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



A White Paper Prepared with a Grant from the Ohio Developmental Disabilities Council

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EXECUTIVE SUMMARY



Research shows that families caring for children with disabilities experience higher levels of family stress, curtailed employment opportunities, and diminished rates of general well being than comparative families. Specifically, these stressors have a negative impact on the family's economic and emotional well being.

To address these impacts, a research team from The Ohio State University and Cincinnati Children's Hospital Medical Center received a grant from the Ohio Developmental Disabilities Council. The findings from this research resulted in the health care policy white paper *Caring for Children with Disabilities in Ohio: The Impact on Families*.

The white paper examines income, financial stress, employment, and emotional impact of families caring for children with disabilities. The study consists of a brief literature review, analyses from the 2008 American Communities Survey, the 2008 Ohio Family Health Survey, the 2007 National Survey of Children's Health, 2005/06 National Survey of Children with Special Health Care Needs, 2009 fiscal year Ohio Medicaid

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.

claims data, and a series of focus groups of families with children with disabilities.

This is the first known study of its kind in Ohio and the key findings are that families caring for children with disabilities are more likely to have: (1) less self-reported annual family income, (2) greater personal financial strife, (3) less employment security, (4) elevated levels of emotional stress, and (5) greater use of health services by their children. In other words, families caring for children with disabilities experience significantly higher rates of chronic stress, as measured by employment, economic and emotional indicators.

INTRODUCTION



Families caring for children with disabilities face particular challenges compared to those caring for children without disabilities. Challenges include demands on time. constrained earning potential, increased financial expenditures related to health care, employment constraints, and emotional constraints limit stress. Additionally, time opportunities for parental social interaction and advanced education. The purpose of this study is to shed light on the family impact of caring for children with disabilities. Using a mixed method research approach we use survey, health care claims data and focus groups to describe family impact.

Estimates of family impact are obtained by analyzing data from four surveys of the Ohio population. These include the 2008 American Community Survey (ACS), the 2008 Ohio Family Health Survey (OFHS), the 2007 National Survey of Children's Health (NSCH) and the 2005/06 National Survey of Children with Special Health Care Needs (NS-CSHCN). Medicaid claims data is also used to analyze health care utilization patterns. Focus groups of family members of children with disabilities helped us better understand the impact on families. Comments and sentiments expressed during these focus groups support data analysis findings from the Ohio population and are found throughout this document.

Caring for Children with Disabilities in Ohio: The Impact on Families concludes that the circumstances for families caring for children with disabilities call for a policy dialogue and additional research in the areas of familycentered care, structures and resources aimed at lessening family stress, and comprehensive health care coordination for children with disabilities and their families.

BACKGROUND

It is estimated that 115,000 to 152,000 children in Ohio have a disability. This represents 4.2% to 5.5% of all children less than 18 years of age (Goudie OFHS Final Report 2009; 2008 ACS). Compared to children without disabilities, children with disabilities tend to be 6 to 17 years of age, predominantly male and disproportionately African-American.

There is relatively little known on the implications for families caring for children with disabilities. Raising a child with a disability causes marital strain, increasing the probability of divorce or separation (Swaminathan, 2006; Riechman, 2004). There is also an impact on employment and income status; mothers of children with disabilities are less likely to be employed outside the home and more likely to receive public assistance (Corman, 2005; Reichman, 2006) and fathers are more likely to work fewer hours (Noonan, 2005). Recent estimates of Ohio families caring for children with disabilities compared to families caring for children without disabilities indicate that they are less likely to have a college education, especially an advanced degree, and are more likely to earn 200% of the federal poverty (FPL) level or less (Graph 1).

No known studies have captured the total overriding economic family burden of caring for a child with disability. Depending on the type of disability, out-of-pocket costs can include expensive medical devices and services, with many services and equipment not being covered by traditional health plans. In a review of the literature, Anderson (2007) found the annual financial impact of disabilities to range from \$108 to \$8,742. Time providing and coordinating care was reported to range from 4 to 84 hours a week. Barnett (1995) reported a net decrease of 7 hours a week of employment for families caring for children with Down syndrome.

The financial impact of raising children with disabilities varies across states - Ohio is ranked

We don't own anything. We go from check to check and ... can't get help.

WORKING MOTHER IN RURAL OHIO

in the middle (Shattuck, 2008). Low-income families raising children with disabilities are likely to incur out-of-pocket expenditures of \$500 or more (Parish, 2009). Nationally, Goudie (2010) calculated that average annual out-ofpocket healthcare costs were \$535 per year for families raising children with special health care needs (including disabilities) compared to an average of \$192 per year for families with non-special needs children. Moreover, 1 in 6 of these families had out of pocket medical expenditures greater than \$1,300 per year.

