

Testimony before the Joint Committee on Finance

Intoxicated Driver Intervention Programs

April 13, 1999

Diane Y. Oonk, Executive Director

Triniteam, Inc.

202 Graham Ave., Eau Claire, WI 54701

(715) 836-8106

My name is Diane Y. Oonk. I am the Executive Director of Triniteam, Inc. a nonprofit social service agency in Eau Claire. I am here today to urge you to include additional state dollars into the Department of Transportation's intoxicated driver pre-trial intervention programs. Last session's state budget bill included \$150,000 for this program. Since that time 4 additional counties have started programs based on the success of the Milwaukee program. The Department has combined these state dollars with federal funds under the Alcohol Incentive Grant funding to expand this program and save lives.

The Eau Claire Intoxicated Driver Intervention Program began in August, 1998. We have worked with 63 people as of March 31, 1999. 19 people have successfully completed the program and 18 are currently enrolled. In looking at the 63 people we have worked with, only 2 of those who were unsuccessful have reoffended. We have saved 710 jail days which would have cost our county \$31,950. We have support for the program from the judges, D.A. and public defenders.

Our concern is that we have two thirds of our funding from the federal funds. These funds are meant only to be a match for pilot programs and gradually need to be replaced by all state funding. The Department is also concerned that changes in the criteria as required of the Transportation Equity Act for the 21st Century may not allow Wisconsin to qualify for these funds.

Intoxicated Driver Intervention Programs work! We need your help to make certain they are sustained. I have attached the Department's estimates of what will be needed to keep these programs operating.

Estimates state funding '99 state funding '00 state finding '01 state funding '02

Kenosha, year one	\$ 79,141.00	\$ 26,380.00	\$ 39,570.00	\$ 52,761.00	\$ 79,141.00
Eau Claire, year one	\$ 57,812.00	\$ 19,271.00	\$ 28,906.00	\$ 38,541.00	\$ 57,812.00
Marathon, year one	\$ 62,608.00	\$ 20,870.00	\$ 31,304.00	\$ 41,738.00	\$ 62,608.00
Waukesha, year one	\$ 99,933.00	\$ 33,311.00	\$ 49,966.00	\$ 66,622.00	\$ 99,933.00
Milwaukee, state funding	\$ 110,000.00	\$ 110,000.00	\$ 110,000.00	\$ 110,000.00	\$ 110,000.00
Oneida, Forest, Vilas* \$5,000	\$ 71,646.00	\$ 23,882.00	\$ 33,232.00	\$ 44,430.00	\$ 66,646.00
Total	\$ 233,714.00	\$ 292,978.00	\$ 354,092.00	\$ 476,140.00	

Interest from following counties:

- Brown
- Chippewa
- Sheboygan

- 1st year efforts, 2/3 fed, 1/3 state
- 2nd year efforts, 1/2 fed, 1/2 state
- 3rd year efforts, 1/3 fed, 2/3 state
- 4th year efforts, all state funding

*estimated start up costs

State Funding Projections without 410 monies

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As a representative of
Nutrition for the Portage County
Coalition of Aging, I strongly
support an increase of 3.6
million dollars in the state budget
to support nutrition for the elderly
in the state of Wisconsin. That
increase would enable many elderly
citizens to receive benefits who are
now neglected due to lack of funds.

Lorraine Dudley
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April 13, 1999

To: Members of the State of Wisconsin Joint Finance Committee

From: Carol Moore, Portage County Department on Aging Nutrition Program Director

RE: INCREASED FUNDING FOR THE ELDERLY NUTRITION PROGRAM

Attached is a summary issue statement developed and endorsed by the Wisconsin Association of Nutrition Directors (WAND), of which I am a member, addressing increased state funding for the Elderly Nutrition Program. Please endorse this request on behalf of older residents of the state of Wisconsin.

Thank you.

ISSUE STATEMENT: The state funding for the Elderly Nutrition Program has not changed since 1994. This service is critical for older persons to remain independent, in their own homes. Wisconsin's Aging Network effectively delivers meals to the elderly with federal, local, charitable and volunteer resources. The need for services grows daily. The Wisconsin Association of Nutrition Directors (WAND) is asking to have an additional \$3.6 million put into the nutrition program to assist the 72 counties and 8 tribes live up to the standards that everyone expects from the State of Wisconsin.

