (a) early screening, (b) specialized assessments, (c) screening trainings, and (d) a public information system similar to the recommendations found in the recommendation for Information and Referral.

Service Shortages. A primary finding from the Community Needs Assessment is that there are gaps in services throughout the county. Individuals with special needs who manage to build a network of supports do so by spending an enormous amount of time “agency hopping”; even then gaps remain. And, in some geographic regions (such as Belle Glade), even agency hopping does not result in adequate services. One recommendation to providing a more

coordinated system of care is establish a clear central agency designated as the agency responsible for coordinating the system of care in Palm Beach County. Children’s Services Council could become the lead agency, but have not taken on this role. In the absence of a central agency, an alternate recommendation is to establish a system of care coordinating council. This council would be responsible for taking steps to increase communication and solve problems across various providers. The council would work with providers to identify services and supports that could be better coordinated across agencies, funding streams, and barriers to our system of care. Moving toward this goal would require the establishment of a strategic plan and a blueprint for the development of a truly coordinated system of care. The blueprint would also tackle issues involving the need for provider recruitment, professional development, and accountability. A systems coordinating council would also help differentiate between services that are needed on a full-time basis (*24-hour service including* evenings, weekends, and summers) versus those that can be delivered at a lower intensity.

A second recommendation includes the development of a provider network in which individual providers and providers from various agencies meet to explore potential solutions to systems issues. A series of “ASSET Summits” would bring service providers together to share their directions in services, and successful practices they have used to reduce service delivery obstacles. These summits could also produce collaborative approaches to delivering certain services.

A third recommendation involves the need to establish a strategic plan specific to the personnel needed to better implement the system of care in Palm Beach County. There are at least three components of a personnel needs plan. First, all agencies identify the need for an absolute increase in the number of professionals trained to implement services in these areas. For example, the school district, employment providers, and housing and health care providers all point to personnel shortage. A county-wide personal plan should summarize the personnel needed to implement the system of care, and identify the short and long-term need for new and better prepared professionals in the field. Second, there is a need to provide additional professional development opportunities for existing personnel. The professional development opportunities are needed for providers regardless of their roles and degree earned. For example, advanced care physicians require continuing education opportunities so they become familiar with the workings of a Medical Home and other systems of care; special education teachers require professional development activities to better prepare them to teach children with medical complications; and paraprofessionals across many agencies require professional development to implement proven job coaching intervention. A county-wide personnel plan should identify professional development content (self-determination training; developmental screening), as well as types of levels of degrees (associate, bachelors, or masters degrees) and certifications (ABA, ITDS) needed. The third component of a personnel needs plan involves identifying the training resources that are already immediately available within the county, including inservice and preservice professional development opportunities.

In addition to the recommendations for strengthening the *system* of care, there are specific services needed to begin to close the many gaps in services. One recommendation is to create more community-based housing options, particularly for people with complex medical,

behavioral, and mental health needs. Another recommendation is for an overall increase in respite services, as well as increases in types of respite services available (in-home, out-of-home, partial day, and longer term options). Although post-secondary education options exist for individuals pursuing associate and bachelor's degrees, options for adults with more complex needs are just beginning to emerge, and there will be a growing need for more and different options. Finally, a host of medical and health care services were identified by some participants as an unmet need, and a healthy system of care will work to reduce the gaps between unmet needs for these services as part of an overall community response to improve services for all citizens. [*Recommendations for increased employment, transition, diagnostic, and transportation services are provided in those sections of this report.*]

Funding Streams. The central finding in the Community Needs Assessment regarding funding streams is that they are unstable and unpredictable. This finding is consistent with the county's own self-assessment published 5 years ago: "Palm Beach County does not compare well to other parts of the country... standing 45th among the 50 states in per capita spending in support of persons with developmental disabilities" (Palm Beach County Department of Community Services, 2010). This self-assessment reported that (a) the county is a long way from meeting its goals to strengthen mental health supports, (b) citizens with developmental disabilities were unable to acquire essential services, and (c) the "indefinite period of time" for funding yields an "indefinite wait to receive services." The key indicator in the county's self-assessment for people with developmental disabilities was redlined, indicating that the county is not meeting its goal and that the trend is getting worse. Funding for services should allow access to an adequate quality and quantity of services, and should be continuous, without interruption, as long as the child and family need the services. To accomplish this goal requires an overall increase in funding, and better coordination of funding that currently exists.

