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Nursing and Respite Care Benefits

by Susan Agrawal

Moses lives in Pennsylvania and has a GJ tube, congenital heart disease, and some mild motor issues. He receives 84 hours per week of nursing care. Megan lives in Illinois and has a GJ tube and severe cerebral palsy. She is not eligible for nursing care and receives only four hours of respite per week. How can children with such similar levels of need receive such different levels of service?

States are given lots of latitude in creating Medicaid waiver programs, respite programs, and other similar programs. They are able to designate their own criteria for admittance into each program, and there are no federal standards as to what levels of medical complexity, technology dependency, or medical fragility require nursing care and respite. As a result, the amount of nursing and/or respite a child receives varies dramatically based on his or her state of residence and insurance status.

In order to get a better understanding of what services children are or are not receiving, we undertook a brief survey of families who either receive nursing/respite or believe they should receive nursing/respite. Surveys were completed for 95 individual children. Questions were asked to determine how many hours of care each child received, what type of provider worked those hours, and how medically complex each child was.

General Results

One of the questions asked was who pays for nursing and respite. Of families whose children currently receive nursing or respite, the vast majority had their care paid for by some type of Medicaid program. 56 out of 67 (84%) children currently receiving services had them paid for in part or wholly by Medicaid. The vast majority of these children, 39 out of 56 (70%), received services through Medicaid waiver programs, including waivers for children who are medically fragile or technology dependent, Katie Beckett waivers, TEFRA waivers, or waivers for children with developmental or physical disabilities.

Shockingly, only 9 of 67 children had some or all of their services covered by private insurance. Even more appalling is the fact that five families were forced to pay for some or all of their services out-of-pocket. See Table 1.

Table 1: Payers for 67 children currently receiving nursing and respite care. Children may have more than one payer, including more than one Medicaid program.

payer	number	percent
Any Medicaid	56	84%
• Regular Medicaid	21	31%
• Waiver for medically fragile or tech dependent	27	40%
• Waiver for developmental or physical disability	12	18%
Insurance	9	13%
Local/state program	9	13%
Out-of-pocket	5	7%
Charity	2	3%
Hospice	1	1%
Other	1	1%

Families were also asked why they needed nursing care or respite. Most children needed these services for a variety of reasons. Almost all children, 84 out of 95 (88%), received these services due to medical needs, such as having a trach, feeding tube, oxygen, or seizures. More than half of the children, 52 of 95 (55%) also had a physical disability. 87 of 95 children (92%) used some form of medical technology, 90 of 95 children (95%) were at least mildly medically fragile, and 59 of 95 (62%) were fully dependent for all of their activities of daily living (ADLs), such as bathing and feeding. See Table 2.

Table 2: Reasons for nursing/respite care. Most children have multiple needs.

need	number	percent
Medical needs	84	88%
Technology dependent	87	92%
Medically fragile	90	95%
Physical disability	52	55%
Cognitive disability	38	40%
Developmental/behavioral disability	34	36%
Fully dependent for all ADLs	59	62%
Other	14	15%

Children received a variety of different respite and nursing services, and some children received no services. Children were categorized by the highest skill level of the providers who cared for them. Thus, a child who only received respite care from a layperson was placed in the layperson provider category, while a child who received both certified nursing aide (CNA) care and respite from a layperson was placed in the CNA provider category. If a child received any nursing, he or she was placed in the nursing category. See Table 3.

Table 3: Type of providers

type of provider	number	percent
No care	28	29%
Layperson only care	14	15%
CNA care	8	8%
Nursing care	45	47%

Needs Assessment Scores

All participating children received a needs assessment score from 0 to 9 categorizing their level of need. Children could receive 0 to 3 points in each of three categories that are typically used to determine medical complexity: technology dependence, medical fragility, and dependency for activities of daily living (ADLs). Points were awarded as follows:

Technology

- 3 points: high level, such as trach, vent, or central line
- 2 points: moderate level, such as feeding tube or oxygen
- 1 point: low level, such as apnea monitor
- 0 points: no technology

Fragility

- 3 points: high level, frequent hospitalizations, life-threatening events, unstable
- 2 points: moderate level, daily seizures, unstable when sick
- 1 point: low level, needs tube feeds or monitoring
- 0 points: not medically fragile

Dependence

- 3 points: high level, dependent for all care
- 2 points: moderate level, dependent for many needs
- 1 point: low level, dependent for some needs
- 0 points: independent for age

Needs Assessment Score (0-9) = Technology (0-3) + Fragility (0-3) + Dependence (0-3)

Scores were totaled based on parental report for each category. The average score for all children was 5.9 points. See Table 4.