The consensus of research suggests that chronic stress associated with long-term care giving is deleterious to the cardiovascular, immune, and gastrointestinal systems (Miodrag and Hodapp, 2010). A recent study even found a poor antibody response to influenza vaccine in parents of children with disabilities compared to other parents (Gallagher, Phillips, Drayson, and Carroll, 2009). Caregivers of children with chronic health problems were twice as likely to report chronic conditions themselves, had limitations in at least one domain of activity, and reported elevated depressive symptoms (Brehaut et al., 2009). Compared to parents of control group children and adolescents, Grosse et al. (2009) found that caregivers of children with spina bifida reported less sleep, fewer days of leisure, and fewer social activities and were twice as likely to report feeling "blue" more than a little of the time. When parents perform high levels of care giving over extended periods, get little sleep, spend little time socializing, and engage in few leisure activities, health-related symptoms quickly escalate (Miodrag and Hodapp, 2010). Health problems associated with chronic stress of care giving can thwart parents' ability to provide care, hinder the parent-child relationship, and more broadly constitute a major public health concern.

Parents of children with disabilities, due to a lack of social interaction, experience less social support (Koshti-Richman, 2009), higher levels of fatigue during the day, a greater number of daily stressful events, and lack emotional

support (Smith, 2009). A lack of social support has been established as a risk factor for impaired psychological and physiological functioning, mortality and morbidity (House, Landis, and Umberson, 1988). Social isolation and perceived low levels of social support are associated with systemic inflammation, inactivity, disturbed sleep, poor diet, and alcohol and tobacco use, each of which exacerbates inflammatory responses (Keikolt-Glaser, Gouin, Huntson, 2009). Systemic inflammation is a significant risk factor for diseases such as type II diabetes, arthritis, and cancer.

Graph 1: Demographics of Families Caring and Not Caring for a Child with a Disability

Parental Education Household Annual Income, FPL Marital Status < Hiah School Advanced Sinale / 9.8% **Divorced** / 301% or More Widowed Dearee Separated 21.3% 19.6% 19.4% 23.3% 100% or Less 36.2% **High School** 201% - 300% 34.7% Some College / 14.2% Married / Bachelors Degree Unmarried 36.1% 101% - 200% Couple 28.4% 57.1% CARING FOR A CHILD WITHOUT DISABILITIES Household Annual Income, FPL Marital Status Parental Education < High Schoo Divorced Single / 7.2% Widowed Separated 100% or Less 15.3% 14.8% Advanced 22.2% **High School** 301% or More Degree 30 1% 32.3% 38.9% 101% - 200% 21.1% Married / Some College **Unmarried** Couple **Bachelors Degree** 69.9% 201% - 300% 30.4% 17.7%

CARING FOR A CHILD WITH DISABILITIES

Source: OFHS 2008

Note: In the case of a married or unmarried couple the education status reflects that of the parent with the highest education.

¹ For the 2008 OFHS, 2007 NSCH, and 2005/06 NS-CSHCN child with disability is defined as a child that is limited or prevented in any way in his or her ability to do the things most children of the same age can do as identified on the CSHCN Screener®.

THE IMPACT ON INCOME

According to the 2008 American Community Survey (ACS) an estimated 115,751 Ohio children aged 0-17, living within 99,740 households, had a disability. This represents 4.9% of all children and 7.4% of all households in Ohio.

Over one-half (52%) of all households containing children without disabilities are headed by a parental couple who are both in the labor force (Table 1). This compares with only onethird (33%) of all households with children with disabilities. Roughly one in five (21%) households

of children without disabilities is headed by a single parent mother. In contrast, single parent mother households comprise greater than one-third (36%) of all households containing a child with a disability and one-third of these parents are not in the labor force (12% of overall households).

Compared to families caring for children where none have disabilities, families caring for children with disabilities have lower mean incomes (Table 2).

Table 1: Child Population Demographics by Disability Status (N, %, 95 CI)

	Household ha: Least One wit	s Children, At h a Disability	Household Has Children, None with Disabilities		
Family and Household	Number of		Number of		
Demographics	Households	Percent	Households	Percent	
Households with Children Aged D-17 Years	89,740	7.4%	1,245,253	82.6%	
Family Type and Employment Status *					
Parental Couple, Both Parents in Labor Force	33,061	33.1%	641,823	51.6%	
Parental Couple, Only Father in Labor Force	17,429	17.5%	224,249	18.0%	
Parental Couple, Only Mother in Labor Force	5,473	5.5%	33,395	27%	
Parental Couple, Parents NOT in Labor Force	3,429	3.4%	22,074	1.8%	
Single Parent, Father in Labor Force	3,145	3.2%	52,825	4.2%	
Single Parent, Father NOT in Labor Force	1,335	1.3%	7,697	0.6%	
Single Parent, Mother in Labor Force	23,907	24.0%	217,874	17.5%	
Single Parent, Mother NOT in Labor Force	11,961	12.0%	45,444	3.7%	
Food Stamp Recipiency *					
Yes	37,502	37.6%	204,070	16.4%	
No	82,238	62.4%	1,041,183	83.6%	
Residential Status *					
Owned with Mortgage or Loan	48,832	49.0%	773,898	82.1%	
Owned Free and Clear	7,567	7.6%	87,950	7.1%	
Rented	41,393	41.5%	385,640	29.4%	
Occupied Without Payment of Rent	1,848	20%	17,765	1.4%	

Source: ACS 2008

* All category comparisons across family and household demographic categories are statistically different at p<0.05

Note: Parental couple is defined as a married or cohabitating couple. Labor force participation is defined as employed or currently seeking employment and unemployed less than 1 year. Not in labor force is defined as unemployed and currently not seeking employment, or unemployed more than 1 year.

