FACT SHEET | MN LEND Program

FAMILY CAREGIVERS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS: THE NEED FOR CAREGIVER SUPPORT AS TRULY FAMILY-CENTERED CARE

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Background: Caregiving and Life Course

In families with children and youth with special health care needs (CYSHCN), the family caregiver provides daily support above and beyond the role of typical parenting. This support includes care management, monitoring the child's condition, advocating on behalf of the child in a variety of settings (schools, health care, government agencies, and the community), performing therapies and treatments, and administering medicine and medical care.[1-3] In a 2009 report, family caregivers of CYSHCN spend on average 29.7 hours per week providing care, while 24% provide care at least 41 hours per week.[1] As health care costs rise, CYSHCN are increasingly dependent on home-based family caregivers to meet their formal health care needs.[3] Despite this, family caregivers do not receive the training or ongoing support they need from health care systems.[2-3] Family caregivers provide invaluable—and often life sustaining—services for the CYSHCN, however their importance is often not recognized and overlooked.

Family caregivers are unpaid and are often the sole caregiver of the CYSHCN: in addition to any other children they may have.[1-3] Due to the lack of support and resources available to family caregivers, they often provide this care to the detriment of their own health and wellbeing. Research has shown that family caregivers of CYSHCN tend to report their health as fair or poor twice as much as the general population and one-in-four believe that caregiving has made their health worse.[1] In addition, family caregivers often deal with physical and emotional strain, financial issues, lack of social support and loss of relationships, marriage strain, stress, and feelings of loss and grief for what they dreamed their life and future—and the life and future of their child—would be like.[1-3] The poor health of family caregivers not only impacts the caregiver, but also affects the ability of the caregiver to adequately care for the CYSHCN, to be a parent to that child and to any other children she/he may have, and to be a partner to her/his spouse or significant other.[1-3] Therefore, the lack of support—informational, financial, emotional, physical—for family caregivers of CYSHCN affects the entire family system including the CYSHCN.

When the U.S. government, programs, providers, and health care insurers fail to recognize the importance of family caregiver support, the family caregiver lacks important supports—respite care, time, mobility, money, and supportive networks—which reduce her/his ability to self-care with personal health visits, mental health services, support groups, social

What is the Life Course Perspective?

http://mchb.hrsa.gov/lifecourse/

The Life Course Perspective views health on a continuum in which biological, environmental, social, behavioral, and psychological factors interact to impact an individual's health throughout his/her lifespan. It builds on recent public health and social science literature that states that each stage of life influences the next and that the social, physical, and economic environments interact across the lifespan, profoundly impacting the health of the individual, the family, and the community.

support, and personal time to de-stress.[3-4] This impacts the health and well-being of the CYSHCN and the entire family throughout the life course.

Issues, need, and facts

- According to a 2009 report by the National Alliance for Caregiving, there are 16.8 million unpaid family caregivers of CYSHCN in the U.S.[1]
- Family caregivers provide vital care management, transportation services, social support, socialization, advocacy, medical treatment, therapies, and services for their CYSHCN that have great impact on their overall health and quality of life. Because family caregivers are often the primary and/or sole caregivers to their CYSHCN, the physical, mental, and emotional health and wellbeing of the family caregiver impacts how they provide care and thus the physical, mental, and emotional health and wellbeing of the CYSHCN.[1-3]
- Having a family member with complex medical needs impacts more than the current physical, mental, and emotional health and wellbeing of the caregiver, it impacts the health and wellbeing of the entire family. Also, as events from one stage of life influence later stages, it is important to note that lack of appropriate and timely family supports and resources can dramatically impact the life course of each family member.
- As family caregivers are not the "identified patients" there is often little to no evaluation of their health or well-being by health and mental health providers.[5]
- A 2004 Canadian study of family caregivers of children with cerebral palsy found that the family caregivers had very high self-reported stress and almost one-third had three or more chronic health problems themselves.[6]
- In 2009, 64% of family caregivers of CYSHCN reported physical strain, 34% reported high emotional stress, 60% reported lack of time for other family members and friends, and 27% reported strong financial hardship.[1]
- In the 2005-2006 National Survey of Children with Special Health Care Needs, 57% of family caregivers of more complex CYSHCN reported having health care-related financial issues and 46% reported paying more than $1000 annually in out-of-pocket health care costs. Additionally, 46% of these families needed additional income for medical expenses, whereas 54% of these families had a family member stop working to care for the child's health and 45.6% cut back on working.[2]

- In the 2009 study, researchers found 70% of family caregivers of CYSHCN were employed at some point while they were caregiving with 53% currently employed (35% full time and 18% part-time), 12% unemployed and looking for work, 8% disabled, 7% retired, 4% students, and 14% homemakers.[1]
- In 2009, 46% of family caregivers of CYSHCN reported they were the sole unpaid caregivers. Additionally, only 35% reported having paid help from aides, housekeepers, or others in the prior year and only 19% used respite services or a sitter.[1]

