

Caring for Children with Disabilities in Ohio: The Impact on Families

A Health Care Policy Brief from the Ohio Developmental Disabilities Council

Anthony Goudie, Ph.D., Cincinnati Children's Hospital • Lorin Ranbom, Barry Jamieson, Susan M. Havercamp, Ph.D., Ohio State University

Research shows that families caring for children with disabilities experience higher levels of family stress.

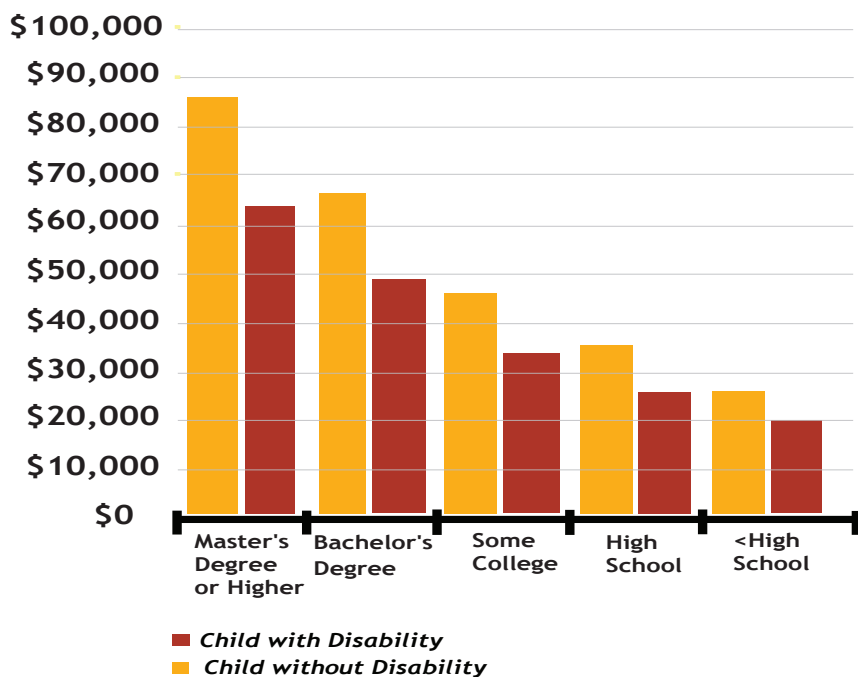
Key findings of our study show that compared to other families, families caring for children with disabilities are more likely to have:

- Less self-reported annual family income
- Personal financial strife
- Less employment security
- Elevated levels of emotional stress
- Children with greater use of health care services

Impact on Income

Comparatively, families caring for children with disabilities earn less than those without children with disabilities. The difference varies across a number of factors including the parent's labor force participation, education, age, number of children in the household, and race.

Graph 1: Estimated Average Income of Families Caring for Children with and without Disabilities



“My husband, he used to be a truck driver, and I don't work, but he ended up having to take a lower paying job and doesn't hardly get any hours because I couldn't do it [care for our child] by myself”

A RURAL MOTHER OF A YOUNG CHILD WITH DEVELOPMENTAL DISABILITIES

Graph 1 shows the estimated average income difference for a two-parent family scenario where the oldest parent is 35 years of age, only the father is in the workforce, and the family is caring for 1 child. Under this scenario and depending on the highest level of education across parents, families not caring for a child with disability earn, on average, between \$7,000 and \$22,500 more than families caring for a child with disability.

Reasons for these income differences likely include:

