A Research Report Sponsored by a Grant from the Ohio Developmental Disabilities Council

Evaluating Services that Support Families with Children with Disabilities

William Hayes, PhD, The Ohio State University - Barry Jamieson, MA, Timothy Sahr, MA, MPH, MDiv, ThM, and Xiaoxi Yao,M.P.H., Ohio Colleges of Medicine Government Resource Center - Anthony Goudie, Ph.D., University of Arkansas for Medical Sciences - Susan Havercamp, Ph.D., The Ohio State University Nisonger Center

EXECUTIVE SUMMARY

Families who have children with developmental disabilities (DD) face numerous and unique challenges and stressors compared to families of children without disabilities. To alleviate the overall burden of stress, families with children with disabilities (FCD) employ various coping mechanisms to address their circumstances. Many of these mechanisms impose economic and emotional burdens on FCDs. Research has shown these overall higher levels of stress result in diminished rates of employment opportunities and incomes for FCDs.

Building upon prior research funded by the Ohio Developmental Disabilities Council, this study develops a conceptual framework for understanding how FCDs evaluate services in relation to alleviating their overall stress level. The findings of the academic team from the Ohio State University and the University of Arkansas are reflected in the study *"Evaluating Services that Support Families with Children with Disabilities."*

The study builds a conceptual framework to evaluate potential policy tradeoffs related to increasing the level and access of services to FCDs and then tests this framework by using surveys of FCDs and other key stakeholders.

Key findings of the study include: 1) The totality of the child's need is the priority for caregivers, 2) The agency arranging services for FCDS rate those services under their control as being more effective than those services they do not control, 3) Parents ranked effectiveness of health care services, other than special equipment, higher than other key stakeholders, and 4) Family effectiveness ratings of services change with the needs and the age of the child. Policymakers need to emphasize the role of FCDs in deciding what services are provided to children of disabilities. Having one entity actively coordinating services is likely to improve the overall stress of FCDs, leading to improved health outcomes for the family member and the child with a disability.

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I. BACKGROUND

Families who have children with developmental disabilities (DD) face numerous and unique challenges and stressors compared to families of children without disabilities. Families of children with disabilities (FCD) employ various coping mechanisms to address their circumstances. Many of these mechanisms impose economic and emotional burdens on FCDs. A recent study estimated that approximately 32% of FCDs have an adult who ceased employment due to their child's health burden and 26% of families reported spending 11 or more hours per week coordinating care for their child/children with a disability (Goudie et. al, 2009).

Time spent caring for a child with DD negatively impacts an adult's earning potential. The Ohio Family Impact Study (Goudie et al., 2009) found that mean income differences between FCDs and non-FCDs was approximately $20,000 annually, controlling for socioeconomic factors. This finding is consistent with the Disability and American Families Report: 2000, that median income for FCDs providing care is 15% less than for non-care giving families. In other words, FCDs, who have less income, incur elevated care giving expenses. Results from the NS-CSHCN 2005/06 found that most Ohio FCDs experience minor to severe financial hardship, with 20% of FCDs spending more than $1,000 per year in related out-of-pocket medical bills (Goudie et al., 2009). Fujiura, Roccoforte, and Braddock, in a University of Michigan policy brief (2005), estimated that FCDs with adult DD children (greater than 18 years of age) spend approximately $6,300 per year in related out of pocket expense.

Beyond economic difficulties, FCDs experience heightened emotional stress. Related to a lack of social interaction, FCD parents experience less social support, resulting in higher levels of fatigue (Koshti-Richman, 2009) and a greater number of daily stress events (Smith, 2009). Low social support is associated with higher levels of impaired psychological and physiological functioning and higher rates of mortality and morbidity (House, Landis, Umberson, 1988). Caregivers of children with a disability who also have chronic physical health problems were twice as likely to experience chronic conditions themselves and to report activity limitations and elevated depressive symptoms (Brehart et. al, 2009).

Regardless of economic, psychological, and time pressures, families most often choose to care for their child with DD in a home setting (Johnson, Kastner, et al., 2005). In response to FCDs' preference for non-institutional care settings, state and local developmental disability entities have worked to enable better and less costly care to DD individuals within home settings, resulting in the contraction of the number of institutionalized beds available to individuals with disabilities for many states. In Ohio, the number of developmental center beds has decreased by 36% in the past ten-years, from 1,978 in 2001, to 1,258 in 2011. The intensified interest in home settings and community-based care has resulted in an increased demand for FCD home-based support services.

Access to support services increases a families' willingness to care for children with DD in a home setting (Birenbaum, Guyot & Cohen, 1990; Cole & Meyer, 1989, Fujiura et al., 1994). States have responded to the increase in home care services by increasing the amount of funding for family support. Rizzolo, Hemp & Braddock (2009) note that nationwide family support funding has increased from just over a billion dollars in 1998, to $2.3 billion in 2006. Despite increased budgets, family support services remain a small fraction (5%) of the overall service expenditures to individuals with developmental disabilities (Rizzolo, Hemp & Braddock 2009). In Ohio, the 2011 budget line item for FCD support service spending was approximately $6 million, compared to total home and community based expenditures of over $1 billion dollars for individuals with disabilities. However, the 2011 Ohio budget understates the true amount of family support services provided, since respite care is often utilized by families on Level I or I/O services (the amount spent on respite services is information that is currently unavailable).

Given the limited funding for family support services, policy makers should consider services that best support all members of families of children with disabilities. Since assistance to a child with DD and their families is linked, policy should address unit-based (family and child) support services. The resource dilemma is that often policy makers debate family support expenditures for children with disabilities and support for their families as zero-sum adjustments – to allocate more in family assistance is to lessen assistance to the child with DD. Conversely, policy makers should consider services that are most effective in easing caregiver burden both the individual and the family, to avoid the risk of institutionalization.

One approach to addressing the zero-sum dilemma is to develop a model that assesses the relationship between caregiver burden and child needs to determine services that are likely to reduce caregiver burden (McManus et al., 2011). A challenge is the lack of caregiver and disability outcome data needed to develop models. One approach to determine services to reduce caregiver burden is to study programs and services provided in other states. Activities data would be collected to examine services that might be useful to Ohio FCDs. A challenge of this approach is direct comparability of systems in one state might not be applicable to the service structure of another state. For example, providing direct cash subsidies to FCDs might be considered wasteful in some states and helpful in another, depending upon political and cultural climates. The study, Evaluating Services that Support Families with Children with Disabilities applies multiple approaches to surveying state policy makers, field experts and FCDs to determine services that best alleviate overall family stress relating to children with disabilities. The rationale for this approach is that services that are rated most effective by families and stakeholders should serve as a guide to determining the best support of FCDs and children with disabilities.

The primary objective of this study is to determine what services provided to FCDs alleviate family stress associated with caring for children with disabilities. To assess these services, this study researched:

- A conceptual framework to evaluate potential policy tradeoffs related to increasing the level and access of services for families.

- Preferences of services compared between families, payers and DD experts;

- Given preferences, potential gaps that exists between services; and

- Given preferences, the conceptual framework to propose policy considerations.

II. CONCEPTUAL FRAMEWORK FOR EVALUATING SERVICES THAT SUPPORT FAMILIES OF CHILDREN WITH DISABILITIES

Assessing the family stress reduction potential of different policy options requires a conceptual framework for understanding sources of stress for FCDs and an analytical approach to assessing policy options against this framework.

These analyses are built upon the recent work of McManus et al. (2011). Their framework contains three main domains:

(1) Ease of accessing/navigating the health care system;
(2) Unmet health care needs; and
(3) Caregiver burden.

The authors hypothesized that caregiver burden, measured as financial burden, time coordinating care, and time providing care, is lower for people who have an easier time navigating the care system and higher for people whose child with DD has unmet needs. Their model included the moderating variables of race/ethnicity, poverty, insurance, and severity as predisposing, enabling, and need factors that affect the relationships between ease of accessing/navigating and unmet health care needs to caregiver burden.

The model contains four factors related to ease of accessing/navigating the system:

(1) A usual source of care;
(2) Ability to obtain referrals;
(3) Ability to receive routine care; and
(4) Having a personal nurse or doctor.

Using NS-CSHCN 2005/06 data and Maternal and Child Bureau core outcomes variables, the authors found that having a personal nurse or doctor was important for creating a positive accessing and navigating the health care system.

The McManus et al.'s analyses also included six factors for assessing unmet health care needs:

(1) Receives no special education;
(2) Rarely has family-centered care;
(3) Lacks specialty care;
(4) Experiences delayed care;
(5) Has difficulty using services; and
(6) Rarely has care coordination.

The Evaluating Services that Support Families Project modifies the McManus et al. conceptual framework. McManus et al. focused analyses solely on children ages 5 through 17. Our analyses looks at children with DD across the age spectrum with three key age blocks of 0-5, 6-21, and 22 and older. The McManus model creates a statistical measure of caregiver burden, while our approach conceptualizes burden as an event that varies over time. Our analysis also includes an additional potential unmet need: lacks a trusted place or person for childcare support, including respite care. Further, our model divides access to specialty care into several elements (mental health, therapies, special equipment and dental care). These additions in types of needed specialty health care become important for assessing where families experience service gaps in the care system. Finally, our conceptual framework adds additional moderating characteristics of the population at risk, including:

(1) Onset of new physical, behavioral, or other health challenges;
(2) Caregiver's existing skills in navigating complex service systems;
(3) Presence of an engaged, extended family support system in close geographic proximity;
(4) Number of service systems that caregiver needed to coordinate care;
(5) Number of children with DD in family;
(6) Number of total children in family;
(7) Relationship status of caregiver to child with DD; and
(8) County where family lives, given resource variation across Ohio counties.

The project's conceptual framework has 8 key underlying assumptions. These assumptions are informed from the results of the FCD survey described later in this report.

First, family stress is fed by many factors – stress is not a single phenomenon. FCD survey comments identified 10 broad categories (some overlap) that contribute to family stress. The first six of these categories relate to the family's ability to secure needed childcare (see Appendix C for all listing of all family comments). These categories compare to McManus et al.'s ease of accessing/navigating the health care system and unmet health care needs, including:

(1) Access to coverage/payment assistance for needed services;
(2) Access to needed health care services for the child with DD (preventive, primary care, acute care, chronic care, dental care, mental health care, special equipment, and therapies);
(3) Access to needed developmental disability services (special education for 0-5 year olds);
(4) Access to special education and educational services during primary and secondary school years;
(5) Access to workforce training services for the child with DD; and
(6) Access to a trusted person and/or program for childcare

Three additional categories related to caregiver burden for the child with DD include:

(1) Time spent coordinating care/advocating for a child with DD;
(2) Time spent providing health care;
(3) Time needed for family errands, family business, and caring for non-DD family members; and

The final stress factor, which cuts across all of these other stressors is the caregiver's degree of sense or perception of being in control.

Second, as noted above, several factors challenge the caregiver's ability to meet the needs of the child with DD. These factors categorize into issues of (1) access to resources and/or services, (2) alleviation of stressors to enable routine family function, and (3) caregiver perceptions of situational control.

Third, the experience of caregiver stress varies over time and is contextual. Stress is highest at several transition periods when the family confronts new experiences and challenges in accessing needed care for their child with DD. These transition periods often increase time management burdens, a sense of a lack of control, and financial pressures on the family. Acclimation to new experiences as a DD caregiver may foster success or toleration in navigating the DD settings and likely lessens the intensity or impact of stress. These transition periods include:

(1) When the child first develops the developmental disability and enters the service system;
(2) Movement for a child with DD to a school setting;
(3) Transition for the child with DD from childhood to adolescence, with continuing shifts in school setting and the onset of puberty;
(4) Transition out of secondary school;
(5) Post-school movement to independent living or more independence while living at home;
(6) Aging and/or loss of parents or loss of familiar family network; and
(7) Any changes in access to resources to assist in paying for needed services.

Fourth, the lack of a trusted source of care for the child is a critical impediment for parents in that it impacts work and family schedules for the caregiver. This challenge may be greatest when a child with DD is younger and more vulnerable to potentially unhealthy or unsafe care environments, but can continue into later years, contingent upon the severity of the child's condition. A lack of trust can be poly-affectioned, being experienced from the parent to the relief caregiver and from the child to the relief caregiver. A lack of trusted source of care for parents can increase stress and can also limit the parent's ability to work outside of the home, impacting family financial security.

Fifth, uncertainty of plausible care options fuels stress. Families reported concerns about not

knowing of available options to get their child needed services.

Sixth, time and experience can build confidence. As parents adjust to a child with a developmental disability and experience being able to advocate for their child's needs, their ability to manage this source of stress usually increases.

Seventh, time is a necessary and precious commodity for parents of a child with DD. The more time spent coordinating care, transporting the child to services, or accessing services for the child with DD, the less time there is for other family and personal needs.

Eighth, parents are reluctant to trade services that their child with DD need for services they perceive as focused on their needs. In other words, parents elevate the needs of their children over their own state of stress.

The Family Stress Flow Conceptual Model

Based upon our knowledge of family stress determined from surveys conducted of families and a review of the literature, four levels of object-oriented family stress, each category in rank order was developed. These levels are:

(1) Make sure care for child with DD is being met (Stress Level 1);
(2) Address time and financial burdens related to accessing needed care/services for child (Stress Level 2);
(3) Make sure care for others in the family are being met (Stress Level 3); and
(4) Make sure care for self is being met (Stress Level 4).

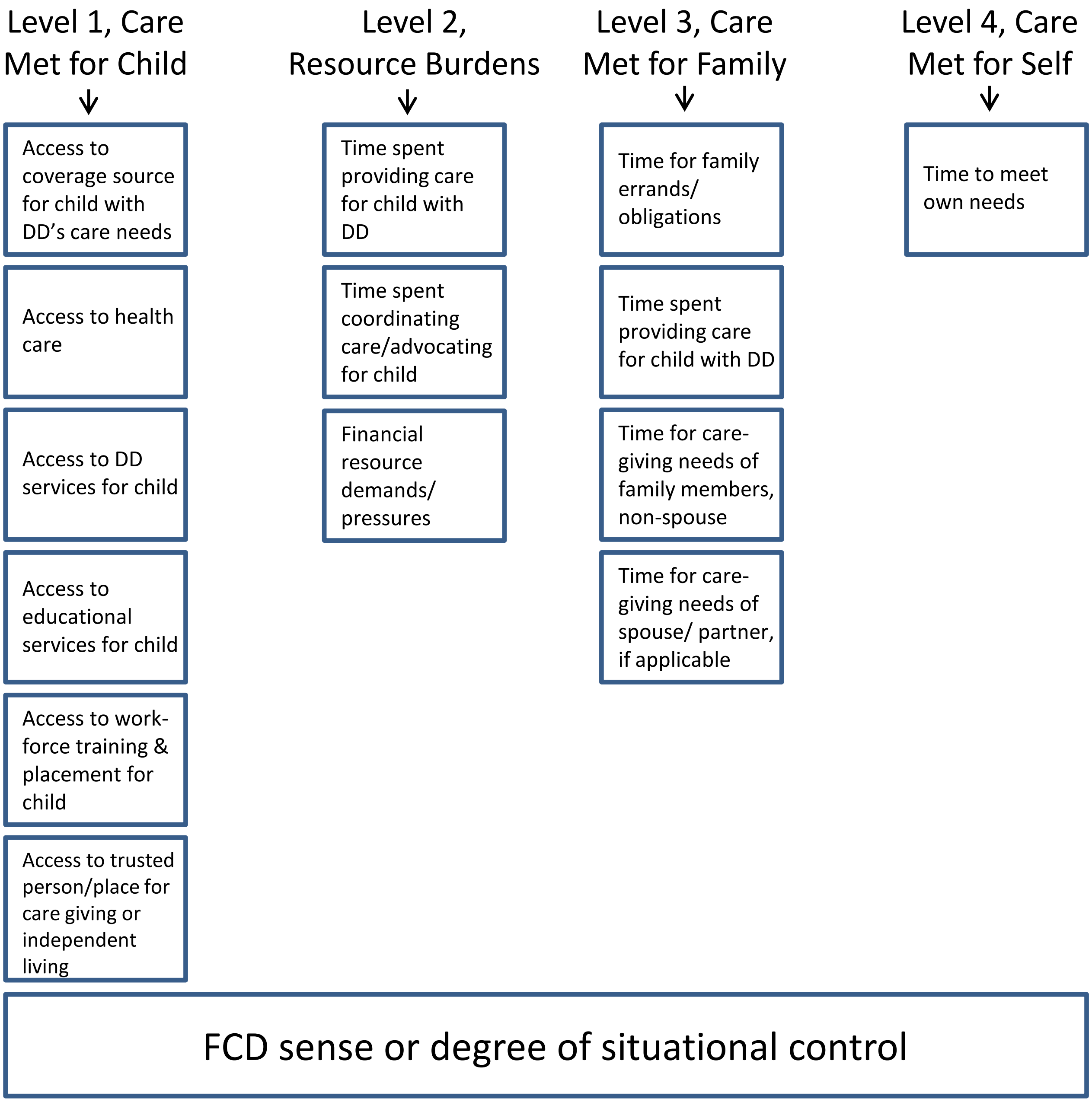
Impacting stress across all of these categories is the degree to which caregivers feel a sense of control regarding being able to meet the needs of the child with DD and the family overall.

Figure 1 displays our conceptual model for assessing and prioritizing caregiver stress. We posit that this model is how caregivers will evaluate policy options to address family stress. The model flow assesses how a policy option may affect...:

1) ...a child with DD's access to needed care/ services;
2) ....a caregiver's time and financial burdens;
3) ....caregiver's sense of situational control;
4) ...caregiver's ability to meet care needs of general family - specifically other children and/ or relatives in need of care support;
5) ...the caregiver's relationship with a spouse or adult partner; and
6) ...the caregiver's personal needs.

Figure 1

Family Stress Flow Conceptual Model



The Developmental Disabilities System Policy Flow Model

The policy process does not simply involve the assessment of family impact. The process is bounded by systemic financial and organizational constraints. Therefore, policy assessments must address the implications for a particular policy option for the system or systems affected. Figure 2, on the following page, reflects our conceptual model of this assessment process. The conceptual model contains five stages:

(1) Identification of a potential new or expanded requested service (Stage 1);
(2) Assessment by an organizational entity on its capacity to provide a requested service (Stage 2);
(3) Determination of costs for providing more of the requested service (Stage 3);
(4) Assessment of options to pay for requested services – including the tradeoffs that the system may need to make between existing services expanded requested service (Stage 4); and
(5) Making a decision on whether to add more resources to provide the requested service(s) (Stage 5).

At Stage 1 an individual, a group, or the agency providing services identifies a potential need for a requested service. This request could either be for more of an existing service or for provision of an entirely new service. Part of this identification includes an analysis on the anticipated need for and benefits of the requested service.

Upon identification of a need for a new service the agency responsible for providing the service needs to assess its existing capacity to meet this request (Stage 2). This assessment includes determining if there is additional staff and other capacity required to provide the requested service in the existing system. This agency also needs to decide if it can meet this need on an individual basis or must make this service available to all families they serve. Finally, if the requested service is being provided currently, the agency needs to determine if the family needs more of the service or is having problems effectively accessing and using the existing service capacity.

Next, policy assessment needs to establish the financial cost for providing those requirements (Stage 3). This assessment not only includes calculating the total cost for providing the service, it should also explore if there are cost savings options for how to provide more of this service, especially existing services.

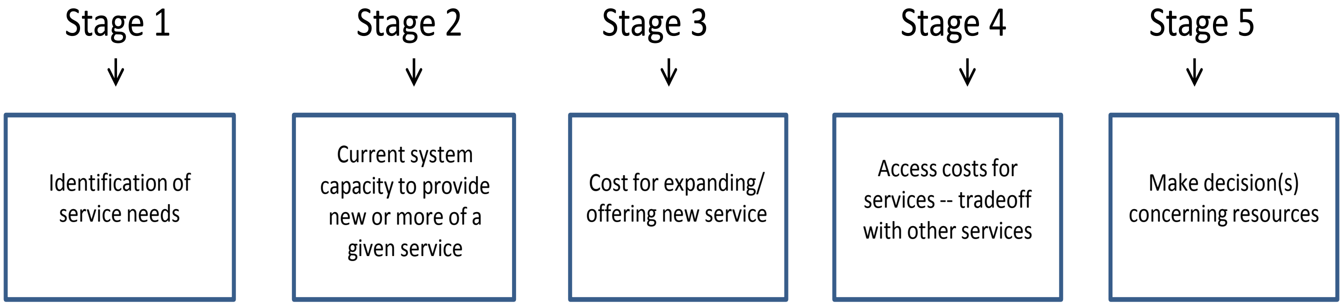
Having determined the cost of providing the requested service, a policy assessment needs to determine if the agency has the financial resources available to cover those costs in its current budget (Stage 4). If not, then the assessment must determine where those financial resources will come from, which includes assessing the potential tradeoff for the individual family or families as a whole if those resources would need to come from reducing the amount of support from other services. In evaluating the costs and benefits of such a tradeoff, the assessment needs to calculate the value to the individual family or families of the requested service versus the downside of reducing other services.

In some cases the agency might be able to reduce the tradeoff dilemma if it is able to find a source of new funding to test the service, perhaps from a grant.

After evaluating the resources demands and tradeoff issues, the agency needs to make a decision on whether or not to provide the requested service (Stage 5). This decision is easier to make when it only involves an individual family. The decision gets more complicated when its ramifications affect multiple families, each with their own specific needs.

Figure 2

Developmental Disabilities System Policy Flow



To understand how the family services conceptual framework can be applied to evaluate a particular service's ability to ease caregiver burden, four separate surveys of families and stakeholders were conducted. Surveys were conducted of family members, county board DD superintendents, state DD directors and state DD council executive directors. Although the FCD perspective is crucial to understanding how overall family stress could be lessened, the service provider and coordinator perspectives are important to determine administratively how caregiver burden might be lessened.

Families perceive the value of services through the lens of their individual experience. Their value judgment of a particular service and how it relates to their overall stress level is discussed in the Family Stress Flow Conceptual Model. Superintendents, perceive the value of a given service through not only the need of the individual and parent but various administrative considerations discussed in the Developmental Disabilities System Policy Flow. State DD directors and DD council executive directors, although not directly involved in the administrative considerations of the service organizing entity, understand the key policy and administrative considerations that should be considered in order to understanding the needs of the caregiver, child with DD, and family members.

III. METHODOLOGY

Survey Sample

The Evaluating Services that Support Families Project consist of four sample populations that seek to address s that seek to address: (1) the priorities and experiences of FCDs and their children with DD; (2) the priorities and experiences of Ohio DD administrators who channel or direct service options to FCDs and their children with DD; (3) a group of state developmental disability directors; and (4) executive directors of state disability councils who offer external comparisons to Ohio's developmental disability system's service and assistance structures. These surveys do not include those families of individuals who received services outside the county board of DD system. A significant share of children with disabilities, particularly those with physical handicaps, receives services and supports outside the county board of DD system. Therefore any results obtained from the study may not necessarily apply to families of these children.

The survey sample was collected from lists of state developmental directors and disability council directors, Ohio county superintendents of developmental disability directors, and families receiving DD assistance services. Items for the surveys were drawn from prior reviewed instruments and, in some instances, were developed by the research team after consultation with a project review team and survey methodologists. The surveys presented to the main target populations varied slightly, due to variance in administrative function and experiences of FCD assistance (e.g., service distribution questions varied slightly between those receiving assistance and those responsible for administering services).

The foundational/baseline population for this study were families who receive DD assistance services. The goal was to collect input relating to the perceived effectiveness and access of 24 services received and/or needed by FCDs. The secondary population for the study was the Ohio county superintendents, who provided insight to the effectiveness, access, and resource intensity of 24 service offerings for FCDs. Finally, external input was sought in order to gain insight beyond a closed service system (Ohio's DD system) from other states. (See appendix A for the complete survey service listing and definitions.)

