

Evaluating Services for Families with Children with Disabilities

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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.

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.

The primary objective of the Evaluating Services to FCD project is to determine what services 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, conceptual frameworks to propose policy considerations.

Conceptual Framework for Evaluating Services to FCDs

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.

The conceptual framework was tested by conducting surveys of family members, County Board of DD superintendents, state DD directors and state DD council executive directors. Out of a list of 24 different DD options, all respondents were asked to rate which programs or services most effectively alleviated family stress and how accessible each of these services is based upon the perception of the respondent. The assumption is that each respondent has a unique perspective in evaluating these services. A full description of the framework and the survey tools can be found in the *Evaluating Services to Families of Children with Disabilities* report at <http://grc.osu.edu>.

Study results are listed in tables 1 and 2. Table 1 details the efficacy ratings of families (n=204) for different age children for the top quartile of services. These services were the most highly rated by parents in terms of alleviating overall stress.

Table 1: (% 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.

Table 2 exhibits the efficacy ratings of services of the families compared to ratings of CBDD superintendents, DD Council Executive Directors, and State DD Directors. The services listed are those that were rated most highly by families.

	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, Rank=22
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

Tables 1 and 2 from the Ohio family and Ohio DD superintendent surveys reveal commonalities and disagreements related to policy needs and access to resources for FCDs.

- Table 1 shows that, regardless of type, 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.
- Table 2 shows CBDD superintendents tend to rate those services they provide and control as being relatively more effective than services they do not provide. For example, Ohio Superintendents ranked "Specialized Medical Care" 13th, while families ranked this service 4th (see Table2). 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.

“ I am always seeking for my child and it is exhausting. ”
FAMILY MEMBER

“ Good doctors are hard to find for children with disabilities... there is definately a need for this within a 60 mile radius of our home. ”

FAMILY MEMBER

- Parents ranked effectiveness of health care services, other than special equipment, higher than Ohio DD superintendents. 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

- Family effectiveness ratings of services change with the needs and the age of the child. Early Intervention Services, for example, although rated highly by all parents, are significantly higher for 0-5 FCDs compared to 22+ FCDs.
- The Family Stress Conceptual Model may explain why FCDs rate respite care as being less effective compared to superintendents and other stakeholders. This difference may reflect the caregiver perception that respite care may not solely relieve stress related to getting needed services for the child with DD. The lack of a trusted source for respite care may help also explain difference in effectiveness ratings between FCDs and other stakeholders.



“ Parents of individuals with medical needs cannot leave home for uninterrupted periods because respite workers cannot administer medications. ”
FAMILY MEMBER

Next Steps

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

First, conduct qualitative analyses of families with a child with DD and Ohio Superintendents 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. It 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.