The goal for better coordination and increased funding could be met by convening future working groups focused on the creation of manageable funding streams. This could be initiated by calling for a summit (or congress) of funders and service providers who share information about their aims and interests in implementing services. In many ways this will expand on the community conversations that were held for this needs assessment, but the specific agenda would be to target means to (a) increase the overall revenues brought in to county services, and (b) better coordinate information and decision making for funding county services. Participants should include individuals with both private and public funding experience. An initial summit should identify working groups tasked with specific functions involving funding. One such task force would involve identifying county commissioners and state legislators (and their staff) who might support coordinated efforts to fund particular types of services, and ease regulatory burdens that are obstacles to existing funding streams. Other working groups might target specific needs and services (e.g., employment training, respite, and housing) and identify funding efforts that would result in improvements in these services. A third type of working group would establish recommendations from the funders on how to incorporate consumer satisfaction as a condition of continued funding and future contracts should also be produced. Finally, another working group should generate pragmatic information for families on how to navigate the nuances of funding including family uses of a special needs trust to promote access. Started as an initial summit, this event should be held annually or bi-annually. County-wide efforts to promote the summit will be needed, and the results of the working groups and the overall outcomes of the

summit should be published and disseminated widely. Follow-up efforts will include funding seminars in public and on-line forums.

Although these recommendations are for better systemic coordination of funding, *there is no suggestion* that specific funding for services should be reduced, or funding for new services frozen, pending a better coordinated model. To the contrary, many services delivered to individuals in need in Palm Beach County rely on the good will of private benefactors, and these services contribute much to the people who need them. The efforts of willing providers should not be hampered during the time it takes to build and disseminate more coordinated funding streams, and to integrate individual funders into a more coordinated funding system.

Another recommendation is to establish a mechanism to support the continuous dissemination of information on health insurance for individuals with special needs. Financing for health care and social services has become increasingly complex. Both families and providers need up to date and reliable information to attend to their on-going problems related to financing services. An outgrowth of the funders' summit should be an electronic discussion board with periodic and topical Frequently Asked Question (FAQ). The site should be staffed by people familiar with family service needs, who understand the myriad of insurance networks and services. Providers, families, physicians, and others could submit queries and answer questions, and find providers with certain services. The Funding Streams FAQ could be established by releasing an RFP for the development and maintenance of the system; the RFP could come from CSC or United Way as a county initiative, or from Florida Developmental Disabilities Council (FDDC) as a state initiative.

Transition Practices. Transition is a phenomenon that affects recipients of all services and supports, across all categories of disabilities, across all age groups. For example, young children transition from early intervention programs to preschool or other school settings; school-aged children transition from classes taught by individual teachers to high school classes taught by several different teachers; and unemployed people might transition to a busy retail environment, and then to a self-employment situation. Because of this, there is no single agency who is expected to have comprehensive expertise as a transition provider. Instead, recommendations to improve transition practices target different service providers.

One transition recommendation is for the school district to establish more explicit protocols for young children who receive ESE Preschool services. Because these children will move to Kindergarten placements, ESE preschool teachers should have explicit planning information that will make this move smoother. For example, teachers of preschool children who participate in *follow-the-child* programs must have information on the number of activities and minutes in Kindergarten in which children will be expected to (a) participate in academic instruction, (b) work independently, and (c) participate in performance assessments. A second recommendation involving school district practices involves the development of post-school transition plans. As the district prepares to eliminate Special Diplomas and align IEPs to the Florida State Standards, an explicit message will be needed that teachers will still incorporate transition protocols involving community employment and community access by all students with disabilities. In addition, transition protocols should be offered to students who do not have disabilities, but who would benefit from explicit transition planning. Offering transition planning to *all* secondary

students would raise the expectation for this, and lower the probability of transition duress by all students exiting high school.

The third transition recommendation is to increase professional development activities for teachers and others involved with transition practices. In many ways this parallels the professional development activities found in the section on *Employment* (next section). Because the need for increased expertise in developing and implementing transition plans crosses agencies and age groups, the recipients of this professional development include but are not limited to school district employees. Professional development also includes adult service providers, VR counselors, early childhood teachers, and others. This training could be linked to university offerings for degrees or continuing education, or offered as agency-sponsored professional development.

