MINNESOTA
Consortium
OF CITIZENS WITH DISABILITIES

Joel Ulland, Co-chair
National Multiple Sclerosis Society, Minnesota Chapter
200 12th Ave. S
Minneapolis, MN 55415
Phone 612-335-7933
Fax 612-335-7997
julland@mssociety.org

Comprehensive Proposal to Preserve Independence of Minnesotans with Disabilities

The Minnesota Consortium of Citizens with Disabilities, a coalition of more than 40 statewide provider and advocacy organizations committed to advancing the state's public policies and programs for individuals of all abilities, has adopted a comprehensive legislative proposal to guide policymakers during the 2005 Session.

The plan, forged by seven subcommittees and adopted unanimously by all member organizations, is designed to ensure the health, safety, and independence of Minnesotans with disabilities. It recognizes that individuals with disabilities often rely on a complex array of government programs that span multiple state and federal agencies. While many positive advances have been enacted at the state level over the last several years that foster greater economic and social independence and self-sufficiency, continuing budgetary pressures significantly threaten these gains.

Three guiding principles were used in formulating the package: access to needed services; empowerment and choice; and quality of care. Included in the legislative proposals addressing health care, transportation, employment, housing, and education:

- A state-level commission to formulate a plan in response to the *Olmstead* decision. This body, similar in composition to the Long-Term Care Task force of 2001, would formulate a comprehensive plan to meet the program and policy needs of the non-elderly disabled;

- De-institutionalizing the non-elderly population of individuals with disabilities in nursing homes. Currently, there are 2,800 Minnesotans under the age of 65 who call a nursing home their home;

- Greater access to transit in Greater Minnesota. Currently, several counties have no form of accessible transportation for people with disabilities. Transit funding remains static or declining. People with disabilities in rural Minnesota need transit options;

- Expansion of Minnesota Disability Health Options (MnDHO), the state's voluntary managed care program for people with physical disabilities. Currently, it's available only to Medical Assistance recipients in five Metro Area counties. This program saves money and produces better health outcomes. More people – and other disability populations – need access to it;

- Modified parental fees for families with children with disabilities enrolled in the TEFRA program. Premium increases in 2003 were too steep and too punitive;

- Additional protections for special education students, including additional certification of qualified teachers and standards on the use of locked time out rooms.

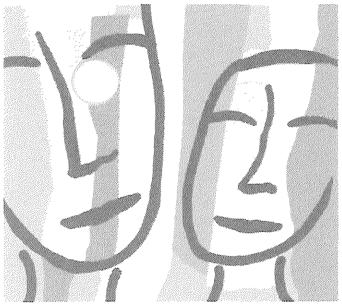
Mental Health Treatment Related Medications Provided through Pre-Paid Health Plans (PPHP) Prescriptions During FY04 for GAMC and MinnesotaCare Adults without Children Enrollees

Number of Clients- All Ages
MHCP

Type of Medication**	**GAMC**	**MNCare Adults without Children*****	**Total***
Stimulants- Mainly for ADHD	451	453	904
Antidepressants	12,974	11,689	24,663
Antimanic Agents	377	209	586
Antipsychotic Agents	3,199	1,273	4,472
Benzodiazepines- Anti-Anxiety Medications	3,140	3,000	6,140
Anticonvulsants- for Mood Disorders	3,465	2,012	5,477
Sedatives - Anxiety Disorders	2,789	2,049	4,838
Miscellaneous Central Nervous System Agents	318	205	523
Unduplicated Count of Persons	**15,912**	**14,268**	30,180
Percent of those enrolled in Program anytime during FY04	**33%**	**28%**	

*Note: The totals for rows contains duplication for those persons who were in both programs during the year.
**Note: Medications chosen are those often used to treat mental health symptoms, but may be used for other purposes.
***Note: MinnesotaCare program (BB) Adults without children was used for this category of MinnesotaCare.

Brain Injury
Association
of Minnesota



34 13th Ave NE, Suite B001
Minneapolis, MN 55413
(612) 378-2742
(800) 669-6442
Fax: (612) 378-2789
www.braininjurymn.org
info@braininjurymn.org

Traumatic Brain Injury Waiver
Enabling Minnesotan's living in institutions or at risk of placement in an institution to live in the community.

Traumatic brain injury (TBI) in Minnesota?

- The Centers for Disease Control and Prevention estimates there are 94,000 Minnesotan's living with a disability resulting from a traumatic brain injury.
- Each year 3,500 Minnesotans are hospitalized with a TBI and 15,000 will be treated in the emergency rooms.
- Brain injury is the leading cause of death and disability for children and adults under the age of 44.
- Consequences of TBI range from minimal to significant, including behavioral changes, Memory issues and even coma.

The TBI Waiver is cost effective.

- The TBI Waiver serves as an alternative to either placement in a nursing facility (NF) or the neurobehavioral hospital entitlement in the state's Medicaid Plan. Governors 2005 budget
- "the *TBI Waiver recipients cost $145,000 less per recipient per year for individuals needing a neurobehavioral level of care*. The waiver serves *individuals needing a nursing facility level of care at a per capita cost that is $14,300 per year less than the comparable institutional population"*. Governors 2003 budget

If not the TBI Waiver then what will happen with the nearly 450 individuals forecast over & above the 300 the Governor budgeted for the biennium?

- A 2003 study reported "87% of subjects in a county jail population reported a TBI over their lifetime; 36% reported TBI in the prior year. In Minnesota it costs more to incarcerate an individual than to support them in the community with a TBI NF or CADI Waiver.
- The Wilder Report *Homeless in Minnesota 2003* reported 29% (1,450 individuals) who were long term homeless had sustained a brain injury. In Minnesota it is expected to cost the state and county more for an individual who is homeless then with a TBI or CADI Waiver
- 20% of the MN Regional Treatment Centers population screened positive for brain injury.

Key questions:

- How will MN enable individuals with disabilities under the age of 65 to move out of more costly institutions like nursing facilities with only 300 TBI waivers when the forecast calls for nearly 750?
- How will MN address the long term homeless population without sufficient TBI waivers?
- How will MN reduce the RTC population without sufficient waivers?

February 4, 2005

Re: Mental Health Day on the Hill

Patient: R[redacted]

This patient came to our hospital for admittance on 11-8-04. He was committed as mentally ill on 12-18-04 but was put on a wait-list that had forty other patients ahead of him. He was not transferred from our hospital to Anoka Metro Regional Treatment Center until a bed opened up on 1-24-05. His inpatient hospital stay on our unit averages about $2,000/day! Calculate the cost to care for this patient!

Anoka Metro Regional Treatment Center has many fewer beds than years ago. This patient is one of hundreds in Twin Cities hospitals who are incurring enormous medical bills because the State system is inadequate to handle the population of mentally ill people who need longer-term care.

The staff at AMRTC reports that they have a hard time discharging patients from their facility due to lack of community resources---i.e. County Case Managers, group homes.

A Therapist/Case Manager
Inpatient Unit
Twin Cities Hospital

Because of funding cuts, a 24 year old male with Schizophrenia was getting his food by finding out-dated deli sandwiches in a dumpster at the Holiday Gas station and eating them. He did not have enough money to pay rent, utilities and food. He was too paranoid to go to a food shelf.

This is only one example of many clients who have had cuts in funding or services. For many, their symptoms exacerbate and many have needed costly hospitalizations because of cuts in funding and services. The cuts seem short-sided when looking at the thousands of dollars spent in one psychiatric hospitalization.

Dr. Gay Joel
Licensed Psychologist
Fairview Day Treatment Program
612-273-9117
02-10-2005

A female day treatment client in her 30s on a stay of commitment after a serious suicide attempt was on general assistance. Client received a notice saying her benefits were being terminated 1/31. When she called to inquire was told that she gave the wrong address on her application in August 04, which was confirmed that she had given the correct address. When the client's social worker called to check into it she was told it was due to a problem with a form that had not been filled out to report termination from client's previous employer, which was also not the case. In trying to get the situation straightened out, the client was told it would take between 30 and 60 days to get her medical benefits reinstated. In the meantime the client has run out of medications and is unsure of funding for the services she needs and is court ordered to attend. The client is frustrated, confused, and overwhelmed. The professionals are spending their time trying to straighten out the paperwork problems and get the client samples of medication, which are not all available, and the focus has been taken away from stabilizing her mental health to treating the paperwork problem.

