

SURVEY FOR FAMILIES WHOSE CHILD IS MEDICALLY FRAGILE

We thank you in advance for taking the time to fill out this survey. We know this is a difficult subject. A group of service providers and families have created a coalition in Pittsburgh that is working to improve the care of medically fragile children and their families. In order to achieve this mission, we have created a needs assessment survey to document the needs and experiences of medically fragile children and their caregivers. If you have any questions, comments or suggestions, please feel free to contact Yvonne Van Haitisma at the Bayer Center for Nonprofit Management at Robert Morris University at 412-227-6874 or vanhaitisma@rmu.edu.

You can also complete the survey and learn more about the Pittsburgh Pediatric Palliative Care Coalition online at www.pitt.edu/~tbauerlpppc/questionnaire.html. By completing this survey, you will be a part of improving the system!

DEMOGRAPHICS

This section will allow the coalition to discover and address any differences in services to families of various backgrounds (e.g. race, finances, family structures, etc.)

Would you consider yourself: (Check all that apply)

- African American
- Caucasian
- Asian
- Latino
- Multi-Racial
- Other

What is your marital status?

- Married
- Single/Divorced/Widowed

What county do you live in?

- Allegheny
- Beaver
- Butler
- Fayette
- Washington
- Westmoreland
- Other

Household income

- Less than \$25,000
- \$25,001 – \$50,000
- \$50,001 – \$75,000
- \$75,001 – \$100,000
- More than \$100,000

What kind(s) of health insurance did you have in the last year to help pay for your child's health care costs? (Check all that apply)

- Medicare
- Medicaid/ DPA
- Other government health insurance plan (e.g., military, state plan)
- Private health insurance plan
- Other program that pays for medical care
- None. What one reason best explains why?

What is your relationship to the child who is medically fragile?

- Mother
- Father
- Grandparent
- Guardian
- Other

How old is this child?

- Under a year
- 1+ to 3 years
- 3+ to 5 years
- 5+ to 8 years
- 8+ to 11 years
- 11+ to 14 years
- 14 + to 18 years
- 18+ to 21 years

What is this child's diagnosis? (Check all that apply)

- Cancer/Oncology
- Heart/Cardiology
- Lungs/Pulmonology (cystic fibrosis, etc.)
- Gastroenterology (ex. liver failure, stomach/bowel diseases, metabolic diseases, etc.)
- Blood/Hematology (sickle cell, Fanconi's, etc.)
- Neurology (M.S., cerebral palsy, seizures, etc.)
- Rheumatology (systemic lupus, dermatomyositis, etc.)
- Transplants (bone marrow, stem cell, organ, etc.)
- Immunology (immune deficiencies, HIV, etc.)
- Urology/Nephrology (renal diseases, etc.)
- Other – Please specify: _____

Was this child born with this condition?

- Yes
- No

How many siblings does this child have?

- None
- One
- Two
- Three
- More than three

Which of the following services are being received by this child and his or her family in relation to this child's diagnosis?

- Case management/social worker services
- Pain management
- Home health care
- Support group
- Hospice care
- Respite care (short-term, temporary care)
- Spiritual support
- None
- Other – Please specify: _____

Services: We have focused on five service areas for medically fragile children and their families: respite care, long-term care, case management, hospice and end-of-life care. The following sections ask about your experiences with these services.

RESPITE CARE

Have you heard the term “respite care”?

- Yes No

Respite care is short-term, temporary care that the family receives apart from the care provided by the child’s primary caregiver or insurance-allotted nursing hours. Respite care allows time for the primary caregivers to take a break from the daily routine of caregiving. This time allows the caregiver the opportunity to do such things as attend appointments for themselves or for other children, complete chores, attend social functions, or be used in a crisis situation. Respite care can last for a few hours, overnight or for a few days. It can be provided by family, friends or professionals. It can be also be provided in the family’s home or in a facility.

Based on the definition given above, who provides respite care for your medically fragile child when you need to be away or need a break? *(Check all that apply)*

- Extended family member
 Organization/nonprofit
 Day care facility
 Home health care agency
 Other – Please specify: _____
 We don’t use respite care

Based on the definition given above, how many hours of respite care did you **receive** in the past year *(Jan ‘04 – Jan ‘05)*?

Day/Evening time:

- Non-applicable because respite care was not available
 None
 Less than 1 hour/month
 1-2 hours/week
 3-6 hours/week
 12-24 hours/week
 48-72 hours/week
 Full-time assisted care

Overnights:

- Non-applicable because respite care was not available
 None
 1-2 nights/year
 3-7 nights/year
 2-4 weeks/year
 Child primarily lives outside of the home

How much did you **need**?