Employment. As with most services in the Palm Beach County system of care, there is no single agency responsible for promoting employment in the county. Instead, agencies like Vocational Rehabilitation, the school district, local colleges and universities, and private providers all play some role, and many gaps exist. The agency most central to coordinating comprehensive care and services to individuals with special needs is CSC but, per their Board mandate, they have traditionally targeted children. As a consequence, employment outcomes have received only minor attention from CSC. The school district has devoted some attention to preparing its graduates for post-school employment, but the findings in the needs assessment reported gaps in these services. A comprehensive system of care should include employment as central component of the system. To move the county closer toward this, three employment recommendations are provided. First, there is a need for increased employment options in a range of typical community settings. Second, there is a need for more and better post-school employment training options for adults with special needs. Third, there is a need for professional development opportunities for people who work with these adults to enhance their employment outcomes.

Although there were positive examples of effective community-based employment opportunities identified in the needs assessment, they were not common, and many participants identified the absence of integrated, community-based employment opportunities. Also, many of the employment opportunities that were available were limited to food service and custodial work – a phenomenon regularly identified as a national problem as well. In the absence of a central organization promoting inclusive supported community employment as an expectation in a system of care, funders can help move the county in this direction by increasing support for these services. This should not be interpreted as an immediate reduction in dollars for segregated (i.e., disability-only) employment options. However, targeted efforts to promote funding and supports for community-based employment will gradually shift the ratio of funding to these options. This includes support for efforts to establish microenterprises for some adults with complex medical or behavioral needs.

There is also a need to increase post-school employment training options for adults with special needs. The primary means for this has been school-based vocational training, but the effectiveness of this model has been erratic. Recent efforts to shift school district efforts to local colleges has been limited in scope (e.g., limited to students in certain age groups and disability characteristics) and effectiveness (e.g., unclear focus of the programs, absence of any structured

curriculum). Post-school employment training options at colleges and universities will add to a system of care only if they establish employment programs as a regular part of a system of higher education (i.e., create curriculum, establish certificate programs, develop admissions procedures, create tuition policies, create linkages with VR). The Academy for Community Inclusion under development at FAU is an example of a post-secondary program with supported community employment and living as clear outcomes, with a curriculum focus in support of these outcomes. The Academy's intent to become a self-sustaining program within the regular university infrastructure is an example of employment training as part of a system of care. Similar efforts to establish employment training options outside of colleges and universities are often successful for individual citizens, but have yet to be integrated into a system of care.

The third recommendation is to increase professional development opportunities for people in the school district and in adult service agencies that involve employment services. This includes administering and interpreting vocational assessments, expanding career awareness activities, and preparing job coaches. One recommendation to do this includes a district - university partnership, but from a systems perspective this remains a challenge. Although the need to increase these professional development opportunities is clear, there is no state "recognition" for the professionals who pursue this effort (i.e., no "certification" or "endorsement" recognition for successful graduates). This recommendation then would require state or local funding to create a path to professional development based on local recognition (such as a university certificate)

Transportation Availability. The findings related to the availability of transportation were somewhat mixed. The conversations involving transportation frequently identified this as a common need, however the survey results showed that the majority of people who reported this need also reported that they found ways to meet this need. The most obvious weakness was the degree of effort needed to access transportation, and the absence of backup options when transportation is not accessible. Because transportation is uneven, and most problematic when disability co-occurs with financial hardship, the recommendation for bringing accessible transportation into the system of care is to solve the issue involving Palm Tran not being eligible for Medicaid Waiver. To accomplish this recommendation, two action plans are needed. The first involves information collection (i.e., establishing how this service became waiver eligible in Broward and Miami Dade Counties). The second requires a lobbying and implementation effort. That is, efforts will need to be directed to county officials, state DOT officials, and state legislators to create conditions for regulatory relief, followed by developing and submitting an application for the waiver to the appropriate bodies. This could be accomplished by linking this recommendation to the funding summer working group (see **Funding Stream** recommendations) or by securing the expertise of a consultant.