A woman with schizophrenia was changed to Medicare Oct. 2004. She then had a large spend-down monthly before she could have her medications paid for. She was unable to afford the spend-down and went into dept. The pharmacy gave her medications and billed her for $600. The next month she could not afford medications again and the pharmacy was unable to give her any of her prescribed medications. We worked with social services. No funding was available to assist her in getting her medications. She had been referred for a rep-payee to help her with finances (she is on SSI) but now it has been 6 weeks, no rep-payee has yet been assigned, and the client had to go into the hospital to get her medications for her schizophrenia disorder and seizure disorder. We knew this was coming but we had exhausted all avenues to prevent the hospitalization.

There needs to be more social workers and rep-payees available and perhaps more emergency funds to prevent a hospitalization that cost thousands of dollars.

Dr. Gay Joel
Licensed Psychologist
Fairview University Medical Center
Day Treatment Program
6120273-9117
02-10-2005

onset schizophrenia -
early 30's -

single
no kids
MA

Single Male - onset Schizophrenia 30 years old. Voices told him to harm himself. He took off from his metro area residence - drove north to Lake Superior area - walked in - tried to drown himself (in late Fall) a local town person pulled him out - police brought him to the local clinic - he was transferred to Duluth - then to the Fume-Riverside as he was psychotic -

single - no kids - lost job due to onset of schizophrenia - and being in the hospital - put on MA

His long-term goal was to return to work - It is possible to do this -

College kid
onset - Bipolar Disorder
with psychotic features

College Age is
usual onset for
Bipolar Disorder / Schizophrenia
Sometimes it comes in
teens

Single -
no kids
MA

Young female - college age
onset of Bipolar Disorder - also had voices
telling her to harm herself.
Unable to focus at college - unable
to maintain a part-time job.
Argued with parents - as manic episode
escalated. Was so upset she
walked into oncoming traffic
Was suicidal. Was admitted to the
inpatient unit.
Lost her insurance due to dropping
out of college - from onset of Bipolar Disorder
not on parents -

"command-type
hallucinations"
voices
tell them to
harm themselves

She did attend the Outpatient Adult
Day Tx program - She did get education
and learn to monitor her health.
her diet, her sleep, her medications and
communicate with her clinic / psychiatrist
She did return to college

newly diagnosed
Onset - Schizophrenia -
college age -

single
no kids
MA

Adult Male 20's - College kid - Psychotic episode - Flew by airplane to East Coast to be a model in NY. - no contacts - just went - got psychotic - got hospitalized there - ran out of money - was wondering the street.

Parents got him - brought him back to Minnesota - He was brought to inpatient unit immediately He agrees to come to the Day Treatment program - He still has many delusions - needs much "Reality Check Plans" to tell him he must stay in Minnesota - not take another plane to the East Coast - focus on his goal of college - Had to drop out of college - Cannot hold a job due to psychosis lost his insurance from college.

I saw him on the inpatient unit

Note — He does attend - gets education about his disease - gets proper medications and returns to college

Newly diagnosed **
Schizophrenic -
early 20's -
on MA
single
no kids

Adult male - early 20's - newly diagnosed
with Schizophrenia - Was hospitalized for
a psychotic episode - was a danger to others.
is single - on MA - no kids.
Was homeless before hospital stay.
sleeping in the park.
He tried to walk to a small northern
town one night - up near Brainerd -
from the cities - in the winter - inappropriately dressed.
The police brought him back home - and then
to the hospital
Too old to be on parents insurance -
Couldn't function at a job or in
college due to psychotic symptoms.
lost his insurance from college - ended up on
inpatient unit quickly

** Schizophrenia - Bipolar Disorder (Manic Depression
and (Severe) Major Depression Recurrent - are seen in
college kids - usual onset.
Sometimes in teens.

No county Case Manager

homelessness
prostituting himself

Adult male in 30's. Hospitalized several times over years. Homeless. suicidal (Thought Disordered - with mood swings -) Bipolar / Schizo affective - Disorder

To get money he prostitutes himself and has engaged in pornography. His family is in Wisconsin and are dysfunctional, mentally ill - abuse alcohol - abusive to him. He has a hard time managing his money and his medication. He has lived on the streets and been assaulted when homeless.

He needs a stable place to live.
He was in a board & care - needs more supervision to stay on his medications.
He attends the program for a short time then leaves - No communication of his whereabouts.

post-partum depression
no child care

poor -
no money
no emergency money

(I)

Female in early 30's. Many young kids in the home ranging from 12 yr down to baby. Depressed, crying throughout the intake assessment. She is unmarried but has a supportive boyfriend. She has had thoughts of harming her baby. She has no family support. She is sober. They are not. She is poor.

She tells me she is not certain she can come because she has no child care. She is a minority. I give her numerous resources in the community support groups. She probably would not qualify for a County Case Manager because she had only been in the hospital once for depression. I try to communicate with her to get her set up in the program, I am unable to get a return call. I notify her referring clinic of the problem.

post partum depression

no child care

&

no emergency money

(C)

Patient is a post partum depression lady, married with kids - many - ranging from teenager down to a baby. She is too depressed to take care of herself - She is having problems with thoughts of harming her baby. She has financial difficulties. Her husband works around 18 hours a day. She must stay home with the kids. She reports that her level of depression worsened after the birth of each child. She has no child care and they cannot find resources to pay. She has never been in the hospital for depression. She is uncertain she can come - I give her a list of resources and phone numbers in her area. She and her husband decide to talk about what they can afford to do and I will contact them later. I try for weeks - no response - I contact her psychiatrist to notify of no communication

No beds

suicidal

Feb-05

Patient is a father to many children age ranges from teen to baby. Patient has financial, job, marital, family stress. Patient told me at intake that he was depressed and suicidal and went to the ER to be admitted to an inpatient hospital.

Patient could not be admitted unless he went to Duluth. No psychiatric bed available in the metro. This includes St Cloud and Rochester.

no beds anywhere.

I arrange to start him in outpatient Adult Day Treatment as soon as he can arrange child care with his wife - who must work to pay the bills. Patient is on-leave from his job. He is too depressed to function. He can't do his work.

Post Partum
depression

no child
care available

(AA)

Patient is new mother and has a post-partum depression. She cannot take care of herself or her baby due to depression and complications of hormones after pregnancy. Patient has thoughts and a means to harm her baby. Patient is referred to Adult Day Treatment. She is scheduled for an intake. She doesn't come. I later get a call from another hospital - indicating that she is there - on the inpatient unit.

I talk to the patient later. She has no child care. She checks on available resources but finds none.

She has no family support.

She has no husband - She is unmarried.

I try to communicate with her. She won't answer her phone. I notify her psychiatrist.

1B

County Case manager -
Child Care

Patient is referred to Adult Day Treatment by the inpatient unit at Sumc. Patient was raped 8 months ago and since then has been unable to do parenting duties, take care of the apartment or self.

Patient has been in and out of psychiatric hospitals at least 8 times over the past year. Different hospitals. She does not have

and many → ER visits for "fainting spells"

a County Case manager - although she qualifies and definitely needs one. She is psychotic she is delusional - paranoid - She has fainting spells which are determined not to be seizures but actually 'conversion disorder'

I write up a referral and call the County and collect records. I request a Case manager. As services are few - due to cuts, it takes time. I keep in contact with her and try to assist in placement. After several months, child care and transportation are arranged. She started. She has not been in the hospital since

MA co-pay -

Patient is a single adult - schizophrenic - no kids - on MA - in late 30's. Patient has a limited income - must pay so much for rent because of living in Section 8 housing. Patient must buy groceries and pay bills. Patient has a thyroid condition, but cannot afford to pay the co-pay. Patient foregoes the thyroid medication in order to pay other bills. Patient is dependent, patient would benefit from assistance from a Rep-payee and/or more County Case Management - possibly a visiting nurse -, no resources are available at this time

MA copay

patient is a retired teacher, who was forced to take early retirement due to Major Depressive Disorder, fibromyalgia, and a serious heart condition. Patient is an MA. (is married)

no kids -

Patient is disabled. Finances are stressed.