Study participants were emailed and/or mailed the developmental disabilities services and use survey (see Appendix D for copies of the survey instruments). Survey data was collected electronically via SurveyMonkey over a 6 week period for the State DD directors, DD council executive directors, and county board superintendents. For the FCD sample, surveys were mailed to a randomly selected list of families within select counties who had at least one child living with the parent and who were receiving at least one service from a Developmental Disability Board. Survey contacts to FCDs were made via mail by county developmental disability board field staff over a 10 week period to account for differing delivery dates for when surveys were received by a FCD from their county developmental disability boards. Completed surveys from 204 FCDs were returned from 15 Ohio counties, representing a mix of suburban, urban, and rural counties.

Families were sent a cover letter from the participating county developmental disability board and the academic research team specific to the project. Additionally, families were sent a copy of the survey instrument along with a self-addressed stamped envelope for the completed survey to be returned. Besides completing a paper survey, families had the option of completing the survey online or by telephone. A limit of the sample design is that FCD survey results do not reflect a statewide representation of Ohio – a statewide probability sample was not employed.

Response rates for the target populations varied: 38% of state developmental directors (n = 19), 57% of state executive directors of developmental disability councils (n = 31), 42% of county superintendents of DD (n = 37), and 13% of families (n = 204). It is believed that the low FCD response rate may be due to the length and complexity of the survey. A prior extensive service survey by the Ohio Developmental Disability Council resulted in a 7% response rate.

The study instruments were reviewed and approved by The Ohio State University Institutional Review Board. The Ohio State University Internal Review Board process was accepted by the State of Ohio Internal Review Board.

Instruments

The survey instruments were developed to obtain information from FCDs, Ohio county superintendents, and external state DD services administrators. All respondents were asked to rank, out of a list of 24 different DD options, which programs or services most effectively alleviated family stress and how accessible was the service. A list of 24 programs and services was created from: (1) a list of commonly provided state family support services (Rizzolo, 2009); (2) services currently offered to FCDs and individuals with developmental disabilities in Ohio; and (3) services considered by the research team to be potentially helpful to FCDs, but are not commonly offered (e.g., concierge services). Selection of the 24 programs and services also considered whether they could jointly address the overall stress level of FCDs and children with DD (Perry, 2005).

Operationalized service definitions were developed from publicly available sources and shared with a panel of disability experts for further refinement. Five-point response scales/options were offered for respondents to rate the efficacy, accessibility, and resource intensity of each of the 24 services listed. Participants were asked to rate these services as to whether or not the services were currently provided in their residential area.

Efficacy responses were categorized in terms of how effective a service is in alleviating overall family stress associated with raising a child with DD. Response categories were coded as "1," representing not at all effective, to "5," representing exceedingly effective impact. Service and program access was defined in terms of a respondent's experience or perception of access, and county board superintendents, state DD directors, and DD council executive directors rated each service according to resource intensity. Service access and resource intensity questions used the same response coding as the efficacy options. Demographic variables were used to examine differences between and within groupings. Additionally, respondents were asked to describe any barriers they experienced or perceived among their top-rated programs and services.

Data Analysis

The main emphasis of analyses is descriptive and should be considered as only descriptive of the counties selected to participate in the study – inference to the entire State of Ohio is discouraged. Since the goal of this study is to determine what DD services FCDs and service provision administrators think most effectively alleviating stress, the proportions and confidence limits (at 5%) of those who felt the service was "Exceedingly" or "Very" effective or "Exceedingly" or "Very Accessible" or "Exceedingly" or "Very" resource intensive were determined for each of the analytical tables produced.

Data Limitations

As previously discussed, data was collected through county boards of DD, which tend to represent children with intellectual developmental disabilities as opposed to those with physical disabilities Another limitation of the FCD data was that the sample was collected from a limited number of Ohio counties (n = 15). These selected counties prohibit inferential results for the entirety of Ohio.. These results, therefore, emphasize the needs of FCDs and do not necessarily reflect the preferences of families of a child with physical disabilities who may not face severe learning challenges. Finally, there are a number of FCDs who do not receive any county board of DD services. This population may have different preferences regarding which services are effective and accessible.

IV. RESULTS

Graph I portrays the general demographics of FCDs that participated in the survey. Nearly one-third of children represented by proxy adults in the sample are adults with DD who live with their parents. Two-thirds of the children represented in the sample are on Medicaid, compared to about 30% of the general population (OFHS 2010). Most of the responding FCDs had at least an associate's degree and reported an average income range between $25,000 to $50,000, which is lower than the general population but similar to other DD studies' findings (Ohio Family Impact 2010). The FCD respondents were more likely to be married and were racially similar to Ohio's non-DD population (American Communities Survey, 2010).

Graph 1: Survey Demographics (N=204) of Parent Respondents and Children

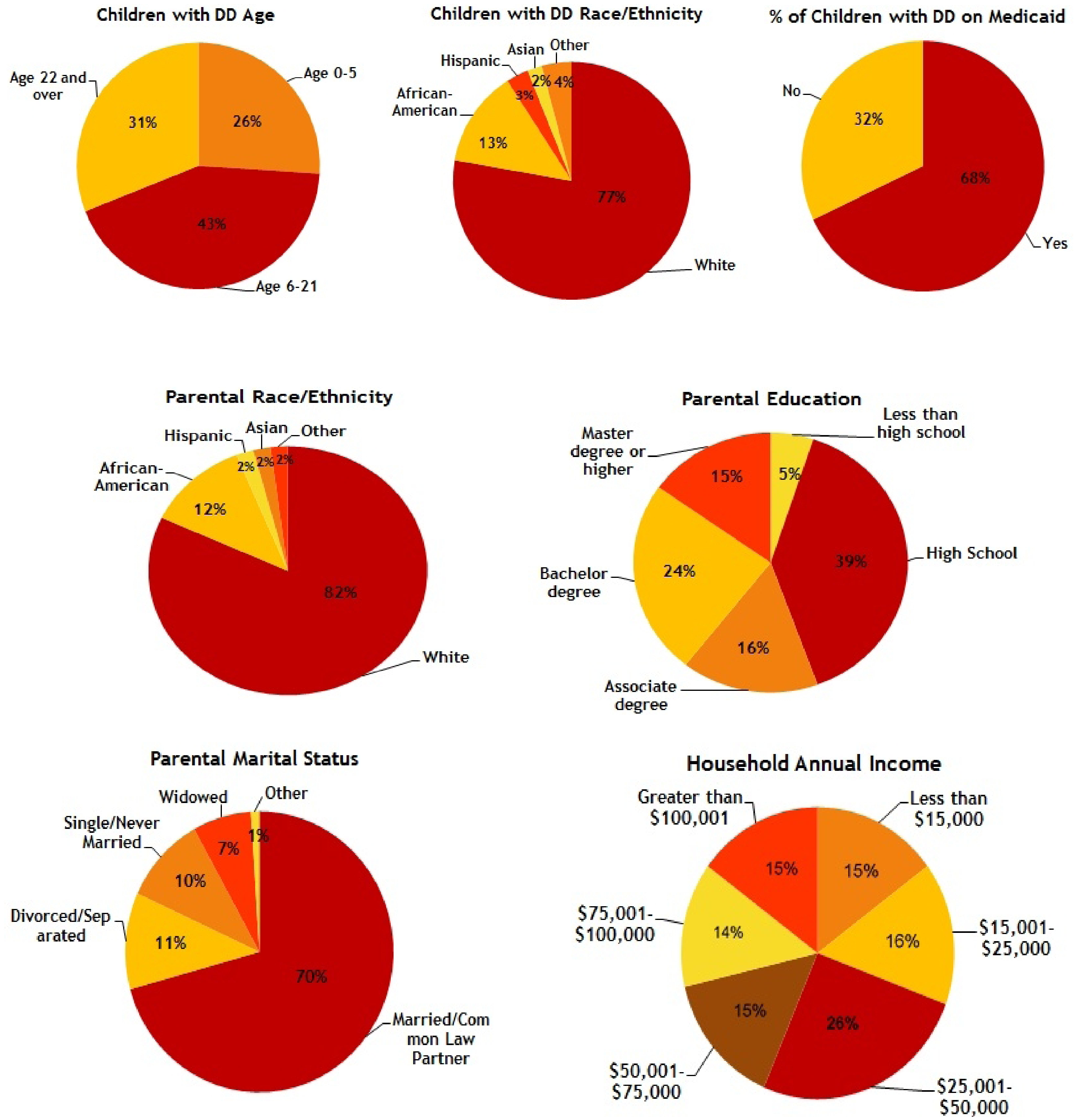


Table 1 details family efficacy ratings by age cohorts 0-5, 6-21 and 22 and older for the top 10 rated services (Appendix B- Table 1 provides a complete listing of family efficacy rating of services.) Top-rated services include:

1) Pre-School;
2) Early Intervention Services;
3) Therapy;
4) Specialized Medical Care;
5) Vocational Training Programs; and,
6) Care Coordination

74% of families rated pre-school services as exceedingly or very effective in alleviating overall family stress. Similarly, 64% of families rated care coordination services as exceedingly or very effective in alleviating overall family stress. The rating difference between these services is statistically significant at the 5% level using a two-proportion t-test. For services ranked immediately above or below, however, there was no statistically significant difference (e.g. early intervention, therapy and pre-school). For most services, there was a statistically significant difference in proportion ratings for a given service and a service that was ranked several "rungs" lower or higher (e.g. pre-school and care coordination). Generally, families tended to rank those services which directly impact their child much higher than services that are thought of as family support services (e.g. respite services, future care planning, residential services, and concierge services).

The ratings differences also illustrate how the needs for services change with the age of the child. For example, "Early Intervention Services," although rated highly by all families, are most highly rated by parents from 0 to 5 years – considerably less

Table 1. Efficacy Rating of Families (N=204) by Age Cohort for Top 10 Ranked Services (% of respondents who indicated "exceedingly" or very effective)

	Service	Overall	0-5 years	6-21 years	22 years and over
1	Pre-School	**74.39%** (69.99%, 78.79%) N=164	**82.22%** (74.72%, 89.72%) N=45, Rank=2	**74.32%** (67.71%, 80.94%) N=74, Rank=1	**66.67%** (57.08%, 76.26%) N=42, Rank=5
2	Early Intervention Services**	**72.67%** (68.29%, 77.06%) N=172	**83.67%** (76.74%, 90.61%) N=49, Rank=1	**72.37%** (65.69%, 79.04%) N=76, Rank=2	**61.36%** (51.70%, 71.03%) N=44, Rank=8
3	Therapy	**66.67%** (62.06%, 71.28%) N=174	**77.78%** (69.62%, 85.93%) N=45, Rank=3	**64.56%** (57.56%, 71.56%) N=79, Rank=4	**57.45%** (47.97%, 66.93%) N=47, Rank=13
4	Specialized Medical Care	**65.06%** (60.28%, 69.84%) N=166	**65.79%** (55.61%, 75.97%) N=38, Rank=5	**66.22%** (59.06%, 73.38%) N=74, Rank=3	**60.78%** (51.82%, 69.75%) N=51, Rank=9
5	Vocational Training Programs*	**63.97%** (58.65%, 69.29%) N=136	**45.83%** (32.12%, 59.54%) N=24, Rank=16	**57.69%** (48.71%, 66.67%) N=52, Rank=8	**75.44%** (67.98%, 82.90%) N=57, Rank=2
6	Care Coordination	**63.91%** (59.14%, 68.67%) N=169	**73.33%** (64.66%, 82.01%) N=45, Rank=4	**54.93%** (47.24%, 62.62%) N=71, Rank=11	**68.00%** (59.34%, 76.66%) N=50, Rank=4
7	Transportation Services*	**61.96%** (57.05%, 66.87%) N=163	**55.26%** (44.60%, 65.93%) N=38, Rank=11	**47.62%** (39.40%, 55.84%) N=63, Rank=18	**80.00%** (73.25%, 86.75%) N=60, Rank=1
8	Day Habilitation	**60.31%** (54.78%, 65.83%) N=131	**46.15%** (33.03%, 59.28%) N=26, Rank=15	**55.32%** (45.79%, 64.85%) N=47, Rank=9	**69.09%** (60.93%, 77.25%) N=55, Rank=3
9	Special Equipment	**59.24%** (54.17%, 64.30%) N=157	**61.11%** (50.35%, 71.87%) N=36, Rank=7	**53.33%** (45.83%, 60.83%) N=75, Rank=12	**65.12%** (55.54%, 74.69%) N=43, Rank=6
10	Specialized Dental Care	**57.05%** (51.93%, 62.17%) N=156	**45.71%** (34.55%, 56.88%) N=35, Rank=17	**58.21%** (50.35%, 66.07%) N=67, Rank=6	**60.78%** (51.82%, 69.75%) N=51, Rank=9

*significant at the .05 level where a Chi square test of difference between proportions is used.

** significant at the .1 level where a Chi square test of difference between proportions is used.

than the rating from parents with adult children. Nevertheless families of adult children are still able to see some value in services that they may have benefitted from in the past, even though it does not apply to their present situation. Conversely, adult families value vocational training programs much more highly than families of very young children. Family preferences do not always change with the age of the child. "Specialized Medical Care," for example, is rated relatively high among parents regardless of the age of the child.

Table 2 exhibits the access ratings of families for top rated services by age cohorts. In general, FCD access ratings were lower than their efficacy ratings (Appendix B Table 2 provides a complete listing of family access rating of services.).

This persistent gap in perception between what services are rated as effective and what services are accessible illustrate to some extent the frustration FCD experiences. There were a few services, for example "Specialized Medical Care," where there was a notably high difference between the proportions of families who rated the service as exceedingly or very effective to those who rated the service as exceedingly or very accessible (65% efficacy vs. 53% access).

Table 2. Access Rating of Families by Age Cohort for Top Ten Efficacy Ranked Services (% of respondent who indicated "exceedingly" or very accessible)

	Service	Overall	0-5 years	6-21 years	22 years and over
1	Pre-School	**70.19%** (65.53%, 74.84%) N=161	**68.89%** (59.81%, 77.97%) N=45, Rank=3	**76.39%** (69.87%, 82.91%) N=72, Rank=1	**60.98%** (50.93%, 71.03%) N=41, Rank=6
2	Early Intervention Services	**69.05%** (64.44%, 73.65%) N=168	**76.00%** (68.07%, 83.93%) N=50, Rank=2	**67.57%** (60.48%, 74.65%) N=74, Rank=2	**63.41%** (53.49%, 73.34%) N=41, Rank=5
3	Care Coordination	**57.49%** (52.55%, 62.42%) N=167	**57.78%** (48.09%, 67.47%) N=45, Rank=5	**47.89%** (40.16%, 55.61%) N=71, Rank=4	**70.83%** (62.22%, 79.45%) N=48, Rank=3
4	Therapy	**56.57%** (51.74%, 61.41) N=175	**76.09%** (67.82%, 84.36%) N=46, Rank=1	**49.37%** (42.05%, 56.68%) N=79, Rank=3	**46.81%** (37.24%, 56.37%) N=47, Rank=14
5	Vocational Training Programs	**55.91%** (50.21%, 61.60%) N=127	**37.50%** (24.18%, 50.82%) N=24, Rank=15	**42.55%** (33.07%, 52.03%) N=47, Rank=8	**73.58%** (65.65%, 81.52%) N=53, Rank=1
6	Specialized Medical Care	**52.69%** (47.71%, 57.68%) N=167	**61.54%** (51.25%, 71.83%) N=39, Rank=4	**44.59%** (37.07%, 52.12%) N=74, Rank=7	**54.90%** (45.76%, 64.04%) N=51, Rank=8
7	Transportation Services	**52.44%** (47.41%, 57.47%) N=164	**52.63%** (41.92%, 63.34%) N=38, Rank=6	**31.75%** (24.09%, 39.40%) N=63, Rank=13	**72.13%** (64.63%, 79.63%) N=61, Rank=2
8	Day Habilitation	**48.84%** (43.15%, 54.53%) N=129	**30.77%** (18.62%, 42.92%) N=26, Rank=21	**40.43%** (31.02%, 49.83%) N=47, Rank=9	**64.81%** (56.30%, 73.33%) N=54, Rank=4
9	Behavior Support Programs	**46.05%** (40.83%, 51.27%) N=152	**47.22%** (36.20%, 58.24%) N=36, Rank=10	**45.45%** (37.46%, 53.45%) N=66, Rank=5	**42.55%** (33.07%, 52.03%) N=47, Rank=16
10	Recreational Activities	**45.93%** (41.03%, 50.83%) N=172	**51.22%** (40.92%, 61.52%) N=41, Rank=7	**31.51%** (24.43%, 38.59%) N=73, Rank=14	**58.18%** (49.47%, 66.89%) N=55, Rank=7

The difference between efficacy and access, defined in this study as an access gap can be used as criteria in evaluating the potential benefit of providing more resources to a particular service. Table 3 illustrates these differences and points to some notable service gaps for the top 10 efficacy rated services (Appendix B table 3 provides a complete listing of gaps for all services). FCDs in the 0 to 5 age group, for example, had an access gap of 16% for care coordination, while FCDs in the 6-21 age group had an access gap of 22% for specialized mental health care and 23% for specialized medical care. These access gaps suggest the need for more coordination of services to help FCDs identify when and where these services are available.

Table 3 Access Gaps of Families by Age Cohort for Top Ten Ranked Services (Gap=Percentage of FCDs who rated a services very and exceedingly effective minus the percentage of FCDs who rated a service very and exceedingly accessible)

Efficacy Ranking	Service	Family Overall	Age 0-5	Age 6-21	Age 22 and over
1	Pre-School	4%	13%	-2%	6%
2	Early Intervention Services	4%	8%	5%	-2%
3	Therapy	10%	2%	15%	11%
4	Specialized Medical Care	12%	4%	22%	6%
5	Vocational Training Programs	8%	8%	15%	2%
6	Care Coordination	6%	16%	7%	-3%
7	Transportation Services	10%	3%	16%	8%
8	Day Habilitation	11%	15%	15%	4%
9	Special Equipment	17%	12%	23%	12%
10	Specialized Dental Care	12%	9%	13%	11%

Appendix B Tables 4 and 5 show the family efficacy and access ratings by families indicating a “severe stress level” or not. Families with a Kessler 6 depression scale score of 13 and above were classified as severely distressed, while families with a score of 12 or less were classified as not severely distressed. Severely distressed families tended to rate services as not being as effective or accessible compared to those families who were not severely distressed. Although not the only factor in causing family stress, lack of perceived access to a service is certainly a major factor in contributing to overall family stress.

Table 6 compares the efficacy ratings of county board superintendents, families, DD council executive directors, and state DD directors of the top 10 rated services of FCDs (See also a Appendix B Tables 6 , 7, and 8. Tests of statistical significance were not calculated between groups because of the differing sampling populations. Agreement of services between respondents helps validate the survey responses from FCDs regarding how effective a particular service might be. In general, superintendents rated most services as more effective than did FCDs, while DD council and state DD directors rated them lower. The service that was ranked most differently between stakeholders and families was therapy. It was the only service that superintendents rated lower than FCDs and also ranked considerably lower (#17 ranked) for superintendents versus FCDs (#3 ranked). Further research is needed to understand why key stakeholder perceived value of this service is so different from the perception of families.

Table 6. Efficacy Ratings of DD Stakeholders of Top 10 Family Rated Services (% of respondents who indicated “exceedingly or “very effective”)

	Service	Family	Superintendent	DD Council	DD Directors
1	Pre-School	**74.39%** (69.99%, 78.79%) N=164	**97.14%** (93.41%, 100.9%) N=35, Rank=2	**53.33%** (41.18%, 65.48%) N=30, Rank=12	**31.58%** (17.00%, 46.15%) N=19, Rank22
2	Early Intervention Services	**72.67%** (68.29%, 77.06%) N=172	**100.0%** (100.0%, 100.0%) N=37, Rank=1	**80.65%** (71.19%, 90.10%) N=31, Rank=1	**89.47%** (79.85%, 99.10%) N=19, Rank=2
3	Therapy	**66.67%** (62.06%, 71.28%) N=174	**61.11%** (50.35%, 71.87%) N=36, Rank=17	**40.00%** (28.07%, 51.93%) N=30, Rank=20	**52.63%** (36.97%, 68.29%) N=19, Rank=10
4	Specialized Medical Care	**65.06%** (60.28%, 69.84%) N=166	**71.43%** (61.30%, 81.55%) N=35, Rank=13	**61.29%** (49.64%, 72.94%) N=31, Rank=7	**63.16%** (48.03%, 78.28%) N=19, Rank=6
5	Vocational Training Programs	**63.97%** (58.65%, 69.29%) N=136	**78.38%** (69.42%, 87.34%) N=37, Rank=8	**61.29%** (49.64%, 72.94%) N=31, Rank=7	**57.89%** (42.41%, 73.38%) N=19, Rank=7
6	Care Coordination	**63.91%** (59.14%, 68.67%) N=169	**94.44%** (89.39%, 99.50%) N=36, Rank=3	**35.48%** (24.04%, 46.93%) N=31, Rank=22	**52.63%** (36.97%, 68.29%) N=19, Rank=10
7	Transportation Services	**61.96%** (57.05%, 66.87%) N=163	**78.38%** (69.42%, 87.34%) N=37, Rank=8	**64.52%** (53.07%, 75.96%) N=31, Rank=4	**57.89%** (42.41%, 73.38%) N=19, Rank=7
8	Day Habilitation	**60.31%** (54.78%, 65.83%) N=131	**86.11%** (78.48%, 93.75%) N=36, Rank=6	**26.67%** (15.90%, 37.44%) N=30, Rank=24	**36.84%** (21.72%, 51.97%) N=19, Rank=20
9	Special Equipment	**59.24%** (54.17%, 64.30%) N=157	**88.89%** (81.95%, 95.83%) N=36, Rank=4	**70.97%** (60.11%, 81.83%) N=31, Rank=3	**78.95%** (66.16%, 91.73%) N=19, Rank=3
10	Specialized Dental Care	**57.05%** (51.93%, 62.17%) N=156	**57.14%** (46.05%, 68.23%) N=35, Rank=19	**61.29%** (49.64%, 72.94%) N=31, Rank=7	**52.63%** (36.97%, 68.29%) N=19, Rank=10

Table 7. Access Ratings of DD Stakeholders of Top 10 Family Rated Services (% of respondents who indicated “exceedingly or “very effective”)

	Service	Family	Superintendent	DD Council	DD Directors
1	Pre-School	**70.19%** (65.53%, 74.84%) N=161	**88.57%** (81.44%, 95.70%) N=35, Rank=2	**13.33%** (5.06%, 21.61%) N=30, Rank=7	**21.05%** (8.27%, 33.84%) N=19, Rank=5
2	Early Intervention Services	**69.05%** (64.44%, 73.65%) N=168	**89.19%** (82.43%, 95.95%) N=37, Rank=1	**54.84%** (42.93%, 66.74%) N=31, Rank=1	**52.63%** (36.97%, 68.29%) N=19, Rank=1
3	Care Coordination	**57.49%** (52.55%, 62.42%) N=167	**86.11%** (78.48%, 93.75%) N=36, Rank=3	**32.26%** (21.07%, 43.44%) N=31, Rank=3	**36.84%** (21.72%, 51.97%) N=19, Rank=2
4	Therapy	**56.57%** (51.74%, 61.41) N=175	**22.22%** (13.04%, 31.40%) N=36, Rank=18	**6.67%** (0.59%, 12.74%) N=30, Rank=17	**5.26%** (- 1.74%, 12.27%) N=19, Rank=12
5	Vocational Training Programs	**55.91%** (50.21%, 61.60%) N=127	**64.86%** (54.48%, 75.25%) N=37, Rank=5	**22.58%** (12.58%, 32.58%) N=31, Rank=5	**5.26%** (- 1.74%, 12.27%) N=19, Rank=12
6	Specialized Medical Care	**52.69%** (47.71%, 57.68%) N=167	**20.00%** (11.03%, 28.97%) N=35, Rank=19	**12.90%** (4.88%, 20.92%) N=31, Rank=9	**0.00%** (0.00%, 0.00%) N=19, Rank=19
7	Transportation Services	**52.44%** (47.41%, 57.47%) N=164	**48.57%** (37.37%, 59.77%) N=35, Rank=8	**12.90%** (4.88%, 20.92%) N=31, Rank=9	**0.00%** (0.00%, 0.00%) N=19, Rank=19
8	Day Habilitation	**48.84%** (43.15%, 54.53%) N=129	**86.11%** (78.48%, 93.75%) N=36, Rank=3	**36.67%** (24.93%, 48.40%) N=30, Rank=2	**21.05%** (8.27%, 33.84%) N=19, Rank=5
9	Behavior Support Programs	**46.05%** (40.83%, 51.27%) N=152	**35.14%** (24.75%, 45.52%) N=37, Rank=13	**3.23%** (-1.00%, 7.45%) N=31, Rank=22	**15.79%** (4.36%, 27.22%) N=19, Rank=8
10	Recreational Activities	**45.93%** (41.03%, 50.83%) N=172	**40.54%** (29.86%, 51.22%) N=37, Rank=11	**3.23%** (-1.00%, 7.45%) N=31, Rank=22	**5.26%** (- 1.74%, 12.27%) N=19, Rank=12

Table 7 compares the access ratings of county board superintendents, families, DD council executive directors, and state DD directors for the top 10 rated services of FCDs. Services that are generally provided through the county boards of DD (e.g., pre-school, early intervention, vocational training and care coordination) were rated by superintendents as being more accessible than the perception of FCDs. Services not typically provided directly through the boards such as therapy and specialized medical care were rated as being less accessible than the ratings by FCDs. Access ratings were uniformly lower for the state DD directors and DD council executive directors.

