

PAYING PARENTS OF MINOR CHILDREN WITH DISABILITIES TO PROVIDE DIRECT SUPPORT SERVICES

WHAT KIND OF SUPPORT SERVICES?

The most common types of services authorized are Personal Care Attendant (PCA) and In Home Support Services. The goal of these services is to provide the necessary care needed to keep children in their family homes. Services authorized reflect the level of care needed that is ABOVE and BEYOND normal parenting for a child of similar age without disabilities.

WHO RECEIVES THESE SERVICES?

Children with disabilities who have been determined eligible receive authorizations for support services through a variety of Medical Assistance Home Care and Medicaid Waiver programs. Examples of the types of disabilities include cerebral palsy, mental retardation and autism.

WHAT ARE THE CHALLENGES FACING FAMILIES WHO HAVE A CHILD WITH DISABILITIES?

There is a wide gap between services that are authorized and those that are actually received. Children tend to receive significantly fewer services. A number of factors contribute to this disparity:

- ◆ The need for direct service workers far exceeds the availability (For example, in Dakota County in 2000, 78% of PCA hours and 52% of In Home Support hours went unfilled).
- ◆ Families are reluctant to trust the care of their children with disabilities to strangers whose attendance is unreliable, whose turnover rate is anywhere for 50 – 75% annually, and of whom 15% are fired within their first 12 months of employment.

The norm in this country has become the two-income family. However, in two-parent families who have children with disabilities, it is typical that one parent has either had to quit their job, significantly curtail their work hours or been fired as a direct result of the needs of their disabled child. In single-parent families, when the parent is unable to work because of the care needed by their child, the result is devastating.

Giving strangers access to their homes and leaving them alone with their child while they are at work has proven too great a risk. Families have had far too many experiences of workers not showing up for work at all, of providing substandard care if they do, and of being stolen from.

Due to the emotional and financial stresses, the divorce rate for parents with a child with disabilities greatly exceeds that of the general population.

WHO BENEFITS IF PARENTS OF MINORS ARE PAID?

Children with disabilities benefit. Children are able to remain in their family homes. They are cared for by those who love them and who are completely invested in their health and well-being. Parents are the first choice, not the caregiver of last resort.

Entire families benefit because they have a greater chance of remaining intact.

- Tax payers?

Families and the community benefit because the parent who has been unable to work is again gainfully employed and a taxpaying citizen.

HOW DO WE PAY FOR IT?

Services are funded by Medical Assistance. These are not new services for these children. They are the support services that have already been authorized.

WHAT HAPPENS IF WE DO NOTHING?

When the emotional and financial strain on families becomes too great, children are at greater risk of out-of-home placement. Out-of-home placement is expensive. Children grow and develop most successfully in nurturing families. Families are also the most cost-effective alternative.

Families are less likely to remain intact.

Families, particularly single-parent families, are at greater risk of having to rely on other forms of public assistance.

IS THERE PRECEDENCE?

West Virginia and Florida have received permission to use Medical Assistance funds to pay parent of minors. The Consumer Support Grant, a state-funded program in Minnesota, allows parents of minors to be paid.

Concern about fraud is often expressed. However, the truth of that matter is that less than 1% of all fraud is committed by parents. Fraud is committed by provider agencies.

THE LEGISLATURE SHOULD ADDRESS THIS PRESSING NEED BY:

Directing the State of Minnesota Department of Human Services to seek Federal approval to amend the state Medicaid plan to allow Medical Assistance funds to be used to pay parents of minor children with disabilities to provide authorized support that has already been determined to be ABOVE and BEYOND normal parenting.

THE CONGRESS SHOULD ADDRESS THIS PRESSING NEED BY:

Lifting the Medical Assistance restriction on paying parents of minor children with disabilities to provide authorized support that has already been determined to be ABOVE and BEYOND normal parenting.