Table 2: Parental Mean Income Level by Family Type and Labor Force Participation Category

	Families Caring for Children					
Mean Income Level	At Le	ast One Child w	ith a Disability	N	o Children with D)isabilities
Number of Households with Children Aged 0-17 Years		99,740	7.4%		1,244,081 ^a	92.6%
Parental Income by Family Type and Labor Force Participation *	n	Mean Income	95% CI	n	Mean Income	95% CI
Parental Couple, Both Parents in Labor Force	33,061	\$79,985	72,512 - 87,210	641,823	\$89,803	88,001 - 91,805
Parental Couple, Only Father in Labor Force	17,429	\$54 428	52,537 - 78,320	224,249	\$84,514	80,35 0 - 88,878
Parental Couple, Only Mother in Labor Force	5,473	\$41,476	24,460 - 58,492	33,395	\$52,545	46,499 - 58,591
Parental Couple, Both Parents NOT in Labor Force	3,429	\$18,627	11,304 - 21,949	22,074	\$31,417	25,725 - 37,109
Single Parent, Father in Labor Force	3,145	\$38,018	25,163 - 48,872	52,625	\$50,434	45,520 - 55,440
Single Parent, Father NOT in Labor Force	1,335	\$14,256	8,033 - 20,482	7,897	\$24,003	17,538 - 30,467
Single Parent, Mother in Labor Force	23,907	\$25,307	21,480 - 29,134	217,674	\$28,560	27,298 - 29,833
Single Parent, Mother NOT in Labor Force	11,961	\$8,380	8,641 - 10,079	45,444	\$11,093	9,548 - 12,638

Source: ACS 2008

*Mean income level comparisons across family type and labor force participation categories are statistically different at p<0.05.

^aContains only households with reported parental income

Note: Parental couple is defined as a married or cohabitating couple. Labor force participation is defined as employed or currently seeking employment and unemployed less than 1 year. Not in labor force is defined as unemployed and currently not seeking employment, or unemployed more than 1 year.

The calculations that determine mean family income are dependent upon a number of factors including age, education level, and gender. To obtain a more accurate depiction of the difference in mean income levels for families who care for a child with a disability and those that do not, a regression model was created to predict family income.

Using results from the model, we compared families of similar characteristics varying on whether they care for a child with a disability. In Table 2, our model calculated a mean family income difference of \$20,086. Table 2 shows how this difference varies when only one variable changes. For instance, for similar families (parental couple, father only in the labor force, oldest parent is 35 years of age, 1 child in the household, white race,

and both parents not graduating high school) the predicted income difference is less than negative \$10,000. For families where the highest educated member has at least a Masters degree, the mean income difference is almost negative \$25,000. When examining single mothers with similar characteristics who are in the labor force, the income difference between those caring and not caring for children with disabilities is much smaller by education level (negative \$1,000 to \$3,000).

Potential reasons for the difference in mean family income across similar families are not definitively known. However, employment concerns were often expressed in the parental focus groups. Many of the parents in these focus groups experience one or more of the following problems: • Time stress: parents work fewer hours because of increased time needed to provide and coordinate care;

• Employment proximity: parents take lower paying jobs closer to home, limiting employment opportunities, to be available to help with care giving needs;

• Job lock: parents take lower paying jobs, limiting employment opportunities, because health insurance benefits are better for their children; and

• Fatigue: parents are less available to work and are less productive due to physical and emotional exhaustion related to care-giving burden.

What we do know is that after adjusting for socioeconomic factors (e.g. household composition, education, race) there is an income differential between families caring for children I had to quit my job. So I have a Master's Degree and I'm delivering newspapers so that I'm available [for my son] because there are behavior issues. The school will call me by 1:00 on any given afternoon and I will pick him up.

> RURAL FATHER CARING FOR A CHILD WTIH AUTISM SPECTRUM DISORDER

with disabilities versus those not. Using 2007 data, we calculated that there was approximately a \$480,000,000 income gap in Ohio between families who care for children with and without disabilities (see Appendix B for calculation). While this annual income gap is large, policies or programs addressing one or more of the above employment stressors would increase annual family household income, resulting in increases in local and state business activity, tax revenues, and work productivity.

Graph 2: Difference in Mean Family Income for Families Caring for Children with and without Disabilities by Education Status (Scenario Analysis)



Child without Disability

Source: ACS 2008

FINANCIAL AND EMPLOYMENT CHALLENGES

For families caring for children with disabilities, employment challenges segue into family financial challenges. According to results from the 2008 Ohio Family Health Survey, many families in Ohio have difficulty paying medical bills. An estimated 78,771 families (52%) caring for children with disabilities have had difficulty paying medical bills - this compares to onethird (32%) of families with children without disabilities.

For families caring for a child with a disability who report difficulties paying medical bills:

• 50% report being unable to pay for basic necessities such as food, heat, or rent;

• 71% report having used most of their savings to pay medical bills; and

• 43% report having incurred large credit card debt or taking a loan to cover medical expenses.