Advocacy and Futures Planning. Two recommendations are provided to improve advocacy and futures planning within a system of care. First, there should be regular communication among providers (including physicians), families, government officials, agencies and advocates regarding guardianship and financial planning issues that affect individuals with special needs. This regular communication should include system-wide resources that cut across disability groupings and ages. Second, increased support is needed to provide self-advocacy and self-determination training to individuals with special needs throughout the county.

Providers play a key role in a system of care far beyond delivering a particular service. Providers are often the first point of contact for an individual or family into the system of care. For children in particular, the provider is often a pediatrician or primary care physician, and is the impetus for many of the calls for establishing a Medical Home as the system of care. The recommendations provided in the *Information and Referral* section will go far to improve the ability of families to locate and access services. However, advocacy and futures planning also relies on current and accurate information exchange among all stakeholders in the system of care. For example, guardianship issues touch families whose members need a variety of interventions including bio-medical interventions, and these guardianship supports can easily drop to the bottom of the list when families have to work to secure services that will help them manage life and daily functioning issues. Also, financial planning and money issues (including managing assets) affects families' ability to obtain the services they need, and this too cuts across service needs. An improved system of information exchange that targets guardianship, futures planning, and other advocacy needs would elevate these supports and shift the focus of advocacy from a crisis orientation to a system intervention that helps individuals stay "in care" as their needs change across the lifespan.

Specific actions that would improve current information to all stakeholders include (a) creating and maintaining system-wide directories focused on advocacy and futures planning, (b) providing regular public events in which professionals (including private attorneys with special needs expertise) and families can engage in progressively more detailed opportunities for futures planning (the STARS transition seminars are a model for these public events), (c) creating a county-wide portal with advocacy and futures planning information and tools for providers and families, and (d) disseminating contact and application information for families in need of short-term crisis intervention funds and assistance. An *Advocacy and Futures Planning* communication initiative could be established by releasing an RFP for the development and maintenance of the system; the RFP could come from CSC as a county initiative, or from FDDC as a state initiative.

The second recommendation is to increase the role played by individuals with special needs in their own advocacy and futures planning. Self-advocacy and self-determination are goals found in the mission statements of most service organizations, but few systematic efforts are found that promote these goals. Becoming more self-determined and learning to self-advocate effectively do not occur automatically. Various skills sets that help to develop self-advocacy and self-determination have been proposed (Carter et al., 2011; Wehmeyer et al., 2012) but typically include:

1. Choice Making
2. Decision Making
3. Problem Solving
4. Goal Setting and Attainment
5. Self-Advocacy and Leadership
6. Self-Management and Self-Regulation
7. Self-Awareness and Self-Knowledge

To acquire and use these skills effectively, increased attention should be paid to teaching and supporting a "curriculum" of self-advocacy and self-determination. Training models for both

currently exist, and this training has become a best practice in high school programs with effective post-school transition outcomes. To incorporate this training into the system of care would require increased attention by the school district to provide this training to students with (and potentially, without) IEPs. It would also require a means to increase these training opportunities to individuals once they leave high school. Incentives to adult service providers who participate in housing, employment, post-secondary training, and other services would elevate advocacy and futures planning as a core component in the system of care.

