



Family Support for Persons with Developmental Disabilities in the United States: Financing Trends and Emerging Initiatives

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Purpose of Presentation

- This presentation is based on research on the trends in family support spending and services for people with developmental disabilities and their families.



Families as Caregivers

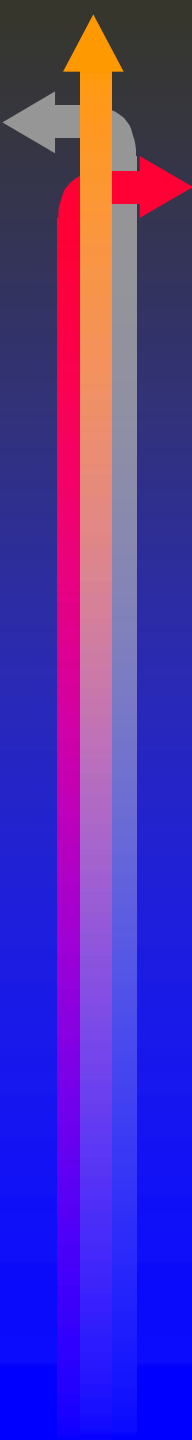
- The greatest amount of care for people with developmental disabilities is provided by families.
- Over 60% of people with developmental disabilities live with their family of origin.
- Only 15% of people with developmental disabilities receive care in the formal residential service system.

(Fujiura, 1998)

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Families receive little support

- Despite the fact that they provide the greatest amount of care, families receive a disproportionately tiny share of public spending allocated for developmental disabilities services (Braddock, 2002).



Parenting children with developmental disabilities has lifelong impact

- Greater levels of perceived burden
- Depressive symptoms
- Stress
- Health problems
- Lower rates of employment
- Lower rates of social participation
- Economic disadvantages accrue over time

(Blacher, Lopez, Sharpiro, & Fusco, 1997; Parish, Seltzer, Greenberg & Floyd, 2004; Crnic, Friedrich, & Greenberg, 1983, Selzer, Greenberg, Floyd, Pettee & Hong, 2001)



Historical Background

- Prior to 1970, institutionalization was the only service available to most families of children with developmental disabilities
- Since 1970s, family advocacy and empowerment has helped shift the trend to offer families more services for their children with developmental disabilities.



Future Needs

- It is likely that families of people with developmental disabilities will face increasing competition for social service funding from the needs of the aging baby boom cohort.
- Inadequate residential services for people with developmental disabilities may precipitate crises in many states – increasingly frail or dying elderly parent caregivers must continue to care for their own aging children with developmental disabilities.

(Braddock, 1999)

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What are Family Support Services?

- Designed to improve families' ability to cope with and decrease the burden of providing care while the family member with DD lives in the family home.

(Heller, Miller, & Hsieh, 1999)



Examples of Family Support Services

- Any service developed with state funds including:
 - Home modifications
 - In-home and out-of-home respite
 - Sibling programs
 - Family counseling
 - Parent support groups
 - After school programs
 - Behavioral training
 - Crisis management programs/assistance
 - Any other funded service to assist families.



Research Questions

- What level of financial commitment did states make for family support services?
- What new family support initiatives are states pursuing?



Research Method

- State spending – Analysis of ongoing longitudinal investigation of expenditures on services in the United States. (Braddock, 2002)
 - Data collected from a mail and telephone survey of the director or chief financial officer of each state's developmental disabilities or mental retardation agency.
- New Family Support Initiatives – data collected via telephone survey of state DD Planning Councils (federally funded, exist in each state)



Means of Providing Family Support

- Data were collected on two means of providing family support:
 - *Cash subsidy*
 - All payments or vouchers given directly to families in which they control spending allocation
 - *Direct payment/other services*
 - All services provided by state or by 3rd party organizations
 - Respite
 - Home modifications
 - Parent training
 - Family counseling
 - Recreational programs
 - Support groups
 - Behavioral interventions



Response Rates – State Spending

- 49 states reported family support spending levels, yielding an overall response rate of 98%.
- 49 states also reported the number of families who received services for an overall response rate of 98%.
- Minnesota officials did not report either funding levels or number of families in programs – budget records and other official state documents were used to construct spending and service estimates.



Response Rates – New Initiatives

- 46 states participated in the survey, yielding a response rate of 92%.
 - Data collected regarding new family support activities that were underway or planned.