Table 8 compares the resource ratings by county board superintendents, DD council executive directors, and state DD directors for all services, ranked by FCDs as most effective. Services generally provided through the county boards (e.g., pre-school, early intervention, vocational training and care coordination) were rated as being more resource intensive. Superintendents tended to rate the same services as being more resource intensive than state DD directors or DD council executive directors.

Table 8. Resource Ratings of DD Stakeholders of Top Ten Family Rated Services
(% of respondents who indicated “exceedingly or “very effective”)

	Service	Superintendent	DD Council	DD Directors
1	Pre-School	**94.12%** (88.76%, 99.47%) N=34	**27.59%** (16.50%, 38.67%) N=29, Rank=7	**21.05%** (8.27%, 33.84%) N=19, Rank=12
2	Care Coordination	**88.57%** (81.44%, 95.70%) N=35	**26.67%** (15.90%, 37.44%) N=30, Rank=8	**26.32%** (12.51%, 40.12%) N=19, Rank=9
3	Day Habilitation	**88.57%** (81.44%, 95.70%) N=35	**31.03%** (19.56%, 42.51%) N=29, Rank=6	**36.84%** (21.72%, 51.97%) N=19, Rank=6
4	Early Intervention Services	**86.11%** (78.48%, 93.75%) N=36	**46.67%** (34.52%, 58.82%) N=30, Rank=2	**42.11%** (26.62%, 57.59%) N=19, Rank=4
5	Vocational Training Programs	**86.11%** (78.48%, 93.75%) N=36	**56.67%** (44.60%, 68.73%) N=30, Rank=1	**47.37%** (31.71%, 63.03%) N=19, Rank=2
6	Residential Services	**80.56%** (71.82%, 89.29%) N=36, Rank=6	**41.38%** (29.16%, 53.60%) N=29, Rank=4	**68.42%** (53.85%, 83.00%) N=19, Rank=1
7	Homemaker Services	**69.44%** (59.27%, 79.61%) N=36	**13.33%** (5.06%, 21.61%) N=30, Rank=20	**10.53%** (0.90%, 20.15%) N=19, Rank=19
8	Special Equipment	**68.57%** (58.17%, 78.98%) N=35	**23.33%** (13.03%, 33.63%) N=30, Rank=10	**21.05%** (8.27%, 33.84%) N=19, Rank=12
9	Transportation Services	**68.57%** (58.17%, 78.98%) N=35	**26.67%** (15.90%, 37.44%) N=30, Rank=8	**15.79%** (4.36%, 27.22%) N=19, Rank=16
10	Recreational Activities	**61.11%** (50.35%, 71.87%) N=36	**6.67%** (0.59%, 12.74%) N=30, Rank=23	**5.26%** (- 1.74%, 12.27%) N=19, Rank=22

Appendix C details the comments of DD directors, county board superintendents, DD council executive directors, and FCDs regarding the barriers they perceive in providing services. DD directors, county board superintendents, and DD council executive directors were asked to comment on barriers to services to their top-rated service for each age cohort (0 to 2, 3-5, 6-21 and 22 and older). FCDs were asked to comment upon barriers that exist for any of the services. All comments were sorted by age cohort. Some common themes that emerged from all respondents included a lack of information of available services, the bureaucratic hurdles FCDs have to endure to obtain services, and the lack of access to professional medical services.

To summarize, families tended to rate those services which directly impact their child more highly in terms of alleviating family stress. These services generally were also perceived as being relatively accessible. There were a number of services that families rated differently depending on the age of their child – early intervention services for younger children, specialized mental health services for school-age children, and vocational training and transportation services for older adult children. There are some notable access gaps when examined by age cohorts. For children, ages 0-5, care coordination had the highest access gap, while for school-age children the greatest access gap exists for specialized medical care and special equipment. The greatest service gap for all FCDs was in the area of specialized medical care. For the top quartile of family rated services, superintendents tended to rate these services as being more effective than families, while DD council executive directors and state DD directors tended to rate them less effective than family members of individuals.

V. DISCUSSION: RELATING RESULTS TO THE CONCEPTUAL FRAMEWORK OF EVALUATING SERVICES

Table 6 reveal commonalities and disagreements between Ohio FCD and County Board of DD Superintendents related to the policy needs and access to resources for FCDs. This information focuses centrally on the parent's challenges accessing needed services for the child with DD (Level 1 Stressors according to the project's conceptual model). It identifies disjoints between the perceptions of families and DD superintendents regarding both the effectiveness and accessibility of services for the child with DD and/or the family.

The Ohio family and Ohio DD superintendent surveys revealed commonalities and disagreements related to policy needs and access to resources for FCDs. First, the totality of the child's need is the priority for caregivers. The most effective services that parents tend to identify are those that directly meet the needs of their child, regardless of whether the service is DD-related or non-DD related. This finding is not simply about the parent putting the child first, but relates to the elevated stress that parents experience when their child cannot access a needed service. Appendix B Tables 4 and 5 supports this statement: high stressed families perceive that services are not as accessible to them as low stressed families.

Concurrently, the DD superintendents focus is on the effectiveness of the services they provide and can control – the emphasis being upon the effective and efficient administration of service offerings. For example, Ohio Superintendents ranked "Specialized Medical Care" 13th, while families ranked this service 4th (see Appendix C Table 4) . Since the superintendents do not control how this service is offered, they gave this service a relatively lower ranking compared to services they do provide – for example, early intervention services.

Second, the family effectiveness ratings (seen in Table 1) are highest for many key services in the 0-5 age group, possibly showing sensitivity to the perceived vulnerability of this age group. It is also likely that this higher effectiveness rating results from the delivery of those services in one place, a centralized service location, versus parental stress associated with the need to coordinate services across systems for older children with DD. The decline in the rating of effectiveness for therapies from 77.8% for children 0-5, to 64.6% for children 6-21, and 57.5% for children 22 and older underscores this contention. The effectiveness scores for care coordination show similar variation from 73.3% for the 0-5 age group, to 54.9% for 6-21, and then up to 68% for 22 and older. However, the increase in effectiveness for children 22 and older suggests a care coordination challenge for school-aged children that may warrant special attention.

Third, the lack of a trusted source for respite care may help explain the great difference in effectiveness rating for respite care between the DD national leader survey, the Ohio superintendent survey, and the Ohio FCD survey. Respite services ranked 14th for parents (20th if child is 0-5 years of age, 7th if child is 6-21, and 14th if child is 22 and older) versus a raking of top priority (# 1) for national DD leaders and 7th for Ohio superintendents. (see Appendix C Tables 1 and 6) The relatively low ranking of respite service could also reflect the parent's perception that the service is not as valuable since it does not directly address the needs of the child.

Fourth, parents ranked effectiveness of health care services, other than special equipment, higher than Ohio DD superintendents. They also rank therapies as a top 7 effective strategies for ages 0-5 and 6-21, and 15th for age 22 and over, compared to 19th for superintendents (see Appendix B Tables 1 and 6). This difference may reflect that the DD system does not provide many of these services, making the DD board's involvement and control over them minimal, while the need for health care services remains high for FCDs.

Fifth, Table 7 above shows that Ohio superintendents rank access to services higher than do FCDs, substantially higher (see also

Appendix B Table 7). This difference may reflect the DD board's offering of a service versus the FCD's sense of their ability to take advantage of that service, given other family challenges, logistics, and limitations. This is important to understand in order to overcome the difference in access perceptions/realities between FCDs and DD boards.

VI. APPLICATION OF THE CONCEPTUAL FRAMEWORK IN EVALUATING THE FUTURE PROVISION OF SERVICE

The surveys asked about 24 service options and their potential impact on reducing FCD stress. These services are not all available to FCDs throughout Ohio. As the FCD survey indicates, many of these services are not as accessible as the FCDs wish they would be. The responses from superintendents confirm the resource challenges that make it difficult to meet all of the demand for services from FCDs.

Our conceptual model can help guide informed decision making. A brief review of three policy options included in the surveys (care coordination, respite, and therapy) illustrates this possibility. About service options that align with stress reduction in FCDs.

Care Coordination

For Ohio families and Ohio Superintendents care coordination ranked as a highly effective service (6th for families and number and 3rd for superintendents). Care coordination also ranked 10th for DD Directors, though only 22 for DD Council leaders (see Appendix B Table 6). All survey respondents ranked care coordination as the third most accessible service (second for DD Directors). However, the Ohio superintendents rated it as much more accessible (86.1%) than Ohio FCDs (57.5%) (See Appendx B Table 7).

Based on our family stress model, the high effectiveness rating for care coordination is related to its value in both helping children with DD access needed services and in reducing caregiver time burdens in accessing those services. The difference in accessibility ratings between Ohio superintendents and Ohio families for a service that both rated high on effectiveness scale suggest a potential service gap and policy expansion opportunity.

Based on our policy flow model, the first step for agencies is to assess the extent of additional need for care coordination services. The difference in access ratings to care coordination between FCDs and Ohio superintendents suggests that such a need could well exist. However, since care coordination is being provided to some extent through the service and support coordinators of the DD boards, an assessment is needed to understand why FCDs find access to care coordination lacking and to determine if they truly want more of this service.

If this review finds a need for more care coordination the agency then needs to determine if it has additional care coordination capacity in its existing system or if it needs to add capacity. Since care coordination is an existing service the agency provides, it should be relatively straightforward to determine the cost of adding more capacity.

According to Ohio superintendents, care coordination is the second most resource intensive service, tied with day habilitation and more resource intensive than EI, vocational training, and residential services. Only pre-school is more resource intensive (see Appendix B Table 8). This ranking suggests if more care coordination is required it could enact a reallocation of service dollars. Therefore, the agency needs to determine how it would pay for additional care coordination services and what service trade-offs that would require. If a service trade-off needs to happen to pay for additional care coordination, the agency needs to assess the consequences of that service reduction to families to determine if the trade-off is worth it (the zero-sum dilemma).

Also, before making a final decision on how to pay for more care coordination, the agency needs to carefully assess its current efficiency in providing for this service. Information from the DD Directors and DD Council survey suggest a much lower resource intensity potential to care coordination.

Therapy

Therapy reflects a service that FCDs ranked as much more effective (3rd) than Ohio superintendents (17th), national DD Council leaders (20th), and DD Directors (10th) (see Appendix B Table 6). Part of this difference likely reflects that therapy is a service that FCDs receive from outside the county board system, as families ranked it as the 4th most accessible services versus 18th for Ohio superintendents, 17th for DD Council leaders and 12th for DD Directors (see Appendix B Table 7). Even though FCDs ranked therapy as the fourth most accessible service, only 56.6% of families rated it as exceedingly or very accessible, suggesting a need for more access to therapy would be helpful for families of children with DD.

Based on our family stress model, the parent's rating of therapy reflects their perception on its importance in helping their child deal with disability. The potential value of increasing access to therapy for FCDs would involve the following assessment. In the service need identification stage the agency needs to determine three things: (1) If the child benefits from additional therapy, (2) the extent to which an FCD controls the provision of additional therapy, and (3) if it does not provide the therapy, the benefit of assisting the family in more effectively accessing therapy services from another provider and the service system. This latter activity may be a valuable and a relatively low-cost source of assisting a FCD to reduce stress.

If the agency is the provider of therapy services, it needs to assess its capacity to provide more therapy. If the agency is not the provider of the needed therapy it needs to assess its capacity to assist families in accessing these services from another system.

Once assessing the capacity needs for providing assistance, the agency needs to calculate the costs of additional assistance and how it could pay for these costs. As part of the assessment on paying for these costs, the agency needs to calculate what service(s) it might need to reduce to obtain the funds needed to pay for more therapy. Should there be trade-offs required with these funds, the agency then needs to ascertain if the trade-off brings more benefits than costs to families that the agency serves.

Respite

Respite care is a service highly rated as effective by national DD leaders (1st), DD Council leaders (2nd), and Ohio superintendents (7th). However, while some individual FCD surveys included comments on the value of respite care, overall FCDs ranked respite as the 14th most effective service (20th for FCDs with children 0-5, compared to 7th for FCDs with children 6-21, and 14th for FCDs with children age 22 and older) (see Appendix B Table 6 and 1).

This difference highlights an interesting policy gap given the national push for increasing access to respite services. Based on our family stress model, this difference may reflect the caregiver perception that respite care in and of itself may not relieve stress related to getting needed services for the child with DD. Also, based on survey and discussion comments, some families do not find that respite eases stress if they worry about the effectiveness of the respite care provider.

Based on our policy flow model, the burden of identifying respite as a needed service may rest more with the DD system than with FCDs, overall. The assessment at this stage needs to both focus on determining how much respite services FCDs want and need and how best to offer respite services so that FCDs will find this service more effective and acceptable.

The agency then needs to determine what is its current respite capacity and how much more capacity it needs to obtain to more effectively provide respite care. After this determination, the agency can ascertain the cost for providing any additional level of respite care. Upon calculating that cost, the agency needs to determine where it has funds to support additional respite care. Given current FCD perceptions on respite care versus other services, the agency will need to be careful about what, if any, services it reduces to increase the amount of respite care available.

As with every service, the preference for respite care varies between individual FCDs. Several survey comments reflected the frustration of some FCDs on the low level of respite care and

reductions in funds they received to be able to purchase respite care.

Other Policy Evaluation Issues

The FCD and superintendent surveys identify some additional issues to consider when assessing the benefits and needs for different services.

First, there are some clear differences between FCDs who are at higher levels of stress versus FCDs at lower levels of stress (see Appendix B Table 3 and 4). For example, FCDs who report higher levels of stress generally had much lower ratings of both effectiveness and accessibility of services. These differences suggest a potential value in screening FCDs on their level of stress and targeting some additional care coordination or similar support services to these FCDs.

Second, the survey comments show that FCD need is always specific to that FCD's experience and situation, whereas service agencies tend to focus on administrative protocols and structures that enable services to FCDs (see Appendix C). While similar in the desire to serve children with DD, service emphases differ. Variance in FCD need based on the age of their child or other factors often compounds challenges to agencies who need to balance the needs of individual clients to an entire range of clients the agencies may serve. Therefore, policy analysis should assess FCD need comparatively to service administration stressors in order to balance this tension.

Third, the survey comments show that FCD need is always specific to that FCD's experience and situation, while agencies need to focus on creating an array of services that benefit a range of FCDs. This variation may be based on the age of the child with DD. Policy assessment needs to keep these differences in mind.

Fourth some of the resource challenges that FCDs and agencies face are outside of their respective control. This reality increases stress and challenges the capacity of agencies to address that stress.

Fifth, it would be useful to investigate further why parents rated some services relatively low in terms of effectiveness or accessibility. This information may show a need for better education about these services, how to access them, and how they could help the FCD and their child with DD. This information might also identify barriers to address to make these services work better for FCDs.

VII. POLICY CONSIDERATIONS

This project's conceptual framework and policy model identify three areas of policy need and challenge. These areas are: (1) the family and its degree of risk and need; (2) structural challenges and needs faced by county boards of DD; and (3) structural challenges and needs faced by systems that families need to access services from beyond the DD boards. Each of these areas operate within a zero-sum dilemma on how to provide and pay for needed services, while meeting other needs.

In times of constrained budgets and expanding demand for assistance, county boards of DD and FCDs with children with DD face difficult challenges in prioritizing and allocating scare resources. Through the surveys of FCDs and stakeholders, this study reveals the difficulty in prioritizing these resources when services are provided across multiple settings. As a preliminary consideration on how to best allocate resources, the Evaluating Services that Support Families Project survey results raise a fundamental policy question for Ohio's DD system: For FCDs is there one system that they can turn to for comprehensive assistance to access needed services and reduce caregiver burden?

If the answer is NO, then it becomes difficult to address caregiver stress burdens. If the answer is YES, then it becomes more feasible to identify strategies that can assist FCDs accessing needed services and managing time and financial burdens, even if the leadership system does not control all of the services or have sufficient resources to provide all of the needed care.

Any organization or entity, like the county boards of DD, that provides comprehensive assistance will be assuming additional costs. How these costs get paid for is beyond the scope of this paper. However, the authors believe that the likely savings that accrue to the health care system resulting from this additional care coordination (e.g. reduced unnecessary hospitalizations and emergency room use) should be used to help fund these services.

VIII. LIMITATIONS OF STUDY

We acknowledge several limitations of this study. First, the study was limited to FCDs who received services through the county boards of DD. Although the county board system touches a wide array of children with developmental disabilities, there is still a significant number of children with disabilities and their FCDs who receive services outside this system either through local departments of health or local human services agencies. The family services survey was limited to FCDs receiving services from 15 of the 88 County Boards of DD. A random statewide sample of FCDs across the state will ensure these results are representative of all Ohio families of children with disabilities. Finally, the FCD services survey provided only limited information about the preferences and opinions of FCDs, DD policy makers, and superintendents. Focus groups for each of these respondents would provide more detailed information about what services best meets the needs of FCDs and why.

IX. NEXT STEPS

Because of the project limitations, and to enhance and confirms its findings, three next steps are recommended.

First, conduct qualitative analyses of families with a child with DD and Ohio Superindentents to test their respective reaction to the conceptual framework, policy flow model, report findings, stress burdens, and FCD needs. This analysis would have three components. Component A would focus on the families. Its would consist of 7 regional meetings distributed throughout Ohio's regions (Appalachia, rural non-Appalachia, metropolitan, and suburban). After completing these regional meetings, a comparative follow-up report would be issued that specifies a refined explanation of specific FCD needs, challenges, and burdens related to obtaining services for their child with a development disability.

Component B would incorporate the information from this current study, the FCD regional meetings, and the follow-up family report for use in qualitative analyses with county DD directors to gain added information within and beyond the findings of prior research. These results would be reported in a brief that compares the qualitative findings of FCDs to county DD directors.

Component C, would entail repeating a refined version of the FCD and superintendent surveys based on information collected from this qualitative research process. It would also employ additional techniques to both increase the survey response rate and to establish a refined sample design to allow statewide inference.

Second, conduct a comprehensive survey of FCDs who receive services through the state or local health departments or human service agencies to examine service preferences and access gaps of these families compared to county board FCDs. This step would necessitate a statewide target population. Following this survey, conduct a qualitative analysis using the same three components as listed in next step one.

Third, , sponsor questions in the 2012 Ohio Family Health Survey instrument that would facilitate state level and sub-state level analyses of persons with development disabilities, within the parameters of a population-based study.

X. CONCLUSION

The stress level of FCDs is only one of many considerations in the provision of services to children with disabilities. However, the overall health of the FCD is crucial to the overall health of the child with DD. Reducing caregiver burden has multiple dimensions as described in the conceptual framework. Providing more coordination of care and more access to care may ameliorate family stress more than increasing family support services.

This study reveals the challenge of prioritizing scare resources between individuals with DD and the families who care for them, particularly when resources and services are provided across multiple care settings. Nonetheless, policymakers need to emphasize the role of FCDs in deciding what services are provided to children of disabilities. Having one entity actively coordinating services is likely to improve the overall stress of FCDs, leading to improved health outcomes for the family member and the child with a disability.

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APPENDIX A: FCD SERVICE DEFINITIIONS

Early Intervention Services : Services provided to infants and toddlers and their families in accordance with Part C of the Individuals with Disabilities Education Improvement Act (IDEIA).

Preschool: A school especially designed for children with special needs. Services including speech therapy, physical therapy and occupational therapy and are staffed with certified special education teachers.

Tutoring: private, remedial instruction provided to individuals.

Post Secondary Education: Schooling beyond the high school level.

Vocational Training Programs (workshop, job enclave, supported employment):
Education, training, coaching, skill reinforcement, vocational assessment, job development and placement, worksite accessibility, ongoing job support and other services needed to prepare people with disabilities for work, define a suitable employment goal and become employed.

Day Habilitation: Training, support, and supervision activities that maximizes functional abilities and skills necessary to enable adults with disabilities to access the community.

Parent Training: Materials, personal assistance and resources (including relevant conferences and membership organizations) provided to parents.

Transportation Services: Beneficial provision of or arrangement for travel, including travel costs of individuals, in order to access social services, or obtain medical care or employment.

Specialized Medical Care: Services provided by licensed health care practitioners whose practice includes serving individuals with disabilities.

Specialized Dental Care : Services provided by a licensed dentist whose practice includes serving individuals with disabilities.

Specialized Mental Health Care: Services provided by a mental health professional whose practice includes serving individuals with disabilities.

Therapy Services: Services provided by a licensed therapist or professional whose practice includes serving individuals with disabilities.

Behavior Support Programs: Programs that apply basic learning techniques, such as conditioning, biofeedback, reinforcement, or changes to the environment to reduce problem behavior and teach prosocial functional behavior.

Special Equipment and Accessories: Equipment that is used to assist consumers to better function in their home environment.

Residential Services: (e.g., independent living support, group homes, ICF)
Care given to a group of people with similar disabilities within a residence. Services include both custodial care and care that is provided by skilled and medically trained professionals.

Care Coordination (including case management): The deliberate organization of an individual's activities between two or more participants (including the individual) involved in an individual's care to facilitate the appropriate delivery of services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required individual care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.

Navigator Services: Assistance provided to families to locate and arrange needed school, health, or disability services offered to individuals with disabilities.

Parent Support Groups: an informal association of families with similar care giving issues that assist participants in dealing with a variety of problems and challenges.

Future care Planning: Arrangement for the provision of care when the parent is no longer able to care for the individual.

Cash Subsidies and/or Vouchers: Money provided directly to families to assist in the payment of services.

Concierge Services: Flexible personal assistant to help the family engage in routines (e.g., grocery shopping and other errands, transport of siblings to activities, homework assistance)

Family Training: services and information provided to assist the family in understanding the special needs of children with disabilities and in promoting the child's development.

Recreational Activities: Sports, camping, and other fun activities offered outside the home.

Homemaker Services: Non-medical support services, such as food preparation and bathing, provided by trained personnel to individuals with disabilities and their families.