There is regional variation in health care cost stress across Ohio for families of children with disabilities, with 63% of rural families reporting having difficulty paying medical bills (Graph 3).

Suburban and metropolitan areas have higher rates of being unable to pay for necessities and credit card or loan use, while the rural area has a higher rate for using up savings. Controlling for select demographics (age, gender, race/ethnicity,

Graph 3: Difficulty Paying for Medical Bills and Other Financial Hardships Experienced by Families Caring for a Child with Disabilities by Region



Been Unable to Pay for Basic Necessities Due to Paying for Medical Bills*

- Used Up all or Most of Savings Due to Paying for Medical Bills*
- Had Large Credit Card Debt or Took Out a Loan to Pay for Medical bills*

* Only those who responded YES to Difficulty Paying for Medical Bills responded to these questions. *Appalachians may have less credit card resources to utilize.

*The suburbs and Appalachian are similar, as are the Metropolitian and Rural areas.

Source: OFHS 2008

health, insurance status of the child, parent's marital and education status and residential region) families caring for a child with a disability are 1.7 times more likely to report difficulty paying medical bills, and 1.5 times more likely to have used credit cards or a loan to pay medical bills.

Results from the NS-CSHCN 2005/06 demonstrate that Ohio families caring for children with disabilities experience financial hardship, with one in five having to spend more than \$1,000 a year out-of-pocket on medical bills. Almost one-third (31%) of these families indicated that the child's health care has caused financial problems (Table 3).

Financial hardship may be associated with having to change work schedules to meet the needs of the child. Over one-quarter (26%) have had family members cut back employment hours and nearly 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

one-third (32%) of all families have had a family member stop working altogether to care for a child with a disability.

Most families who experience financial and employment hardships due to caring for a child with a disability also experience increased emotional stress.

Table 3: Financial and Employment Impact of Caring for a Child with Disability

Families caring for a child with	
disability	Percentage
Out-of Pocket Spending	
> \$1,000	21.5%
\$501 - \$1,D0D	18.2%
\$250 - \$500	15.3%
\$1 - \$240	15.8%
\$ 0	31.2%
Child's Health Care Caused Financial Problems	
Yes	31.0%
No	69.D%
Needed Additional Income for Child's Medical Expenses	
Yes	32.8%
No	67.2%
Family Members Have Cut Work Hours to Care for Child	
Yes	28.3%
No	73.7%
Family Member Stopped Working Due to Child's Health	
Yes	32.3%
No	67.7%
Family Spend 11+ Hrs / Week Arranging and/or Coordinating	Health Care for Child
Yes	28.0%
No	72.0%

Source: NS-CSHCN 2005/06

EMOTIONAL HARDSHIP



Compared to families who care for children without disabilities, those who care for children with disabilities experience more difficult challenges interacting with their child. This increased level of burden results in higher rates of emotional stress. Considering increased obligations and emotional stress, parents of children with disabilities reported You don't sleep most of the time. You worry, no matter what's going on. So for [my husband and I], it wasn't a big deal to not go on family vacations and not do all the family gatherings, and [not] go out with friends and all of that. But it was kind of hard to watch my [typically developing] son not be able to have friend over...

> URBAN MOTHER OF A YOUNG WOMAN WITH A DEGENERATIVE NEUROLOGICAL CONDITION AND MENTAL HEALTH PROBLEMS

having less social support compared to parents of children without disabilities (Table 4). Although we lack direct measures of health outcomes for the parents in our data, there is strong evidence in the literature for a relationship between chronic stress and physical and mental disease (c.f., Background section).

Table 4: Emotional Impact of Caring for a Child with Disability compared to a Child without Disability

	Families Ca	ring for Children
	At Least One	
	Child with a	No Children with
	Disability	Disabilities
Emotional Hardship	Percentage	Percentage
Level Coping with Demands of Parenthood/Raising Children		
Very Well	51.62	56.4%
Somewhat Well / Not Very Well / Not Very Well at All	-9.6%	41.5%
In Past Month, How Often Have You Felt Your Child Has Been		
Harder to Care for Than Other Children of the Same Age?		
Never / Ravely	55.87	82.95
Somewhat / Usually / Always	44.2%	17.1%
In Past Month, How Often Has Your Child Done Things That Really		
Bother You?		
Never / Randy	50.37	66.5%
Somewhat / Usually / Always	49.7%	33.75
In Past Month, How Often Have You Felt Angry with Your Child?		
Never / Rarely	59.75	e.s.
Somewhat / Usually / Always	40.9%	30.5%
Is There Someone That You Can Turn to For Day-to-Day Emotional		
Help with Parenthood/Raising Children?		
Yes	78.6%	92.2%
No	21.6%	7.8%

Source: NSCH 2007

Note: Ohio percentages are presented, but there are too few families caring for children with disabilities represented in the NSCH sample to have the statistical power to detect differences. National percentages are similar and using National data there is a statistical difference (p<0.05) between families who care for children with disabilities and those that do not across all emotional hardship categories.