- ◆ \$1.2 million These funds would be used to keep up with the current increase in the Home Delivered Program. This Program delivered over 2.5 million meals last year which amounted to a nearly 200% increase in the last 11 years. These dollars would help with increased costs in food, condiments, disposable, transportation (to deliver more meals to more outlying areas of the counties), and reduce or eliminate waiting lists.

- ◆ \$950,000 These funds would be used to expand Congregate Services. This would allow counties to provide county-wide service. Our Congregate Meal Sites provide the basis of the 20,000 volunteers used by the Home Delivered Program. Our Congregate Meal Sites also provide the most cost effective settings for the Aging Network to address issues facing the elderly. Just as a small example; some of the topics discussed at Congregate Meal Sites include nutrition education, scams and frauds that are targeting the elderly, elder abuse issues, education, and numerous social activities.

- ◆ \$800,000 These funds would be used to provide specialized diets throughout the State of Wisconsin. Currently, only 25% of the Nutrition Programs offer any types of specialized diets. This would allow counties to expand existing specialized diets and offer an opportunity for counties not offering specialized diets a way to serve their clients more fully.

- ◆ \$650,000 These funds would be used to expand dietician services offered by the Elderly Nutrition Program. This would increase our emphasis in preventive services to help reduce our clients medical costs. These services would primarily be available to our homebound clients of which 57% are already at high nutritional risk. This could provide nutrition education, intervention, and provide a much higher quality of life than they have had in the past allowing them to stay independent and in their homes longer.

INTERGOVERNMENTAL TRANSFER PROGRAM

The facilities in Wisconsin that care for individuals with the most complex and challenging care needs are at risk of being forced out of business due to state policy. County nursing homes in Wisconsin have historically accepted the individuals who privately run facilities routinely turn away. Accepting these high-need, high-cost individuals obviously has an effect on a facility's bottom line.

In recognition of this unique nature of county homes, the Intergovernmental Transfer Program (ITP) was established in 1992. This program allowed the state of Wisconsin to use county homes' Title XIX allowable expenses to garner federal matching dollars.

This federal "matching" program provides enough dollars for Wisconsin to fully reimburse county homes for their losses and have additional funds left to use for other state expenses. From 1992-1995 that is how the program worked. Since 1995, however, despite continuous increases in the amount of federal funds coming to Wisconsin, the state has returned a decreasing share of those funds to reimburse county losses and utilized the difference to supplant General Purpose Revenues (GPR) (see chart).

(In Millions)

Fiscal Year	County Nursing Home Certified Losses	Fed. Funds Received to Cover Those Losses	Funds Returned to Counties	Taxes Paid by County Property Taxpayers for Funds Received by State
1992-93	46.3	70.6	15.0	31.3
1993-94	43.1	65.9	52.1	-9.0
1994-95	48.1	72.1	55.7	-7.6
1995-96	52.2	77.3	37.1	15.1
1996-97	59.2	85.7	37.1	22.1
1997-98	63.6	91.0	41.7	21.9
1998-99	68.0	96.4	37.1	30.9
TOTAL	380.5	559	275.8	104.7

As you can see, since 1995 an increasing portion of county homes' expenses are not being reimbursed. This is despite the fact that the amount of federal dollars these losses are generating is increasing every year.