Respite Care: A service designed to provide temporary residence for a person with a disability who ordinarily lives with family or friends, or to assume temporary responsibility for care of the person in his or her own home. This service provides back-up support, and in some cases relief, to people responsible for care of an ill or disabled person who ordinarily lives in their household.

APPENDIX B: REFERENCES

Birenbaum, A., Guyot, D., & Cohen, H. (1990) Health care financing for severe developmental disabilities. Monographs of the American Association on Mental Retardation. 14:1-150.

Brehaut, J. C., Kohen, D. E., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F., Rsoenbaum, P.L. (2009) Health among caregivers of children with health problems: Findings from a Canadian population-based study. American Journal of Public Health, 99(7): 1254-1262.

Cole, D.A. and Meyer, L.H. (1989) Impact of needs and resources on family plans to seek out-of-home placement. American Journal of Mental Retardation. 93(4): 380–387.

Fujiura, G. T., Roccoforte, J. A., & Braddock, D. (1994) Costs of family care for adults with mental retardation and related developmental disabilities. American Journal on Mental Retardation. 99(3): 250-261.

Goudie A, Fairbrother G, Simpson L & Mandel K. (2009) Profile of Children with Special Health Care Needs in Ohio. Columbus, OH: 2008 Ohio Family Health Survey.

Goudie, A., Havercamp, S., Ranbom L., and Jamieson, B., (2010) Caring for Children with Disabilities in Ohio: The Impact on Families. Columbus, OH: 2010 report for the Ohio Developmental Disabilities Council.

House, J. S., Landis, K. R., & Umberson, D. (1988) Social relationships and health. Science, 241(4865): 540-545.

Johnson, C.P., Kastner, T.A. (2005) Helping families raise children with special health care needs at home. Pediatrics. 115(2): 507-511.

Koshti-Richman, A. (2009) Caring for a disabled child at home: Parents' views. Pediatric Nursing, 21(6): 19-21.

McManus, B., Carle, A.,.Acevedo-Garcia D., Ganz M., Hauser-Cram P., and McCormick M. (2011) Modeling the Social Determinants of Caregiver Burden Among Families of Children With Developmental Disabilities. American Journal on Intellectual and Developmental Disabilities: May 2011, Vol. 116, No. 3, pp. 246-260.

Parish, S.L,I, Pomeranz, Al, Hemp, R., Rizzolo, M.C., and Braddock, D. (2001) Family Support for Families of Persons with Developmental Disabilities in the U.s.: Status and Trends. Policy Research Brief (University of Minnesota: Minneapolis, Institute on Community Integration), 12 (2).

Smith, L.E., Hong, J., Seltzer, M.M., Greenberg, J.S., Almeida, D.M., and Bishop, S.L. "Daily experiences among mothers of adolescents and adults with autism spectrum disorder" Journal of Autism and Development Disorders, 2010, 40(2), 167-178.

Appendix C: Tables

Table 1: Efficacy Rating of FCDs (N=204) by Age Cohort (% of respondent who indicated “exceedingly” or very effective)

	Service	Overall	0-5 years	6-21 years	22 years and over
1	Pre-School	**74.39%** (69.99%, 78.79%) N=164	**82.22%** (74.72%, 89.72%) N=45, Rank=2	**74.32%** (67.71%, 80.94%) N=74, Rank=1	**66.67%** (57.08%, 76.26%) N=42, Rank=5
2	Early Intervention Services**	**72.67%** (68.29%, 77.06%) N=172	**83.67%** (76.74%, 90.61%) N=49, Rank=1	**72.37%** (65.69%, 79.04%) N=76, Rank=2	**61.36%** (51.70%, 71.03%) N=44, Rank=8
3	Therapy	**66.67%** (62.06%, 71.28%) N=174	**77.78%** (69.62%, 85.93%) N=45, Rank=3	**64.56%** (57.56%, 71.56%) N=79, Rank=4	**57.45%** (47.97%, 66.93%) N=47, Rank=13
4	Specialized Medical Care	**65.06%** (60.28%, 69.84%) N=166	**65.79%** (55.61%, 75.97%) N=38, Rank=5	**66.22%** (59.06%, 73.38%) N=74, Rank=3	**60.78%** (51.82%, 69.75%) N=51, Rank=9
5	Vocational Training Programs*	**63.97%** (58.65%, 69.29%) N=136	**45.83%** (32.12%, 59.54%) N=24, Rank=16	**57.69%** (48.71%, 66.67%) N=52, Rank=8	**75.44%** (67.98%, 82.90%) N=57, Rank=2
6	Care Coordination	**63.91%** (59.14%, 68.67%) N=169	**73.33%** (64.66%, 82.01%) N=45, Rank=4	**54.93%** (47.24%, 62.62%) N=71, Rank=11	**68.00%** (59.34%, 76.66%) N=50, Rank=4
7	Transportation Services*	**61.96%** (57.05%, 66.87%) N=163	**55.26%** (44.60%, 65.93%) N=38, Rank=11	**47.62%** (39.40%, 55.84%) N=63, Rank=18	**80.00%** (73.25%, 86.75%) N=60, Rank=1
8	Day Habilitation	**60.31%** (54.78%, 65.83%) N=131	**46.15%** (33.03%, 59.28%) N=26, Rank=15	**55.32%** (45.79%, 64.85%) N=47, Rank=9	**69.09%** (60.93%, 77.25%) N=55, Rank=3
9	Special Equipment	**59.24%** (54.17%, 64.30%) N=157	**61.11%** (50.35%, 71.87%) N=36, Rank=7	**53.33%** (45.83%, 60.83%) N=75, Rank=12	**65.12%** (55.54%, 74.69%) N=43, Rank=6
10	Specialized Dental Care	**57.05%** (51.93%, 62.17%) N=156	**45.71%** (34.55%, 56.88%) N=35, Rank=17	**58.21%** (50.35%, 66.07%) N=67, Rank=6	**60.78%** (51.82%, 69.75%) N=51, Rank=9
11	Cash Subsidies	**55.83%** (50.81%, 60.85%) N=163	**55.00%** (44.61%, 65.39%) N=40, Rank=12	**52.78%** (45.11%, 60.44%) N=72, Rank=13	**60.42%** (51.14%, 69.69%) N=48, Rank=11
12	Recreational Activities	**55.23%** (50.34%, 60.12%) N=172	**59.52%** (49.54%, 69.51%) N=42, Rank=8	**48.61%** (40.94%, 56.28%) N=72, Rank=15	**58.18%** (49.47%, 66.89%) N=55, Rank=12

*significant at the .05 level where a Chi square test of difference between proportions is used.

** significant at the .1 level where a Chi square test of difference between proportions is used.

Table 1: Efficacy Rating of FCDs (N=204) by Age Cohort (% of respondent who indicated “exceedingly” or very effective) continued...

	Service	Overall	0-5 years	6-21 years	22 years and over
13	Behavior Support Programs	**53.95%** (48.73%, 59.17%) N=152	**58.33%** (47.45%, 69.22%) N=36, Rank=9	**55.22%** (47.30%, 63.15%) N=67, Rank=10	**45.65%** (35.99%, 55.31%) N=46, Rank=21
14	Respite Services	**53.42%** (48.09%, 58.76%) N=146	**43.75%** (32.08%, 55.42%) N=32, Rank=20	**58.06%** (49.88%, 66.25%) N=62, Rank=7	**55.10%** (45.77%, 64.43%) N=49, Rank=14
15	Navigator Services	**53.09%** (48.03%, 58.15%) N=162	**61.90%** (52.03%, 71.78%) N=42, Rank=6	**47.06%** (39.17%, 54.95%) N=68, Rank=19	**53.06%** (43.70%, 62.42%) N=49, Rank=15
16	Specialized Mental Health Care	**52.94%** (47.41%, 58.47%) N=136	**44.83%** (32.49%, 57.16%) N=29, Rank=18	**59.02%** (50.79%, 67.24%) N=61, Rank=5	**46.51%** (36.49%, 56.53%) N=43, Rank=19
17	Family Training	**52.20%** (47.09%, 57.32%) N=159	**56.10%** (45.87%, 66.32%) N=41, Rank=10	**49.28%** (41.43%, 57.12%) N=69, Rank=14	**50.00%** (40.31%, 59.69%) N=46, Rank=17
18	Future Care Planning**	**50.72%** (45.22%, 56.23%) N=138	**44.83%** (32.49%, 57.16%) N=29, Rank=19	**40.35%** (31.85%, 48.85%) N=57, Rank=21	**63.27%** (54.22%, 72.31%) N=49, Rank=7
19	Homemaker Services**	**46.04%** (40.58%, 51.51%) N=139	**26.67%** (15.90%, 37.44%) N=30, Rank=24	**48.44%** (40.28%, 56.59%) N=64, Rank=16	**52.38%** (42.22%, 62.54%) N=42, Rank=16
20	Parent Support Groups	**44.52%** (39.36%, 49.67%) N=155	**52.78%** (41.76%, 63.80%) N=36, Rank=13	**36.76%** (29.14%, 44.39%) N=68, Rank=22	**47.92%** (38.44%, 57.39%) N=48, Rank=18
21	Post-Secondary School	**42.34%** (36.27%, 48.42%) N=111	**37.50%** (24.18%, 50.82%) N=24, Rank=23	**47.83%** (38.14%, 57.51%) N=46, Rank=17	**36.84%** (26.49%, 47.19%) N=38, Rank=24
22	Tutoring	**42.25%** (36.90%, 47.61%) N=142	**51.52%** (39.95%, 63.08%) N=33, Rank=14	**35.38%** (27.64%, 43.12%) N=65, Rank=24	**41.46%** (31.31%, 51.61%) N=41, Rank=22
23	Residential Services	**42.06%** (36.37%, 47.75%) N=126	**39.29%** (26.94%, 51.63%) N=28, Rank=22	**40.82%** (31.60%, 50.03%) N=49, Rank=20	**41.30%** (31.76%, 50.85%) N=46, Rank=23
24	Concierge/Errand Services	**41.79%** (36.28%, 47.30%) N=134	**40.00%** (28.07%, 51.93%) N=30, Rank=21	**36.21%** (27.95%, 44.46%) N=58, Rank=23	**46.51%** (36.49%, 56.53%) N=43, Rank=20

*significant at the .05 level where a Chi square test of difference between proportions is used.

** significant at the .1 level where a Chi square test of difference between proportions is used.

Table 2. Access Rating of FCDs by Age Cohort (% of respondent who indicated "exceedingly" or very accessible)

	Service	Overall	0-5 years	6-21 years	22 years and over
1	Pre-School	**70.19%** (65.53%, 74.84%) N=161	**68.89%** (59.81%, 77.97%) N=45, Rank=3	**76.39%** (69.87%, 82.91%) N=72, Rank=1	**60.98%** (50.93%, 71.03%) N=41, Rank=6
2	Early Intervention Services	**69.05%** (64.44%, 73.65%) N=168	**76.00%** (68.07%, 83.93%) N=50, Rank=2	**67.57%** (60.48%, 74.65%) N=74, Rank=2	**63.41%** (53.49%, 73.34%) N=41, Rank=5
3	Care Coordination	**57.49%** (52.55%, 62.42%) N=167	**57.78%** (48.09%, 67.47%) N=45, Rank=5	**47.89%** (40.16%, 55.61%) N=71, Rank=4	**70.83%** (62.22%, 79.45%) N=48, Rank=3
4	Therapy	**56.57%** (51.74%, 61.41) N=175	**76.09%** (67.82%, 84.36%) N=46, Rank=1	**49.37%** (42.05%, 56.68%) N=79, Rank=3	**46.81%** (37.24%, 56.37%) N=47, Rank=14
5	Vocational Training Programs	**55.91%** (50.21%, 61.60%) N=127	**37.50%** (24.18%, 50.82%) N=24, Rank=15	**42.55%** (33.07%, 52.03%) N=47, Rank=8	**73.58%** (65.65%, 81.52%) N=53, Rank=1
6	Specialized Medical Care	**52.69%** (47.71%, 57.68%) N=167	**61.54%** (51.25%, 71.83%) N=39, Rank=4	**44.59%** (37.07%, 52.12%) N=74, Rank=7	**54.90%** (45.76%, 64.04%) N=51, Rank=8
7	Transportation Services	**52.44%** (47.41%, 57.47%) N=164	**52.63%** (41.92%, 63.34%) N=38, Rank=6	**31.75%** (24.09%, 39.40%) N=63, Rank=13	**72.13%** (64.63%, 79.63%) N=61, Rank=2
8	Day Habilitation	**48.84%** (43.15%, 54.53%) N=129	**30.77%** (18.62%, 42.92%) N=26, Rank=21	**40.43%** (31.02%, 49.83%) N=47, Rank=9	**64.81%** (56.30%, 73.33%) N=54, Rank=4
9	Behavior Support Programs	**46.05%** (40.83%, 51.27%) N=152	**47.22%** (36.20%, 58.24%) N=36, Rank=10	**45.45%** (37.46%, 53.45%) N=66, Rank=5	**42.55%** (33.07%, 52.03%) N=47, Rank=16
10	Recreational Activities	**45.93%** (41.03%, 50.83%) N=172	**51.22%** (40.92%, 61.52%) N=41, Rank=7	**31.51%** (24.43%, 38.59%) N=73, Rank=14	**58.18%** (49.47%, 66.89%) N=55, Rank=7
11	Specialized Dental Care	**45.22%** (40.09%, 50.35%) N=157	**37.14%** (26.31%, 47.97%) N=35, Rank=17	**44.93%** (37.12%, 52.73%) N=69 Rank=6	**50.00%** (40.72%, 59.28%) N=50, Rank=12
12	Respite Services	**43.05%** (37.84%, 48.25%) N=151	**38.24%** (27.17%, 49.30%) N=34, Rank=13	**40.00%** (32.07%, 47.93%) N=65, Rank=10	**51.02%** (41.64%, 60.40%) N=49, Rank=10

Table 2. Access Rating of FCDs by Age Cohort (% of respondent who indicated “exceedingly” or very accessible) continued...

	Service	Overall	0-5 years	6-21 years	22 years and over
13	Special Equipment	**42.31%** (37.20%, 47.42%) N=156	**48.65%** (37.77%, 59.52%) N=37, Rank=9	**30.14%** (23.14%, 37.13%) N=73, Rank=15	**53.49%** (43.47%, 63.51%) N=43, Rank=9
14	Navigator Services	**38.61%** (33.61%, 43.61%) N=158	**48.72%** (38.14%, 59.29%) N=39, Rank=8	**30.00%** (22.86%, 37.14%) N=70, Rank=16	**42.55%** (33.07%, 52.03%) N=47 Rank=17
15	Specialized Mental Health Care	**37.41%** (32.11%, 42.71%) N=139	**35.48%** (24.04%, 46.93%) N=31, Rank=19	**34.38%** (26.63%, 42.12) N=64, Rank=11	**39.02%** (28.97%, 49.07%) N=41, Rank=19
16	Residential Services	**37.21%** (31.71%, 42.71%) N=129	**43.33%** (31.27%, 55.40%) N=30, Rank=11	**24.49%** (16.42%, 32.56%) N=49, Rank=21	**42.55%** (33.07%, 52.03%) N=47, Rank=17
17	Family Training	**36.71%** (31.76%, 41.66%) N=158	**37.50%** (27.39%, 47.61%) N=40, Rank=15	**32.35%** (24.96%, 39.75%) N=68, Rank=12	**38.30%** (28.98%, 47.62%) N=47, Rank=20
18	Cash Subsidies	**36.36%** (31.53%, 41.20%) N=165	**39.02%** (28.97%, 49.07%) N=41, Rank=12	**25.00%** (18.35%, 31.65%) N=72, Rank=19	**48.98%** (39.60%, 58.36%) N=49, Rank=13
19	Parent Support Groups	**35.44%** (30.53%, 40.36%) N=158	**37.84%** (27.29%, 48.39%) N=37, Rank=14	**29.58%** (22.52%, 36.63%) N=71, Rank=17	38.30% (28.98%, 47.62%) N=47 Rank=20
20	Future Care Planning	**34.48%** (29.38%, 39.58%) N=145	**31.25%** (20.35%, 42.15%) N=32, Rank=20	**20.00%** (13.25%, 26.75%) N=60, Rank=23	**50.00%** (40.72%, 59.28%) N=50, Rank=11
21	Homemaker Services	**33.82%** (28.58%, 39.07%) N=136	**20.00%** (10.26%, 29.74%) N=30, Rank=24	**29.03%** (21.50%, 36.56%) N=62 Rank=18	**46.34%** (36.07%, 56.62%) N=41, Rank=15
22	Post-Secondary School	**30.56%** (24.81%, 36.30%) N=108	**30.43%** (17.47%, 43.40%) N=23, Rank=22	**25.00%** (16.41%, 33.59%) N=44, Rank=19	**34.21%** (24.03%, 44.39%) N=38, Rank=22
23	Tutoring	**29.08%** (24.14%, 34.02%) N=141	**36.36%** (25.24%, 47.49%) N=33, Rank=18	**23.08%** (16.26%, 29.90%) N=65, Rank=22	**31.71%** (22.12%, 41.29%) N=41, Rank=23
24	Concierge/Errand Services	**25.74%** (20.89%, 30.58%) N=136	**26.67%** (15.90%, 37.44%) N=30, Rank=23	**17.74%** (11.40%, 24.08%) N=62, Rank=24	**31.71%** (22.12%, 41.29%) N=41, Rank=23

Table 3: Access gaps of FCDs by Age Cohort for Top Ten Ranked Services (Access Gap=Percentage of FCDs who rated a services very and exceedingly effective minus the percentage of FCDs who rated a service very and exceedingly accessible)

Efficacy Ranking	Service	Family Overall	Age 0-5	Age 6-21	Age 22 and over
1	Pre-School	4%	13%	-2%	6%
2	Early Intervention Services	4%	8%	5%	-2%
3	Therapy	10%	2%	15%	11%
4	Specialized Medical Care	12%	4%	22%	6%
5	Vocational Training Programs	8%	8%	15%	2%
6	Care Coordination	6%	16%	7%	-3%
7	Transportation Services	10%	3%	16%	8%
8	Day Habilitation	11%	15%	15%	4%
9	Special Equipment	17%	12%	23%	12%
10	Specialized Dental Care	12%	9%	13%	11%
11	Cash Subsidies	19%	16%	28%	11%
12	Recreational Activities	9%	8%	17%	0%
13	Behavior Support Programs	8%	11%	10%	3%
14	Respite Services	10%	6%	18%	4%
15	Navigator Services	14%	13%	17%	11%
16	Specialized Mental Health Care	16%	9%	25%	7%
17	Family Training	15%	19%	17%	12%
18	Future Care Planning	16%	14%	20%	13%
19	Homemaker Services	12%	7%	19%	6%
20	Parent Support Groups	9%	15%	7%	10%
21	Post-Secondary School	12%	7%	23%	3%
22	Tutoring	13%	15%	12%	10%
23	Residential Services	5%	-4%	16%	-1%
24	Concierge/Errand Services	16%	13%	18%	15%

Table 4: Efficacy Rating By Stress Level (% of respondent who indicated “exceedingly” or “very” effective)

	Service	Overall	Low Stress	High Stress
1	Pre-School*	**74.39%** (69.99%, 78.79%) N=164	**77.87%** (73.01%, 82.73%) N=122, Rank=2	**46.67%** (28.73%, 64.60%) N=15, Rank=4
2	Early Intervention Services*	**72.67%** (68.29%, 77.06%) N=172	**78.74%** (74.04%, 83.44%) N=127, Rank=1	**57.89%** (42.41%, 73.38%) N=19, Rank=2
3	Therapy**	**66.67%** (62.06%, 71.28%) N=174	**70.16%** (64.85%, 75.48%) N=124, Rank=4	**50.00%** (34.77%, 65.23%) N=20, Rank=3
4	Specialized Medical Care*	**65.06%** (60.28%, 69.84%) N=166	**69.03%** (63.39%, 74.66%) N=113, Rank=5	**35.00%** (20.47%, 49.53%) N=20, Rank=14
5	Vocational Training Programs	**63.97%** (58.65%, 69.29%) N=136	**67.71%** (61.52%, 73.90%) N=96, Rank=7	**58.33%** (38.07%, 78.60%) N=12, Rank=1
6	Care Coordination*	**63.91%** (59.14%, 68.67%) N=169	**71.07%** (65.74%, 76.41%) N=121, Rank=3	**33.33%** (18.09%, 48.58%) N=18, Rank=15
7	Transportation Services**	**61.96%** (57.05%, 66.87%) N=163	**67.83%** (62.19%, 73.47%) N=115, Rank=6	**41.18%** (24.73%, 57.62%) N=17, Rank=8
8	Day Habilitation**	**60.31%** (54.78%, 65.83%) N=131	**65.93%** (59.48%, 72.38%) N=91, Rank=9	**38.46%** (19.41%, 57.51%) N=13, Rank=11
9	Special Equipment*	**59.24%** (54.17%, 64.30%) N=157	**66.36%** (60.53%, 72.20%) N=110, Rank=8	**35.00%** (20.47%, 49.53%) N=20, Rank=13
10	Specialized Dental Care	**57.05%** (51.93%, 62.17%) N=156	**60.38%** (54.22%, 66.53%) N=106, Rank=10	**40.00%** (25.08%, 54.92%) N=20, Rank=10
11	Cash Subsidies	**55.83%** (50.81%, 60.85%) N=163	**59.13%** (53.20%, 65.07%) N=115, Rank=11	**42.11%** (26.62%, 57.59%) N=19, Rank=7
12	Recreational Activities	**55.23%** (50.34%, 60.12%) N=172	**57.50%** (51.66%, 63.34%) N=120, Rank=16	**45.00%** (29.85%, 60.15%) N=20, Rank=5

*significant at the .05 level where a Chi square test of difference between proportions is used.

** significant at the .1 level where a Chi square test of difference between proportions is used.

Table 4: Efficacy Rating By Stress Level (% of respondent who indicated "exceedingly" or "very" effective) continued...

	Service	Overall	Low Stress	High Stress
13	Behavior Support Programs*	**53.95%** (48.73%, 59.17%) N=152	**58.33%** (52.19%, 64.48%) N=108, Rank=13	**33.33%** (18.09%, 48.58%) N=18, Rank=15
14	Respite Services**	**53.42%** (48.09%, 58.76%) N=146	**58.65%** (52.40%, 64.91%) N=104, Rank=12	**35.29%** (19.32%, 51.26%) N=17, Rank=12
15	Navigator Services*	**53.09%** (48.03%, 58.15%) N=162	**57.89%** (51.91%, 63.88%) N=114, Rank=15	**30.00%** (16.04%, 43.96%) N=20, Rank=19
17	Family Training	**52.20%** (47.09%, 57.32%) N=159	**54.87%** (48.81%, 60.93%) N=113, Rank=18	**44.44%** (28.37%, 60.51%) N=18, Rank=6
18	Future Care Planning**	**50.72%** (45.22%, 56.23%) N=138	**55.79%** (49.18%, 62.40%) N=95, Rank=17	**29.41%** (14.18%, 44.64%) N=17, Rank=20
19	Homemaker Services	**46.04%** (40.58%, 51.51%) N=139	**44.79%** (38.21%, 51.38%) N=96, Rank=21	**31.25%** (15.21%, 47.29%) N=16, Rank=18
20	Parent Support Groups**	**44.52%** (39.36%, 49.67%) N=155	**50.47%** (44.20%, 56.73%) N=107, Rank=19	**25.00%** (11.81%, 38.19%) N=20, Rank=21
21	Post-Secondary School	**42.34%** (36.27%, 48.42%) N=111	**43.21%** (36.05%, 50.37%) N=81, Rank=24	**33.33%** (10.05%, 56.61%) N=9, Rank=15
22	Tutoring	**42.25%** (36.90%, 47.61%) N=142	**43.69%** (37.35%, 50.02%) N=103, Rank=23	**40.00%** (22.39%, 57.61%) N=15, Rank=9
23	Residential Services*	**42.06%** (36.37%, 47.75%) N=126	**49.41%** (42.37%, 56.46%) N=85, Rank=20	**12.50%** (1.05%, 23.95%) N=16, Rank=24
24	Concierge/Errand Services	**41.79%** (36.28%, 47.30%) N=134	**44.57%** (37.84%, 51.29%) N=92, Rank=22	**25.00%** (10.01%, 39.99%) N=16, Rank=21

*significant at the .05 level where a Chi square test of difference between proportions is used.