References

- Association of Maternal and Child Health Programs (2009). *Models of care for children and youth with special health care needs: Promising models for transforming California's system of care*. Lucile Packard's Foundation for Children's Health.
- Brady, M. P., Duffy, M. L., Hazelkorn, M., & Bucholz, J. (2014). Policy and systems change: Planning for unintended consequences. *The Clearing House: A Journal of Educational Strategies, Issues, and Ideas*, 87(3), 102-109.
- Brady, M., & Wood, D. (2005). *Broward County children with special needs: System model recommendations*. Sunrise, FL: Broward Regional Health Planning Council.
- Carter, E. W., Lane, K. L., Crnobori, M., Bruhn, A. L., & Oakes, W. P. (2011). Self-determination interventions for students with and at-risk for emotional and behavioral disorders: Mapping the knowledge base. *Behavioral Disorders*, 36, 100-116.
- Christakis, D. A., Wright, J. A., Zimmerman, F. J., Bassett, A. L., & Connell, F. A. (2003). Continuity of care is associated with well-coordinated care. *Ambulatory Pediatrics*, 3, 82-86.
- Florida Developmental Disabilities Council and The Able Trust (2010). Innovative approaches for increasing transportation options for people with disabilities in Florida. The Florida Developmental Disabilities Council, Inc. transportation feasibility study. Available at: <http://www.fddc.org/sites/default/files/file/publications/transportation%20feasibility%20study.pdf>
- Goodman, J. I., Hazelkorn, M., Bucholz, J. L., Duffy, M. L., & Kitta, Y. (2011). Inclusion and graduation rates: What are the outcomes? *Journal of Disability Policy Studies*, 21, 241-252.
- Lucile Packard Foundation for Children's Health (2012). *Six models for understanding how families experience the system of care for children with special health care needs: An ethnographic approach*. Available at: www.lpfch-cshcn.org
- National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project (2014). *Standards for systems of care for children and youth with special health care needs*. Association of Maternal & Child Health Programs and Lucile Packard's Foundation for Children's Health.
- Palm Beach County Department of Community Services (2010). A report of health and human services in Palm Beach County – Based on key community indicators 2010. Available at: <http://www.pbcgov.com/communityservices/pdf/Health-Human-Services-Report.pdf>
- Vermont Family Network (n.d.) *Health care financing for your child with special needs: Six ways to access Medicaid & other health care benefits*. Williston, VT: Vermont Family Network. Available at: www.VermontFamilyNetwork.org

Wehmeyer, M. L., Shogren, K., Palmer, S., Williams-Diehm, K., Little, T., & Boulton, A. (2012). The impact of the *Self-Determined Learning Model of Instruction* on student self-determination. *Exceptional Children*, 78, 135-153.

APPENDIX

Appendix Data Collection and Analysis

The following individuals provided their hours and expertise to the data collection and analysis in this needs assessment. The community needs assessment could not have been conducted without their skilled and careful involvement.

Mary Lou Duffy, PhD
Professor: Exceptional Student Education
Florida Atlantic University

Michael Frain, PhD
Professor: Rehabilitation Counseling
Florida Atlantic University

Peggy Goldstein, EdD
Associate Professor: Exceptional Student Education
Florida Atlantic University

Jazarae McCormick
Doctoral Scholar: Exceptional Student Education
Florida Atlantic University

Amy Newton, MPH
Quality Improvement Manager
Broward Regional Health Planning Council

Kathleen Randolph
Doctoral Scholar: Exceptional Student Education
Florida Atlantic University

Michele Rosiere, MSW
Division Director
Broward Regional Health Planning Council

Cynthia Wilson, PhD
Professor: Exceptional Student Education
Florida Atlantic University

Mila Wyman
Graduate Assistant: Exceptional Student Education
Florida Atlantic University

Appendix
INDIVIDUALS WITH DISABILITY INTERVIEW QUESTIONS

Name:

Date:

Zip Code:

Interviewer:

1. Do you mind telling me how old you are?
2. What is your disability?
3. How does your disability affect you?
Ability to work? Live by yourself? In school?
4. Were you in special ed (special classes) in school? Describe them.
5. Were you in regular classes in school? Describe them.
6. Did you get any extra services like speech or physical therapy while you were in school?
Now that you are not in school....do you receive any special service like that?
Who provides them? Who pays for them?
7. When you are not in school what types of things did you (do you) like to do?
Leisure, employment, family
8. How did you find these fun things to do?
9. Where do you live?
 - a. With family? In Group home? On your own? With friends? At college?
 - b. Would you like to live on your own?
 - c. What needs to happen to be able to live on your own?
10. How did you find this place to live?
11. Do you have a job? Tell me about it.
12. How did you find this job? How long have you worked there?
13. How did you learn to do your job?
14. How do you get to your job?

15. If you are not working...what do you do all day?
- a. Tell me about your day. Where do you go? Where do you hang out?
16. Is there something about having a disability that you want us to tell us?
- a. What is really hard for you now?
 - b. What is really good in your life right now?
 - c. What could make your life better?