Table 4: Needs assessment scores. Number of children in each group is in parentheses.

group	average score
All children (95)	5.9
Children who received no services (28)	5.7
Children who received any respite/nursing (67)	6.0
Children who only received care from a layperson only (14)	4.9
Children who received care from a certified practitioner (CNA) +/- layperson care (8)	5.5
Children who received care from a nurse +/- CNA and layperson care (45)	6.5

Children Who Received No Services

A large percentage of children, 28 of 95 (29%) received neither respite nor nursing care. Of these, eight children (29%) chose not to participate in a program or receive hours, often after a negative experience with nursing or respite in the past. Two children, both with high levels of needs, were unable to participate in their program due to a lack of staffing. These ten children scored higher than average on their needs assessment, with an average score of 6.4 points.

On the contrary, children who were not eligible for any programs or whose parents were unaware of any available programs scored much lower than average. These children averaged 5.3 points for their needs assessment score. It is important to note that these children still scored higher than the average score of children who received respite care from a layperson (4.9). In other words, most of these children would clearly be eligible for services if they lived in other states.

Of children who received no services, 8 of the 29 children (29%) were high or moderate users of technology, moderately or extremely medically fragile, and dependent for all needs. These children clearly have unmet needs due to their high level of care.

Children Who Only Received Respite Care from a Layperson

Some children, 14 out of 95 (15%) only received a small number of respite hours provided by a layperson with no formal medical training or certification. In general, these children had significantly lower needs, with an average needs assessment score of 4.9. Most of these children had lower scores for technology and medical fragility, but had very significant dependency needs, with 8 of the 14 children (57%) being fully dependent for all ADLs.

With one exception, all of the children received less than 40 hours per week of services. Four children (29%) received 2-8 hours per week, five children (36%) received 9-16 hours per week, and four children (29%) received 17-40 hours per week.

The number of hours children received had little relationship to their level of need. The average needs assessment score for children receiving the least hours (2-8 hours per week) was actually significantly higher than the scores for children receiving either 9-16 hours or 17-40 hours. The average needs score for children receiving 2-8 hours was 5.5, while children receiving 9-16 hours averaged 4.0, and children receiving 17-40 hours averaged 5.3.

In total, children receiving respite care had lower levels of overall need, and had lower levels of technology use and medical fragility. These children, however, still had substantial needs, with the vast majority of them being dependent for some or all of their ADLs. Four children in this group had a total needs score of 7 or above, showing a great need for assistance, and two of these four children only received 2-8 hours per week of care. There are clearly unmet needs among many of these children.

Children Who Receive CNA-Level Care

A small number of children, 8 of 95 (8%), received CNA-level care or CNA care plus care provided by a layperson. Because of the small number of children receiving this type of care, it is difficult to make any judgments regarding these children's needs or hours.

On average, children who received CNA-level care scored 5.5 points in their needs assessment. Children who only received a small number of hours per week, 2-16 hours, had much lower scores, averaging 4.75. On the other hand, children who received a moderate or high number of hours, 17-100 hours, scored much higher, averaging 6.25. In other words, the number of hours received was roughly proportionate to the amount of need for most children.

Once again, children in this category tended to have high levels of dependency for their ADLs, with 6 out of 8 children (75%) being fully dependent for all of their care. Levels of technology tended to be lower, and most children were mildly to moderately medically fragile. Three children in this group, however, had scores of 7 points or above on their needs assessment, demonstrating a great need for assistance. While two of these children received a high number of hours, one only received 9-16 hours per week. In addition, two of these children had high levels of medical technology, such as a trach, vent, or central line, which cannot be cared for adequately or legally by a CNA.

Children Who Receive Nursing Care

Just under half the children, 45 out of 95 children (47%), received some form of nursing care from a licensed or registered nurse. In general, children who received nursing had higher overall levels of need, with the average child scoring 6.5 points, as compared to the overall average of 5.9 points.