** significant at the .1 level where a Chi square test of difference between proportions is used.

Table 5: Access Rating By Stress Level (% of respondents who indicated "exceedingly" or "very" effective)

	Service	Overall	Low Stress	High Stress
1	Pre-School	**70.19%** (65.53%, 74.84%) N=161	**73.11%** (67.85%, 78.37%) N=119, Rank=1	**62.50%** (45.74%, 79.26%) N=16, Rank=1
2	Early Intervention Services	**69.05%** (64.44%, 73.65%) N=168	**72.13%** (66.88%, 77.38%) N=122, Rank=2	**57.89%** (42.41%, 73.38%) N=19, Rank=2
3	Care Coordination*	**57.49%** (52.55%, 62.42%) N=167	**62.50%** (56.78%, 68.22%) N=120, Rank=3	**22.22%** (8.78%, 35.67%) N=18, Rank=9
4	Therapy*	**56.57%** (51.74%, 61.41) N=175	**60.48%** (54.80%, 66.16%) N=124, Rank=4	**35.00%** (20.47%, 49.53%) N=20, Rank=4
5	Vocational Training Programs	**55.91%** (50.21%, 61.60%) N=127	**60.00%** (53.30%, 66.70%) N=90, Rank=5	**36.36%** (15.49%, 57.24%) N=11, Rank=3
6	Specialized Medical Care*	**52.69%** (47.71%, 57.68%) N=167	**57.02%** (51.01%, 63.02%) N=114, Rank=7	**25.00%** (11.81%, 38.19%) N=20, Rank=6
7	Transportation Services**	**52.44%** (47.41%, 57.47%) N=164	**58.62%** (52.70%, 64.54%) N=116, Rank=6	**26.67%** (10.77%, 42.56%) N=15, Rank=5
8	Day Habilitation*	**48.84%** (43.15%, 54.53%) N=129	**56.82%** (49.96%, 63.68%) N=88, Rank=8	**15.38%** (1.26%, 29.51%) N=13, Rank=12
9	Behavior Support Programs**	**46.05%** (40.83%, 51.27%) N=152	**48.62%** (42.42%, 54.83%) N=109, Rank=11	**22.22%** (8.78%, 35.67%) N=18, Rank=9
10	Recreational Activities**	**45.93%** (41.03%, 50.83%) N=172	**49.59%** (43.71%, 55.47%) N=121, Rank=10	**25.00%** (11.81%, 38.19%) N=20, Rank=6
11	Specialized Dental Care**	**45.22%** (40.09%, 50.35%) N=157	**45.79%** (39.55%, 52.03%) N=107, Rank=13	**25.00%** (11.81%, 38.19%) N=20, Rank=6
12	Respite Services*	**43.05%** (37.84%, 48.25%) N=151	**48.60%** (42.34%, 54.86%) N=107, Rank=12	**16.67%** (4.61%, 28.72%) N=18, Rank=11

*significant at the .05 level where a Chi square test of difference between proportions is used.

** significant at the .1 level where a Chi square test of difference between proportions is used.

Table 5: Access Rating By Stress Level (% of respondents who indicated “exceedingly” or “very” effective) continued...

	Service	Overall	Low Stress	High Stress
13	Special Equipment*	**42.31%** (37.20%, 47.42%) N=156	**51.38%** (45.17%, 57.58%) N=109, Rank=9	**5.00%** (- 1.64%, 11.64%) N=20, Rank=22
14	Navigator Services*	**38.61%** (33.61%, 43.61%) N=158	**43.36%** (37.33%, 49.40%) N=113, Rank=14	**5.26%** (- 1.74%, 12.27%) N=19, Rank=21
15	Specialized Mental Health Care*	**37.41%** (32.11%, 42.71%) N=139	**42.11%** (35.53%, 48.68%) N=95, Rank=15	**6.25%** (- 2.13%, 14.63%) N=16, Rank=18
16	Residential Services*	**37.21%** (31.71%, 42.71%) N=129	**42.05%** (35.21%, 48.88%) N=88, Rank=16	**11.76%** (1.00%, 22.53%) N=17, Rank=14
17	Training*	**36.71%** (31.76%, 41.66%) N=158	**39.82%** (33.86%, 45.79%) N=113, Rank=19	**11.76%** (1.00%, 22.53%) N=17, Rank=14
18	Cash Subsidies*	**36.36%** (31.53%, 41.20%) N=165	**41.88%** (35.98%, 47.78%) N=117, Rank=17	**10.00%** (0.86%, 19.14%) N=20, Rank=17
19	Parent Support Groups*	**35.44%** (30.53%, 40.36%) N=158	**41.28%** (35.18%, 47.39%) N=109, Rank=18	**4.76%** (-1.55%, 11.07%) N=21, Rank=23
20	Future Care Planning**	**34.48%** (29.38%, 39.58%) N=145	**36.36%** (30.09%, 42.63%) N=99, Rank=20	**11.11%** (0.95%, 21.27%) N=18, Rank=16
21	Homemaker Services**	**33.82%** (28.58%, 39.07%) N=136	**36.17%** (29.74%, 42.60%) N=94, Rank=21	**12.50%** (1.05%, 23.95%) N=16, Rank=13
22	Post-Secondary School**	**30.56%** (24.81%, 36.30%) N=108	**32.05%** (25.18%, 38.93%) N=78, Rank=22	**0.00%** (0.00%, 0.00%) N=8, Rank=23
23	Tutoring*	**29.08%** (24.14%, 34.02%) N=141	**31.68%** (25.68%, 37.69%) N=101, Rank=23	**6.25%** (- 2.13%, 14.63%) N=16, Rank=18
24	Concierge/Errand Services	**25.74%** (20.89%, 30.58%) N=136	**26.60%** (20.68%, 32.51%) N=94, Rank=24	**6.25%** (- 2.13%, 14.63%) N=16, Rank=18

*significant at the .05 level where a Chi square test of difference between proportions is used.

** significant at the .1 level where a Chi square test of difference between proportions is used.

Table 6: Efficacy Ratings of DD Stakeholders (% of respondents who indicated "exceedingly or "very effective")

	Service	Family	Superintendent	DD Council	DD Directors
1	Pre-School	**74.39%** (69.99%, 78.79%) N=164	**97.14%** (93.41%, 100.9%) N=35, Rank=2	**53.33%** (41.18%, 65.48%) N=30, Rank=12	**31.58%** (17.00%, 46.15%) N=19, Rank22
2	Early Intervention Services	**72.67%** (68.29%, 77.06%) N=172	**100.0%** (100.0%, 100.0%) N=37, Rank=1	**80.65%** (71.19%, 90.10%) N=31, Rank=1	**89.47%** (79.85%, 99.10%) N=19, Rank=2
3	Therapy	**66.67%** (62.06%, 71.28%) N=174	**61.11%** (50.35%, 71.87%) N=36, Rank=17	**40.00%** (28.07%, 51.93%) N=30, Rank=20	**52.63%** (36.97%, 68.29%) N=19, Rank=10
4	Specialized Medical Care	**65.06%** (60.28%, 69.84%) N=166	**71.43%** (61.30%, 81.55%) N=35, Rank=13	**61.29%** (49.64%, 72.94%) N=31, Rank=7	**63.16%** (48.03%, 78.28%) N=19, Rank=6
5	Vocational Training Programs	**63.97%** (58.65%, 69.29%) N=136	**78.38%** (69.42%, 87.34%) N=37, Rank=8	**61.29%** (49.64%, 72.94%) N=31, Rank=7	**57.89%** (42.41%, 73.38%) N=19, Rank=7
6	Care Coordination	**63.91%** (59.14%, 68.67%) N=169	**94.44%** (89.39%, 99.50%) N=36, Rank=3	**35.48%** (24.04%, 46.93%) N=31, Rank=22	**52.63%** (36.97%, 68.29%) N=19, Rank=10
7	Transportation Services	**61.96%** (57.05%, 66.87%) N=163	**78.38%** (69.42%, 87.34%) N=37, Rank=8	**64.52%** (53.07%, 75.96%) N=31, Rank=4	**57.89%** (42.41%, 73.38%) N=19, Rank=7
8	Day Habilitation	**60.31%** (54.78%, 65.83%) N=131	**86.11%** (78.48%, 93.75%) N=36, Rank=6	**26.67%** (15.90%, 37.44%) N=30, Rank=24	**36.84%** (21.72%, 51.97%) N=19, Rank=20
9	Special Equipment	**59.24%** (54.17%, 64.30%) N=157	**88.89%** (81.95%, 95.83%) N=36, Rank=4	**70.97%** (60.11%, 81.83%) N=31, Rank=3	**78.95%** (66.16%, 91.73%) N=19, Rank=3
10	Specialized Dental Care	**57.05%** (51.93%, 62.17%) N=156	**57.14%** (46.05%, 68.23%) N=35, Rank=19	**61.29%** (49.64%, 72.94%) N=31, Rank=7	**52.63%** (36.97%, 68.29%) N=19, Rank=10
11	Cash Subsidies	**55.83%** (50.81%, 60.85%) N=163	**48.57%** (37.37%, 59.77%) N=35, Rank=22	**62.07%** (50.03%, 74.10%) N=29, Rank=6	**38.89%** (23.12%, 54.65%) N=18, Rank=18
12	Recreational Activities	**55.23%** (50.34%, 60.12%) N=172	**75.68%** (66.34%, 85.01%) N=37, Rank=11	**41.94%** (30.13%, 53.74%) N=31, Rank=19	**36.84%** (21.72%, 51.97%) N=19, Rank=20

Table 6: Efficacy Ratings of DD Stakeholders (% of respondents who indicated "exceedingly or "very effective") continued...

	Service	Family	Superintendent	DD Council	DD Directors
13	Behavior Support Programs	**53.95%** (48.73%, 59.17%) N=152	**75.68%** (66.34%, 85.01%) N=37, Rank=11	**64.52%** (53.07%, 75.96%) N=31, Rank=4	**68.42%** (53.85%, 83.00%) N=19, Rank=4
14	Respite Services	**53.42%** (48.09%, 58.76%) N=146	**83.78%** (75.76%, 91.80%) N=37, Rank=7	**79.31%** (69.26%, 89.36%) N=29, Rank=2	**100.0%** (100.0%, 100.0%) N=15, Rank=1
15	Navigator Services	**53.09%** (48.03%, 58.15%) N=162	**68.57%** (58.17%, 78.98%) N=35, Rank=14	**60.00%** (48.07%, 71.93%) N=30, Rank=11	**55.56%** (39.49%, 71.63%) N=18, Rank=9
16	Specialized Mental Health Care	**52.94%** (47.41%, 58.47%) N=136	**52.94%** (41.58%, 64.30%) N=34, Rank=20	**50.00%** (37.82%, 62.18%) N=30, Rank=15	**47.37%** (31.71%, 63.03) N=19, Rank=16
17	Training	**52.20%** (47.09%, 57.32%) N=159	**67.57%** (57.38%, 77.75%) N=37, Rank=15	**51.61%** (39.66%, 63.57%) N=31, Rank=13	**52.63%** (36.97%, 68.29%) N=19, Rank=10
18	Future Care Planning	**50.72%** (45.22%, 56.23%) N=138	**67.57%** (57.38%, 77.75%) N=37, Rank=15	**48.39%** (36.43%, 60.34%) N=31, Rank=16	**42.11%** (26.62%, 57.59%) N=19, Rank=17
19	Homemaker Services	**46.04%** (40.58%, 51.51%) N=139	**78.38%** (69.42%, 87.34%) N=37, Rank=8	**51.61%** (39.66%, 63.57%) N=31, Rank=13	**52.63%** (36.97%, 68.29%) N=19, Rank=10
20	Parent Support Groups	**44.52%** (39.36%, 49.67%) N=155	**50.00%** (38.96%, 61.04%) N=36, Rank=21	**48.39%** (36.43%, 60.34%) N=31, Rank=16	**68.42%** (53.85%, 83.00%) N=19, Rank=4
21	Post-Secondary School	**42.34%** (36.27%, 48.42%) N=111	**41.18%** (29.97%, 52.38%) N=34, Rank=24	**46.43%** (33.82%, 59.04%) N=28, Rank=18	**0.00%** (0.00%, 0.00%) N=19, Rank=24
22	Tutoring	**42.25%** (36.90%, 47.61%) N=142	**58.82%** (47.62%, 70.03%) N=34, Rank=18	**28.57%** (17.15%, 39.99%) N=28, Rank=23	**22.22%** (8.78%, 35.67%) N=18, Rank=23
23	Residential Services	**42.06%** (36.37%, 47.75%) N=126	**86.49%** (79.05%, 93.93%) N=37, Rank=5	**40.00%** (28.07%, 51.93%) N=30, Rank=20	**52.63%** (36.97%, 68.29%) N=19, Rank=10
24	Concierge/Errand Services	**41.79%** (36.28%, 47.30%) N=134	**44.44%** (33.47%, 55.42%) N=36, Rank=23	**60.71%** (48.37%, 73.06%) N=28, Rank=10	**38.89%** (23.12%, 54.65%) N=18, Rank=18

Table 7: Access Ratings of DD Stakeholders (% of respondents who indicated “exceedingly or “very effective”)

	Service	Family	Superintendent	DD Council	DD Directors
1	Pre-School	**70.19%** (65.53%, 74.84%) N=161	**88.57%** (81.44%, 95.70%) N=35, Rank=2	**13.33%** (5.06%, 21.61%) N=30, Rank=7	**21.05%** (8.27%, 33.84%) N=19, Rank=5
2	Early Intervention Services	**69.05%** (64.44%, 73.65%) N=168	**89.19%** (82.43%, 95.95%) N=37, Rank=1	**54.84%** (42.93%, 66.74%) N=31, Rank=1	**52.63%** (36.97%, 68.29%) N=19, Rank=1
3	Care Coordination	**57.49%** (52.55%, 62.42%) N=167	**86.11%** (78.48%, 93.75%) N=36, Rank=3	**32.26%** (21.07%, 43.44%) N=31, Rank=3	**36.84%** (21.72%, 51.97%) N=19, Rank=2
4	Therapy	**56.57%** (51.74%, 61.41) N=175	**22.22%** (13.04%, 31.40%) N=36, Rank=18	**6.67%** (0.59%, 12.74%) N=30, Rank=17	**5.26%** (- 1.74%, 12.27%) N=19, Rank=12
5	Vocational Training Programs	**55.91%** (50.21%, 61.60%) N=127	**64.86%** (54.48%, 75.25%) N=37, Rank=5	**22.58%** (12.58%, 32.58%) N=31, Rank=5	**5.26%** (- 1.74%, 12.27%) N=19, Rank=12
6	Specialized Medical Care	**52.69%** (47.71%, 57.68%) N=167	**20.00%** (11.03%, 28.97%) N=35, Rank=19	**12.90%** (4.88%, 20.92%) N=31, Rank=9	**0.00%** (0.00%, 0.00%) N=19, Rank=19
7	Transportation Services	**52.44%** (47.41%, 57.47%) N=164	**48.57%** (37.37%, 59.77%) N=35, Rank=8	**12.90%** (4.88%, 20.92%) N=31, Rank=9	**0.00%** (0.00%, 0.00%) N=19, Rank=19
8	Day Habilitation	**48.84%** (43.15%, 54.53%) N=129	**86.11%** (78.48%, 93.75%) N=36, Rank=3	**36.67%** (24.93%, 48.40%) N=30, Rank=2	**21.05%** (8.27%, 33.84%) N=19, Rank=5
9	Behavior Support Programs	**46.05%** (40.83%, 51.27%) N=152	**35.14%** (24.75%, 45.52%) N=37, Rank=13	**3.23%** (-1.00%, 7.45%) N=31, Rank=22	**15.79%** (4.36%, 27.22%) N=19, Rank=8
10	Recreational Activities	**45.93%** (41.03%, 50.83%) N=172	**40.54%** (29.86%, 51.22%) N=37, Rank=11	**3.23%** (-1.00%, 7.45%) N=31, Rank=22	**5.26%** (- 1.74%, 12.27%) N=19, Rank=12
11	Specialized Dental Care	**45.22%** (40.09%, 50.35%) N=157	**5.71%** (0.51%, 10.92%) N=35, Rank=24	**9.68%** (2.60%, 16.75%) N=31, Rank=14	**0.00%** (0.00%, 0.00%) N=19, Rank=19
12	Respite Services	**43.05%** (37.84%, 48.25%) N=151	**32.43%** (22.25%, 42.62%) N=37, Rank=14	**13.79%** (5.24%, 22.35%) N=29, Rank=6	**26.67%** (10.77%, 42.56%) N=15, Rank=3

Table 7: Access Ratings of DD Stakeholders (% of respondents who indicated “exceedingly or “very effective”) continued...

	Service	Family	Superintendent	DD Council	DD Directors
13	Special Equipment	**42.31%** (37.20%, 47.42%) N=156	**61.11%** (50.35%, 71.87%) N=36, Rank=6	**12.90%** (4.88%, 20.92%) N=31, Rank=9	**10.53%** (0.90%, 20.15%) N=19, Rank=9
14	Navigator Services	**38.61%** (33.61%, 43.61%) N=158	**48.57%** (37.37%, 59.77%) N=35, Rank=8	**3.33%** (-1.04%, 7.70%) N=30, Rank=21	**22.22%** (8.78%, 35.67%) N=18, Rank=4
15	Specialized Mental Health Care	**37.41%** (32.11%, 42.71%) N=139	**5.88%** (0.53%, 11.24%) N=34, Rank=23	**12.90%** (4.88%, 20.92%) N=31, Rank=9	**5.26%** (- 1.74%, 12.27%) N=19, Rank=12
16	Residential Services	**37.21%** (31.71%, 42.71%) N=129	**54.05%** (43.21%, 64.90%) N=37, Rank=7	**13.33%** (5.06%, 21.61%) N=30, Rank=7	**10.53%** (0.90%, 20.15%) N=19, Rank=9
17	Training	**36.71%** (31.76%, 41.66%) N=158	**37.84%** (27.29%, 48.39%) N=37, Rank=12	**6.45%** (0.57%, 12.33%) N=31, Rank=19	**5.26%** (- 1.74%, 12.27%) N=19, Rank=12
18	Cash Subsidies	**36.36%** (31.53%, 41.20%) N=165	**20.00%** (11.03%, 28.97%) N=35, Rank=19	**12.90%** (4.88%, 20.92%) N=31, Rank=9	**5.26%** (- 1.74%, 12.27%) N=19, Rank=12
19	Parent Support Groups	**35.44%** (30.53%, 40.36%) N=158	**13.89%** (6.25%, 21.52%) N=36, Rank=22	**25.81%** (15.34%, 36.28%) N=31, Rank=4	**10.53%** (0.90%, 20.15%) N=19, Rank=9
20	Future Care Planning	**34.48%** (29.38%, 39.58%) N=145	**27.03%** (17.36%, 36.69%) N=37, Rank=15	**9.68%** (2.60%, 16.75%) N=31, Rank=14	**0.00%** (0.00%, 0.00%) N=19, Rank=19
21	Homemaker Services	**33.82%** (28.58%, 39.07%) N=136	**44.44%** (33.47%, 55.42%) N=36, Rank=10	**9.68%** (2.60%, 16.75%) N=31, Rank=14	**0.00%** (0.00%, 0.00%) N=19, Rank=19
22	Post-Secondary School	**30.56%** (24.81%, 36.30%) N=108	**26.47%** (16.43%, 36.51%) N=34, Rank=16	**6.67%** (0.59%, 12.74%) N=30, Rank=17	**5.26%** (- 1.74%, 12.27%) N=19, Rank=12
23	Tutoring	**29.08%** (24.14%, 34.02%) N=141	**23.53%** (13.87%, 33.19%) N=34, Rank=17	**3.45%** (- 1.08%, 7.97%) N=29, Rank=20	**16.67%** (4.61%, 28.72%) N=18, Rank=7
24	Concierge/Errand Services	**25.74%** (20.89%, 30.58%) N=136	**19.44%** (10.71%, 28.18%) N=36, Rank=21	**3.23%** (-1.00%, 7.45%) N=31, Rank=22	**0.00%** (0.00%, 0.00%) N=18, Rank=19

Table 8: Resource Ratings of DD Stakeholders (% of respondents who indicated “exceedingly or “very effective”)

	Service	Superintendent	DD Council	DD Directors
1	Pre-School	**94.12%** (88.76%, 99.47%) N=34	**27.59%** (16.50%, 38.67%) N=29, Rank=7	**21.05%** (8.27%, 33.84%) N=19, Rank=12
2	Care Coordination	**88.57%** (81.44%, 95.70%) N=35	**26.67%** (15.90%, 37.44%) N=30, Rank=8	**26.32%** (12.51%, 40.12%) N=19, Rank=9
3	Day Habilitation	**88.57%** (81.44%, 95.70%) N=35	**31.03%** (19.56%, 42.51%) N=29, Rank=6	**36.84%** (21.72%, 51.97%) N=19, Rank=6
4	Early Intervention Services	**86.11%** (78.48%, 93.75%) N=36	**46.67%** (34.52%, 58.82%) N=30, Rank=2	**42.11%** (26.62%, 57.59%) N=19, Rank=4
5	Vocational Training Programs	**86.11%** (78.48%, 93.75%) N=36	**56.67%** (44.60%, 68.73%) N=30, Rank=1	**47.37%** (31.71%, 63.03%) N=19, Rank=2
6	Residential Services	**80.56%** (71.82%, 89.29%) N=36, Rank=6	**41.38%** (29.16%, 53.60%) N=29, Rank=4	**68.42%** (53.85%, 83.00%) N=19, Rank=1
7	Homemaker Services	**69.44%** (59.27%, 79.61%) N=36	**13.33%** (5.06%, 21.61%) N=30, Rank=20	**10.53%** (0.90%, 20.15%) N=19, Rank=19
8	Special Equipment	**68.57%** (58.17%, 78.98%) N=35	**23.33%** (13.03%, 33.63%) N=30, Rank=10	**21.05%** (8.27%, 33.84%) N=19, Rank=12
9	Transportation Services	**68.57%** (58.17%, 78.98%) N=35	**26.67%** (15.90%, 37.44%) N=30, Rank=8	**15.79%** (4.36%, 27.22%) N=19, Rank=16
10	Recreational Activities	**61.11%** (50.35%, 71.87%) N=36	**6.67%** (0.59%, 12.74%) N=30, Rank=23	**5.26%** (- 1.74%, 12.27%) N=19, Rank=22
11	Respite Services	**61.11%** (50.35%, 71.87%) N=36	**21.43%** (11.05%, 31.80%) N=28, Rank=11	**13.33%** (1.11%, 25.55%) N=15, Rank=18
12	Navigator Services	**58.82%** (47.62%, 70.03%) N=34	**13.79%** (5.24%, 22.35%) N=29, Rank=18	**16.67%** (4.61%, 28.72%) N=18, Rank=14

Table 8: Resource Ratings of DD Stakeholders (% of respondents who indicated "exceedingly or "very effective") continued...