EMOTIONAL HARDSHIP AND THE UTILIZATION OF HEALTH CARE SERVICES

Children with disabilities access health care services at a much higher rate than those without disabilities. These health demands place strains on the family with coordination of health care requiring additional investments of time, patience, and resources. If the parent is employed, a flexible schedule may be essential to meet these responsibilities. For parents who are not working, increased insurance copayments and deductibles may be a burden to the family. Table 3 shows that 28% of families of children with disabilities spend 11 or more hours a week arranging or coordinating health care for the child. Additionally, it is estimated that in 30% of families, a parent guit working because of their child's health. Project data suggest that increased utilization of health services is associated with higher levels of chronic stress for parents of children with disabilities

Ideally, both public and private insurance claims would be analyzed to determine health care utilization of children with disabilities. However, only Medicaid claims data was available for this study. Although overall utilization and access to services may not reflect usage patterns of the non-Medicaid population, we believe the general inferences from Medicaid the differences in utilization and data about access patterns approximate privately insured children with disabilities (see Appendix C). Children with disabilities enrolled in Medicaid are disproportionately male, 6-17 years of age, and African-American. For those children with a disability enrolled in Medicaid for at least 12 months, 17% were participating in a Medicaid waiver program. The Medicaid waiver for children with a disability is defined as a supplemental package that offers wrap-around benefit activities/services to families such as homemaker, personal care, and respite services (see full discussion on Medicaid waivers on page 16).



Graph 4: Characteristics of Children with Disabilities in Ohio



Source: FYO9 Medicaid Claims

ACCESS TO HEALTH CARE SERVICES

For the purposes of this study, accessing health care services is defined by the percentage of children who had at least one health care visit for a particular service (e.g. therapy) within a 12 month period. Using Medicaid claims data, we examined access to health care services using the categories of primary care (e.g., general medical visits), specialty care (e.g., physical therapy, speech and occupation), dental care, and mental health. Lack of appropriate care can lead to health complications and emotional stress by placing additional resource demands on the family.

All Ohio children have relatively good access to primary care (Graph 5-A). However, Medicaid-enrolled children have much less access to dental care, with fewer than 46% of children with disabilities having visited a dentist within the past 12 months, compared to 37% of children without a disability. Given the rate of physical problems for children with disabilities, the therapy use rate is much higher for Medicaid-enrolled children than for children without disabilities (Graph 5-B).

As with physical health, Medicaid-enrolled children with disabilities access mental health services to a much greater extent than Medicaid-enrolled children without disabilities. Graph 5-A shows that children with disabilities are more than two times more likely than children without disabilities to access nonhospital mental health services. Emotional and behavioral problems are prevalent in children with certain developmental disabilities and present a significant burden for families. Research indicates that young people with developmental disabilities have about three times as much psychiatric disturbance as children of average intelligence (Rutter, Tizard, & Whitmore, 1970; Corbett, 1979).

The mental health needs for children with disabilities are complex. Organic, psychosocial, and environmental factors contribute directly

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. I'm trying to look for more help so I can take him to go get speech and occupational, and all that stuff.

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

and indirectly in the etiology of mental health problems for children with disabilities (Bradley et. al., 2007). Children and adolescents with developmental disabilities are more likely to have a range of physical and sensory impairments and medical illnesses. These children are also more likely to have medical illnesses or brain abnormalities such as:

(1) Epilepsy, which is associated with psychiatric disorder (Tonge, 1991);

(2) Autism, which is associated with a range of medical conditions such as tuberous sclerosis and other psychiatric conditions such as Tourette syndrome (Prior & Tonge, 1990), and concurrent psychiatric disorder (Bradley, Bolton, & Bryson, 2004); and

(3) Genetic syndromes associated with intellectual disabilities (e.g., Williams, fragile X, and Prader-Willi syndromes), which confer greater risk for psychiatric disorder (Dykens, Hodapp, and Finucane, 200).

Finally, children with developmental disabilities have higher rates of inadequate social and coping skills (Bradley et. al., 2007).



Graph 5-A: Access of Health Care Services for Children on Medicaid



Graph 5-B: Access of Therapy Services For Children on Medicaid



Source: FY09 Medicaid Claims

Source: FY09 Medicaid Claims

HEALTH CARE ACCESS OF CHILDREN WITH DISABILITIES

show variance in health utilization and access patterns - specifically between waiver enrollees and non-waiver enrollees.

Graph 6 depicts differences in access to health care between children with disabilities with and without a waiver. The graph shows:

• Non-waiver children accessed primary health care and dental services at a higher rate than those receiving waiver services; and

Graph 6: Health Care Access of Medicaid Children with **Disabilities**



WHAT IS A MEDICAID WAIVER?:

State Medicaid programs are required to meet certain program conditions established by the federal government. Some of these conditions (e.g. universal access to services for qualifying individuals) are exempted/waived for federally approved waiver programs. Waiver programs usually provide services to people who would otherwise be in an institution to receive long-term care. There are many factors that determine a person's eligibility for a waiver, such as the type and extent of their disability, the prognosis, and financial assets. The array of services offered through a waiver almost always includes homemaker and personal care. There are three primary waiver programs for children with disabilities in Ohio: (1) the Individual Options (I/O) waiver and (2) the Level I waiver, both managed by the Ohio Department of Developmental Disabilities, and (3) the Ohio Home Care waiver, managed by the Ohio Department of Job and Family Services. In FY09 17% of Medicaid enrolled children with a disability received waiver services.