The National Picture in 2000

- Family support expenditures totaled \$1.05 billion across the U.S.
 - This represents 4% of \$29.3 billion in total spending for developmental disabilities services
- Nearly 385,000 families received support.
 - As compared with approximately 450,000 people with developmental disabilities in residential services in 2000
- Annual average amount of support a U.S. family received was \$2,728.
- Cash subsidy spending provided by 19 states totaled \$60 million.
- Spending for non-cash services totaled \$980 million.

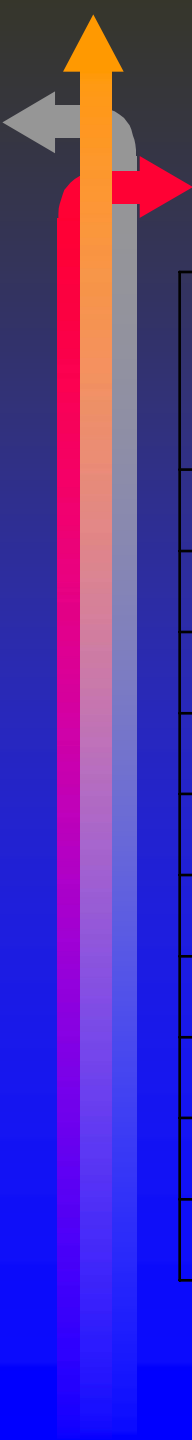


The State Picture

- In 2000, funding for family support services was provided by all 50 states.
- Total state spending for family support ranged from less than \$500,000 in Idaho, Hawaii, and Arkansas to \$233 million in California.

Top 10 States in Family Support Spending (per family), 2000

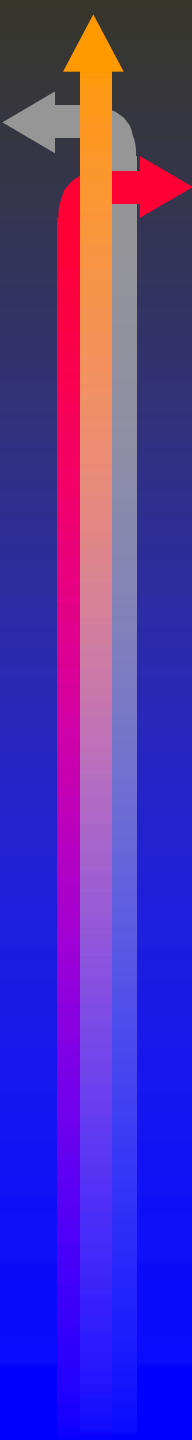
State	FS spending (\$) in millions	# of Families Receiving Services	Average Annual Spending per family	Rank: Spending per family
NC	\$57.8	4,248	\$13,614	1
VT	\$12.3	1,003	\$12,248	2
OK	\$23.5	1,990	\$11,817	3
KS	\$32.7	3,030	\$10,785	4
LA	\$57.9	5,629	\$10,294	5
RI	\$9.3	965	\$9,642	6
MN	\$19.9	2,183	\$9,121	7
WY	\$4.8	641	\$7,552	8
OR	\$6.9	999	\$6,909	9
AZ	\$83.7	13,188	\$6,347	10

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Bottom 10 States in Family Support Spending (per family) in 2000

State	FS spending (\$) in Millions	# of Families Receiving Services	Average annual spending per Family	Rank: Spending per family
ME	\$0.53	500	\$1,065	41
NV	\$1.38	1,296	\$1,064	42
OH	\$12.54	12,110	\$1,036	43
SD	\$1.60	1,613	\$993	44
NY	\$46.85	63,343	\$740	45
ID	\$0.47	988	\$477	46
HI	\$0.27	632	\$420	47
IN	\$0.88	2,400	\$365	48
GA	\$1.82	5,648	\$322	49
AL	\$0.65	2,800	\$234	50

States with Cash Subsidies

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State	Spending in Millions	# of Family Recipients	Average spending per family	Rank: spending per family
IL	\$16.55	1,941	\$8,524	1
AZ	\$0.89	151	\$5,868	2
SC	\$2.60	544	\$4,779	3
IA	\$1.52	379	\$4,011	4
RI	\$0.18	54	\$3,416	5
LA	\$4.41	1,574	\$2,799	6
NV	\$0.75	278	\$2,709	7
OK	\$2.69	997	\$2,698	8
MI	\$13.72	5,264	\$2,607	9
TX	\$12.71	5,148	\$2,469	10
KS	\$2.62	1,093	\$2,400	11
MN	\$2.10	1,118	\$1,877	12
NJ	\$3.36	1,852	\$1,815	13
FL	\$1.00	636	\$1,573	14
ND	\$0.59	387	\$1,523	15
MO	\$1.04	901	\$1,157	16
CT	\$0.99	911	\$1,085	17
UT	\$0.93	1,573	\$593	18
NC	\$0.35	1,001	\$351	19