	Service	Superintendent	DD Council	DD Directors
13	Behavior Support Programs	**55.56%** (44.58%, 66.53%) N=36	**43.33%** (31.27%, 55.40%) N=30, Rank=3	**31.58%** (17.00%, 46.15%) N=19, Rank=7
14	Therapy	**54.29%** (43.12%, 65.45%) N=35	**13.79%** (5.24%, 22.35%) N=29, Rank=18	**31.58%** (17.00%, 46.15%) N=19, Rank=7
15	Cash Subsidies	**50.00%** (38.62%, 61.38%) N=34	**13.33%** (5.06%, 21.61%) N=30, Rank=20	**16.67%** (4.61%, 28.72%) N=18, Rank=14
16	Future Care Planning	**47.22%** (36.20%, 58.24%) N=36	**16.67%** (7.59%, 25.74%) N=30, Rank=17	**15.79%** (4.36%, 27.22%) N=19, Rank=16
17	Training	**47.22%** (36.20%, 58.24%) N=36	**13.33%** (5.06%, 21.61%) N=30, Rank=20	**5.26%** (- 1.74%, 12.27%) N=19, Rank=22
18	Specialized Medical Care	**47.06%** (35.70%, 58.42%) N=34	**40.00%** (28.07%, 51.93%) N=30, Rank=5	**47.37%** (31.71%, 63.03%) N=19, Rank=2
19	Post-Secondary School	**45.45%** (33.94%, 56.97%) N=33	**20.69%** (10.64%, 30.74%) N=29, Rank=13	**26.32%** (12.51%, 40.12%) N=19, Rank=9
20	Concierge/Errand Services	**42.86%** (31.77%, 53.95%) N=35	**20.69%** (10.64%, 30.74%) N=29, Rank=13	**5.56%** (- 1.85%, 12.96%) N=18, Rank=20
21	Tutoring	**39.39%** (28.09%, 50.70%) N=33	**21.43%** (11.05%, 31.80%) N=28, Rank=11	**5.56%** (- 1.85%, 12.96%) N=18, Rank=20
22	Specialized Mental Health Care	**33.33%** (22.43%, 44.24%) N=33	**20.00%** (10.26%, 29.74%) N=30, Rank=15	**42.11%** (26.62%, 57.59%) N=19, Rank=4
23	Specialized Dental Care	**32.35%** (21.70%, 43.00%) N=34	**20.00%** (10.26%, 29.74%) N=30, Rank=15	**26.32%** (12.51%, 40.12%) N=19, Rank=9
24	Parent Support Groups	**20.00%** (11.03%, 28.97%) N=35	**6.67%** (0.59%, 12.74%) N=30, Rank=23	**5.26%** (- 1.74%, 12.27%) N=19, Rank=22

APPENDIX D: STAKEHOLDER AND FAMILY COMMENTS

1. Directors Survey: Barriers to Services Themes

Age 0 to 2

Availability/Getting a Diagnosis

- Lack of availability of Early Intervention Services is a barrier. Ensure that any child with developmental delay or developmental disabilities has access to Early Intervention Services
- Sufficiently early diagnosis and information about availability of services
- Getting information to physicians and other medical personnel
- Getting a diagnosis that qualifies child for these services. Develop resources to provide assessments
- Availability of adequately trained professionals
- Availability of services and assessments are not widely or equally distributed (i.e. "East of the River" syndrome - Wards 6, 7, and 8 possess a disproportionate percentage of low income residents, but early intervention services are nearly none existent)

Funding

- Funding
- Barrier: Funding for services. Method: Advocate for funding
- Reduction in program due to state budget deficit. commit additional funds to program
- Need more therapists and funding per child, increase funding per child to get more therapists
- Early intervention helps to alleviate many later problems - early intervention also includes teaching family how to deal with the disability. Barriers include funding and then specific things for different disabilities
- State budget allocations; education for legislators & taxpayers
- Lack of trained EI specialists and funding to support the specialists in remote areas of the state. Sharing and funding of specialists across county lines
- Part C dollars are traditionally on the chopping block when cuts are needing to be made
- Concern that program will be cut from state budget
- Lack of funding resources. Better education of Legislators to understand the significance of supporting and funding these programs
- Limited funding
- Physician referral and money
- Difficulty providing services (due to high travel costs and retaining staff) to communities in remote areas of Alaska (off the road system)
- Part C funds limited for proper assessments

Accessibility of Information/Awareness/Marketing

- Gaining information about service availability; method to overcome would be enhanced communication by service providers to ensure the best methods of "getting the word out" are being utilized
- Part C Services are provided through the Office of the State Superintendent of Education. Barriers: -Advertising/availability of services not well communicated
- Lack of education and understanding Strategies/Methods: Year-Long Community Campaign, physically go out into the community, meet the parents, educate, and connect eligible families to services
- Access to information on obtaining early intervention services.
- Lack of information
- Awareness of services by families

Transportation

- Difficulty providing services (due to high travel costs and retaining staff) to communities in remote areas of Alaska (off the road system)

More Services Desired

- Need more therapists and funding per child, increase funding per child to get more therapists
- Under- identification of children, lack of services in natural settings / enhanced outreach to underserved areas and populations
- OSSE needs to develop and build capacity within their early intervention program and department

Other

- Assuring that emphasis is placed on the family and having the family doing the teaching, the including of the child, and the use of generic resources available to all children
- Recently imposed co-payments
- Fear

Age 3 to 5

Availability of Services

- Lack of availability of Early Intervention Services is a barrier. Ensure that any child with developmental delay or developmental disabilities has access to Early Intervention Services
- Available, well-trained personnel
- Need to be available
- Lack of integrated pre-school services. Provide incentives to establish inclusion in regular pre-schools
- It is difficult to find providers who accepts Medicaid's low reimbursement rates and co-pays are too high for most individuals
- Availability of services and assessments are not widely or equally distributed
- Lack of therapeutic services

Funding

- Funding / silos
- On-going funding to support behavior support programs is a must
- Need more hours of preschool available, increase funding and mandates for required number of hours in preschool to receive funding
- Many services are being cut/eliminated due to budget cuts
- Financial assistance to parents; vouchers
- Concern that program will be cut from state budget
- Limited funding and coordination of multiple service delivery systems
- Cost and organization/leadership Increase parent leadership training and funding
- Funding as the state withdraws funding for pre-school. Vouchers for parents of children with disabilities under a 300% of poverty
- Part B funds limited for proper assessments
- Lack of time and knowledge of resources to connect families to the resources and opportunities available in their community. Deficit model
- Building broad-based support for pre-school education; resources and lack of access for children with disabilities is a barrier particularly in cities parent education

Training

- Need more people and families trained in positive behavior supports, more outreach and training to preschools, grade schools and families

Transportation

- In remote areas of Alaska, difficult to provide appropriate services when there are only one or two children

- In this age group, also lack of speech, OT, PT therapists
- Transportation that would alleviate participation stress

More Services Desired

- Preschool does provide some respite, gets the child accustomed to different settings, working with other children, and is to be individualized
- Early Intervention is up to 3 and school districts' early intervention services vary
- There is not quality integrated preschools for sufficient hours statewide
- Integrated models not available to all Lack of qualified teachers
- Lack of integrated preschool services in many areas of the state. Better education and support of local school districts
- My concern is there isn't enough formal transition from early intervention to pre-school and school-age services
- Parents are ill-informed of their rights, and don't know or aren't allowed to be full partners with education professionals
- Parents must be trained in rights and responsibilities, and need to work in teams with educators
- There are some person-centered planning tools that would help with this transition.
- Public assistance is needed for single parents
- Break down the barriers and make sure children are included.
- Locating and securing access to pre-school services - they vary greatly from area to area
- OSSE needs to develop and build capacity within their early intervention program and department

Accessibility of Information/Awareness/Marketing

- Reaching all families to provide training/information. Method: Collaborate with agencies that provide family training and with those that work directly with children/families to disseminate information on resources and training opportunities
- Advertising/availability of services not well communicated in community   (i.e., "East of the River" syndrome - Wards 6, 7, and 8 possess a disproportionate percentage of low income residents, but early intervention services are nearly none existent) -lack of education and understanding
- Strategies/Methods: -Year-Long Community Campaign - physically go out into the community, meet the parents, educate, and connect eligible families to services
- Assuring that the family uses the generic resources of the community for all needs of a child between ages 3-5 years
- Child find activities are extremely important in ensuring that families are aware the part C resource
- Parent support, including materials, so a parent knows what to look for and how to access services
- Again, the need for treatment at an early age allows for long term benefit and long term best outcomes

Other

- Accessibility
- Part B Services are provided through the Office of the State Superintendent of Education

Age 6-21

Availability of Services

- Lack of Parent Support Partners programs as well as lack of family Navigators is a barrier. Ensure Parent Support Partners and Navigator Services are available to families with children with developmental disabilities
- Lack of vocational training and transitional services into vocational rehabilitation
- Lack of therapists (SLP, OT, PT) in remote communities, lack of practical transition services to adult life

More Services Desired

- Schools expected to take care of all problems even when not educational in nature. Need to recognize that families with children in schools need family support services and specialized services so that home and school can be successful
- Adequately preparing students with disabilities for employment or post-secondary education
  Lack of collaboration and understanding between parents, professionals and IEP team
- Lack of true collaboration between regular teachers, special ed coordinators and parents -Lack of proper assessments conducted regularly on the students to identify the most appropriate services
- More students on the diploma track, NOT the certificate track; focus more on basic academic needs (i.e., reading and math)
- All teachers and administrators must value these students' minds and actually educate them; don't baby sit them if they have an IEP/Section 504 plan
- School can and should include behavior therapy, vocational training, day habilitation, special equipment, transportation, all at no cost to the family
- The major barrier for this group is an appropriate/integrated public education based upon the needs of the individual
- Knowing what to ask for in school system is helpful. Schools don't all provide what is needed and don't let you know what to ask for. Having other parents or professionals there to help parents ask for appropriate services & supports is most helpful
- Education is the most important issue and assuring that children are fully included with the supports that are needed
- There is a disconnect between education and community Services, and due to rollbacks few kids get comprehensive service packages. Navigation is critical to overcoming these barriers
- The major barrier here is that the child/youth with the disability is not provided with advocacy training or support. The individual must know, from an early age, about his disability, the services and supports he requires, his rights, his responsibilities, and how the system works. Further, transition services come too late and are limited. We must provide children and their parents proper training on their educational rights and case management access to persons between the ages of 6 and 15 is limited. Additional funding is needed to create more opportunities. At 16, persons are entitled to State Plan case management. I'd love to see more advocacy training programs aimed at young adults with disabilities. Youth Leadership Forums are an excellent opportunity
- Enough trained and qualified staff and integration with school programs; continually working with schools to coordinate programs
- Finding quality day/after school care and paying for it without going broke
- Lack of Adequate/Appropriate Support from Schools

Funding/Resources

- Funding
- Lack of resources for out of home respite
- Limited funding
- State budget allocations; education for legislators & taxpayers
- Need higher respite rates to pay providers to provide this service
- Barriers to school based services are lack of inclusion practices in teacher preparation, lack of administrative support for full inclusion, stigma, and funding
- Need for BCBA resources
- State wideness and funding incentives for medical practices in rural areas
- We have a large waiting list for respite services.... Need more money and availability of qualified direct care staff
- Availability of adequately trained professionals

- Insufficient providers; provider development underway
- Cuts in General Funds to the Community Mental Health Services Programs (CMHSP) are resulting in the elimination of some of the family support services for non-Medicaid eligible children and their families. The ability-to-pay scale to receive respite care is unaffordable to most families

<u>Institution</u>

- Coordination of multiple service systems and agencies
- Coordination of multiple service delivery systems

<u>Accessibility of Information/Awareness</u>

- Lack of time and knowledge of resources to connect families to the resources and opportunities available in their community. Deficit model
- Marketing and outreach to family members via list serve. Colorado mentors via internet Parent-2-Parent. Can get answer to question within 24 hours usually. Also can access phone contact if parent wishes. Very efficient use of money and the best referral service statewide and locally
- lack of knowledge by educational staff; perception of professionals that that can't be involved until after age 21; lack of preparation of the person with a disability for either post-secondary or competitive employment; assumption that person with DD will be "attending" a community support provider not going on to school or work
- Communication and information accessibility; trainings on organizing contacts, gaining internet access and establishing and maintaining enthusiastic "point of contact" would help overcome communication challenges
- The motivation to keep families in the know

<u>Transportation</u>

- Transportation
- Rural areas have limited access. If you have a crappy car you are not eligible

<u>Other</u>

- Provided by IEP able to access for it
- Time for people to devote
- I can't select one issue as top ranked for a such a diverse age range of 6-21
- Transition planning, high expectations for students and an emphasis on developing functional adults rather than graduation rates. Parents, teachers and the public need to have higher expectations--awareness, training, demonstrations

Age 22 and Over

<u>Availability</u>

- Waiting Lists are the major barrier
- We have a large waiting list for respite services.... Need more money and availability of qualified direct care staff
- The waiting lists are long, and time on the WL is increasing
- Provider capacity
- Too few Care Coordinators and too many needing services

<u>More Services Desired</u>

- Education for parents to help them plan early for needs of their children when they exit school.
- There is a disconnect between education and community Services, and due to rollbacks few kids get comprehensive service packages. Navigation is critical to overcoming these barriers
- Make Post-Secondary Education Opportunities more accessible to non-tradition students
- Work with programs such as vocational rehabilitation to service more individuals with DD
- Transition from School to Vocational Program
- I think the major barrier here is that so much effort and advocacy is focused on school-based

systems of support that families aren't looking long-term and big-picture. In truth, school is 18-21 years of time at most. That leaves 50+ years (typically) of living as an adult in the community. We have to use person-centered planning tools and techniques to get individuals and families to become the leading voice on life planning way beyond education

- Early planning must occur to help students prepare for a successful life after school. Increasing family involvement improves student attendance, achievement, behavior, and positive attitudes. This gives students the best chance for success in school and life
- Parent-2-Parent is the answer again. List serve is specifically for Adults with Disabilities in Colorado and includes public policy information as well as I and R

Accessibility of Information/Awareness

- Future care planning is also 4 important to families in connection with residential services-families need to know that
- Families do not have the information they need to help prepare their child for post-secondary opportunities
- There simply is not enough information for families to make informed future planning decisions for individuals with disabilities. Ways to overcome this include having a resource, including funding and personnel, dedicated to providing on-going support information, trends, etc. to assist families in future planning efforts

Funding/Resources

- Medicaid reimbursements into community supports, we must support families in planning for the adult life of their loved ones, we must enhance compensation and career ladders for direct support professionals to have a well trained, stable workforce to support independent living in the community and we must shift resources from institutions to less restrictive, more self-directed living environments
- To live with adequate supports and planning for the future; barriers are the lack of adequate funding is moving services backward to congregate living and working environments
- Funding for services
- Availability of funding
- Increased funding for Medicaid Waiver programs; funding is limiting the growth of residential services. We are trying to develop more efficient models
- Funding
- Low DSP wages; budget cuts; lack of quality training for DSPs; staff shortages
- I was thinking when I answered the question that the bottom line for any service for the family (day, work, school, etc.) is that it provides respite for the caregiver!
- Limited funding and coordination of multiple service deli4 systems
- Funding - waiting list
- Enough trained and qualified staff; continuously trying to upgrade staff
- Waiting Lists and staff turnover More funding Staff training and salaries
- More funding for vocational services to incentivize the service and decrease day hab numbers
- Sufficient funding to supported employment and supports for living outside the family home.
- Need for BCBA resources

Employment

- The opportunity for a person with a developmental disability to have real and meaningful employment is the best way
- Availability of employment opportunities
- To integrate society as a whole and make all persons valued. It is good for the employer and for all employees
- More vocational education programs are needed. Ensure availability of vocational ed for any youth or adult with developmental disabilities
- Plenty of programs, few employment outcomes. Change focus of programs to find people jobs

- Not enough employment partners (i.e., private companies) to place people in meaningful employment positions
- Reauthorize the Vocational Rehabilitation Act AND FUND IT
- Fix SSA stipulations if people want to work - find the balance
- Limited funding and limited mind-set on employment options. Sheltered employment is not real employment
- People with disabilities need assistance in marketing themselves to the job so their skills and likes are recognized and honored for long-term employment success
- Need job coaches and personal attendant services for those with physical limitations, but can still work
- Low expectations and lack of values around the fact that all individuals can and should work, and that community-based, competitive-wage work is the preferred and realistic outcome of vocational training efforts
- Quality of service varies. Families don't see the child as being employable
- The top ranked service should be employment not VR. It is cost effective
- Jobs are the biggest barrier because of the economy; the economy is improving so jobs will improve; another barrier is expectation. We have to work on peoples' expectations that people with disabilities can and should work
- Vocational/career development into adulthood so that people can change their minds, develop new interests and pursue those. Also post secondary community education classes to learn new skills and hobbies
- Employment and living in a home of your own are the top picks; inclusive post-secondary education options also rank in the top 3. This survey seems to be leaning toward segregated services. Finding a job that is fully
- Inclusive is a top priority. Too often funding is oriented to the system of day training programs; if possible, the individual should have a successful transition and be employed. That is difficult since most transition programs are not working across the U.S.

Transportation
- Need transportation resources to access worksites
- Access to all services (group homes, supported employment, day habilitation, etc) in remote communities off the
- Road system in Alaska

Other
- A system that is not family friendly
- Your survey did not provide some of what I believe to be the greatest concerns - the need for an independent place
- Their loved one will be able to have a home with appropriate services and supports- states must reinvest
- It depends upon the ability of the person - it is individualized - some need vocational programs, other day habilitation, therapy, medical, transportation - no one program meets all individual's needs!
- Poverty

2. Superintendent Comments

Age 0-2

Funding
- Help Me grow budget reductions
- Lack of funding for Early Intervention services. The state of Ohio needs to make this a priority

in the budget

- Funding cuts may make these services go away. Less strings attached to funds for serving young children would allow for more dollars to be spent on services than on admin
- Financial ability to meet the needs
- Lack of additional system partners to fund Early Intervention Services
- Lack of funding EI services should be Medicaid funded
- Limited resources
- Financial
- Funding is a barrier but we are aligning our program with the federal guidelines in the hopes of being ready when federal Medicaid reimbursement becomes possible for Ohio
- Funding
- Insufficient funding
- No state or federal support in Ohio for Early Intervention Services, especially evidence based services that teach parents to be experts in their child's needs
- None except the money to employ sufficient staff

Accessibility of Information/Awareness

- Others telling parents...it will be fine, give it time, infant/toddler will come around...just wait and see
- Increasing awareness of the service so people are referred during these crucial years

Transportation

- Transportation

More Services Desired

- County Board should have the option for therapy services to go to the home or centered based.
- Not equal services across the state
- Early identification and family physician referral
- Need for more Early Intervention Specialists to fulfill the need
- Probably should have additional Early Intervention Specialists
- Family issues other than disability issues. Providing EI in the home helps to better identify these issues and help to make appropriate referrals

Institution

- The convoluted Help Me Grow system. It would be extremely helpful for the process to move back to DD Boards. There would be less duplication of services and one point of contact for families
- ODH's handling of the HMG program
- Confusing rules and policy from Dept of Health. Need to move responsibility for EI from DOH to either DOE or DODD
- The help me grow bureaucracy

Family Related Barriers

- Poverty/dollars
- Parental participation
- Sometimes families of infants and toddlers are overwhelmed by the diagnosis, number of medical appointments, family dynamics, etc.
- Access to families
- Levy income

Age 3-5

<u>Funding/Resources</u>

- Space limitations in current school building
- Having enough spots available for all children who need preschool services, including those who may not qualify but have definite needs. This comes down to funding as well. It is important for

the state to understand that we can make the greatest impact when we start as early as possible and with intensity

- Uncertain funding
- Families need the support of others to deal with the challenges of adjusting to life with a child with a disability. No resources to fund a coordinator to make support groups happen.
- No funding to support parent organizations
- Limited resources
- Insufficient funding
- Adequate funding to provide necessary number of classrooms and therapies
- Effective instruction. Not enough funds prioritized for this service in public schools as experienced teachers are often too pricy for them to hire

Transportation

- Funding and transportation. Parents in Carroll County need transportation and funding for transportation so children can attend Preschool

More Services Desired

- Returning service to public schools as a non-mandated services of the DDS
- Enough opportunities for children with severe challenges
- Not enough disability services for pre-school all schools should provide access to pre-school
- If preschool is not in public schools, the transition to kindergarten needs to be more planful to assure parents and teachers are connected and understand expectations
- Close to home school (neighborhood)
- Expectations of parents and professionals for small sized classes with many staff to operate the class
- It can be difficult to stay in touch with families after their children enter pre-school. Better collaboration with pre-school educators so we can stay involved with families and provide on going training and assistance
- These parents often need assistance handling behaviors and setting boundaries. We often could use a “supernanny” to visit the home, assess the situation, identify issues, and help parents develop skills to set boundaries for their young children

Family Related Barriers

- Poverty/dollars
- Time for parent/school planning
- Parental involvement
- Levy income
- Although parent support is most needed, most families are too busy to participate no matter when the support sessions are offered

Age 6-21

Funding/Resources

- Availability, lack of match for IO waivers
- Funding. This service is only funded through local dollars as no state or federal dollars are available for this service
- Limited access to specialized medical/dental personnel
- Insufficient funding
- Adequate funding to provide navigator services to support student/family while individual is in public school system
- I would choose respite, but it was not on the list. Many children of this age have behavior issues. Families benefit from a break. Limited resources are available to county boards to make respite an ongoing service

- Lack of trained qualified behavioral specialists recruit more professionals to this field
- Families really need help with knowing what they need and how to address those needs. Service coordination/case management can be very helpful. Money is the biggest barrier to employing sufficient staff to get this done

<u>Transportation</u>

- Lack of flexible transportation is the biggest complaint heard because parents are working and a student needs to get to some special meeting or training. The lack of free transportation is really the issue because there are taxi options that cost

<u>More Services Desired</u>

- Therapies are critical for children with disabilities. Schools do not have the resources to provide an appropriate level of service. Children receive minimal services and parents often can't afford to pay for additional services
- Functionally-based public school curricula
- We haven't provided sufficient case management services
- Again, loss of contact with school age children becomes a barrier. Once children reach transition age (14-21) it is crucial to have service coordination in place in order to provide options and planning for opportunities after high school
- Transition planning continues to be a weak link but improving
- Many counties have limited vocational training opportunities. RSC services focus on adults.
- Preparedness - Transition of School to Work activities and curriculum
- Respite and Behavior supports for families and lack of system partners to provide service
- I actually would have selected transition services to help school age youth with disabilities prepare for employment after high school, but that was not an option. My second choice would have been respite, which I thought was on the list, but did not see
- There need to be opportunities for students to experience work, both at school and at home so they value work, understand expectations in the workplace, and can find work that matches their skills and abilities.