Children enrolled in Medicaid with disabilities • Children on waivers are twice as likely to access mental health services than non-waiver children.

> An explanation for why waiver children differ from non-waiver children in health care usage could be attributed to better case management or consistent preventive care. Additionally, there is a gap between mental health services for waivers and non-waivers (41% to 22%). The research team is not sure of the factors influencing this gap.



HEALTH CARE UTILIZATION INTENSITY

The study defines health care intensity as the number of encounters an individual incurs over a period of a year for a specific health care service. Only those individuals who accessed a specific service at least once during the year were included in this analysis. Table 5 details the average number of visits and the percent of children with a disability who visited a health care practitioner more than 12 times during the year. The table shows:

- Children with disabilities utilize primary care, mental health and therapy services more intensively than children without disabilities;
- Children on a waiver with disabilities utilize primary care more intensively; and
- Children on a waiver with disabilities use mental health services less intensively.

Conceptually, one would anticipate that Medicaid enrolled children with disabilities would utilize health care services more intensively than Medicaid enrolled children without disabilities because of their underlying physical and mental health care needs. Table 5 confirms this with a difference rate of 1.3 times for general medical office visits, 1.5 times for mental health visits, and 1.8 times for physical therapy visits. For children with disabilities, the range of services between waiver and non-waiver children are less patterned, with waiver children having 2.5 times more office visits and non-waiver children have 1.1 times more mental health visits, and physical therapy visits were equivalent.

In terms of intense utilization, defined as 12 or more visits within a year, the children with disabilities use the health care system more than children without disabilities by a rate of 4.5% for office visits, 5.7% for mental health services and 6.4% for physical therapy.

For non-wavier versus waiver children with disabilities who intensively seek services, the pattern of intensity is mixed, with 6% of waiver children having more office visits and 17.2% of non-wavier children having more mental health visits - physical therapy visit were approximately even.

The higher use of primary care visits by the waiver population is curious, since this population is already receiving regular case management services. One would think the use of physician services would be comparatively less.

		_			Disab	ility			
	No Disab	ility	All		No W	aiver*	Waiver		
	Average		Average		Average		Average		
	Number of	Percent	Number of	Percent	Number of	Percent	Number	Percent	
	Visits	>12 Visits	Visits	>12 Visits	Visits	>12 Visits	of Visits	>12 Visits	
Office Visit	5.59	7.2%	7.39	11.7%	6.81	10.7%	10.8	16.7%	
Mental Health	20.81	38.1%	30.32	43.8%	30.86	45.5%	27.1	28.3%	
Physical Therapy	3.14	4.7%	5.77	11.1%	5.77	11.4%	5.78	10.6%	

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Source: FY09 Medicaid Claims

HOSPITAL SERVICES

A Robert Wood Johnson Foundation sponsored study notes that a high number of chronic conditions correlates with increased inappropriate hospitalizations (www.rwif.org, 2010). Children with disabilities often have multiple chronic conditions, which makes them susceptible to unnecessary service utilization, including trips to the emergency room and admissions to hospital. Poor coordination between service providers often forces families of children with disabilities into using hospitals as a provider of last resort. For these families. preventable hospital visits can increase time constraints, out of pocket expenses and emotional stress.

Graph 7-A and 7-B examine hospital utilization among non-waiver and waiver children with and without disabilities - the analyses categories are those who had a least one emergency room visit or an overnight hospital admission within a 12 month period. Graph 7-A and 7-B show:

• Children with disabilities are much more likely to have an emergency room visit or hospital admission than non-disabled children, regardless of age; and

• Children with disabilities under 5 years of age and on a waiver are twice as likely to have a hospital admission than children without disabilities.

The relatively high emergency room use for children with disabilities, with and without a waiver, might relate to a lack of primary care physician or specialist access (Lishner et. al., 1996). Hospital admissions are also higher for children with disabilities. Of special concern is that hospital admissions are so much higher for children with disabilities on waivers. Even after adjusting for diagnoses that are associated with preventable hospital admissions, it was found that the hospital admissions were much higher for this group. Children on waiver programs receive case management services for their long-term care needs (The Pediatric Quality Indicators Technical Report, 2006). If these case management services were integrated with case management services for preventive, primary and acute care (which are not available for waiver children), then emergency room visits and hospital admissions might decrease.





Source: FY09 Medicaid Claims





Source: FY09 Medicaid Claims

SUMMARY

Raising children with a disability can be an enlightening experience that brings families together, but often can be associated with overwhelming stress. In part, stress can be attributed to the lack of financial and employment security, and emotional and social support. These stresses are driven by time and resource requirements to care for a child with disability.

This study has demonstrated that families caring for children with disabilities have lower incomes than families who have similar characteristics but who care for children without disabilities. For many, lower income is partly due to cutting back on the number of hours worked, for others a cacophony of reasons related to providing necessary care for their disabled child underlies lower income. The reduction of income coincides with increased health care expenditures. Families caring for children with disabilities are more likely to incur financial hardship at a higher rate, exacerbating stresses due to financial realities.