Promising steps

- In 2005, the Family Caregiver Alliance addressed the fundamental principles for caregiver assessment—service providers can help the entire family of the care recipient by identifying appropriate support services to uphold the physical and mental health of the CYSHCN, the family caregiver, and all members of the family—in a national development conference that developed guidelines for practice, strategies to change the health field acceptance of caregiver assessment, and reimbursement to implement caregiver assessment across disciplines.[4]
- Healthy People 2020 includes the goals of both caregiver surveillance and of creating health promotion programs aimed at improving the health and well-being of caregivers of people with disabilities.[7]
- The Maternal and Child Health Bureau's (MCHB) adoption of the life course perspective lends the opportunity for its Children's Bureau and Title V Program to address a range of factors—including caregiver health—that impact children's (CYSHCN and siblings) health and well-being.[8]
- Patient/Family Navigators are a key component in the Affordable Care Act (ACA), while they have been primarily used in the cancer setting, now are emerging in the CYSHCN setting. The Patient/Family Navigator is a professional who assists patients in overcoming healthcare barriers.

Solutions

- Application of MCHB life course theory as policy in practice to support the family caregiver to mitigate chronic conditions developed by siblings and prevent chronic disease manifestations in parents/caregivers.[8]
- Adoption of the caregiver assessment protocols and recommendations by providers of CYSHCN to identify and provide referrals to appropriate services and supports (family navigator and social worker) for the family caregiver and family in general to help them meet their physical, mental, and social support needs.[4]
- Reimbursement for caregiver assessment as a standard practice of providers caring for CYSHCN by government and third-party payers.[4]
- A family caregiver tax credit of $3,000 to help alleviate some financial strain on families with CYSHCN.[1]
- A voucher program that would pay family caregivers of CYSHCN minimum wage for at least some of their time spent caregiving.[1]
- Coverage of formal and informal respite services—personal care attendants, day programs, caregiver support groups, etc.—by public and private insurance, benefits, government funds, and by local organizations.[1]

DONNA AND AUDREY'S STORY: A MOTHER'S PERSPECTIVE

My beautiful daughter, Audrey Grace, was seriously ill with multiple life-threatening diagnoses for 13 of her 15 years of life. Multiple genetic tests for the suspected mutations, which could verify a diagnosis, were negative. Over many years, the best diagnostic clinical consensus identified autoimmune polyglandular syndrome as the underlying condition.

Life interrupted

Life-threatening diagnoses kept appearing without prediction. Audrey's life was more than a physical life; it was a social life, academic life, and emotional life - all interrupted without our control.

Audrey Grace was born in 1995 and seriously ill from age two onward. In 2009 we were assigned our first social worker. In 2010 three social workers made it apparent to us what range of family needs could be met through their efforts. Due to the years of chronic stress and loss of my child, I continue to have therapeutic visits with one of those clinical social workers.

I know I did the best I could but could have done so much more with much needed education, assessments, and interventions based on clinical social worker recommendations. The rest of my life I will work to advocate for these children until the system recognizes the need to insert into the MCH life course the health of the family caregiver.

Knowledge deficit

For eleven of Audrey's 15 years, I did not know —

- There is a name for children who are very sick (CYSHCN)
- There is a name for parents who cared for very sick children and their siblings (family caregiver)
- Each state has programs for CYSHCN—even if they lack a diagnosis or have a diagnosis not defined as an "eligible" condition
- The term "special needs" applies to the medically fragile or medically complex
- Family-to-family programs are available in every state

Unnecessary suffering

Resources for CYSHCN and their family caregivers would have been available for us had I know any of those points. This means the child with special needs, their family caregivers, and siblings suffer unnecessarily. My experience is not unique. My daughter Audrey Grace died in 2011 at the age of 15 and it is my hope to help other families obtain professional assessments and interventions they not only need, but that are also the focus of national health objectives.

Because so many resources are diagnosis-specific, when there is no confirmed diagnosis, or conditions are medically complex, supportive resources can be evasive. From my experience, no professional is better equipped to deliver this specialized knowledge and follow up than a clinical social worker. A family navigator can also add a unique level of surveillance and support.

Mission possible

For 15 years preserving Audrey's vitality and quality of life was my mission and it was pursued with militaristic diligence and fortitude. Given knowledge of the Life Course Theory, I cannot help but wonder: would earlier interventions for chronic traumatic stress of a chronically ill child and family caregivers have favorably impacted Audrey's outcome? Although I cannot change a thing I did, I certainly can use the experience I gained to help other CYSHCN and their family support system. Families need to be 'fit' for battle. MCH Life Course Theory and HealthyPeople 2020 must follow through with their findings.

