

OHIO FAMILY HEALTH SURVEY

POLICY BRIEF

Stressors Associated with Caring for Children with Complex Health Conditions in Ohio

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In Ohio, an estimated 302,598 children 0-17 years of age either have a functional limitation (children who are limited or prevented in any way in their ability to do the things most children the same age do) or a developmental, behavioral, or emotional problem that requires ongoing treatment or counseling. These children with complex health conditions (CCHC) represent 12.3% of all children in Ohio in 2010.

Caring for CCHC requires an increased commitment in time and financial resources impacting all members of the family, especially parents. Parents caring for children with complex health conditions report high levels of stress, distress, emotional problems, and depression, as well as diminished rates of overall quality of life compared to parents caring for typically functioning children (non-CCHC).

The goal of this study is to understand and increase the knowledge of how caring for CCHC impacts the stress placed on parents in Ohio. All statistical model results control for child and parent characteristics. When statistical power permits, statistical models include both children with functional limitations and those with developmental, behavioral, or emotional problems, instead of the aggregated CCHC categorization.

Stressors

Table 1 presents a list of financial, economic and psychological (Kessler 6) stressors for parents caring for CCHC and non-CCHC.

Across all 15 stressors listed, parents caring for CCHC have a higher probability of incurring stress compared to parents caring for non-CCHC.

Table 1. Ohio Parents Caring for Children Stressors (% Responding YES) by CCHC Status

Stressor	CCHC	Non-CCHC
Financial		
1. Problems paying or unable to pay for medical bills	48.7	35.2
2. Unable to pay for basic necessities	27.8	12.6
3. Used up most of personal savings	35.2	21.8
4. Had large credit card debt or had to take out loan to cover bills	12.9	10.4
5. Has to declare bankruptcy	6.8	4.8
Economic		
6. Problems paying rent, mortgage, or utility bill	44.4	27.1
7. Received financial help to pay rent, mortgage, or utility bill	16.2	8.5
8. Children moved in with others due to inability to pay bills	10.1	5.2
9. Savings will not cover paying bills for 6 months or more	84.9	74.4
Psychological (responded feeling this way all or most of the time in the last 30 days)		
10. Sad	14.4	6.8
11. Nervous	16.4	8.1
12. Restless or fidgety	23.7	9.3
13. Hopeless	10.9	5.4
14. Everything is an effort	23.0	15.6
15. Worthless	7.4	3.2

Note: Percentages represent weighted population estimates.

Table 2 presents the likelihood that parents caring for children with functional limitations and developmental, behavioral, or emotional problems experience more stress than parents caring for non-CCHC. Children that have both functional limitations and developmental, behavioral, or emotional problems are categorized as having functional limitations.

Table 2. Likelihood of Experiencing Stressor for Parents Caring for Children with Functional Limitations or Developmental, Behavioral, or Emotional Problem Compared to Parents Caring for Non-CCHC (AOR)

Stressor	Functional Limitations	Developmental, Behavioral, Emotional Problems
Financial		
1. Problems paying or unable to pay for medical bills	1.4	1.8
2. Unable to pay for basic necessities	2.7	2.0
3. Used up most of personal savings	2.0	1.7
4. Had large credit card debt or had to take out loan to cover bills	2.0	0.9
5. Has to declare bankruptcy	1.2	1.3
Economic		
6. Problems paying rent, mortgage, or utility bill	2.4	1.3
7. Received financial help to pay rent, mortgage, or utility bill	2.1	1.1
8. Children moved in with others due to inability to pay bills	2.1	1.8
9. Savings will cover paying bills for 6 months or more	2.2	1.4
Psychological (responded feeling this way all or most of the time in the last 30 days)		
10. Sad	2.7	1.4
11. Nervous	3.5	0.7
12. Restless or fidgety	3.1	1.8
13. Hopeless	3.3	0.9
14. Everything is an effort	1.0	1.8
15. Worthless	2.6	1.1

AOR = Adjusted Odds Ratio

Note: Red bolded AOR indicates statistically significant difference at $\alpha=0.05$.

Parents caring for children with functional limitations (or functional limitations and developmental, behavioral, or emotional problems) are more than twice as likely to experience most economic and psychological stressors compared to parents caring for non-CCHC.

Parents Experience Patterns of Stresses

Latent class analysis is used to determine whether particular patterns of stresses are triggered simultaneously in parents caring for children. Almost two-thirds of parents caring for children respond to having very little or no stress of any kind (assigned to Latent Class 3). One-quarter of the remaining parents have a higher probability of experiencing higher than average financial and economic stress but very low levels of psychological stress (assigned to Latent Class 2). One in ten parents was assigned to Latent Class 1, indicative of having a very high probability of responding YES to many financial, economic, and psychological stressors concurrently (Table 3).