There is also a gap in the level of emotional and social support between families with and without children with disabilities. The accumulation of stresses of all types impact the well being of the parents and families as a whole.

There are many successful public programs in Ohio that assist families caring for children with disabilities. The Ohio county boards of developmental disabilities provide services to over 80,000 individuals with disabilities and their families. Over 15,000 individuals with disabilities are being served by some kind of Medicaid waiver. These services, offered at the state and local levels, provide tangible assistance to children with disabilities and their families.

POLICY DISCUSSION

Findings from this study suggest three overarching policy implications:

• Lessen Stressors: Lessening stressors related to caring for children with disabilities will result in relief on family income, lessened family emotional turmoil, better parental employment opportunities, and less community burden. There is room for improvement in helping families who care for children with disabilities to lessen levels of stress. Of notable consideration are: 1) Promote greater workplace flexibility for working parents who also care for a child with disability; 2) Adopt a savings approach to very high health care expenditures; 3) Foster community or withinfamilies caring for children with disabilities support systems; and, 4) Develop stress coping strategies for families caring for children with disabilities that engages nuclear and extended families.

• Medical Home: Improved health care coordination and the delivery of familycentered health care services for children with disabilities will: 1) Structure parents' time and resource utilization more efficiently by aligning the child's health care needs in a staged and systematic fashion; 2) Potentially lessen unnecessary or inappropriate emergency department use or hospital stays by helping assure that primary health care visits are attended and quality care is received; and, 3) Offer prevention strategies related to family stress.

• 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. Such an inventory should be inclusive of state and local government and private resources and efforts and should include the matching of resources to health and economic risks. An expected impact of a comprehensive tracking system would include: 1) Better detailed information concerning the relationship of resources to outcomes; 2) Establishing of risk zones for Ohio for children with disabilities and their families (e.g., cluster of risks and service gaps), and 3) Identifing best practice information from other state programs that provide services for children with disabilities.

Families overwhelmed by care giving demands suffer chronic stress, which negatively impacts the parents' physical and mental health and impedes their ability to provide care for their child. Conversely families that have a better life balance are more likely to have children who have relatively better health outcomes. Relatively modest efforts that offer support groups to parents with children with disabilities could be of great benefit to families. Overall, it is felt that actionable policy directed at lessoning stressors and ensuring that children with disabilities are provided health care within a medical home will go a long way in bridging the well-being gap between families who care for children with and without disabilities.

NEXT STEPS

A Phase II of Caring for Children with Disabilities would include: 1) the development of a comprehensive research-backed model measure program and intervention to effectiveness; 2) applied recommendations concerning the potential expansion of respite services, parental stress coping training, and care coordination models for children with disabilities; 3) the development of a statewide children with disabilities health system coordination system; and 4) more thorough analysis of income gap needs through a qualitative exploration of income stressors.

First, the development of a comprehensive model of family stress is proposed in order to identify and measure effective programs and interventions that have been demonstrated to reduce stress. The model would identify characteristics of families who are most likely to benefit from reductions in stress through workplace flexibility and those who are most at risk of being unable to regularly provide care for their children with disabilities. Both types of families could be targeted for services. Best evidence and practices can be identified from programs implemented in other states.

Second, an analysis using literature, stakeholder interviews, and Ohio-specific data would examine the pros and cons of expanding respite and expanded direct services through Medicaid waiver mechanisms, and would craft a strategy for the expansion of parental trainings, and care coordination best practices.

Third, an electronic tracking system for children with disabilities that would examine health system coordination for these children and their families could be developed - standardizing throughout Ohio's 88 counties the data flow relating to services provided to children with disabilities and their parents.

Fourth, most of the information gathered in this white paper concentrated on children with disabilities and their parents. A subpopulation not examined is siblings. It is proposed that siblings of children with disabilities be examined relating to physical, social, and emotional function, as compared to siblings of non-disability children.

Finally, although this paper shows a clear association between income and caring for children with disabilities, a precise estimate between income and caring for children with disabilities cannot be specified. The factors involved in the dynamics that result from these income gaps need to be examined in order to address specific areas of financial risk for families of children with disabilities.

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Appendix A. Definitions of Disability

For the 2008 OFHS, 2007 NSCH, and 2005/06 NS-CSHCN, a child with disability is defined as a child that is limited or prevented in any way in his or her ability to do the things most children of the same age can do as identified on the children with special needs screener (CSHCN Screener®). Based on results from the 2005/06 NS-CSHCN, seven out of eight children with a disability using this definition have at least one of the follow conditions or difficulties:

i) Autism ii) Down Syndrome iii) Mental Retardation (actual guestion wording) iv) Heart Problems v) Blood Problems vi) Cystic Fibrosis vii) Cerebral Palsy viii) Muscular Dystrophy ix) Seizure Disorder x) Migraine or Frequent Headaches xi) Joint Problems xii) Hearing Even with a Hearing Aid xiii) Seeing Even with Glasses xiv) Breathing xv) Swallowing, Digesting, or Metabolism xvi) Blood Circulation xvii) Repeated or Physical Pain

For the 2008 ACS, a child with disability is defined by the US Census Bureau as a child aged 0-17 years who has sensory (blind or hearing impaired) disability. In addition, children aged 5-17 who have physical, mental, or self-care disability, and aged 16-17 who has limitations going outside the home or gaining employment are also categorized as having a disability.