Appendix
PARENT AND CAREGIVERS INTERVIEW QUESTIONS

Parent's name _____

Zip Code _____ **Date** _____

Child's name _____

Interviewed by _____

(Phase I – Past)

1. Tell me about your child. Name? Age?
2. What other children live with you, or do you care for regularly?
3. What is your child's diagnosis (disability)?
4. How old was he/she when this diagnosis was made?
5. How/where was this diagnosis (and possible earlier diagnoses) made?
6. If the initial diagnosis was not made in Palm Beach County, have any subsequent diagnoses been made in the county? If so, ask questions 5 – 7 based on the Palm Beach based diagnosis.
7. FOR ANY DIAGNOSIS MADE IN PALM BEACH COUNTY - At the time his/her diagnosis was made, what medical and/or educational information was provided to you regarding your child's disability?
8. FOR ANY DIAGNOSIS MADE IN PALM BEACH COUNTY - At that time what information were you given considering providers of services that could be of help to you and your child?
9. FOR ANY DIAGNOSIS MADE IN PALM BEACH COUNTY – At that time, were you given contact information for a support group?

(Phase II – Present and Future)

1. As _____'s parent, what are your greatest challenges?

2. Which Palm Beach County based services have been or are presently being provided to your child? (e.g., Physical therapy, Occupational Therapy, Speech/Hearing/Vision Therapy). For list, see pg. 3.

For each service identified by the parent:

- Where does he/she receive this service? (Location and name of provider)
 - Why there? What made you choose that provider?
 - Is transportation needed/provided for your child?
 - Describe your typical experience with this service provider. (e.g., wait times, reception at the location, response to your phone calls and concerns, financial arrangements, etc.)
 - What should this service provider do differently to improve things for your child?
 - What should this service provider be commended for? What does it do well?
 - Would you recommend this service provider to other parents? Why or why not?
 - What amount of out-of-pocket costs do you incur for these services?
 - Is your child better off as a result of receiving this service?
3. Are you eligible to receive respite service?
 - Do you avail yourself of the above service? If not, why?
 - Are there other services provided for you as a parent?
 - If so, which of the services do you like best? Why?
 - How could those services to you be improved?

 4. Is your child currently enrolled in an educational program?
 - Is this a program you have chosen?
 - Why did you choose this placement?
 - Have you been consulted in the development of an Individualized Educational Plan (IEP) for your child?
 - If so, describe the experience(s).

 5. How well are your child's needs for assistance met throughout the year?
 - What services/help does your child need but cannot get?
 - What would it take for that service to be offered in Palm Beach County?
 - Do you belong to any advocacy groups? Tell me about them.

 6. What do you like best about the help and services that your child receives?

POTENTIAL SERVICES

After School
Assisted Technology for hearing, vision, communication, mobility
Advocacy (School)
Advocacy (Social Services)
Audiology/Hearing Therapy
Behavioral Analysis, Assessment, & Intervention
Case Management/Coordination (“whole picture” guide – often a social worker)
Cognitive Therapy
Child Care
Dental Care
Dental Care – Specialty
Developmental Assessment
Durable Medical Equipment
Early Intervention
Family Support Services & Training
Health Education
Health Services
Home Nursing
Individual & Family Counseling
Information & Referral
Legal Services
Medical & Therapeutic Equipment
Medical Primary Care
Medical Specialty Care
Medications
Medications Co-Pay
Mental Health Counseling
Nursing Services
Nutrition Services
Occupational Therapy
Physical Therapy
Respiratory Services
Respite Care – Parent or Guardian
Screening Services
Speech/Language Therapy
Subsidized Day Care/Head Start
Summer Programs
Surgical Specialty Care
Transportation
Vision Therapy
Hospital Home Bound (teacher from Palm Beach Schools comes to home or hospital)
Other _____

Appendix
PARENTS AND CAREGIVERS FOCUS GROUP QUESTIONS

30 Minutes

Explanation of this study and this meeting
Introductions
Introductions of Parents/Caregivers*

20 Minutes

Review of Provider Directory Mock-Up

60 Minutes

Review of Parent Survey Mock-Up
Mid-Point Findings

- a. diagnosis experience
- b. service provider experience
- c. Palm Beach County Public Schools experience
- d. Transition experience
 - ages (3-5) (6-7)
 - older teens-age 22

10 Minutes

Best experiences within Palm Beach County system

*Briefly, please tell us:

1. your name
2. your child's name
3. child's *primary* diagnosis
4. city in which you live
5. how long you have lived in Palm Beach County

Thank you for sharing and being a vital part of our research!

