

Position Statement on the Payment of Parents, Spouses, and Relatives of Children and Adults With Intellectual and Developmental Disabilities in Their Homes

Position Statement

It is the position of The Arc Minnesota that parents of minor children or adult children, as well as spouses or relatives of individuals with intellectual or developmental disabilities, should be paid for services rendered through Medical Assistance programs under the same terms as non-family personal care providers.

People who are part of the natural family support system of an individual with intellectual or developmental disabilities are familiar with the care needs of their loved ones and are often their best caregivers. It should be the decision of the individual and his family whether family members and relatives should provide that care as paid caregivers or not. Paying family or relatives can result in more stability in care, less disruption of families, and some replacement of lost family income. It can also provide a solution to language or cultural issues and increase the likelihood that the family unit will remain intact. When the natural support system falters due to serious financial or emotional strain, out-of-home placement can result. This is significantly more expensive than paying family members the same pay for the same work done by caregivers outside of the family.

Family or relatives that are paid through Medical Assistance should meet the same requirements as non-family caregivers. This includes:

- Being subject to the overall budget of funds allocated for the individual's care;
- A rate of pay equivalent to the current hourly rate set by the State of Minnesota for personal caregivers' from outside the home (including payroll taxes);
- No more than 40 hours per week for any paid caregiver;
- A criminal background check;
- Training as required by the State of Minnesota;
- Submission of time sheets for payment to an approved Fiscal Support Entity which, along with the case manager or county, will monitor compliance.

The community support plan for the individual must provide for enough contact with others outside the family or couple to ensure that the individual is not subject to neglect or abuse, which can occur when one individual or entity has twenty-four control of the individual. (See The Arc Minnesota Position Statement on Twenty-Four Hour Services to Persons With Intellectual and Other Developmental Disabilities.)

Issue

In the past decade, the State of Minnesota has adopted a successful and proactive policy to pay wages to parents, spouses, and relatives for work done to care for their children, spouses and relatives with intellectual and developmental disabilities. These wages are for services provided in the individual's community support plan for their care at home, which keeps them with their family and in the community.

Despite the fact that this policy promotes inclusion and long-term care in the least costly setting, many legislative and administrative entities have sought and continue to seek to prohibit or limit payment of parents, spouses, and relatives through Medical Assistance programs for services they provide to individuals with disabilities in their homes. Parents, spouses, and relatives are expected to limit or give up their jobs in order to stay at home and provide unpaid care for children and adults whose level of care was above and beyond normal care for someone of similar age without disabilities. Medical and therapy appointments and the need to be constantly and instantly available to assist their child at school because of medical or behavioral issues cause many parents to lose their jobs. Spouses and other relatives of adults with intellectual and developmental disabilities are also expected to provide free or partially free care for their loved ones. This causes serious emotional and financial difficulties for families and spouses who lose income and give the families no choice but to trust their vulnerable loved ones to caregivers outside of the family, who often have a high turnover rate and could be unavailable or unreliable. Sometimes, these situations result in more expensive, out-of-home placement when the parents, spouses, or relatives burn out.

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