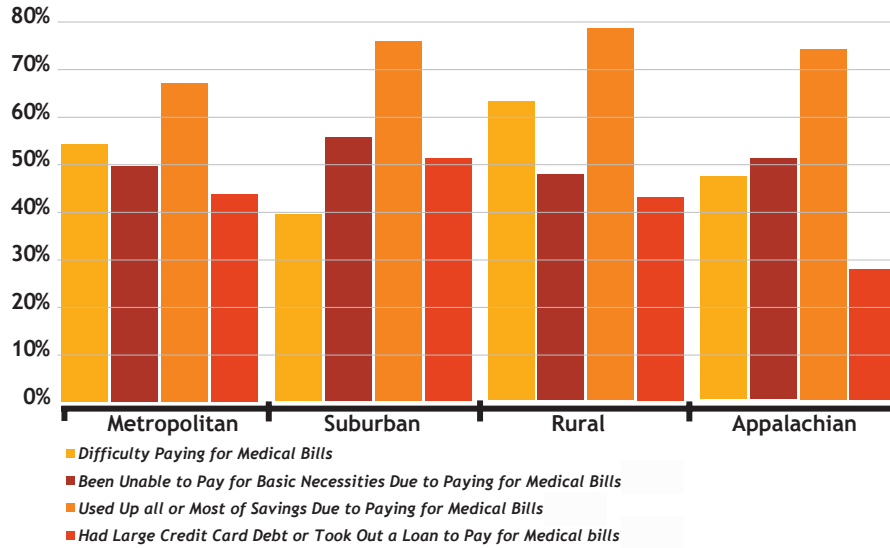
- **Child Care Efforts:** Many parents caring for a child with disabilities work less hours due to the increased number of hours it takes to provide care (emotional, physical and health-related).
- **Proximity Issues:** Many parents work closer to home and often take lower paying jobs so they can be available to care for their child.
- **Benefit Lock:** Many parents stay in lower paying jobs for employer health benefits, regardless of income considerations.

Impact on Family Finances

Over one-half of families (52%) caring for children with disabilities experience difficulty paying medical bills, compared to 32% of families with children without disabilities. Of those who care for children with disabilities and report having this difficulty:

- 71% report having used up most of their savings;
- 50% report being unable to pay for basic necessities such as food, heat or rent; and,
- 43% report having incurred large credit card debt or having to take out a loan to cover medical expenses.

Graph 2: Financial Problems of Families Caring for Children with Disabilities by Region (%)



“ I can’t have a full-time job. I haven’t been able to have one since my son was born. And our financial aspect is that we are so in debt, that it’s ridiculous. ”

URBAN MOTHER OF THREE YOUNG MEN: ONE WITH DOWN SYNDROME, ANOTHER WITH AN AUTISM SPECTRUM DISORDER, AND A THIRD WHO SUFFERED A TRAUMATIC BRAIN INJURY PLAYING FOOTBALL.

Impact on the Health Care of the Child

Children with disabilities often have multiple chronic conditions which make them susceptible to intensive levels of service utilization, including admissions to the hospital. Twenty eight percent of families of caring for children with disabilities spend 11 or more hours per week providing or coordinating health care for the child. Twenty six percent of families cut work hours to care for children with disabilities. For families, preventable health care utilization results in more emotional stress, time constraints and out of pocket expenses.

Table 1: Health Care Intensity of Services of Medicaid Eligible Children

	No Disability Percent >12 visits	Disability		
		All Percent >12 visits	No Waiver* Percent >12 visits	Waiver* Percent >12 visits
Office Visit	7.2%	11.7%	10.7%	16.7%
Mental Health	38.1%	43.8%	45.5%	28.3%
Physical Therapy	4.7%	11.1%	11.4%	10.6%

“ I can’t get [Medicaid services] because I’m not poor enough. I can’t get [therapy for my son] because I can’t afford it. So I’m that in between person that cannot pay for all these services. ”

WORKING MOTHER OF A YOUNG CHILD WITH A DEVELOPMENTAL DISABILITY LIVING IN RURAL OHIO

Table 1 demonstrates that families caring for children with disabilities frequent the health care setting at a much higher intensity than parents of children without disabilities. Among families of children with disabilities, those with Medicaid waivers have higher levels of primary care visits but less intensive levels of mental health and physical therapy visits.

Policy Considerations

- **Lessen Stressors:** Lessening stressors related to caring for children with disabilities will have a positive impact on family well being and on family income.
- **Medical Home:** Improved care coordination of health care services for children with disabilities will better align resources and potentially reduce preventable hospitalizations and health system services.
- **Data Tracking:** Policy deliberations concerning the state of families caring for children with disabilities in Ohio should consider a thorough evaluation of current assistance programs for children with disabilities and their families and an evaluation of best practices of other state programs

* Waiver services are supplemental to Medicaid and are provided to support people with disabilities in the community, thereby avoiding institutionalization.

Note: All statistics reported in this brief are significant at the .05 level or are sourced from peer-reviewed publications