Arc Minnesota

Legislative
Action Center

The Arc (National) Legislative Action Center

The Arc (National) Minnesota State Action Center

The Arc of Minnesota's Position Statements

The Arc of Minnesota's 2004 Legislative Agenda

The Arc of Minnesota's Mission:

The Arc of Minnesota supports and advocates to secure and enhance opportunities for people with mental retardation and related developmental disabilities and their families to choose how they live, learn, work, and play in their communities.

The Arc of Minnesota is the largest advocacy organization for persons with developmental disabilities in Minnesota with 22 chapters and over 5,000 members throughout the state.

The 2003 legislative session was extremely challenging and during the 2004 session The Arc of Minnesota will work to inform legislators of the impact of legislation that past and work to modify some of the more egregious legislation while laying the groundwork for more substantial changes in the 2005 session.

Lead Role Priorities: (Issues Where The Arc of Minnesota Will Take The Leading Role)

- MR/RC Waiver and Rebasing – The Arc will continue to monitor its federal lawsuit and the management and availability of MR/RC waivered services.
- Parental Fees – The Arc will propose legislation to modify the impact of substantially increased parental fees which threaten the ability of families to continue to receive vital supports through medical Assistance funded services.
- Commitment to Quality. The Arc will strive to improve the quality of our service system by improving the vulnerable adult processes and ensuring a system exists that promotes person-to-person interviews for quality assurance measures.
- Consumer Support Grant Exceptions – The Arc will advocate that families losing this service be a high priority for reuse waiver slots.

- Waiting Lists – The Arc will track waiting lists for the MR/RC, CADI, TBI and CAC waivers.

Co-Leadership: (Issues Where The Arc of Minnesota Assumes a Co – Leadership Role)

- Maintain Commitment to Education for All. The Arc will work to support and strengthen our special education system by supporting adequate funding at both the state and federal levels. The Arc will work to maintain due process rights and informed consent and will inform legislators of the consequences the No Child Left Behind legislation. The Arc will oppose special education vouchers based on the Florida model.
- Medical Assistance Co-Pays. The Arc will work to exempt individuals receiving waivered services from co-pays and to seek relief for other medical assistance recipients.
- Minnesota Family Investment Program and Supplementary Security Income recipients and MFIP work requirements
- Limited Dental Coverage. The $500 restriction is harmful and counter productive.
- Rate Reductions – The Arc will work with individuals with disabilities, families, providers and counties to monitor the impact of this reduction and work to prevent further reductions to services for persons with disabilities.
- ICF/MR's 10% County Share – The Arc will work to overturn this legislation.
- DT& H Mandate – The Arc will work to maintain this mandate.

The Arc will support and/or track the strategies developed by others on the following issues:

- Workforce Issues
- Childcare
- Healthcare
- Transportation
- Fetal Alcohol Syndrome
- MCSHN Funding
- Maintaining state funded disability organizations
- Housing Services for persons with autism
- Medical Assistance for Employed Persons with Disabilities (MA-EPD)
- Administrative Monitoring and Action

(The Arc will be prepared to take a leadership role on the following issues if necessary):

- Waiver Audit Report
- Residential Size
- Public Guardianship
- CCSA Outcomes for Adults
- Extending DHS Licensure to 5 years
- CDCS Waiver Amendment - including paying parents of minors and spouses
- ICF/MR Look Behind Audits

Fair Fees for Families

A Campaign to Reduce the Dramatic Increase In Fees That Families Pay for the
In-Home Supports for Their Children with Developmental Disabilities
Sponsored by The Arc of Minnesota – February, 2004

Proposed Parental Fee Legislation for 2004

➢ *Overview:*

Parents of children with disabilities who receive Medical Assistance (MA) through waivered services, TEFRA, Consumer Support Grants, ICF/MRs, or residential treatment programs were targeted for a huge increase in parental fees following the 2003 legislative session. Families typically received an increase of 200 – 700%. The fee increases have jeopardized the ability of many families to stay on the MA program or provide for the needs of other family members. These services provide assistance to help parents meet the extraordinary demands of raising a child with a disability. The Arc of Minnesota has drafted legislation for the 2004 legislative session that will improve the fairness of parental fees and provide relief for strapped families. ***While the $4 million raised through the fee increases is a very small percentage of the overall MA budget, the impact on this group of families is totally disproportionate to what other citizens are being asked to sacrifice to balance the state budget.***

Minnesota is one of only three states that charges parents of children on MA a parental fee. Parents have paid these fees since 1991 and have contributed significantly to paying for the cost of support services for their children with disabilities. A 1998 study by the Minnesota Department of Human Services entitled *Caring For Our Children: A Study of TEFRA in Minnesota*, reported that 69% of the families on TEFRA also covered their child with a disability under a private health insurance policy. Parental fees are assessed on top of premiums for private health insurance that most families pay. The same study showed that "families with a child on TEFRA spend more than 11% of their adjusted gross income on medical care – *excluding* out-of-pocket expenses for non-disabled family members." The "average" Minnesota family *without* a child with a disability spent about "5.5% of their income on medical care *for the entire family.*"