Compared to parents caring for non-CCHC, parents caring for CCHC were 2.0 times as likely to be assigned to Latent Class 2 as Latent Class 3 and 3.4 times as likely to be

assigned to Latent Class 1 as Latent Class 3. This demonstrates that overall, parents caring for CCHC are more likely to have many concurrent stressors compared to parents who care for non-CCHC.

Table 3. Probability of Responding YES to Stressor Given Latent Class Assignment

Stressor	Overall	Latent Class		
		1	2	3
Financial	Yes	10.2%	24.9%	64.9%
1. Problems paying or unable to pay for medical bills	37.0	67.0	100.0	7.5
2. Unable to pay for basic necessities	14.5	42.2	40.2	0.0
3. Used up most of personal savings	23.5	49.7	73.1	0.0
4. Had large credit card debt or had to take out loan to cover bills	10.7	19.0	34.6	0.0
5. Has to declare bankruptcy	5.0	13.3	14.6	0.0
Economic				
6. Problems paying rent, mortgage, or utility bill	29.3	66.1	53.7	13.8
7. Received financial help to pay rent, mortgage, or utility bill	9.5	20.9	16.9	4.7
8. Children moved in with others due to inability to pay bills	5.8	24.7	7.7	2.1
9. Savings will cover paying bills for 6 months or more	75.7	91.7	89.5	67.7
Psychological (responded feeling this way all or most of the time in the last 30 days)				
10. Sad	7.8	60.4	1.3	1.9
11. Nervous	9.1	69.1	3.4	1.7
12. Restless or fidgety	11.1	71.7	8.0	2.7
13. Hopeless	6.1	52.1	2.9	0.0
14. Everything is an effort	16.5	74.5	14.4	8.1
15. Worthless	3.8	35.6	0.2	0.0

Labels for Latent Classes

- 1: High Financial Stress, Very High Economic and Psychological Stress
- 2: Very High Financial Stress, High Economic Stress, Low Psychological Stress
- 3: **Very Low Financial, Economic, and Psychological Stress**

Serious Depression

Using a composite score from the Kessler 6, we are able to conclude that parents caring for a child with functional limitations are 4.2 times as likely to be classified as having serious depression compared to parents caring for non-CCHC.

Mental Health Needs

Compared to parents caring for non-CCHC, parents caring for CCHC are at least 2.3 times as likely to need treatment or counseling for mental health, substance abuse or an emotional problem.

Psychological Stress Levels in Medicaid Parents

With only one exception (feeling sad), parents caring for CCHC with Medicaid insurance have higher levels of experiencing all psychological stressors all or most of the time compared to parents caring for CCHC with job-based coverage (Graph 1).

Respite Care

One manner to curb increased levels of stress in parents caring for CCHC is the provision of respite care. Respite care is defined as “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 sometimes relief, to people responsible for care of an ill or disabled person who ordinarily lives in their household.

As a coping mechanism for caregiver stress, respite care has been demonstrated to produce significant reductions in stress levels. Regardless of a child’s disability, respite is a needed support service for families caring for CCHC. Respite care may also be considered an intervention for child abuse, especially for those children suffering from challenging behaviors.

Policy Recommendations

Medicaid waivers are offered through the Ohio Department of Job and Family Services (ODJFS) and administered by county-level Ohio Department of Developmental Disabilities (DODD) agencies. Respite care, offered through Medicaid waivers, for children and their parents, is a less expensive alternative than institutionalizing a severely disabled child and a proven service to help lower the level of chronic stress in parents (and the subsequent negative health effects associated with chronic stress).

The following are recommendations to incrementally build on existing Medicaid waiver policies and programs to help decrease the level of stress in parents caring for CCHC:

- Among existing waiver holders and those on waiting lists, conduct a thorough needs assessment for respite care that is incorporated as part of a medical home.
- Compile an inventory of existing respite care-givers to gauge the impact on the existing respite care labor force prior to the expansion of respite care benefits under public programs. Respite care must be able to be accessed in a timely manner.
- Based on the results of a needs assessment, increase the allocation of respite care dollars available through the Medicaid waiver programs. If remuneration for formal respite care is a barrier to the supply of respite care, increase remuneration rates.
- Partition the benefits component of waivers to include the provision of respite care before full-benefit coverage waivers are secured.
- Evaluate the benefits of respite care through demonstration projects.

Graph 1. Psychological Stressors by Health Insurance Status