Day/Evening time:

- None
 Less than 1 hour/month
 1-2 hours/week
 3-6 hours/week
 12-24 hours/week
 48-72 hours/week
 Full-time assisted care

Overnights:

- None
 1-2 nights/year
 3-7 nights/year
 2-4 weeks/year
 Child primarily lives outside of the home

If you have used overnight respite, has it been provided:

- At home
 At relative’s/friend’s home
 In a facility
 Not applicable

How much have you spent for respite care in the past year? *(Jan. ‘04 - Jan. ‘05)*

- 0-\$250
 \$251-500
 \$501-750
 \$751-1000
 \$1,001-1,500
 More than \$1,500
 Not applicable

How did you pay for it?

- Self-pay
 Insurance
 Grant or fund specifically for respite care
 Free service
 Other – Please specify: _____
 Not applicable

If you had easy access to overnight respite at a facility that was dedicated to quality care for medically fragile children and their families, would you use it?

- Yes
 No – Why not? _____
 Not applicable

How many nights a year do you think you would use an overnight respite facility?

- 1-5
 6-10
 11-20
 21-30
 More than 30
 Not applicable

What kinds of restrictions have made it difficult for your family to access overnight respite services? *(Check all that apply)*

- Didn’t know services were available
 No services are available for my child
 Did not accept technology-dependent children (trach, feeding tubes, ventilator)
 Did not accept children with my child’s diagnosis of: _____
 Too old – Age _____
 Too young – Age _____
 Lack of money
 Times available weren’t convenient
 Too few allowable days per year
 Agency couldn’t meet demand – not enough personnel
 Didn’t like the set-up of program
 Other – Please specify: _____
 Not applicable

Who referred you or told you about your current respite care services or funds? (Check all that apply)

- | | | |
|---|--|---|
| <input type="checkbox"/> Have never been referred | <input type="checkbox"/> Support group | <input type="checkbox"/> Advertising |
| <input type="checkbox"/> Hospital | <input type="checkbox"/> Caseworker | <input type="checkbox"/> Resource guide |
| <input type="checkbox"/> Doctor | <input type="checkbox"/> Social worker | <input type="checkbox"/> Other |
| <input type="checkbox"/> Another parent | <input type="checkbox"/> My own research | <input type="checkbox"/> Not applicable |
| <input type="checkbox"/> School | | |

LONG-TERM CARE

Total care for a medically fragile child at home can be overwhelming and unmanageable. In some locations in the United States, there are residential nursing facilities dedicated to the long-term care of medically fragile children. The following section is about your experiences and views on a long-term care placement for your child.

Has anyone ever spoken to you about placing your child in a long-term care facility?

- No
- Yes – Who?
- Pediatrician
 - Specialty care doctor (oncology, pulmonology, neurology etc)
 - Nurse
 - Social worker
 - Case manager
 - Other – Please specify: _____

Have you ever considered placing your child in a long term care facility?

- Yes No

Has your child ever been placed in a long-term care nursing facility?

- Yes No

If you had access to a long-term care facility designed expressly for children and devoted to the well being of each child, would you consider placement for your child?

- Yes – Why? _____
- No – Why? _____

Do you believe that you and your child would benefit from the care provided in a long-term care facility for children?

- No
- Yes – For how long?
- A few weeks
 - One month
 - 1 to 6 months
 - More than 6 months
 - For respite care only

CASE MANAGEMENT SERVICES

Case managers provide referrals and coordinate services available. These services come in many forms from many different agencies. This section is about your experiences and views of case management.

Does your child have a case manager?

- Yes No

If yes, what agency is your case manager with?

- Insurance company
- MH/MR agency
- Children, Youth and Family Services
- Other – Please specify: _____

What are some of the limitations of your case manager?

- Only able to assist with issues related to their agency
- Is not familiar with other community services
- Only gives me information about things I specifically ask about
- Other – Please specify: _____

Do you believe more comprehensive case management services are needed for your child?

- Yes No

How could a case management service help you and your child more effectively? (Check all that apply)

- Become involved at time of diagnosis
- Provide continuing service through age 21
- Provide emotional support to me and my child
- Assist with navigating the medical system
- Assist with coordinating all of the services involved with my child's care
- Assist with finding other services (such as respite, support groups, educational resources)
- Other – Please specify: _____

HOSPICE

Hospice programs provide family-centered care to enhance the quality of life of children and their family to the fullest extent possible. Hospice assists the child and family in the decision-making process about services and treatment choices.

Has anyone ever provided information about hospice services?

- Yes No

Are you currently receiving hospice services?

- Yes – How has it been helpful to you? _____
 No

What are your thoughts regarding hospice? _____

END-OF-LIFE CARE

Although end-of-life care issues are a difficult subject, many families must think about what would happen if their child's condition becomes terminal.

Has anyone ever talked with you about the possibility of your child dying?

- No
 Yes – Who?
 Pediatrician
 Specialty care doctor (oncology, pulmonology, neurology, etc.)
 Nurse
 Social worker
 Case manager
 Other – Please specify: _____

Was this conversation helpful?

- Yes
 No
 Somewhat

How? _____

What other services would benefit you, your child or your family?

Please feel free to add any comments.

Thank you for completing this survey. We believe that it will help improve the way the community supports those in similar situations.