Patient cannot afford to take all the prescribed medications. Can't afford a co-pay. patient decides to forgo the Blood Pressure medicine this month.

Patient must buy food.

Patient is in 50's.

no housing

Case mgr. County stressed -
can't handle all cases

Patient is a young adult in 20s -
Single - no kids - MA
newly diagnosed with paranoid schizophrenia.
patient is living in a faith based charity residence.
patient will not do his chores as expected
patient is off medications and cannot come
out of his room due to paranoia levels.
Patient hears voices that tell him to harm
others. I talk to the supervisor who says
the patient will be kicked out for not
participating. I explain that I need a
few days to get him housing, as he is
a mental health patient. He agrees.
I call the county case manager and
ask for immediate help with this patient.
The case manager is in process of lining up
housing. The patient decompensates and
requires inpatient hospital stay - he is off
his medications. He is a danger to himself
and to others.

CDMI

Patient is in 30s - and is schizophrenic. The patient has finished a dual focus mental health and chemical dependency program and is still unstable. A doctors order sends her to Adult Day Tx for stabilization of mental health symptoms. She has used her first 115 hours of MA -

She is a single person. no kids -

We send in the paperwork - again 2-3 days for CDMI - Care Delivery Management Inc to receive a fax - 10 more days to process it.

It is rejected. We call back and send more documentation. We must wait another 10 days for an answer. The patient wants to start. Her symptoms worsen. She ends up on the inpatient unit. We write this and fax this to CDMI - Over 25 days from when first requested - we receive an answer - the patient is approved.

An inpatient stay should have been avoided

This is a waste of taxpayer money -

CDMI

Patient is in 40's - ♀

patient is psychotic and diagnosed with Paranoid Schizophrenia - She has a doctor order to come to Adult Day Tx.

She is single, no kids, is on MA.

We write up her paper and fax them to CDMI - Care Delivery Management Inc. the gatekeeper for MA - state plans.

She is rejected. It takes 2 days for them to receive a fax and 10 days to get back to us —

Patient is increasingly more symptomatic. Psychotic symptoms have worsened. Patient is admitted to the locked-inpatient units. A danger to herself - others (Very, very expensive)

Again we call and send more documentation.

We complain to the worker and talk to the supervisor - after 20 days 10 + another 10 they will tell us the status.

1 month later the patient is approved.

no county case manager

needs housing

poor -

few $ resources

patient in 30's - single - no kids. patient has problems with depression and psychosis and has current paranoid symptoms. patient doesn't like his current group home staff. patient calls his Vulnerable Adult Protection Worker daily. He wants to move.

The Vulnerable Adult Protection Worker calls this program to ask Outpatient mental health - hospital staff to get him new housing - (we don't have the resources to do this or to set up meetings for this patient to discuss housing issues - group home issues)

Our program asks to get a County Case Manager - it will happen - but slowly as the budget cuts have caused case loads to increase - others in the community try to help but are limited in what they can do

outpatient
FUMC -
Adult Day Tx

A 46 year-old man diagnosed with schizophrenia was attending Fairview Day Treatment Program and living at Pillsbury Group Home. He was calling an adult protection worker daily to complain about his living situation and insisting he needed a new place to live. The adult protection worker called our program several times requesting we assist the client in finding a new living situation. We do not have the time or resources to help with these issues so the adult protection worker applied for social services. That was many weeks ago and the social worker has not been assigned as of yet. Meanwhile, the client needed to go into the hospital because he became suicidal, in large part due to a living situation that was intolerable to him.

We have noticed how difficult it is to get social services involvement and have felt the burden fall on ourselves, or the clients who do not get the services they need. We are feeling stretched to the maximum. Funding cuts affect client health and we have seen numerous hospitalizations that result from the cuts in services.

Dr. Gay Joel
Licensed Psychologist
Fairview Day Treatment Program
612-273-9117
02-10-2005

Affirmative Options Coalition
2314 University Avenue West, #20, St. Paul, MN 55114
(651) 642-1904 X 229 • FAX (651) 642-1517 • www.affirmativeoptions.org
Karen Kingsley, Director • Michelle Dibblee, Membership & Outreach Coordinator
Promoting *affirmative options* for low-income Minnesotans

February 15, 2005
Testimony of Karen Kingsley
Director of the Affirmative Options Coalition
Senate Finance Health and Human Services Division

Good morning Madame Chair and members. My name is Karen Kingsley. I am the director of the Affirmative Options Coalition. I am here this morning to testify about the child care provisions in Governor Pawlenty's budget proposal.

Affirmative Options is a statewide coalition of more than 55 organizations that come together to promote policy changes that improve the economic well-being of Minnesota families. Our members include social service agencies, faith communities, training providers, and advocacy groups.

I want to talk today about the Governor's proposal to cut $70 million from child care by continuing the freeze on provider reimbursement rates. About $50 million of this cut comes from MFIP and Transition Year Child Care and about $20 million from the Basic Sliding Fee program.

This cut will not only affect child care providers. While the budget savings are achieved by freezing the rate the state will pay to providers, it is families seeking childcare and employers seeking steady workers that will ultimately pay the price. If provider rates remain frozen, families' access to child care providers they can afford will be reduced.

Access to child care has already been reduced as a result of the 2003 freeze on rates. The January 2005 Legislative Auditor's report on child care reimbursement rates (http://www.auditor.leg.state.mn.us/ped/2005/pe0501.htm) notes that by early 2004, only 51% of child care centers and 69% of licensed family child care providers were affordable to families participating in the Child Care Assistance Program (CCAP). This means that close to half of child care centers charge rates *above* the maximum state reimbursement rate. This is a reduction in access of 31% for centers and 14% for licensed family child care since 2001.

When child care providers charge rates that are higher than the rate the state will pay, it is the family that is responsible to pay the difference, in addition to their required co-payment. This means that families have to pay hundreds of dollars more, *above* their co-pay, to access many child care providers. Low-income working families or families transitioning from welfare to work cannot afford to pay this differential.

In fact, DHS assumes that fewer working families who participate in MFIP will use child care assistance. DHS budget projections for the next biennium suppose that on average, 700 fewer MFIP families will access child care assistance each month. We do not know where the children in these families are being cared for while their parents are working.

This finding is of great concern, not only for those children, but also for the state's welfare-to-work goals. In its January 2005 *Cost of Child Care* study, DHS notes that *"State policy goals for promoting economic stability are supported most effectively when parents have access to affordable child care that supports their employment needs."* (p. 9) They also note that "The level of support available to parents as they leave welfare impacts their ability to remain off welfare in the future." We agree. And the research DHS cites confirms it.

The research shows that for former welfare recipients, those that received child care assistance were almost *twice as likely* to be employed two years later than welfare participants who did not receive help with child care (34.9% versus 19.2%). Similar studies also found that working families who received child care assistance were *less likely* to return to welfare than those who did not (19.5% versus. 27.7%). From state data, we know that for families with children under six, getting help paying for child care is the *most often* cited reason for applying for MFIP. (pp. 38-41)

By freezing child care reimbursement rates, the Governor's budget restricts access to child care for low-income working families *and* families working to transition off public assistance. The DHS report notes that "a rate freeze is the strategy *most likely* to restrict access." (p. 51) This proposal is counter-productive to the state's economic stability goals and it violates the promise the state made to MFIP families: that they would be guaranteed help with child care if they made steady progress toward work and self-sufficiency.

While freezing provider rates does contain costs in the short-run, it is very likely to force increased costs in the future by making it harder for families to succeed and making it more likely that they will return to MFIP or stay on assistance longer. Child care assistance is exactly the kind of investment Minnesota should be making today to support working families, the employers who hire them, and the communities we all live in.

I urge the committee to oppose the child care cuts in the Governor's budget.