<u>Family Related Barriers</u>

- Poverty/dollar
- Levy income

<u>Other</u>

- Not all providers well-trained
- Parents tend to limit children's activities with vocational training due to money may reduce current benefits. Individuals should not be penalized for working
- None
- True mainstreaming where child is a part of the program
- School district participation
- Children are often not referred until things are going badly for them at school or home and then more difficult to coordinate care

Age 22 and Over

Funding/Resources

- Uncertain funding for both Medicaid waivers and increased residential options for people with disabilities
- I think we lack vision and funding in this area. Supported employment and integrated employment is harder to fund than traditional day habilitation. We just don't need more of that
- Availability, lack of match for IO waivers
- Funding and people to provide the services
- We need providers that are skilled in working with this population and can provide chances for

better outcomes than what occurs through BVR

- Also we need more funding for residential supports to reduce our waiting lists.
- Lack of funding increase access to waivers for eligible adults
- Adequate funding to provide the level of residential services requested...i.e., waiting lists.
- Insufficient funding
- Lack of funding for waivers; funding cuts have resulted in less resources to support the expansion of waiver services
- Cut backs in funding source and concerns over future Medicaid cut back

Transportation

- Transportation to and from potential work sites
- Transportation is critical but have to have place to go

More Services Desired

- Mental health services
- Great coordination and planning among all involved parties is critical. All entities have to come to the table with open minds and ideas. Developing good plans is critical
- Continue move away from Sheltered Workshops
- We have to rethink how residential services are provided in order to meet future needs
- We need some significant changes to Medicaid to focus on the efficient, effective services
- Readiness for adult living after educational services have ceased
- Lack of residential options/providers
- Service and Support staffs are buried in paperwork and cannot monitor as much as needed. Regulations and priorities need to be changed so staff can monitor and increase service coordination
- While housing is really the biggest demand, its cost far outweighs the cost of the recreation program which is the second biggest request. The biggest barrier to increasing the size of the recreation program is both public perception and client need. Providing recreation when there is a need for residential placement puts an unsupportable pressure on the DD system. Voters don’t want to pay for the fun - they may pay for more residential placements. Recreation may cost about $1,000/person/year while residential placements cost about $55,000/person/year. Recreation and respite are used to keep a client in the family home as long as possible, but the image isn’t always good

Family Related Barriers

- Work and levy income
- Families reluctance to allow their child to leave their home for other residential options

Employment

- Unemployment
- Community employment
- Community based opportunities in this economy
- Employment
- There are not enough providers of vocational training to address the myriad of needs for young adults with developmental disabilities seeking employment
- Jobs have been very difficult to find in past few years
- We need real opportunities for employment for adults with disabilities

Other

- Not all providers well-trained

3. Family Comments

Age 0-2

Availability
- We waited 10 months for EI services to start. Through Franklin county. We were originally approved for BCMH for our child's potential heart condition, but then denied support when our Childs heart was healthy because Down syndrome is not covered. We were approved for family support and residential
- There is no weekly class/gathering for kids age 1-3. Due to budget cut as the coordinator stated. This is real frustrating. Also while, the kids are in class, the parents can have support group
- The timing/scheduling of the services
- Still have to deal w/right time/evening time therapy

Funding
- Not enough funded money to provide speech/ot/pt services at the same time

Accessibility of Information/Awareness
- Awareness of all available help
- More knowledge on part of providers, better effort to inform about all available programs
- We are on the wait list for center-based services. The process of being a new home-based case to deciding that center-based would be better and was confusing and ever-changing. I just wish I would have known up front what all my options were
- While we are waiting, we are going to bridge appt, which are great. I wish they were at least monthly. I also feel I could have benefited from an initial appointment solely dedicated to describing the services available

Transportation
- And 40 mins do away location. W/traffic, Because he has a Medicaid card with the Medicaid card you have to sometimes jump through hoops to get transportation. His brother has a caresource card which is easier to use to get transportation when my mother can't take us

More Services Desired
- More therapists or tutors… the screening process to eliminate children with a less drastic disability. Change the rule and allow Down syndrome and other genetic disorders to relieve assistance through BCMH. Give each family that is approved an annual amount and provide reimbursement checks

Denied Coverage/Lack of Access to Services
- BCMH denied due to over income. Workers of BCMH and job and family were fairly helpful. Paperwork involved with programs to apply is lengthy. Paperwork gets lost in mail
- Denied BCMH- pay out of pocket
- Only can choose 1 service out of 3
- Respite service - we did not qualify because of our income bracket. There is no solution to the respite services because of our income threshold

Other
- FedEx paperwork to ensure it arrives, and makes copies. You must research before talking to people from Job and Family (Services) because they will talk to you like you're ignorant if not. Have more information ready just in case
- Find a way to get that program back
- The location of the services, adding stress
- A lot of paperwork! It took a while from the time Help me grow was contacted to initiation of services. Is once a month speech therapy really effect paperwork could be mailed or frequency of visits emailed so the number of visits could be reduced
- I work full time & everything goes on during the day. And i felt as if my son was missing out on

some of the help he needed due to our work schedule. We ended up sending our son 1 day a week instead of 2 day. Allowing me not to miss so much work. And our son still get some help that went on during the day

- A lot of paperwork! It took a while from the time Help me grow was contacted to initiation of services. Is once a month speech therapy really effect paperwork could be mailed or frequency of visits emailed so the number of visits could be reduced

Age 3-5

Availability
- not sure about wait list too many needs

Accessibility of Information/Awareness
- We aren't really sure what our child is eligible for and has access to in our community. Plus-we don't receive many benefits because our income is high. Not sure how to fix this problem. Just need help and support. We love our son and want the best possible future for him. Why does it have to cost so much
- Initially it was difficult to find out info about Delaware cbdd. I only learned about it from a neighbor who had lived here a long time. We were new to the area and didn't know it existed. Also the disability was with our first child so we didn't really know for sure if he was abnormal. Advertise. Send info to new residents with kids or to new parents when they come home from the hospital with a baby

Funding
- Provide other funding or resources for funding for devices
- It seems as if there is not enough financial support. It has gotten cut twice already. My respite service dropped from $240 to $210 to $180. That hurts a lot. Get more funding from government so parents of disabled children can get some financial services. I think every child w/ a disability should get a min of $400 every month

Transportation
- Doesn't have much accessibility. It's a small county. We usually have to drive 45min to participate in programs for handicapped children

More Services Desired
- Autism scholarship only awarded to kids going full time to specialized autism programs. We wanted our son to attend the public preschool for the three days it's offered and than attend an autism program the additional days. Offer partial/part time scholarships
- Develop a pediatric replacement schedule to accommodate the children's growing and evolving jaw. Add hypohidrotic ectodermal dysplasia to medical insurance covered syndromes. Revert to where over the counter products are covered by a flexible spending account, or have discounts for expensive skin meds
- Follow up from the coordinators, supervisors
- Off site teaching has been horrible. The teachers' communication is terrible. They caused more cautious w/in a schedule day than they did in helping behaviors. Details include potty training. High incident report w/no action plan to fix transportation, assignment, needs & belonging (hat/coat) get a new teaching staff, have one central location w/transportation for student. Off site county schools are not flexible at all

Denied Coverage/Lack of Access to Services
- Our biggest barriers were related to us making more than the poverty level for family of three. This means that we are not eligible to receive a lot of the services or we have to pay a portion. Wait list for waivers which would help fund a communication device./access to Medicaid. Look at the whole family situation how much out of pocket we are paying for many of the services listed. What this percentage is to what use make

- My insurance doesn’t cover speech therapy, OT, dental, etc. We make high income. But have huge student loans & don’t qualify for Medicaid. Free universal heath coverage!!
- Specialized dental services-private dental coverage of dentures on an adult replacement schedule (7yrs) when we need pediatric schedule (2yrs) but it doesn’t exist. We deal w/a rare syndrome that is not on our medical insurance list of conditions that also receive dental assistance
- Respite service - we did not qualify because of our income bracket. There is no solution to the respite services because of our income threshold
- It’s hard to get therapists to write letters of how certain learning tools such as videos, learning toys and many other learning devices would greatly assist our daughter with her disability. We’re also always told we can’t get funding because it may be something that could be purchased for a normal very unsure and heart broken from all previous attempts made because we can’t financially afford it

<u>Other</u>

- I have had a great experience getting the services i need for my child to be as successful as possible
- Previously, in our other county (Franklin) we experienced long waits and not much assistance with urgent needs. We have had no issue with our new county (Delaware) our highest stress is a result of waiting to be reimbursed for services currently. Solutions could be a quicker/easier reimbursement system for parents
- I work full time & everything goes on during the day. And i felt as if my son was missing out on some of the help he needed due to our work schedule. We ended up sending our son 1 day a week instead of 2 day. Allowing me not to miss so much work. And our son still gets some help that went on during the day

Age 6-21

<u>Availability</u>

- Availability wait lists-more available times and services
- Medical, mental health, behavioral-long wait lists. Cannot get service when needed. Providers- almost impossible to find good ones!
- Have never been offered most of them at all
- Child could maybe more independent if services are offered
- There is only one school for all types of “special needs” kids putting all of them together.
- Wait list to long
- Good doctors are hard to find for children w/ disabilities. There has to be more good therapists for these children …there is definitely need for this within a 60 mile radius of our home
- My son was extremely hard to care for because he was weighing 50 lbs, we had not wheel chair and be had no ability to control his own body weight, I can not get help. I was given the run around by an agency - call after call. The best i got was 2 different nurses came to the house to asses Owen. Nothing I mentioned it to my mrdd service coordinator that I needed help, but he has never come through for any of my needs. Navigating through this system alone, with no experience is terrible. That’s why I am Owens only caregiver and I receive no help
- 13 mo wait to get a diagnosis at children’s hosp. This includes 9 mo before initial appt at ddbp, then a few more months to schedule necessary test & complete. On 3 separate occasions over several years + 2 different kids, it was 13 mo from 1st call to ddbp to diagnosis. This is extremely stressful add more staff at children’s
- Long, long waiting times to be seen by behavioral/mental health specialist. Exhaustion and impatience after continually supervising, instituting behavior modifications & other economics, repeating rules & expectations, staying consistent, then having limited access in terms of number of hours to care seeing the impact the individuals with special needs have on the rest of the

family co-ed residence facilities the only choice. Money

- There are all kinds of barriers for children with disabilities and there families. We have been on the wavier list for my son forever. Open up services equally.
- One of my respite providers experienced a great difficulty in billing. She eventually gave up and has elected to not continue to be a provider

<u>Accessibility of Information/Awareness</u>

- Lack of knowledge of services available-we are not aware of most of the services. Case manager-they sent offer much insight. Visit seems useless-once a year
- More education to families and case managers about services and payment options. Better look at financial situations
- I am told I make too much but everyday bills add up. Even living frugally & paying for different things that help my child take any extra. No one sits down & says hey. This help exists, this is what you get & this is who you call. I am always seeking for my child & its exhausting
- Give me someone with the questions and the answers. This survey contained info of services i didn’t know existed
- Not knowledgeable
- Services not told to us
- Tell us you have the services available
- Knowledge of availability of services programs. Knowledge of recommended and or available providers information provided easily and made easy to find
- Not knowing what the services are. Not knowing what to do, who to call or how to get them. Getting conflicting info on who is eligible for services. My son was diagnosed at 2 1/2 & he is now 9 1/2 & we are finally in the process of getting some services
- More information coming from pediatricians about how to get services. A resource person at schools or boards of education to give guidance & advice on what to do
- We have had exceptional help and services from Delaware County. The only issue I’ve had is having a clear cut explanation of the differences in Ohio home care waiver, level one waivered. It does get very confusing. But we love dcbdd. Email communication is so effective!
- Make programs and services well known. The problems we have had have been due to lack of information, you would think it’s a big secret to know about some of the programs. Don’t even try to go through an elected official because they don’t know
- Too many levels among different departments. Don’t want share information to the family. Protect their job or native
- The system makes it difficult to find out which services are available. Nothing is made readily available. You have to dig and fight for services. Pediatricians should have more knowledge as well as medical specialists and school systems. Those dispensing the diagnosis should be able to direct and guide on how and where to receive help and support
- Don’t even know about the services. It seems that most services are either hidden or not displayed. Better advertisement of services that are available
- So many services available, but it requires research and persistence on the part of the caregiver. Many families are missing out on available services because they aren’t aware of them. We lost health insurance for our son, and it took months to figure out how to get him covered by Medicaid. We now q better communication between the different government agencies that handle the programs. Id love to see a comprehensive list of all services available, the eligibility requirements for each
- The accessibility to know what is out there is limited. Maybe have a website explaining it, or a mentoring program with current families mentoring new families
- I think there are probably a lot of services. I don’t know about and don’t have time or energy to investigate for myself. Better communication tips from service coordinator would help. We’ve been assigned to different service coordinators in 2 years, so more consistency would help

- Also finding treatment options is very challenging. Many parents find info via other parents, but we need more info available
- Where to get the information. When you call Clermont county dd to find out what you should be doing to prepare for you child’s future they said they can’t help us as long as she is a student. But you hear from others that there should be a case worker assigned to her. Frustrating not knowing what programs are available an where to get the help to make sure your child is receiving enough help
- Financial/ineffable stress/depression. Oh my god. I totally empathize with individuals who kill a loved on and then commit suicide. We’ve spent thousands & thousands of dollars on our son’s disability and are approaching “retirement” age. Hal our son has a progressive neuromuscular disease and gets tax break: better wages allotted for a personal care assistant. 8 dollars and hour and you get what you pay for-a revolving door of people who can’t do anything else & don’t want to work in fast food free accessible mental health care for parents long term/ongoing as needed.
- Most of these services I didn’t even know I could get. Now I know I can, but I still don’t know how. I looked into respite care a couple years ago but it seemed almost impossible to find someone trained and willing to watch my son for a few hours. The dentist specialist would haven been wonderful to know about more information about all services offered sent to parents/ caregivers at enrollment or re-verification. Follow up questionnaire to answer questions or to clear up confusion
- 1st barrier-didn’t know who to talk to (to get services) so many different titles of personnel, didn’t know really who or what to ask for. 2nd-still wonder if were where we need to be with services.-if there are any other options or help we should be aware of. call county board office or ssa director

Transportation

- No transportation is offered through our school district, so we self-pay
- Too much driving
- Distance to services

More Services Desired

- My child in addition to being developmentally delayed has been diagnosed w/dyslexia. Nothing was done to address dyslexia in his special needs public school. I had to provide a tutor paid for myself to teach my child to read. I was very unhappy w/the public school. I didn’t think they were effective schools should be able to help kids to be successful. They should be able to help all kids at their home school. It isn’t fair for them to be segregated into special schools. Special kids need community involvement. They need to be w/their friends in their neighborhoods. Dyslexia is a disability an
- More non-traditional providers music therapy, art therapy, group therapy, parent therapy, family therapy, hypnotherapy, aquatic therapy, ymca payment assistance, etc. Alternate caregivers to help. Alternate caregivers to drive. Alternate caregivers to research. Iep advocate…respite
- People who use mobility equipment struggle to access outdoor recreation. Parents of individuals w/medical needs (i.e. Takes medication/has g-tube) cannot leave home for uninterrupted periods b/c respite workers usually cannot administer meds. Outdoor environments could be adapted to include lots of different equipment/needs. Respite workers could learn to administer meds
- Locating respite/ home care during school year family vacations need more friends
- Counseling for his specific needs
- Pediatric medical care in Lorain county pediatric respite care in Lorain county government legislation to support special needs services
- Currently my biggest problem is try to get someone that can meet my daughters school bus in the afternoon and stay w/her till i get home from work. It’s difficult enough to find a job these days, but when you have to be at work longer than your child is in school its hard
- I’m not sure i have a solution for the lack of enough respite workers or sitter to assist busy

families. More post-secondary facilities to teach skills to students w/disabilities to make them more independent and self sufficient

- Therapies that would be helpful. Reading and using some suggestions from books & articles
- For Charlie he needs basic life skills. It is hard to teach him to budget money now because the amount he gets keeps changing. The amount we pay for rent will change in March because we have to move and unless my SSI comes through we cannot afford to move. Also Charlie has medical but i do not have
- Lack of answers to questions d/t conflict of interest-why. Mandate school systems to follow the law or lose special Ed funding. Move specially opportunities-social training outside the comfort of home like parents who request it
- We have 3 grandsons that are all special needs and we can't go any place with the 3 boys because they don't behave and no one wants to watch all three boys because they fight and tease each other and don't listen very well. Trying to keep them separated in their own rooms and just staying home instead of going out with the boys
- More studies like this to identify needs better training for health care providers and home health care providers
- Cost of services. As the person ages less seems available. Great infant/preschool programs. Quality of programs down after that age. Evaluations of individually board of dd more often would help with keeping therapies/ behavior strategies current. We have 3 children with disabilities. Making home the training ground is essential working with what we have. Some communication technologies would be nice but are costly as are behavioral not enough income
- One of my children who is autistic attends a social group and individual counseling with the same counseling group, but on different days. A huge barrier for us is that we'd like to obtain individual counseling closer to our home. We can not do this if my child continues in the social group, which
- Clarify why, if a person qualifies for one service, others are no longer an option, because of the primary service. Schools must be held accountable to provide an education not movie days, party days, or unqualified subs. Social training/ job etiquette programs. Central parent co-ordination
- Not enough money. Not enough time. Not supported. Not enough energy
- Nationwide center for autism & county could coordinate so county funds could help to pay for programs they offer, like summer buddy camp
- Long term care, financial planning, frequent in-service trainings
- Not being able to get [services] I need someone to make calls, Signed up for things, research opportunities, get [services]
- We have always felt that income restrictions would have eliminated our access to services and therefore did not seek them. Recently our situation has changed and we are now trying to set Jonathan up to live independently as possible. These services will make a difference to his life. A well run disability services in a school district like we have experienced here a forest hills school district is a parents best ally. I do wish they would have encouraged us to apply earlier. Also the mm clinic at cchmc has been exemplary at providing needed services

<u>Denied Coverage/Lack of Access to Services</u>

- Our income was too high for my son to be able to quickly get into a school for children w/autism. We have to pay for all expenses in excess of the scholarship
- Our income also exceeds respite financial asst. Therapy have conflict allow financial assistance to all families, regardless of income to allow for access to all services (transportation, respite, aides) (who could assist w/taking him to additional therapies). We've been waiting over 3 years for the level i waiver that will help, because of financial restrictions and hour
- Raise whatever $. Threshold exists so that my child has more access to care. She couldn't even get a … to speak for her.

- We tried to apply for Medicare for our son's disability but we were refused because they said we made more than the required amount to be eligible. We are under bankruptcy and i even lost my job at one point and we were still refused. We have never received any other services as far as speech or occupational therapy.
- At first we were able to use BCMH when my child was 1st born and needed lots of medical, later we didn't qualify because our income increased and he was healthier. Finding insurance to cover our son and a company willing to cover my son that my husband works for has been difficult over the years. Out
- Do not disqualify people who have college degrees and work to make large salaries for financial assistance. Children of special needs are expensive whether you make a lot of money or not.
- I have always been told that i could not get services for my daughter because, she's on a long waiting list, or not eligible for services
- Income barrier-not taking into account the size of our family and disabled father lives with us
- Accessibility is still a concern
- Make things accessible
- Financial-great service options listed but who can afford them, even with a waiver. Takes so long, so much paperwork to order special equipment
- Income to high to qualify for vouchers. Limit of # of hours available for home help (aide)
- The lack of communication to other government agencies. Some office that I have inquired did not give me the right answer. I applied disability assistance at SSS office in Dayton office last Aug.2011, it was denied. Four years ago, I applied a cash assistance to help renovate a single bathroom for my son to use so that he can have space to move around. They can give me the most money of $500 but I have to wait. Until now, I have not heard of it at all. Basically, my son enjoyed his school benefits and uses Molina health insurance. The rest of the other program is there but has no access on it. I have to meet the new nurse again in our county that we live in. The old one that we have and had helped has left. I hope that they will give my son fair treatment

Other

- Not sure that putting different types of needs together helps anyone
- I work in a school for dd, and i see as with my own life a lot of parents can't cope with a child with dd. So the parent or parents leave (as my husband) so most DD is either in foster care or with grandparents. It is a very hard life to raise a dd child or adult.
- A-waiting for waivers & the guidelines for them. B-too many people on Medicaid who don't work & don't need it. A-not have it based on income. B-should make them work part time or volunteer to get money
- My child never wants to leave home except for school
- None. But i do not like feeling forced into having to apply for XXX for my son. I told the person in charge i did not want or need it and she would not take no for an answer until i got angry about it. i don't see why you need to know my age, income etc when that has nothing to do with your services
- The "volumes" of paperwork needed. 2. Ineffective & "entitlement" employees as well as the bureaucratic layer to receive services, at county & state level. 1. Centralize "clearing house" for all agencies & resources creating a "client profile" providing information and any needed documentation which includes medical releases etc. 2. Shake the tree at each & every level
- Medical care provider that comes into the home is not here long. They move on to other companies for more hours and better pay. Don't let company providers keep so much of the waivers. Pay the workers better; the child wouldn't have to constantly get used to a new person

Age 22 and over

Availability
- Finding medical professionals who will take Medicaid and who have experience w/ handicapped persons
- Finding caregivers/providers who are certified by the county to care for my child in home.
- Coordinating respite services and obtaining proper medical services
- Encouragement for more in home/respite services from providers. Pay incentives for medical personnel who treat disabled. Hamilton county dd center has been very helpful
- Messing around with her Medicaid back & forth between them and caresource because I could not find a family physician anyone would take a new person. its hard enough being disabled and then switching doctors on them that they don't know
- Need a new wheel chair. Was getting ostomy supplies from ccs medical, but because i have home healthcare, ccs said the home healthcare have to order the ostomy medical supplies the agency orders whenever & of course they use more. Hospitals use more bags& the wrong kind. Wheelchair was ordered months ago, but do not have yet
- On a list 5 years for a resident for my child only the one in a emergency are being placed more placement for the disabled
- Accessing respite care at home, even when we could pay for it ourselves. Help families access respite care solutions. Maybe an agency of homecare specifically for special needs population. Most agencies I'm aware of care specifically for the elderly. Let parents at county board know of help they can get for vacations, etc.

Funding
- Money for gas/ large van is old 93. Money for recreational activities. Was told we would be able to access $ to have a special for a wheelchair for enjoyment at home. And later told there was no $ for anything else. At this time we are waiting to be called if $ found
- More money and access to waivers for camp
- It is difficult to access resource funds, because the process goes through too many people. Funding is harder to get. Eliminate the middle men

Accessibility of Information/Awareness
- Information of resources that are available to my family
- Communication. Perhaps a listing of resources and services be mailed out
- Need help getting info about what to be doing for adult service. Medicare Medicaid and private ins. Etc. Prescription plan
- Everything takes several phone calls and figuring out the right questions to ask. I can eventually get things if i can find them. Where are the parent groups esp. with kids at my sons level. Where are the sibling groups. Where are the doctors who specialize in mr/dd keep trying i have no choice, no re-dos. It seems to find the above, it's a chance encounter with someone who knows. That is why parent groups are so important, we learn from each other
- Simplify the information. Correct personal-should be. Update on the various possibilities.
- Better understanding of long-term care for my daughter after we have died. How it relates to a disabled adult with a nest egg

Transportation
- Our biggest problem is getting transportation to his work. His dad has taken him and another disabled person to work. However as we have gotten older it gets a bit much to transport and then go to his own job access transportation We have gotten a grant but broakes-yates cant find anybody to help us. If this continues our son may have to quit his job of 11 years. This is our biggest issue. They will take him to the movies or the mall but not to the thing that will help us the most. Everyone takes the easy way out. Brooks-yate
- Short transportation times & more allotted money to help with transport

- Transportation not always reliable. Medical care
- Transportation needs to call us when they are running very early or very late
- Having to find my daughter an in the community job because of lack of transportation during the hours needed or that it would cost too much

More Services Desired

- Respite. My use of respite is limited to 20 days. I use these on days i have to work. Found a friend to help
- More work outside. Work shops. Transportation. Disabled alone so caregiver can work. Obtaining more enclaves from community businesses. More people & money available for families to have someone come in & stay with disabled person
- A simple listing of parent recommended professionals could be easily formatted for parents to refer to. (a survey such as this could be done to acquire info.) Listing of short bio on providers in training classes of their preferences to care; ie, prefer children or adults, male or female, etc.
- Reading individual plans. Following thru. Less employee turnover. Need to spend more energy. More 1 on 1
- No post secondary school. No jobs for the disabled, other than at her day habilitation. Living/ residential homes inconvenient or very limited in number. Social security
- The nearby community college could offer classes for the disable computer, etc. Community needs to see worth of hiring disabled. Open businesses where disabled can succeed. Doctors need to advertise that they welcome the disabled.
- Evening respite via group activities. More qualified people to hire. Not easy to find
- The family resource service (FRS) is the only service our family takes part in for our son. The FRS will reimburse therapy for our son. He was involved in a lot of activities. The FRS had a new list of activities that could be reimbursed. This limited our son's activities. He has been on a wait list for a during the long wait period, we needed to keep him busy. Our options were limited the FRS stated the needed to be from a licensed therapist. We did find an activity that met the criteria but it was hard. Our son however does well at this activity
- Some costs not paid for by i/o wavier which creates a hardship
- Case workers and supervisors
- I have described in the previous page about respite money being carried over on a one time basis for a week-end for us when we are in Florida. I have asked Logan County about this but they say the cant do it. It would be of great benefit to us to use this one time service when we are in Florida.