Children who received nursing care tended to be both more dependent on technology and more medically fragile than those who did not receive nursing. In addition, the more technology dependent or medically fragile a child, the more likely he was to receive more nursing care hours. Because most children were fully dependent for all of their needs (30 of 45 children or 67%), dependency scores did not vary based on number of hours received. The higher the child's overall needs score, the greater the likelihood that he received more nursing hours. See Table 5.

Table 5: Number of nursing hours received, correlated with average scores for technology use, medical fragility, dependency for ADLs, and overall total score. Children can score a maximum of 3 points for each category, for a maximum of 9 points for the total score.

# hours per week	number of children	percent	avg. technology score	avg. fragility score	avg. dependency score	avg. total score
2-8	1	2%	2.0	1.0	2.0	5.0
9-16	6	13%	2.2	1.2	2.5	5.8
17-40	10	22%	2.1	1.3	2.5	5.9
41-70	14	31%	2.3	1.9	2.3	6.4
70-100	7	16%	2.9	1.6	2.1	6.6
100+	7	16%	2.7	2.7	2.6	8.0

Children who were extremely medically fragile received the highest number of nursing hours and were the group most consistently awarded nursing care, with all but one receiving 70 or more hours. On the contrary, children who were moderately medically fragile were only slightly more likely to receive more nursing care than those who were mildly medically fragile. All children who received nursing care were either moderate or high users of medical technology, and children with high technology needs tended to receive 41 or more hours of nursing per week.

We considered children with a score of 7 points or higher as having the greatest need for nursing care. Children who scored 9 points, the maximum, did receive significantly more nursing than other children, with 4 out of 6 of them (67%) receiving 100 or more hours per week, and the remaining two receiving between 41 and 100 hours. Children with a total score of 8 points also all received 41-100 hours per week. For children who scored 7 points, a wide spread of hours was seen, with two children (14%) receiving more than

100 hours, 7 children (50%) receiving 41-70 hours, 4 children (29%) receiving 17-40 hours, and 1 child receiving 9-16 hours. It appears that states consistently award large number of hours to children with the greatest overall needs (scores of 8 or 9), but those with more moderate needs (scores of 6 or 7) may or may not receive a large number of hours. Children with mild needs, who scored 5 total points or less, rarely received more than 70 hours per week.

Conclusions

While there were definite overall trends correlating medical need with nursing hours in this survey, the results also show that different states handle children very differently.

While children who had the most needs and scored 9 total points all received substantial amounts of nursing care, children who scored 8 points received a wide variety of hours. For example, one child in Missouri only received 2-8 hours of layperson care, a child in North Carolina had 9-16 hours of CNA care, a child in Colorado received 71-100 hours of CNA care, and one in New York had 71-100 hours of nursing.

Children who received moderate scores of 6 and 7 were even more likely to vary in the amount and type of nursing or respite care they received. While children in Maryland and Idaho were not even eligible for programs, children in New Jersey and California received 100 or more hours of nursing per week.

From this survey, it is clear that there is no standard for awarding specific numbers of hours to children with special needs, nor is there any standard practice determining what level of medical professional should provide care to these children. In order to remedy this problem, states need to better agree on how to identify what children are in need of services, and provide appropriate levels of care and service. While in general children with greater needs received more services, especially if they used high levels of technology or were very medically fragile, children with mild and moderate needs received a hodgepodge of services and hours.

This survey also demonstrates that there are many unmet needs for families across the United States. Many children with significant needs received no or few hours of care, and some children were unable to access care due to a lack of staffing or programming in their locale. Many children who did receive hours were only awarded a small number of hours despite significant needs, including high levels of medical technology or medical fragility. In many cases, children only received hours from a layperson or CNA, who is likely unable to fully meet their medical needs, since these individuals often cannot administer medication or perform certain medical procedures.

Some families were unaware of programs available to them. Many states intentionally do not advertise available programs, and many case managers intentionally or unintentionally tell families they do not qualify when they actually do. It is wise to research what programs are available in your state and apply to all of them, no matter if

you fit eligibility criteria. For more information on available programs, see this previous article on Federal and State Assistance Programs [<http://articles.complexchild.com/may2009/00123.html>].

In sum, this survey demonstrates that where you live is more important in obtaining nursing care or respite than your child's needs, particularly for children with mild or moderate needs. This is truly unfortunate and unacceptable. A child's care should not be dependent on the state in which she was born. She should receive adequate and appropriate services no matter where she is located.

**Names changed to protect identities.*