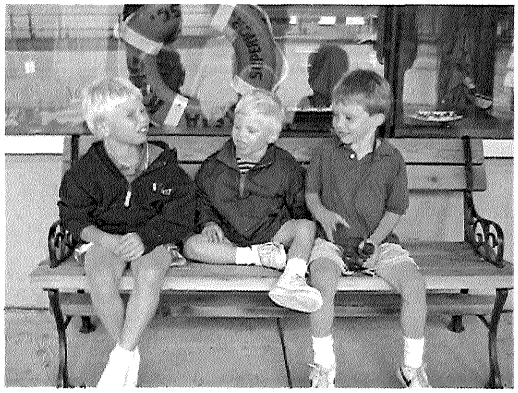
Arc
Minnesota

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 -- December, 2004

Taylor & Marshall Turan



My name is Rochelle Turan. My husband Thomas and I have three sons: Marshall, Ethan, and Taylor. Taylor and his brother Marshall require constant, skilled care. Taylor has Mental Retardation and Sensory Integration Disorder. Marshall has Autism, Sensory Integration Disorder, Sleep Disorder, and Reflux/Rumination. They have tremendous potential, but are very vulnerable. I also act as Guardian for my brother, who has developmental disabilities.

Stepping up to these challenges has helped us tap our inner strength, but there are limitations. We need the partnership and support of our community to help our children reach their full potential as citizens while maintaining the integrity of our family, our marriage, and our personal sanity.

Taylor and Marshall receive medical and other vital services through TEFRA. There is a Parental Fee associated with TEFRA, and that fee has been growing at a pace that imposes serious hardship on our family.

Between 2003 and the present, our Parental Fees have climbed from $50 per month to $180 per month. According to the current formula, our Parental Fees will reach $323 per month in July 2005. Our family income has grown, but so have our out-of-pocket expenses incurred specifically because of the disabilities our sons have.

We pay $611 per month to maintain private health insurance. Medical Assistance reimburses us a part of the premium, but the remaining cost is a responsibility we take on specifically because our boys need that particular type of health policy. The state of Minnesota saves money by the fact that we maintain this type of health insurance policy. Consider also the fact that we pay a deductible of $250 per person, with an 20% co pay. We have to be prepared to pay $5500 annually out-of-pocket for our medical services.

Also, the current formula for calculating Parental Fees does not take into account the cost of home repairs required for damage caused by the manifestations of our boys' disabilities. Added to that are the frequent carpet cleaning, drapery cleaning and replacement, and daily laundering of soiled bedding and clothing.

The CDCS Amendment have caused greater expense, since we now have to pay all expenses and mileage when PCA staff accompany our children to community activities and events.

We accept the fact that our circumstances demand extraordinary amounts of time, emotional and physical energy, and financial resources. But when the State of Minnesota imposes a disproportionate financial burden on our family, it only serves to endanger our progress and threaten our survival.

If the Parental Fees continue in this way, then Taylor and Marshall will be deprived of the services they need to continue healthy progress with us at home. Our whole family will suffer, either through the loss of services, or through being deprived of any future security.

In-home support is an act of compassion. In-home support is a wise investment and pays tangible dividends to society, families, and especially the individuals with disabilities by fostering social and financial achievement and personal dignity.

Pricing families out of the market by raising Parental Fees is a shortsighted cost-saving measure. This action will cost more in the end, and will decrease many people's quality of life in the interim.

The Arc of Minnesota

Consumer Directed Community Supports (CDCS) Amendment

A Fact Sheet for a Campaign to Support Persons with Developmental Disabilities and Their Families to Preserve Consumer Directed Community Supports (CDCS)

Produced by The Arc of Minnesota -- January, 2005

➢ *Background:*

The Consumer Directed Community Supports (CDCS) option is an innovative service available under the Mental Retardation/Related Conditions (MR/RC) waiver that allowed individuals and their families to creatively meet their support needs. Many families and individuals with the most severe disabilities were able to create support systems that enabled them to keep long-term support staff. After being available for several years, it was decided to make this option available on all the waivers, to develop a standardized budgeting process, and to define more specifically what could and could not be purchased under CDCS.

These changes were proposed in a waiver amendment approved by the federal government in March 2004. The amendment was prepared with very limited discussion with stakeholders. The amendment reverses previous policies of DHS, which committed the state to move towards a service delivery system that is truly consumer-directed and affirms the principles of self-determination for individuals and families.

➢ *Impact of the Waiver Amendment:*

In September, 2004, individuals with disabilities and their families were informed of their new individualized budgets. **Two-thirds of the individuals on CDCS were informed that their individual budgets would be substantially duced effective in 2006.** Many will have to return to formalized waivered services that previously did not meet their needs. The hardest hit groups were:

- Adults on CDCS participating in Day Training and Habilitation programs. They will not be able to continue on CDCS.
- Children with significant health care needs. (See story on other side of this sheet.)

The Arc is committed working with all stakeholders and the state to make CDCS work. The Arc asks legislators to support The Arc's efforts to:

☐ *Revisit the Budget Methodology:*
The method DHS is using to calculate individual family budgets under CDCS does not provide sufficient funds to ensure the health and safety of individuals. The budget is based on average costs associated with the failed traditional system where families could not find staff to utilize their authorized hours. The costs of Day Training and Habilitation (DT&H) services will not be covered outside the CDCS budget, as they are in the traditional service system. DHS estimates that at least 40% of the people using the CDCS option will be forced to drop out because of way budgets will be calculated.

☐ *Revisit Restrictions on Expenditures under CDCS:*
The restrictions will affect the ability of individuals to meet their individual needs, provide for their health, safety and welfare, and promote their access to a meaningful life in the community.

➢ *Next Steps:*

The Arc of Minnesota will keep legislators informed of efforts with the Minnesota Department of Human Services to address these issues, and The Arc of Minnesota will propose legislation as necessary.

Produced by The Arc of Minnesota; 770 Transfer Road, Suite 26; St. Paul, MN; 55114
651-523-0823 or 1-800-582-5256; web site: www.arcminnesota.com; e-mail: mail@arcminnesota.com

The Arc of Minnesota

Preserving Lives, Conserving Costs: CDCS Works

A Campaign to Support Persons with Developmental Disabilities and Their Families to Preserve Consumer Directed Community Supports (CDCS)

Sponsored by The Arc of Minnesota -- December, 2004

Taylor Garin

I am writing this letter on behalf of our 11 year-old son, Taylor, who has severe disabilities. Taylor cannot speak for himself, so we will be his voice. The picture above is a photo of Taylor's 10th birthday party. I, my daughter Lisha, and my husband Chris are celebrating with him.

It is almost impossible to explain the extent of Taylor's needs, and even more impossible to explain the magnitude of how he will be affected by the devastating cuts to the Consumer Directed Community Supports (CDCS) we receive. Taylor is legally blind, has several conditions which make him medically fragile, uses a wheelchair, and cannot speak or communicate his needs. Taylor is total care, 24 hours a day.

I personally suffer from a debilitating form of Fibromyalgia and cannot care for Taylor myself. **My husband and I rely entirely on CDCS funding to pay for staff. Staff is not a luxury in our family; it is an absolute necessity.**

This year has been the most difficult year we have experienced since Taylor was born. He missed over 100 days of school and was hospitalized three times. He developed two new life-threatening illnesses that required 24-hour care. This could not have been a more inappropriate time for an unfounded budget cut.

In May, the State PCA assessment increased Taylor's budget to 24 hours a day from 18, after updating his medical complications. Three months later, we received the notice cutting Taylor's CDCS budget by 75%. His daily budget went from $359.02 to $102.20. This has created a crisis. **Taylor could die without proper care.**

These cuts are devastating to our family as well. We use almost every dollar for staff support to keep Taylor at home and not in an institution. If he were to be institutionalized, which would be hospital level care, the cost to the state would more than triple his current budget.

We couldn't get staff when we only had PCA services through an agency. They only pay $8.50 per hour, and yet they charge the state between $15 and $25.00 per hour. We pay our staff $15.00 per hour, and they are trained like nurses. Getting nurses to take care of Taylor (which is impossible due to the nursing shortage in this country) would cost $45-$60 per hour.

We do not have a handicapped accessible vehicle. We cannot afford to buy a van yet, and our hopes for converting a van, when he can afford one, have vanished with the budget cut. My husband still carries Taylor up and down the stairs and into our truck; Taylor weighs 85 pounds.