Home and Community Based Services Waiver

- States that used the Home and Community Based Services (HCBS) Waiver to finance their family support programs had the largest programs (as contrasted with those using only state funds)
- The HCBS Waiver is a Medicaid option that allows states to obtain federal reimbursement for family support and other community services
- States obtain federal reimbursement for 50-77% of their family support spending through the HCBS Waiver



States reported 12 new initiatives

- Development of policy/advisory councils
- Self- or family-directed supports
- Training & technical assistance
- Culturally competent services
- Networking/outreach
- Integration & coordination of services
- Support to aging caregivers
- Flexible funding
- Policy-making activities
- Family support specialists/coordinators
- Guardianship initiatives
- Localized service management



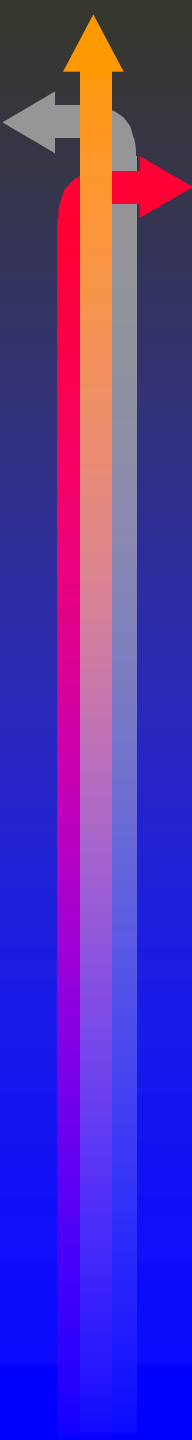
Development of Policy/Advisory Councils

- 19 states reported this initiative
- Councils comprised of at least 51% parents and people with developmental disabilities
- Councils intended to serve as formal mechanisms by which families have input into family support policy decision-making



Self- or Family-Directed Services

- 14 states reported this initiative
- Programs gave families decision-making authority over the services they receive.
- Goal of initiatives included empowering families and devising family-controlled support systems.



Training, Technical Assistance, and Technology Utilization

- 10 states reported this initiative
- Focus of programs was to educate service providers, families, and support staff about available services.
- Many states use interactive Internet websites for outreach.



Culturally Competent Services

- 8 states reported this initiative
- These projects conduct outreach with diverse minority populations
- Programs work to ensure services are sensitive to varying needs of different constituencies.



Networking/ Outreach

- 8 states reported this initiative
- These programs are attempts to improve states' capacities for reaching families in need and improving communication.



Integration, Coordination of Services

- 7 states reported this initiative
- These projects facilitate greater integration and coordination of services across programs or agencies.
 - Comprehensive systems
 - Reduced duplication of services
 - Address the needs of individual who are not receiving services.



Support to Aging Caregivers

- 5 states reported implementing initiatives
- These programs are targeted to assist the particular needs of aging caregivers, including planning for:
 - Transition out of the caregiving role, due to parents' incapacity or death
 - Residential placement
 - Guardianship transitions.



Flexible Funding

- 19 states funded cash subsidies in 2000.
- 5 additional states reported developing new direct payment programs intended to provide families with flexibility and discretion to determine how their family support funds are spent.



Policy-Making Activities

- 4 states reported development of statewide policy initiatives directed at improving their family support services.



Family Support Specialists/Coordinators

- 2 states reported using specialists or coordinators to more effectively provide family support services.
- Coordinators are either paid staff members or volunteers and sometimes included family members, who assisted other families secure needed family support services.



Guardianship

- 1 state reported addressing alternatives to guardianship.



Localized Service Management

- 1 state reported transferring centralized services to separate, locally managed entities.



Limitations of Study

- Study's survey methodology relies on data reported from state officials. However, data were triangulated by comparing with official budget and other state documents.



Need for Future Research

- How are families supported to manage or direct the subsidies they receive, if support is needed?
- Cash subsidies may pose considerable administrative burden on families. How do families manage this issue and care? Are supports in place to assist them?
- What steps are states taking to have equity in the provision of limited family support resources?
- Are families with the greatest needs being served?



Final Notes

- Provision of culturally appropriate, respectful, and competent supports should be a mandate for all states and service providers.
- Policy makers and service providers should consider demographic changes and formulate strategies to meet current and changing needs.



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