The ability of many families to pay these increased parental fees is severely challenged by many other factors. The *Caring For Our Children* study found that 64% of families had one or both parents' ability to hold a job affected by the needs of their child with a disability. Many parents reported that they "accepted a lower paying job with more flexibility or fewer demands." Children with mental retardation and related developmental disabilities also require frequent or constant supervision, and many parents and siblings require counseling to deal with the stress that is a part of daily life. ***Minnesota has proudly been a leader in helping to keep children with disabilities living in the family home. Let's work together to maintain this tradition.***

➢ *Parental Fee Campaign Legislation:*

The Arc of Minnesota will be seeking approval for modifications to the Parental Fee requirements during the 2004 legislative session. Parents have paid fees for many years, and have made many sacrifices to do so. Parents have never asked for a "free lunch" or received one. However, ***it is essential that parental fees are reasonable and still allow families to provide for the needs of all family members. The legislation makes the following changes:***

1. **The sliding fee scale would be spread out over a larger range of income levels.**

   Currently, parents pay a fee that is calculated based on a certain percentage of their Adjusted Gross Income. The percentage increases as AGI goes up. The current fee scale starts at 1 percent of income for those at 175 percent of the federal poverty level and increases to 7.5 percent for those at 375 percent of the federal poverty level. The legislation would increase the fee scale more gradually, so that parents would not have to pay the 7.5 percent fee until their income reached 600 percent of federal poverty level.

2. **If the child lives with his/her parent(s), the AGI is reduced by $5000 prior to calculating the parental contribution.**

   This deduction was previously applied to Adjusted Gross Income, and is made consistent with the other change by using Taxable Income. It recognizes the expenses inherent in raising a child with a disability within the family home, which are over and above the costs of a similar child without a disability.

3. **Changing the calculation of household size to include ALL dependents, not just those under age 21.**

   Some families have more than one child with a disability receiving services, including someone who is over 21. They are paying a fee for the child who is under 18. Currently, parents do not receive credit for dependent children with disabilities who are over 21 when family size is calculated for purposes of establishing parental fees. This change would recognize that many families continue to have expenses related to those children, which should be recognized when the fee is calculated.

ISSUE BRIEF: Cuts in MFIP for SSI Families

2/2/04

Background:

The 2003 legislature reduced MFIP grants for households with family members with a disability who receive SSI. Grants are reduced by $125 per month for *each* family member on SSI. SSI, or Supplemental Security Income, is a federal program that provides assistance to adults and children with severe disabilities. SSI grants are approximately $500 per month and are intended to help meet the family's basic needs. Eligibility for SSI is strictly controlled (more than half of initial applications are rejected), meaning that applicants must demonstrate *significant disabilities* to qualify.

More than 6,800 families, including 8,431 people, have been affected by this legislative change. Twenty percent of the affected families have *two or more* family members with a disability, meaning that the average grant reduction is actually $142 per month. Communities of color are disproportionately affected by the legislative changes. Although the majority of families on MFIP are white, Asians and African Americans were impacted more often by the SSI cuts. This was especially true of those households with two or more family members on SSI.

The cuts significantly limit a family's ability to meet their basic needs and care for their family members with disabilities. It can also limit a parent's ability to maintain employment and move off public assistance. The legislative changes mean that the income of a parent with a disability who receives SSI, has one child and is unable to work has been reduced from $805 per month to only $680 per month, a 15% reduction in the family's total income. Now this family is struggling to meet their basic needs on an income of *only $8,160 per year.*

Change Needed:

Restore the full MFIP grant for households with family members with disabilities receiving SSI

Rationale:

- MFIP households with family members receiving SSI are some of the **poorest and most vulnerable families** in Minnesota and should not bear the brunt of solving the budget deficit
- Reducing the income of households that have family members with disabilities **decreases family stability**
- Caring for a person with a disability often has additional costs; reducing MFIP grants to families receiving SSI **undermines the family's ability to care for their relatives with**

disabilities

- Because of these cuts, close to 7,000 families collectively have **$1 million less in their family budgets** each month
- Minnesota is one of only a few states that reduce assistance for households with family members with disabilities; this **sets a bad precedent** and goes against Minnesota tradition of supporting people with disabilities

MR/RC WAIVER PROFILE
AMOUNT CHANGES

PROFILE	June 20, 2000	November 2001	January 2003
Profile One	$306.41	$222.87	$199.20
Profile Two	$256.33	$188.95	$168.21
Profile Three	$182.42	$156.40	$142.58
Profile Four	$122.80	$126.74	$118.72

DHS DATA
Minnesota Disability Law Center
February 3, 2003

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