We have not been able to use his waiver budget to buy other necessary adaptive equipment, because his level of care uses almost every dollar. What isn't used for staffing is used on special dietary requirements that support his weakened immune system, as well as consultation services to a licensed Naturopathic Doctor endorsed by Taylor's Pulmonologist.

We are exhausted. Taylor is an angel, and we are blessed to have him in our lives. However, life is extremely difficult when you're caring for a child you love, who has such severe disabilities and major medical complications.

We cannot understand how anyone could have calculated the new budget if they knew anything about Taylor and his needs. The news of this budget cut was emotionally devastating. **The only way we can get through a day is because we have Taylor home with us, we have each other, and we have wonderful loving competent staff, which we are in jeopardy of losing. Please help us help Taylor.**

Lenni Garin
Rockford, Minnesota

Fact Sheet:
Medical Assistance Co-Pays and Limits on Dental Coverage

Produced by The Arc of Minnesota -- January, 2005

➢ *Background:*

The 2003 Minnesota Legislature passed legislation that required people on Medical Assistance, MinnesotaCare, and General Assistance Medical Care to pay for part of their medical care. The law requires the following:

Co-payments for people on Medical Assistance, beginning October 1, 2003. These include:
- $3 per office visit.
- $6 per non-emergency visit to the emergency room.
- $3 per brand-name drugs and $1 per generic drugs. There is a $20 monthly cap on all prescriptions.
- Drugs used to treat bipolar disorder, depression, and other mental illnesses; the only exception would be anti-psychotic drugs. Medications requiring co-pays would include Depakote, Eskalith, Lithobid, Luvox, Paxil, Prozac, and Zoloft.
- $3 for eyeglasses.

Limits on Dental Coverage. Dental coverage will be limited to $500 per year for such services as:
- Teeth cleaning
- Fillings
- X-rays
- Root canals

The Center on Budget and Policy Priorities, in a dy titled "Charging The Poor More for Health Care: Cost-Sharing in Medicaid," states that, "Cost-sharing policies that cause only modest reductions in health care use among middle-class individuals can result in more substantial reductions in health care use and lead to significant adverse health consequences among poorer individuals, especially those with chronic health problems."

The report goes onto say that "the RAND health insurance experiment, one of the most rigorous and important health policy studies ever conducted, found low-income adults and children reduced their use of effective medical care services by as much as 44 percent when they were forced to make co-payments, a much deeper reduction than occurred among those with higher incomes."

The University of Minnesota Dental School testified on February 22, 2004 that it would no longer accept public assistance dental patients. Many other dentists are no longer providing services to individuals with disabilities on Medical Assistance.

➢ *The Arc of Minnesota Position:*

Eliminate co-payments for Medical Assistance recipients, and eliminate the $500 cap on dental coverage.

Produced by The Arc of Minnesota; 770 Transfer Road, Suite 26; St. Paul, MN; 55114
651-523-0823 or 1-800-582-5256; web site: www.arcminnesota.com; e-mail: mail@arcminnesota.com

Fact Sheet: Cuts in MFIP for SSI Families

Produced by The Arc of Minnesota -- January, 2005

➢ *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. This family is now struggling to meet its basic needs on an income of **only $8,160 per year.**

➢ *The Arc of Minnesota Position:*

Restore the full MFIP grant for households with family members with disabilities receiving SSI. Support SF 254, which would restore the MFIP cuts made in 2003.

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's tradition of supporting people with disabilities.**

(Thanks to the Affirmative Options Coalition for providing the information for this fact sheet.)

Produced by The Arc of Minnesota; 770 Transfer Road, Suite 26; St. Paul, MN; 55114
651-523-0823 or 1-800-582-5256; web site: www.arcminnesota.com; e-mail: mail@arcminnesota.com

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, 2005

Support Legislation to Lower Parental Fees

➢ *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 ovide assistance to help parents meet the extraordinary demands of raising a child with a disability. 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 has been tremendous.

Minnesota is one of only a handful of states that charges parents of children on MA a parental fee. Parents have paid these fees since 1991 and have contributed significantly to the cost of supports 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 about 80% 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 in 64% of families, the needs of their child with a disability affected one or both parents' ability to hold a job. Many parents reported that they "accepted a lower-paying job with more flexibility or fewer demands." **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.**

➢ *The Arc of Minnesota Position:*

The Arc of Minnesota will support parental fee legislation that brings the maximum relief to families. Current bills we are tracking are SF 254, SF 726, and HF 619.

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.

Produced by The Arc of Minnesota; 770 Transfer Road, Suite 26; St. Paul, MN; 55114
651-523-0823 or 1-800-582-5256; web site: ~~www.arcminnesota.com~~; e-mail: mail@arcminnesota.com

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, 2005

The Bly Family

My husband and I raise four children. Our nine-year old son, David, has a developmental disability called Angelman Syndrome. Because of this syndrome, he has a jerky movement and gait, severe mental and motor retardation, absent speech, excessive laughter, and seizures. His needs are intense, but we are able to keep him at home because of support services from the state.

To receive these supports, we pay a parental fee. However, during the 2003 Legislative Session, our Legislature and the Governor dramatically increased these fees in an effort to balance the state budget. Many families received increases of 200 to 700%.

In 1997 when we started services for our son David, our parental fee was $25.00 per month. On May 31, 2003, we received notice that our fee would jump to $455 per month, effective July 1, 2003. This is an increase of over 1,720 percent over our original fee. Our income spanning this same period of time has increased a modest 10.8 percent.

Legislators have greatly underestimated the financial impact this would have on families. My husband Russ and I both teach full time in the Fosston area. Russ also takes a second job in the summer. I could take a second job; however, since the fee is based on the family's income, our fee would go up even more. The alternative may be to place David in a group home, which is likely to cost more than the state is paying right now to help us keep David with us.

Our hope is that we can raise David as a contributing member of society and as a part of our family. We feel, though, like we've been targeted and punished for having a child with disabilities. Please make parental fees more affordable and reasonable for us and other families across the state who are struggling to pay them.

Dawn Bly
Fosston, Minnesota

ADVOCACY DIRECTOR
Maureen O'Connell

LEGAL SERVICES ADVOCACY PROJECT
Suite 101 Midtown Commons
2324 University Avenue
St. Paul, MN 55114
(651) 222-3749 Fax: (651) 603-2750

visit our website at: www.lsapmn.org

ATTORNEYS
Kathleen McDonough
Reggie Wagner

ADVOCATE
Ron Elwood

OFFICE MANAGER
Colette Bergeron

Senate Health & Human Services Budget Division

Governor's Proposed Health and Human Services Budget Cuts
February 15, 2005

Testimony of Kathy McDonough

Legal Services Advocacy Project (LSAP) is a statewide division of Mid-Minnesota Legal Assistance representing the interests of low-income Minnesotans through legislative and administrative advocacy, research and community education. Many legal services clients are enrolled in state-subsidized health care programs.

- Recently, there have been numerous stories in the media about the high cost of health care, rising health insurance premiums, the decrease in the number of employers who provide health coverage and the increase in uncompensated care One recent article, written Dr. Michael Belzer concluded that, while government tinkers around the edges of the problem, proposing incremental health care reforms, millions of people suffer from the effects of the newly defined and fatal disease called "uninsurance."

- Throughout the 1990s Minnesota was a national leader in providing health care coverage, boasting one of the lowest uninsurance rates in the nation. However, Minnesota's uninsurance rate is steadily increasing. In 2003, approximately 38,000 low-income Minnesotans lost health care coverage due to legislative changes.

- Many others are enrolled in Medical Assistance (MA), MinnesotaCare or General Assistance Medical Care (GAMC) but are unable to access services because they can not afford the copayments enacted in 2003.

- This Session, under the Administration's proposal, more than 45,000 MinnesotaCare enrollees will receive cancellation notices.

- Of that 45,000,
- 14,000 may be eligible for GAMC if they complete the necessary paperwork; and
- 3,400 may be eligible for MA or GAMC on a "spenddown" if they have monthly medical expenses that equal the amount their income exceeds the MA/GAMC income limit and they complete the necessary paperwork.