Other

- Everything was fine. Excellent
- None, if you put effort in. don't quit or give up
- See the end of #27. That is my biggest frustration. It is also difficult to trust strangers with your child even though you would appreciate the time away. Communication barriers with the county board lack of calls returned
- Residential was tried 3 yrs. Too many individuals little patients. Never listen to persons in charge. Or parents
- I do have different times that are more of a challenge and need more help than other times. I ask for help or try to just deal with the situation. When I try to deal with the situation, I just start crying
- Talk and listen to us, we know about our problems
- None-Franklin co. Mrdd/dd has always met our needs through staff. I don't know what barriers they have had to come. I am beginning to research what sources will be available after I am gone and how my son will access them
- My services I received were okay
- Our son was told he could not have any services without a spend down. He does not drive so does not own a car. Lives with us but could never own a home with his present income

- The barriers I feel is not enough friends, but I thank god for what I get. I work with all programs & activities. Michelle is available for her. There are other people with disabilities that receive much more than her. She is on-waiver 1-5 hrs a week other receive 10-40 hrs. “Why” others go to many different activities and receive more. “Why” better knowledge of what is available, acts, money, vouchers, equipment. No food stamps because sher receives too much SSI income.

APPENDIX E1: FAMILY DD SERVICES EVALUATION SURVEY

County Board of Developmental Disabilities

Services to Assist Families Caring for Children with Disabilities Survey

Background: Families caring for children with disabilities experience higher levels of family stress which can have an impact on the family's well-being. The Ohio Developmental Disabilities Council, the Ohio State University and Cincinnati Children's Hospital Medical Center are conducting the *Services to Assist Families Caring for Children with Disabilities Survey* to learn from caregivers which services are most effective in supporting families. Please help us by providing your opinions about these services.

The *Services to Assist Families Caring for Children with Disabilities Survey* asks questions about the services and status of your child with a disability. All questions are related to your child with a disability. If you have multiple children with disabilities, please answer for the child with the most recent birthday. Your responses will be kept strictly confidential and anonymous; no identifying information will be shared. The survey will take approximately 20 minutes to complete.

I. Child Demographics

1. How old was the child on his/her last birthday: _________ years

2. What is the child's race/ethnicity? (please check all that apply) ☐ White ☐ African-American ☐ Hispanic ☐ Asian ☐ Other

3. *What is the child's gender*? ☐ Female ☐ Male

4. What is your relationship to the child? (e.g. mother, father, guardian) ___________________

5. In what county of Ohio does the child live? __________

6. Does the child currently reside with you? ☐ Yes ☐ No

7. What programs does your child currently receive through your County Board of Developmental Disabilities? (please check all that apply)
    - ☐ Case Management
    - ☐ Help Me Grow
    - ☐ Pre-School Special Education
    - ☐ Community-Employment Assistance
    - ☐ Workshop
    - ☐ Level 1 Waiver
    - ☐ I/O Waiver
    - ☐ Transportation Services
    - ☐ Family Support Services

8. Is your child currently covered by Medicaid, the State of Ohio, and government health care assistance program? ☐ Yes ☐ No

II. Service Rating

The Service Rating Section assesses the potential impact of 24 support services. The assessment relates to service effectiveness and service accessibility. Response options service effectiveness are ranked 1 through 5, where “1” represents not effective at all and “5” represents extremely effective services. Similarly, response options service accessibility are ranked 1 through 5, where “1” represents not accessible at all and “5” represents extremely accessible.

A. General Support Services (circle one)

1. Early Intervention Services: *Services provided directly to infants and toddlers and their families.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**
1.Access to Early Intervention Services	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible** **5**
2.Pre-school: *A school especially designed for children with special needs. Services including speech therapy, physical therapy and occupational therapy and are staffed with certified special education teachers.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**
2.Access to Pre-school	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible** **5**
3.Tutoring: *Private, remedial instruction provided to individuals outside a classroom setting. (Includes academic or life-skills tutoring).*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**
3.Access to Tutoring	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible** **5**
4.Post-Secondary School: *Schooling beyond the high school level. (Specifically academic education).*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**

4.Access to Post-Secondary School	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**
5. Vocational Training Programs (including workshop, job enclave, supported employment): *Education, training, coaching, skill reinforcement, vocational assessment, job development and placement, worksite accessibility, ongoing job support and other services needed to prepare people with disabilities for work, define a suitable employment goal and become employed.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**
5.Access to Vocational Training	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**
6.Day Habilitation: *Training, support, and supervision activities that maximizes functional abilities and skills necessary to enable adults with disabilities to access the community.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**
6.Access to Day Habilitation	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**
7.Transportation Services: *Provision of or arrangement for travel.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**
7.Access to Transportation Services	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**

B. Medical Support Services (circle one)

8.Specialized Medical Care: *Services provided by licensed health care practitioners whose practice includes serving individuals with disabilities.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**

8.Access to Specialized Medical Services	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible** **5**
9.Specialized Dental Care: *Services provided by a licensed dentist whose practice includes serving individuals with disabilities.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**
9.Access to Specialized Dental Care	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible** **5**
10. Specialized Mental Health Care: *Services provided by a mental health professional whose practice includes serving individuals with disabilities.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**
10.Access to Specialized Mental Health Care	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible** **5**
11. Therapy: *Services provided by a licensed therapist or professional whose practice includes serving individuals with disabilities.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**
11.Access to Specialized Therapy	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible** **5**
12. Behavior Support Programs: *Programs that apply basic learning techniques, such as conditioning, biofeedback, reinforcement, or changes to the environment to reduce problem behavior and teach pro-social functional behavior.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**
12.Access to Behavioral Support	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible** **5**

13. Special Equipment and Accessories or Other Self Help Devices: *Equipment that is used to assist the child to better function in their home environment.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**
13.Access to Special Equipment, Accessories, or Self-Help Devices	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible** **5**
14. Residential Services (e.g. independent living, group homes, Intermediate Care Facilities): *Care given to the child within a group or residential setting. Services include both custodial care and care that is provided by skilled and medically trained professionals.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**
14.Access to Residential Services	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible** **5**

C. Family Support Services (circle one)

15. Care Coordination (including case management) : *The deliberate organization of the child's activities between two or more participants. Organizing care involves the coordinating of personnel and other resources needed – this coordination is often managed by the exchange of information among participants responsible for different aspects of care.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**
15.Access to Residential Services	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible** **5**
16. Navigator Services : *Assistance provided to families to locate and arrange needed school, health, or disability services offered to individuals with disabilities.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective** **5**

16.Access to Navigator Services	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**
17. Parent Support Groups: *an informal association of families that provides assistance in dealing with a variety of problems and challenges related to the child's condition.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**
17.Access to Parent Support Groups	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**
18. Future Care Planning: *Arrangement for the provision of care when the parent is no longer able to care for the individual.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**
18.Access to Future Care Planning	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**
19. Cash Subsidies/Vouchers: *Money/resources provided directly to families to assist in the payment of services.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**
19.Access to Future Care Planning	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**
20. Concierge/Errand Services: *Flexible personal assistant to help family routines such as grocery shopping and other errands, transport of siblings to activities, and home tasks assistance.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**
20.Access to Concierge/Errand Services	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**
21. Family Training: *Services and information provided to assist the family in understanding the special needs of the child with disabilities and in promoting the child's development.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**
21.Access to Family Training Services	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**

22. Recreational Activities: *Sports, camping, and other fun activities offered outside the home.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**
22. Access to Recreational Activities Services	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**
23. **Homemaker Services**: *Non-medical support services such as food preparation and bathing provided by trained personnel.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**
23. Access to Homemaker Services	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**
24. **Respite Services**: *A service designed to provide temporary residence for a person with a disability who ordinarily lives with family or friends, or to assume temporary responsibility for care of the person in his or her own home. This service provides back-up support, and in some cases relief, to people responsible for care of an ill or disabled person who ordinarily lives in their household.*	**Effectiveness**	**Not at all Effective** 1	2	3	4	**Extremely Effective 5**
24. Access Respite Services	**Service Access**	**Not at All Accessible** 1	2	3	4	**Extremely Accessible 5**

Please list any other program(s) or service (s) that would be helpful to your family in lessening overall stress associated with your child's disability

24. ______________________________________

25. ______________________________________

26. ______________________________________

III. Overall Ranking of Services : Family

Please rank the top three services you believe are most effective in lessening family stress associated with your child's disability. Use the service numbers listed above (e.g. future care planning; #18)

Service #

1. ________________
2. ________________
3. ________________

IV. Overall Ranking of Services : Child

Please rank the top three services you believe are most effective in lessening your child's stress associated with his or her disability. Use the service numbers listed above (e.g. future care planning; #18)

Service #

1. ________________
2. ________________
3. ________________

V. Parental Demographics

1. Last week did either parent have full or part-time employment (include any job from which either parent you were temporarily absent)? ☐ Yes ☐ No

   1 a) If employed, is your employment (check one): ☐ Full Time
   ☐ Part Time ☐ Do not know

2. How old were you on your last birthday: ______ years

3. *Marital Status. Are* you currently (check one): ☐ Married/Common Law Partner
   ☐ Divorced/Separated ☐ Single/Never Married ☐ Widowed ☐ Other

4. What is your race/ethnicity? (please check all that apply) ☐ White ☐ African-American
   ☐ Hispanic ☐ Asian ☐ Other

5. Please indicate your total gross family income during the calendar year 2010. (This includes money from jobs, net income from business, farm or rent, pensions, dividends, interest, social security payments and other money income received): $ ____________ annually

6. Please indicate the highest level of education you have completed:
   - ☐ Less than high school
   - ☐ High School
   - ☐ Associate degree
   - ☐ Bachelor degree
   - ☐ Master degree or higher

County Board of Developmental Disabilities

VI. Barriers to Services

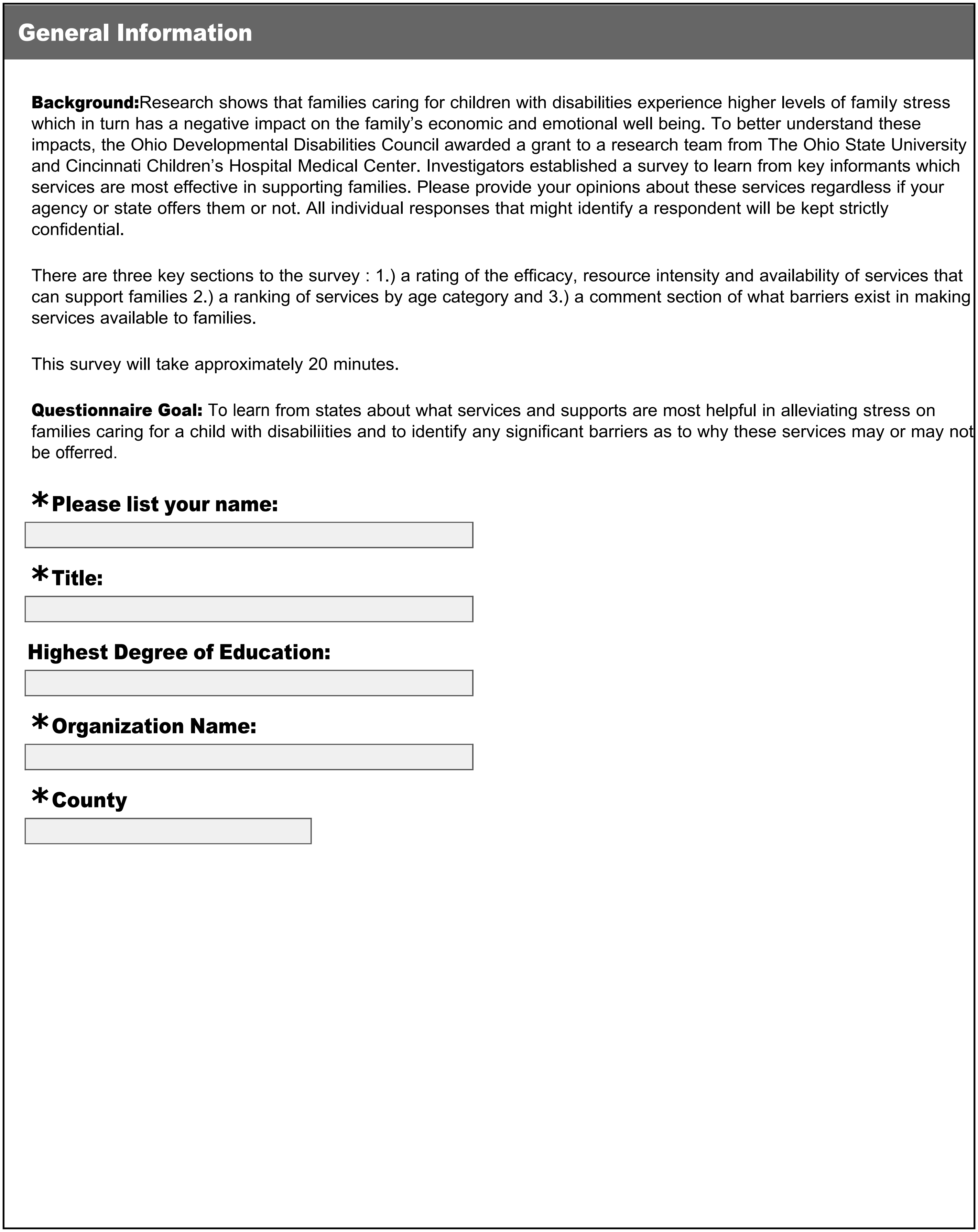
Please describe, for any of the services above, what barriers you have encountered in accessing the service and how these barriers might be overcome.

Describe barriers:

Describe solutions:

Please send your completed survey to:
Services to Assist Families Caring for Children with Disabilities Survey
Attn: Nancy Davis
Office of Health Sciences | The Ohio State University Medical Center
200G Meiling Hall | 370 West 9th Avenue
Columbus, OH 43210

APPENDIX E2: DD STAKEHOLDER FAMILY SERVICES EVALUATION SURVEY



General Information

Background: Research shows that families caring for children with disabilities experience higher levels of family stress which in turn has a negative impact on the family's economic and emotional well being. To better understand these impacts, the Ohio Developmental Disabilities Council awarded a grant to a research team from The Ohio State University and Cincinnati Children's Hospital Medical Center. Investigators established a survey to learn from key informants which services are most effective in supporting families. Please provide your opinions about these services regardless if your agency or state offers them or not. All individual responses that might identify a respondent will be kept strictly confidential.

There are three key sections to the survey : 1.) a rating of the efficacy, resource intensity and availability of services that can support families 2.) a ranking of services by age category and 3.) a comment section of what barriers exist in making services available to families.

This survey will take approximately 20 minutes.

Questionnaire Goal: To learn from states about what services and supports are most helpful in alleviating stress on families caring for a child with disabiliities and to identify any significant barriers as to why these services may or may not be offerred.

***Please list your name:**

***Title:**

Highest Degree of Education:

***Organization Name:**

***County**

Service Rating: Direct Intervention Services

Effectiveness : In terms of helping to alleviate overall family stress associated with raising a child with a disability how effective are the following services, either based on your experience or perception?

Resource Intensity: Based on your experience or perception what is the level of resource intensity in providing the service?

Service Access: Based on your experience or perception, how easy is it for parents to access the service?

1.) Early Intervention Services: Services provided to infants and toddlers and their families in accordance with Part C of the Individuals with Disabilities Education Improvement Act (IDEIA).

	1 Not at all	2 Not very	3 Somewhat	4 Aceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

2.) Pre School: A school especially designed for children with special needs. Services including speech therapy, physical therapy and occupational therapy and are staffed with certified special education teachers.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

3.) Tutoring: Private, Remedial instruction provided to individuals.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

4.) Post Secondary: Schooling beyond the high school level.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

5.) Vocational Training Programs (workshop, job enclave, supported employment): Education, training, coaching, skill reinforcement, vocational assessment, job development and placement, worksite accessibility, ongoing job support and other services needed to prepare people with disabilities for work, define a suitable employment goal and become employed.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

6.) Day Habilitation: Training, support, and supervision activities that maximizes functional abilities and skills necessary to enable adults with disabilities to access the community.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

7.) Transportation Services: Beneficial provision of or arrangement for travel, including travel costs of individuals, in order to access social services, or obtain medical care or employment.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

Service Rating-Medical Supports

8.) Specialized Medical Care: Services provided by licensed health care practitioners whose practice includes serving individuals with disabilities.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

9.) Specialized Dental Care: Services provided by a licensed dentist whose practice includes serving individuals with disabilities.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

10.) Specialized Mental Health Care: Services provided by a mental health professional whose practice includes serving individuals with disabilities.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

11.) Therapy: Services provided by a licensed therapist or professional whose practice includes serving individuals with disabilities.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

12.) Behavior Support Programs: Programs that apply basic learning techniques, such as conditioning, biofeedback, reinforcement, or changes to the environment to reduce problem behavior and teach prosocial functional behavior.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

13.) Special Equipment and Accessories or Other Self Help Devices: Equipment that is used to assist consumers to better function in their home environment.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

14.) Residential Services (e.g. independent living, group homes, Intermediate Care Facilities): Care given to a group of people with similar disabilities within a residence. Services include both custodial care and care that is provided by skilled and medically trained professionals.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

Service Rating-Family Supports

15.) Care Coordination (including case management) : The deliberate organization of an individual’s activities between two or more participants (including the individual) involved in an individual's care to facilitate the appropriate delivery of services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required individual care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

16.) Navigator Services : Assistance provided to families to locate and arrange needed school, health, or disability services offered to individuals with disabilitiesaspects of care.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

17.) Parent Support Groups : an informal association of families with similar care giving issues that assist participants in dealing with a variety of problems and challenges.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

18.) Future Care Planning: Arrangement for the provision of care when the parent is no longer able to care for the individual.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

19.) Cash Subsidies/Vouchers: Money provided directly to families to assist in the payment of services.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

20.) Concierge Services: Flexible personal assistant to help the family engage in routines (e.g., grocery shopping and other errands, transport of siblings to activities, homework assistance).

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

21.) Family Training: services and information provided to assist the family in understanding the special needs of children with disabilities and in promoting the child's development.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

22.) Recreational Activities: Sports, camping, and other fun activities offered outside the home.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

23.) Homemaker Services: Non-Medical support services, such as food preparation and bathing, provided on a consistent basis by trained personnel.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

24.) Respite Care: A service designed to provide temporary residence for a person with a disability who ordinarily lives with family or friends, or to assume temporary responsibility for care of the person in his or her own home. This service provides back-up support, and in some cases relief, to people responsible for care of an ill or disabled person who ordinarily lives in their household.

	1 Not at all	2 Not very	3 Somewhat	4 Acceptable	5 Very
Effectiveness	○	○	○	○	○
Resource Intensity	○	○	○	○	○
Service Access	○	○	○	○	○

Services Offered Either Publically or Privately

Please Check Services Offered in Your County

- ☐ Early Intervention Services
- ☐ Pre School
- ☐ Tutoring
- ☐ Post Secondary
- ☐ Vocational Training Programs
- ☐ Day Habilitation
- ☐ Transportation Services
- ☐ Specialized Medical Care
- ☐ Specialized Dental Care
- ☐ Specialized Mental Health Care
- ☐ Therapy
- ☐ Behavior Support Programs
- ☐ Special Equipment and Accessories
- ☐ Residential Services
- ☐ Care Coordination (including case management)
- ☐ Navigator Services
- ☐ Parent Support Groups
- ☐ Future Care Planning
- ☐ Cash Subsidies/Vouchers
- ☐ Concierge Services
- ☐ Family Training
- ☐ Recreational Activities

Overall Ranking of Services

Please choose your top preferences of service by age category in terms of what is most effective in helping families with the least amount of resources (biggest bang for the buck)

	Ages 0-2	Ages 3-5	Ages 6-21	Ages 21 and older
Top Choice	☐	☐	☐	☐

About the Authors

William Hayes, PhD, . has over twenty years of health care administration, health policy analysis, and health services research. He currently is a consultant to The Ohio State University Office of Health Sciences Administration and an adjunct faculty at the Ohio State University's College of Public Health in the Division of Health Policy and Health Management. From 2004 to April 2010, Dr. Hayes was the founding President of the Health Policy Institute of Ohio, an independent, nonpartisan organization that informs Ohio health policy by forecasting health trends, analyzing key health issues, and communicating current research to policymakers, state agencies and other decision-makers.

Before leading HPIO, Dr. Hayes served as an Assistant Deputy Director for Ohio's Ohio Medicaid program. In this role, he was part of Medicaid's executive management team. Prior to joining Medicaid, Dr. Hayes held several positions at the Ohio Department of Health, the last one being the Deputy Director for Health Policy, Planning, and the Ohio Health Care Data Center.

Barry Jamieson, MA, currently serves as project manager for the Ohio Colleges of Medicine, Government Resource Center, at the Ohio State University. His employment background has included directing the health research efforts of two major health trade associations, including the Ohio Association of County Boards of Developmental Disabilities. He holds an M.A. in economics from the Ohio State University.

Timothy Sahr, MA, MPH, MDiv, ThM is the Director of Research and Analysis for the Ohio Colleges of Medicine Government Resource Center. His prior employment included Director of Research at the Health Policy Institute of Ohio, Head of Policy at the Franklin County, Ohio, Board of Health, and survey researcher with Gallup International/ Gallup Poll. He is also a Dr. George Gallup Foundation Fellow for Health and Humanities.

Xiaoxi Yao, M.P.H., serves as a research specialist for the Government Resource Center. Her primary role is to perform quantitative data analysis on Medicaid Claims data. Xiaoxi received her M.P.H in Health Policy and Management from Columbia University, and is currently pursuing her PhD in Health Services Management and Policy at the Ohio State University.

Susan Havercamp, Ph.D. received her doctorate at the Ohio State University Nisonger Center in the area of in clinical and MRDD psychology. She conducted research and provided direct clinical services to children and adults with developmental disabilities through previous positions. At the University of South Florida she focused on improving the health of persons with disabilities through educating healthcare providers and health promotion activities for children and adults with disabilities. She is currently an Associate Professor of Psychiatry and Psychology at the Ohio State University Nisonger Center where she continues her work on health and healthcare for children and adults with disabilities.

Anthony Goudie, Ph.D. is an Assistant Professor in the Center for Applied Research and Evaluation at the University of Arkansas for Medical Sciences and Arkansas Children's Hospital. Formerly of the Child Policy Research Center in the Cincinnati Children's Hospital Medical Center, he has an interest in studying health outcomes and evaluating the policy and economic implications of children from vulnerable populations as they intersect the health care system and how contextual factors affect the health care they are able to obtain. His most recent research stream has focused on how caring for a child with a disability impacts the health of all members in a family.

Acknowledgments

This project was funded by a Grant from the Ohio Developmental Disabilities Council. The authors gratefully acknowledge the assistance provided by the following people:

Allison Lorenz, MPA	Government Resource Center
Kay Treanor	Ohio Developmental Disability Council
Linda Garrick	Ohio Department of Mental Health
Peggy Martin	Ohio Department of Developmental Disabilities
Jody Fisher	Ohio Department of Developmental Disabilities
Sam Chapman	Ohio Department of Health
Wendy Grove	Ohio Department of Health/Help Me Grow
Shawn A. Henry	Ohio Center for Autism and Low Incidence (OCALI)
Laura Leach	Ohio Department Of Jobs and Family Services
Tammy Savage	Ohio Sibs
Mary Hall	Ohio Provider Resource Association
Tom Fish	Nisonger Center- Ohio State University
Mark Smith	Ohio Department of Education

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