Appendix
PROVIDERS FOCUS GROUP QUESTIONS

1. Introduction of Ourselves and the Project
2. Explanation of Project
 - a. explanation of Unicorn's involvement
 - b. explanation of focus of our parent interviews
 - children's diagnoses, needs, ages
 - services they receive
 - services they would like to receive
 - quality of services received
 - parents' likes/dislikes of services provided
 - improvements in services parents see as needed
3. Service Providers' Data
 - a. online survey of funding stream
 - all providers asked to complete survey
 - information will go into the final report
 - demographic information to go into the parent directory
 - Note: give ex: parents want bilingual staff and more money for services
 - b. 25 service providers to be interviewed by phone
 - c. select few chosen for focus groups
4. Questions
 - a. Introduction:
 - How do parents find out about your service? Walk us through that parent's experience.
 - What have parents told you about the process? Is it easy or difficult?
 - b. Begin with:
 - What do you provide that most other providers do not?
 - What makes your agency unique?
 - How do you know if the best services that you provide have an impact on the children and families you serve?
 - c. End with:
 - What prevents you from providing your best service to more people?
 - You are our first focus group. What other questions should we ask?
 - Note: If discrepancies exist between the parents' and the providers' information, ask the providers to explain those discrepancies.

5. Re-cap

- a. Review the barriers the service providers have mentioned
- b. What would you like to have the Needs Assessment Team get involved in?
- c. Thank you for your time, appreciate you being here, etc
- d. Here's how to send us any statements, clarifications, additions

Appendix
PROVIDERS INTERVIEW QUESTIONS

Interactions

1. How do parents find out about your service?
2. What have parents told you about the process? Is it easy or difficult?

(Use “Barriers List” if necessary)

Your Agency

3. Do you help people navigate the system?
4. What does a support coordinator (or case manager) do? What steps do they take?
5. Through which system are they paid?
6. Under what conditions do you refer parents to other service providers (agencies)?
7. Tell me about the experience of having to transition to different agencies. (For example, when PART C needs to be switched due to a child’s aging-out of the program, [ages 0-3, 4-5, 7-12, teen –young adult] Who is in charge of this process?

Wish List

8. What else would you like the Needs Assessment Team to know about you?
9. What prevents you from providing your best service to more people? (If money, then, money with which to do what?
10. If you had a “wish list” for your agency, what would you put on it? Explain your choice.

Appendix
Interviews and Focus Group Participants
Community Providers, Parents and Caregivers, and Individuals

Young Children and Families' Services

ARC of Palm Beach
211- Special Needs Palm Beach
Palm Beach County Schools
Center for Autism and Related Disabilities at FAU: Birth to 5 contact person
Deaf and Hearing Resources
Easter Seals: Early Steps of Palm Beach County
Easter Seals: Child Development Center of Palm Beach
Gold Coast Down Syndrome
CHADD of the Palm Beaches
West Palm Beach Division of Blind Services
Early Learning Coalition of Palm Beach County
Children's Services Council of Palm Beach County
ESE Resource Teacher (Behavior Specialist) Palm Beach County Schools
Community Services of Palm Beach County

School-Aged Services

Lost & Found of Palm Beach, Inc.
School Psychologist (Retired; provides independent psychological assessments)
Renaissance Learning Academy
Palm Beach School District Transition Specialist
Wellington Landings Middle School Teacher
New Bridge Securities Corporation
South Tech Academy
FAU Communication Disorders Clinic
FAU Center for Autism & Related Disabilities
Palm Beach Youth Services
Palm Beach School for Autism
Palm Beach Youth Services
Special Olympics
Palm Beach County Schools ESE Department
EdVenture Charter School

Post-Secondary and Adult Services

211 Palm Beach / Treasure Coast
Agency for Persons with Disabilities
Career Source / Ticket to Work
Center for Autism & Related Disabilities: Employer Support

Center for Independent Living Options (CILO)
Department of Vocational Rehabilitation: Palm Beach Central Office
Gulfstream Goodwill
Levine Jewish Residential and Family Services
Levine Family Services: Futures Planning
National Alliance for the Mentally Ill (NAMI)
Palm Beach Habilitation Center
Palm Tran and Palm Tran Connections
School District of Palm Beach County
Sunrise Opportunities (housing)
Therapeutic Recreation of Palm Beach County
United Way