- **27,000** will not be eligible for any coverage.

- The Administration has begun calling MinnesotaCare "welfare health care." This is not accurate. MinnesotaCare is funded by a 2% provider tax and premiums, copayments and deductibles paid by enrollees.

- In addition, a 1996 DHS study found that MinnesotaCare coverage prevented more than 4,000 families from applying for cash "welfare" programs because they could afford to stay in low-wage jobs with no health care benefits.

- Calling MinnesotaCare "welfare health care" also stigmatizes people who are unable to access private health care coverage through no fault of their own. Many MinnesotaCare enrollees work but are not fortunate enough to have employer subsidized health insurance. One legal services client is Jan Dechampeau, who can't be here today because she lives in Bemidji and she is working. Jan has managed a video store for 18 years but her employer does not provide health insurance. Jan pays $50 monthly premiums, copayments and deductibles to receive MinnesotaCare. She is paying for her health insurance just like other working Minnesotans.

- Other MinnesotaCare enrollees have past work histories but are not currently working due to their medical conditions.

- A recent study reported in the Health Affairs Journal found that 50% of bankruptcies are due to medical debt. 35% of those filing bankruptcy lost employment due to illness, 56% did not have health insurance because the premiums were not affordable and others were unable to obtain coverage due to preexisting conditions. An increase in the number of uninsured will certainly exacerbate this problem.

Here with me today to talk about his vital need for MinnesotaCare is Robert Smishek.

LSS BOARD OF DIRECTORS
Paul Batz, *Bloomington (Chair)*
Kate Mooney, *Cold Springs (Vice Chair)*
Dayton Soby, *Brooklyn Park (Secretary)*
Patti Andreini Arnold, *Minneapolis (Treasurer)*
Rev. Wayne Anderson, *St. Cloud*
Richard Brubacher, *Hopkins*
Cheryl Chatman, *Maplewood*
Rev. Stephen Cook, *Princeton*
Charlene Dickerson, *Maplewood*
Mary Hauck, *North Oaks*
Rev. Patricia Hinkie, *Frost*
Rev. Jerry Hoffman, *Columbia Heights*
Bishop Craig Johnson, *Bloomington*
Rev. Dr. Christopher Nelson, *Eden Prairie*
David Nycklemoe, *Fergus Falls*
Nancy Ojard, *Knife River*
Ann M. Peterson, *Rochester*
Rev. Cherian Puthiyottil, *West St. Paul*
Tim Schmidt, *Chanhassen*
Bishop E. Peter Strommen, *Duluth*
Dan Thorson, *Battle Lake*
Verne Weiss, *Miltona*

LSS CABINET
Mark A. Peterson, *President & Chief Executive Officer*
Bob York, *Vice President & Chief Service Officer*
Joyce Norals, *Vice President & Chief Human Resources Officer*
Jane Hopkins, *Vice President & Chief Financial Officer*
Jodi Harpstead, *Vice President & Chief Advancement Officer*
Jeri Schoonover, *Vice President - Community Services*
Bill Vanderwall, *Vice President - Family Services*

LSS is a statewide faith-based nonprofit owned by the six synods of the Evangelical Lutheran Church in America (ELCA).

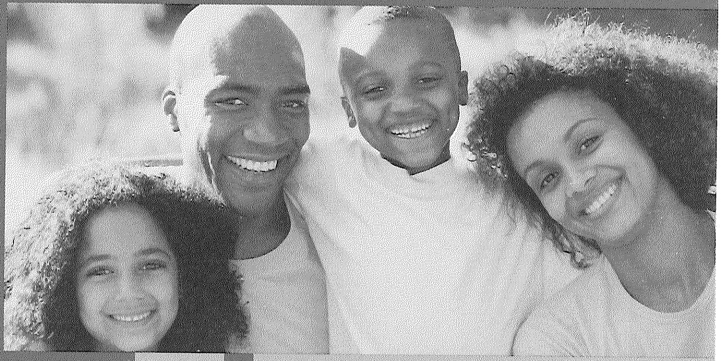
ELCA BISHOPS
Bishop Rolf P. Wangberg, *Moorhead*
Bishop Peter Strommen, *Duluth*
Bishop Jon V. Anderson, *Redwood Falls*
Bishop Craig E. Johnson, *Minneapolis*
Bishop Peter Rogness, *Saint Paul*
Bishop Harold L. Usgaard, *Rochester*

Lutheran Social Service
for changing lives

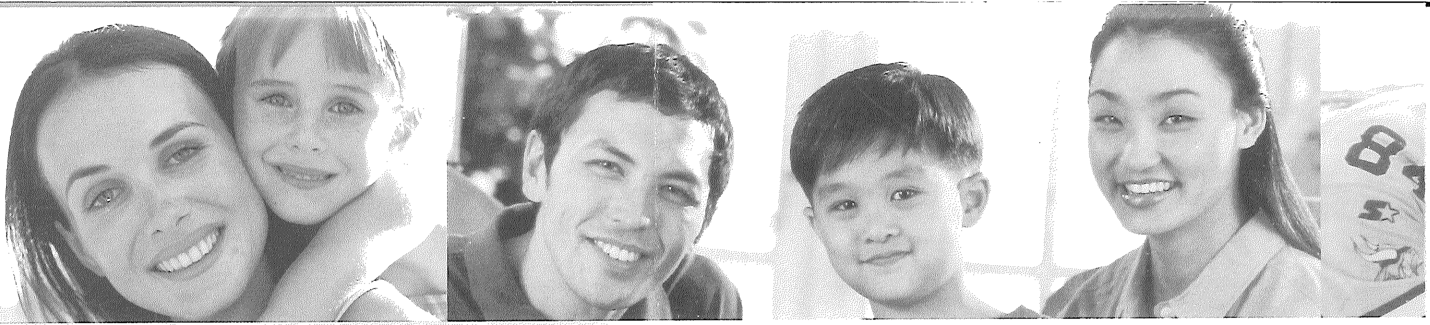
Lutheran Social Service of Minnesota
Office of Public Policy & Advocacy
Claire Thoen-Levin, *Director*
2485 Como Avenue, St. Paul, MN 55108
651.642.5990 1.800.582.5260 Fax 651.969.2360
cthoen@lssmn.org www.lssmn.org

LSS PUBLIC POLICY AGENDA 2005

“For Changing lives”



Lutheran Social Service
for changing lives



Access to care for Minnesota's children and families, seniors and people with disabilities.

We are committed to working with POLICY MAKERS to:

I. **Adequately fund services to children, youth and families**

II. **Adequately support Minnesotans with disabilities and the dedicated personnel who support them**

III. **Adequately fund services so that seniors have community based options**

A Balanced Budget Requires a Balanced Approach

Common sense dictates that both social and economic issues should be addressed with a balanced approach that includes all possible solutions. Minnesota's past history of a balanced approach in supporting both human potential and economic growth has made our state above average in both compassion and per capita income.

The recent approach to the state's budget has left serious deficits in services to Minnesotans in need. The state has cut services, reduced funding and made one-time adjustments. It is now time to increase revenues.

I. Access to Care for CHILDREN and FAMILIES

All children—those who come from stable homes as well as those who come from disrupted homes—are our future. This means that funding is essential for services that help "at-risk" children grow to be healthy, competent and contributing adults.

It has been too easy to overlook children and their needs as the debate over Minnesota's budget deficit takes place. Children's voices were not heard in the budget debates that resulted in reduced funding for already fragile children and families. The combination of reducing children's grants, block granting of the reduced funds for children's services and cuts in Local Government Aid (LGA) has strained the resources of social services and left many more in need.

II. Access to Care for Minnesotans with DISABILITIES

Access to care means adequate funding and waivers (allowed openings) for Minnesotans with disabilities and the dedicated personnel who support them. Because the state has been limiting these openings, people with disabilities—including mental illness, developmental disabilities and brain injuries—will continue to languish in nursing homes, remain homeless, stay at home with inadequate care or in institutional settings. In every instance Minnesotans will be denied a chance to reach their full potential and contribute to our communities.