For Medicaid claims data a child with disability was defined as any child who qualifies for disability status under the Medicaid program. To qualify for disability status under the program a child must:

• have a physical or mental condition(s) that very seriously limits his or her activities; and

• have condition (s) that have lasted, or are expected to last, at least 1 year or result in death.

Appendix B. Estimated Parental Income Methodology

Using the 2008 ACS parental income was constructed as the income earned by parent, step-parent, or guardian and their spouse or cohabitating partner. At most two individuals comprise the total parental income.

Estimated parental income was derived from the following statistical regression model:

ln(parental income) = _0 + _1 (disability)+ _2 (family structure labor force participation) +

- _3 (disability X family structure labor force participation) +
- _4 (number of children in family) +
- _5 + (age of older parent) + _6 (race/ethnicity category) +
- _7 + (highest education level of parents)

where (referent class in bold where applicable):

disability = 1 if household has at least one child with a disability 0 otherwise

family structure labor force participation =

- 1 if parental couple and both parents in labor force
- 2 if parental couple and only father in labor force
- 3 if parental couple and only mother in labor force
- 4 if parental couple and neither parent in labor force
- 5 if single parent and father in labor force
- 6 if single parent and father not in labor force
- 7 if single parent and mother in labor force
- 8 if single parent and mother not in labor force

number of children in family = continuous variable, range 1 to 5

age of older parent = continuous variable, range 16 to 94

- race/ethnicity category = 1 if referent parent is White (non-Hispanic) 2 if referent parent is black (non-Hispanic) 3 if referent parent is Hispanic 4 if referent parent is Other race or ethnicity
- highest education level of parents = 1 if less than high school
 - 2 if high school or equivalent
 - 3 if some college or Associate's degree
 - 4 if Bachelor's degree
 - 5 if Master's degree or higher

Appendix C. Financial and Emotional Information Methodology

2008 Ohio Family Health Survey (OFHS)

OFHS is a statewide, random digit dial telephone survey of over 51,000 Ohio residents. OFHS used a stratified, list-assisted sampling frame that sampled respondents using random digit dialing computer assisted telephone interviewing (CATI) methods. The sample was stratified by county with several additional samples. The six largest metropolitan counties were sub-sampled to ensure greater representation of African Americans. Additional targeted supplemental samples were drawn to ensure good representation of Asian and Hispanic residents. Over 13,000 children, including 2,600 who were determined to have a special health care need, were included in the sample. The 2008 OFHS contains the most recent state-level information we have on CSHCN. Data from the 2008 OFHS were used in this survey to compile profiles of children with disabilities and the Ohio families who care for them.

These data also provide the basis for comparing the financial stressors of paying for medical bills between families who care for a child with disability and those who do not.

2007 National Survey of Children's Health (NSCH)

The NSCH provides information about the health of the nation's children including CSHCN in all 50 States and the District of Columbia. Within each state, telephone interviewers were conducted with at least 1,700 households, with one child per household profiled. The emotional stressors of Ohioan parents who care for children with disabilities was compared with those of parents who care for children without disabilities.

2005/06 National Survey of Children with Special Health Care Needs (NS-CSHCN)

The NS-CSHCN provides information about the health of the nation's CSHCN in all 50 States and the District of Columbia. Within each state, telephone interviewers were conducted with approximately 750-850 households with a CSHCN. Questions included the extent of out-of pocket expenses, other negative financial events, employment changes required to care for a CSHCN, and the amount of time coordinating health care of the child. For Ohio, children with disability were identified and the frequency distribution of their parents financial and employment stressors were determined.

FY09 Medicaid Claims Data

Medicaid claims were used to measure health care utilization of disabled children and non disabled children for the time period July 1, 2008 through June 30, 2009 (FY09), the latest time period for which information is available. Medicaid claims are often used as an overall population measure of health care services for the general population. For the purposes of this study, it is believed that the health care utilization patterns of Medicaid eligible children mirror that of the general population. Only children 17 years and younger who were on the Medicaid program for the entire year were included in the analysis. For the FY09 period, there were 24,185 disabled and 745,065 non disabled Medicaid eligible children who were enrolled all 12 months of the year.

Focus Groups:

A total of twenty family members participated in the three focus groups. Participants were mostly mothers, but fathers, grandparents, and siblings also participated in the two-hour groups. Three focus groups were held in urban (Columbus) and rural (Hocking County) locations and were video-taped. The quotes provides throughout this paper were drawn from the transcribed video-tapes. Family members participated who had children with a wide range of disabilities and special health care needs including autism spectrum disorders, epilepsy, and intellectual disabilities of a variety of etiologies, traumatic brain injury, cerebral palsy, and mental health problems. Focus group participants were given gift cards to a local grocery store in appreciation of their time and candor.

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