My plea

- Educate those involved in the care of these families to have clinical social worker assessments, recommendations, and follow up as a major focus of each and every visit with CYSHCN.
- Establish standards of care consistent with MCH Life Course Theory and HealthyPeople 2020 that require clinical physical, psychological, and social assessments of family caregivers and siblings.
- Provide family navigator assessments and support to all families with CYSHCN whether or not they report social/financial/emotional/health problems to clincial providers.

A PARENT'S PERSPECTIVE

Please don't ask me what I need, rather assess my needs. Offer recommendations and follow up regularly. I was in no position to complain about my own condition and my husband and I did not have a moment to focus on our marriage or our son. I went years without a mammogram or Pap smear. Not because I'm lazy, but because my scheduled appointments had to be cancelled to keep abreast of Audrey's urgent needs. During my pregnancies I never gained more than 27 pounds and took it off right away. After years of stress, I added more than double that weight, have high cholesterol, and depression.

This is why family caregivers need automatic supports to assess and intervene and to let us know that we are normal families attempting to grapple with chronic traumatic stress. **We need to be educated about the unavoidable physiological repercussions of chronic stress,**
living with one foot inside a hospital and one foot outside, trying to maintain a full-time job, two medical insurance policies, and attempting to raise healthy children who have firm values. Complaining about my marital problems, inability to sleep at all, or pay bills would only distract from my daughter's medical needs. (It has been two years since Audrey's death and our house is literally falling apart from years without maintenance.)

I sincerely want to acknowledge an amazingly courageous LEND fellow, Jess Nelson, for giving a voice to this critical national need. Also I would like to challenge each reader to implement our suggestions consistent with federal objectives.

MEDICAL PROVIDER CALL TO ACTION

Advice from a family caregiver: Name it and assign a clinical social worker as standard care

Medical professionals who repeatedly encounter these children, families, and siblings in their clinical settings need to give name to their situation (CYSHCN/ family caregiver) so families are aware of resources available to them. When families are assigned to clinical social workers, they can begin accessing information and support. Resources for families of CYSHCN consist of more than just financial and medical supports. Other valuable resources include peer supports (i.e., family navigator), strong community, public health services, and much more.

Step 1: Define ("Name it")

- Chronically/seriously ill children and youth = children and youth with special health care needs (CYSHCN)
- Parents/guardians/siblings of chronically ill children = family caregivers

Step 2: Assign a clinical social worker to the family

Assign a social worker to routinely evaluate —

- the child with special needs
- the sibling(s) of the CYSHCN
- primary family caregivers of the CYSHCN

Step 3: Inform families

Professionals have to tell families what to expect in addition to providing assessments, recommendations, interventions, and follow up. The following is critical information to share with families.

- **Special needs**
  - Can be medical and/or developmental needs
  - Isn't bad, it just means typical care instructions would need to be modified to meet the medical/ developmental needs of the child
  - May or may not include individuals with disabilities
  - May be chronic, permanent, or transient
- **Physiological stress**
  - Signs and symptoms of stress and simple de-stressing techniques need to be explained to families
  - Instead of just listening, ROUTINELY assess the family caregivers' (including siblings') stress level and other signs of stress (i.e. weight gain)
  - Do something about it – i.e. help them get respite care to go and exercise or to have some needed time alone
- **Loss of sleep has physiological effects**
  - Families fear professionals will think they lack discipline or organization if they report they don't sleep, so tell families it's okay
  - Help families with home/ health respite and help them develop a care plan schedule with friends/ relatives
- **Financial problems may be lessened with support—even it's just informational**
  - Families assume providers think they can't take care of their child if they report they're struggling with money so they hide it from providers.
  - If they aren't deemed eligible by one program, help them find another!
- **Siblings are affected**
  - It doesn't mean the caregiver is an unfair parent, but just as a child who lived with a staff of nannies and housekeepers, that upbringing shapes their experiences, so does having a sibling with special needs.
  - Can providers embrace Life Course Theory without intervening with and mitigating sibling stress?
- **"I can't do one more thing" should be the professional's siren**
  - They are overwhelmed, depressed, and need help.
  - Tell them to call their social worker if they feel this way.
  - Don't just make recommendations but assess their need and follow up.
- **Marital problems are expected**
  - Offer suggestions and follow up.
  - Help families arrange respite care even if it's just to shower.
- **Social isolation often occurs**
  - Friends and family don't understand — but other parents do.
  - Professionals can help families get connected to organizations or other programs that have family resources, support groups, etc.
  - Provide family navigator support to connect emotionally with families, identify existing formal and informal supports and resources, provide application assistance when necessary, and help families develop advocacy skills and reduce isolation.

Resources

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