Wages for essential human service workers providing direct care must be a priority. We depend upon caring individuals who support us when we are ill, as we age or when we experience a disability. Unfortunately this truly essential and demanding work continues to be inadequately recognized and under-compensated.

Adequate compensation to make this essential work is vital or there will be no care providers to meet this critical need.

III. Access to Care in the Community for SENIORS

Our evolving and effective network of community services for elderly Minnesotans should be protected. LSS participates in and supports the network of community senior services that policy makers have built.

These services include: Foster Grandparents, Senior Companions, Senior Nutrition, Community Assisted Living, and Respite Care.

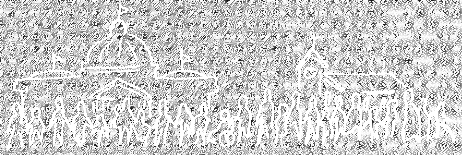
Maintaining this flexible, cost efficient and vital network of community services will allow Minnesotans to retain their independence, meeting human service needs in their own communities, and avoiding more costly institutional placement.

LSS serves all people regardless of race, color, creed, religion, national origin, sex, sexual orientation, disability or age.

We welcome all to join us in our mission of service and employ people of many faiths and backgrounds. LSS exists so that children, youth, families, older adults, and persons with disabilities are safe, valued, and respected.

LSS is accredited by the rigorous standards of the Council on Accreditation (COA) and is affiliated with the national Lutheran Services in America (LSA), which was ranked second in the country by Smart Money on program-to-administrative cost ratios. Our Camp Knutson for children with disabilities is accredited by the American Camping Association (ACA). LSS Guardianship staff are nationally certified as Registered Guardians through the National Guardianship Foundation (NGF). LSS receives all relevant state licensure for our services.

LSS responds to the needs of people through direct services, public policy advocacy, investment of resources, and partnering with others. LSS provides social services in a manner that reflects compassion, integrity, and respect for individuals and cultures.



***Our Mission* is to express**
the love of Christ
for all people
through acts of service.

Lutheran Social Teaching

- ***DIGNITY* OF EACH HUMAN BEING**

  All humanity is created in the image of God.

- **ACTIVE *COMPASSION***

  From Genesis through the learnings and teachings of the disciples of Christ, we know that God expects us to care for the children, the poor, the hungry and the powerless.

- **ACCESS TO *CARE***

  Basic human rights encompass access to employment, food, shelter, health care and the right to self-determination.

- ***COMMUNITY* AND THE COMMON GOOD**

  We know God yearns for us to love the neighbor.

Our Vision is that all people have the opportunity to live and work in community with dignity, safety and hope.

A letter from **MARK A. PETERSON**, President/CEO,
Lutheran Social Service of Minnesota

Just before Christmas, Lutheran Social Service received a $1,000 check from a Pfc. Marine in Afghanistan. This young soldier wanted to say thanks for the support he received from LSS when he was homeless and living under a bridge in Duluth. He, like thousands of other homeless youth whom LSS has served over many years, learned that we believed in him. We encouraged him to embark on a journey of hope with us. He did, and now he serves his country.

Our work with him was paid for through grants LSS received from the State of Minnesota, the Federal government, the United Way, and other philanthropic sources. But mostly, government dollars made it possible for us to serve him.

Now, government is in retreat at a time when there is so much need.

This pullback is so unnecessary.

It's my hope that the 2005 Legislature will adopt a budget that re-establishes Minnesota's commitment to care for vulnerable persons with dignity. There is an awful lot at stake.

February 15, 2005

Dear Reader:

I am a parent writing to share our family story related to using financial dollars towards our son's care. Our son, John, is 20 years old and has medical diagnoses of spina bifida and high functioning autism. We also have a 22-year-old daughter excelling and majoring in physical therapy. We have been married 30 years.

For 20 years, I have been John's full-time caregiver 24 hours a day, 7 days a week with no county respite or foster care help—ever! Although requested, this was never a need that the county could provide. I have utilized limited personal care attendant help (about 4 hours a week), because I needed to be available for medical appointments and care was hard to find. I have put my career and life on hold for 20 years. We have always held a private health care plan for John so that he can receive the best needed surgical care and pediatric care. This benefited him and everyone. This family-paid plan cost $1,000 per month for probably ten years (the County covered John's portion). My husband has had the excruciating pressure and burden of knowing that maintaining constant employment was critical to our family's well being. Caring for John's needs has permanently changed both of our body chemistries. The only monies we have used which the County provided were a monthly $250 Family Subsidy Fund.

John is incontinent requiring help in changing a diaper 4-5 times a day. When John has had the stomach flu it is a very difficult time for me as you can imagine, since his ambulation is slower. A typical night might consist of spending 30 minutes in the bathroom each time, changing all clothes and underwears/diapers maybe 5-7 times all night. This happened many times through the years. John has had over 25 anesthesias for procedures ranging from ear tubes to complications from spinal surgeries (this surgery involved a 1 ½ month stay in a hospital due to hospital errors). I've been to hundreds of medical appointments. Each day, I do a digital stool removal for John, put his socks, braces, pants, belt, shoes, etc., on plus grooming. He receives baths twice a week because that is all we can manage. I brush his teeth, make all his food, and cut all his food. I am his primary social contact since he has no circle of friends outside of school. I take him to the bus and meet him at the bus after school. My day revolves around being there for John.

I love John dearly, but it is time for me and for John for me to pass the baton to someone else. I have needed back surgery, and have after effects from that surgery.

I have advocated for John so that he received the paraprofessional staffing he needed in school. I was one of several parents who pioneered inclusion into our school district because it was basic civil rights. John now worked last year doing data processing. He has an excellent memory, is great at processing information, has good language abilities, and enjoys people immensely, but he will always need support at some level. That is what community is for. Government is part of community.

I have advocated for John medically, socially, and legislatively. I have called hundreds of legislators, and I have written dozens of letters to legislators. I have attended meetings at the Capitol to share needs with the Governor. While being a full-time caregiver I also served on special education boards. I have been John's educator also helping him with homework through his junior high years. His last job was doing data entry on the computer for a governmental position.

The things John has accomplished were because of supports to skilled and caring teachers, physical therapists, physicians, speech and occupational therapists. Preschools (The Children's Farm in Lake Elmo and Valley Preschool in Stillwater) in our community became licensed to serve children with disabilities because John and my dedication to him inspired his teachers. We have many fine people in our community who have amazed and enriched our lives through their service to people with extra needs. They need your support for the excellence of their gifts. All people deserve the right to be successful, to have basic needs met such as being active participants with others in their community, and living with people who enrich their lives.

My son will soon need Waivered dollars so that he can continue the success of his current life, and begin a new adventure living with people his age in a group home. I hope that you will understand that John's family has supported him financially, emotionally, physically, socially, and now he needs his community to help with this now that he is almost 21 years old. We need the support of government dollars (community dollars) to do that.

I have stayed home, used virtually no government dollars for support, and over the last year I have been told by Washington County that there are no Waiver spots available for John unless it is an emergency. That is because supports that we worked so hard for were taken away by the legislature.

The people of the State of Minnesota have been held up as moral leaders exemplifying the way people should be treated by providing food, medical, educational, clothing, and housing needs as well as community needs to people in need. To turn our backs on a neighbor in need would have made us feel ashamed. Our parents, our faith beliefs, and our conscience taught us these truths. We are leaving a legacy to our children. Be careful when someone misguidedly tells you that the primary evil to our next generation is debt. The priority of what we leave our children is a continuance of and an advancement of spiritual community values. The evil is an affluent society that is nonresponsive to pain.

"It was one said that the moral test of government is how that government treats those who are in the dawn of life, the children, and those in the twilight of life, the elderly and those who are in the shadows of life, the sick, the needy, and the handicapped." -Hubert Humphrey

"Government is a contrivance of human wisdom to provide for human wants. Men have a right that these wants should be provided for by this wisdom." -Edmund Burke, Reflections of the Revolution in France

We the people of Minnesota are beautiful people. We all accomplish so many giving, caring gifts to others. All people aspire to good things. We need to reclaim those things of which we can be proud. The baton we pass on to our children should reflect a government that is financially sound, but never at the expense of a vulnerable person.

Both my husband and myself thank you for reading this lengthy sharing.

Judith Blackford James Blackford
9765-45th St. N.
Lake Elmo, MN 55042-9511
651-770-7856

We have a social contract with people who have mental and physical challenges. We embarked on this contract when the horrors of the doors of institutionalization were opened, and belatedly but correctly we made enormous changes to correct this moral and spiritual evil that had been allowed to take place in our society because people turned the other way. We made civil equality changes. Do you remember that institutionalization was still prevalent in the 1970's. Even in the mid 1980's in my school district in Stillwater children were not allowed to be fully included in society and educated other than in segregated special education classrooms.

I received an e-mail yesterday saying that you are being responsive to parent's burdens in lowering parental fees. I applaud you for this, because every financial and emotional burden placed on families stresses and weakens them so that eventually they may be forced to heartbreakingly place their children in institutions.

After the great Depression people were suffering, we saw a need, and we implemented Social Security support, we did not say we do not have the money. We saw the need and found the money. When 911 occurred, we went to Iraq, we did not say we do not have the money. We saw the need and found the money. When people of other countries have suffered under dictatorship we have not said we do not have the money. We see the need and find the money.

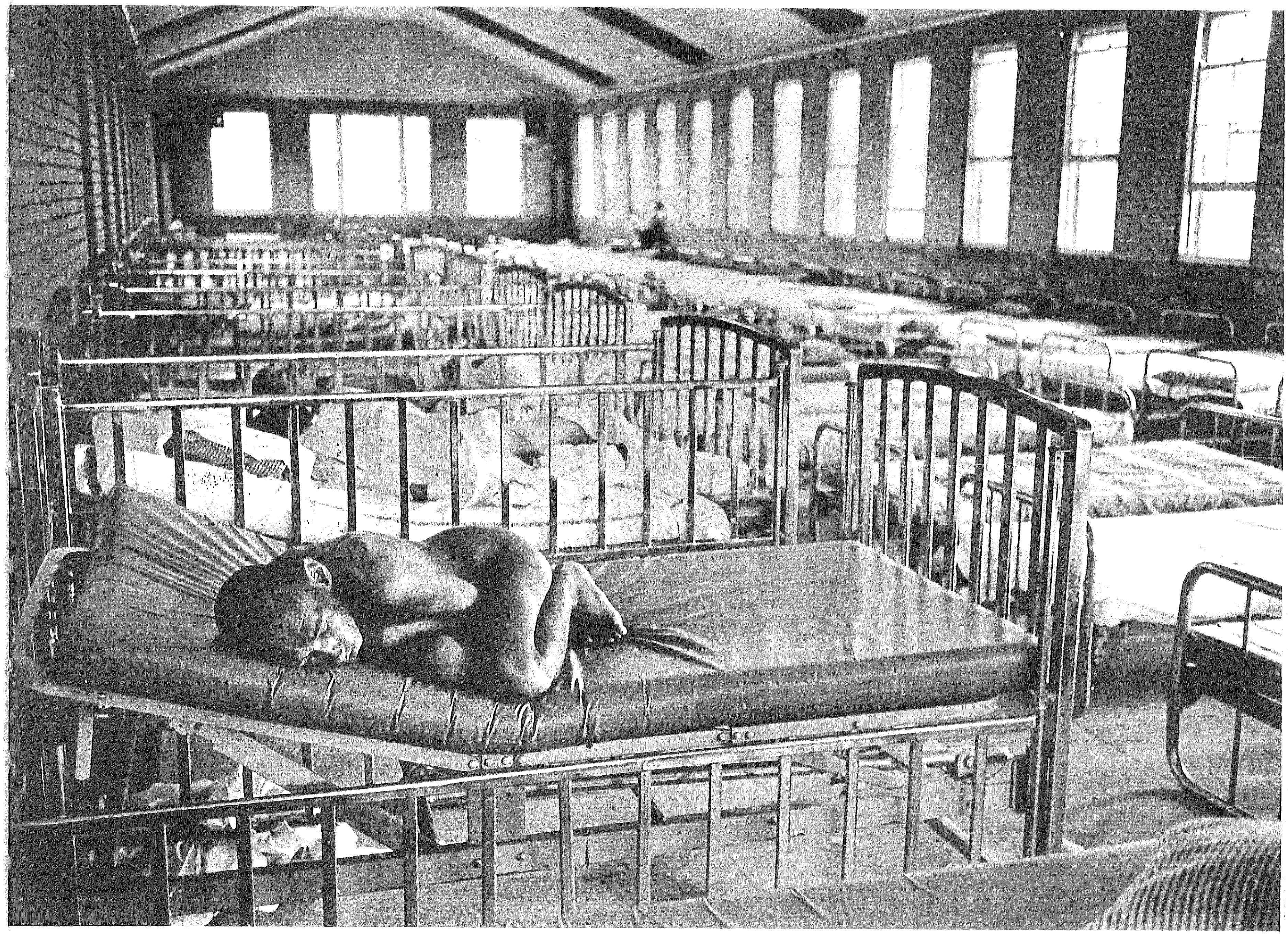
We have a social contract with people with people in our community who have physical and mental challenges. We have made changes to have inclusive community, and educational, and medical opportunities for these people because they are not "these people" they are equal, they are "us".

My final question to you is, "Do we have a social contract with these people or not?" Don't tell me there are money problems because that is not an acceptable answer. We either have a social contract or we do not. And if we do we will find the monies to fulfill that contract.

I have a son who is age 21—age of majority. There are no monies for a Waivered slot for my son even though I have done everything possible to utilize the fewest government dollars possible for the last 20 years. I can see the Governor's budget taking fullness of life from my son, I can project into the future of these state decisions, and what I see and maybe not everyone else sees is that the choices you are making today that are not supportive could lead us back towards institutionalization.

And that is a criminal change, and we should be very afraid. I don't think that is the legacy any of us wish to leave to our great grandchildren.

Legislators and policymakers, you are the spokespeople for those who cannot speak. You either vote your soul convictions or you don't. You are the hands and the minds of the Divine on this earth. These are the strengths of the people of Minnesota. If we must each stand alone, then let us stand for what is right and just.



de G

TECHNICAL DETAILS

CAMERA Leica and Nikon
FILM Kodak

1971 **[FEATURE]**

A Warehouse for People

BY JACK DYKINGA, THE *CHICAGO SUN-TIMES*

Jack Dykinga received one of the earliest of the Pulitzer Prizes to be awarded for images that documented a social issue, as opposed to a news event. The photos he made at the Lincoln and Dixon State Schools for the mentally retarded near Chicago were at once artistic and terrifying, and they shocked Chicagoans.

Dykinga's purpose in visiting the schools—which he called warehouses for unfortunates—was to highlight the effect a proposed reduction of state funding would have on what little care these institutions provided.

The impact of the scenes he encountered was so strong that Dykinga was unable to use his camera during the first hours of his visit to the so-called "cottages," which were actually more like hospital wards.

"I just watched. I was overwhelmed by the horror of it," he said later.

His report described overwhelming odors, retarded children and adults smeared with feces, and beds wet from urine. He talked of severely overworked staff members; the four aides, for example, who attended one hundred patients were forced to feed the retarded much too quickly just in order to get around to them all.

Dykinga brought to the assignment a fine eye for composition and detail and a graphic simplicity that enhanced the drama of the photos and the story. The result of the photos' publication in the *Sun-Times* was that funding was extended at its then-current rate. More importantly, Dykinga's pictures sensitized legislators to the desperate, loveless existence the mentally handicapped endured in the schools.

After he won the Pulitzer, Dykinga moved to the Southwest and turned his pictorialist's eye on the environment. He quickly established himself as one of the nation's most prominent landscape photographers, coupling his photographer's eye with the journalist's perspective of environmental reporting. He lectured widely and produced several books; one entitled *Stone Canyon* was influential in the federal government's decision to make the area he photographed a national monument.

NOVEMBER 1970 ■ *Chilean president*

NOVEMBER ■ *Charles de Gaulle, the*

DECEMBER ■ *The north tower of the*