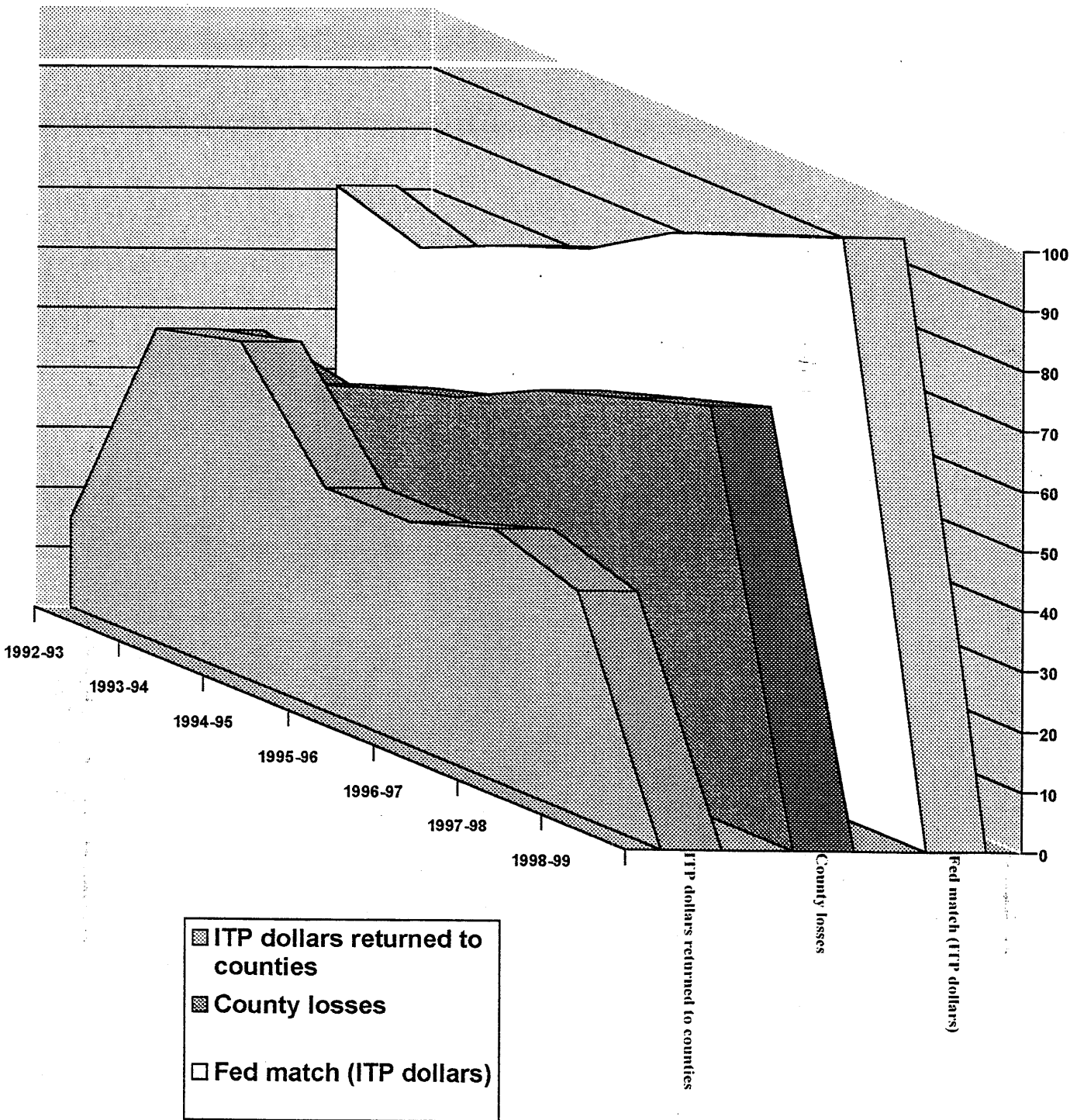
The policy of utilizing more and more of these federal dollars that are "matching" the county home losses for non-county home purposes will ultimately force county nursing homes out of business. That would be a tremendous mistake for everyone involved. First, there would be a void for people with intense needs that have historically ended up in the county nursing home. Second, the tens of millions of federal dollars that Wisconsin is receiving every year via the county nursing homes would disappear.

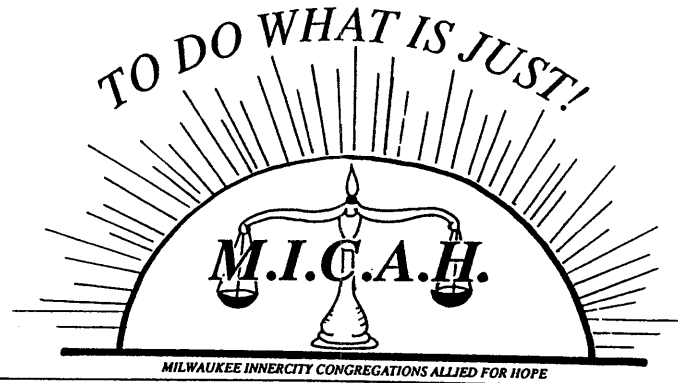
Counties are simply asking that the state reimburse the county homes' losses that were utilized to generate the federal funds. The state can do this and still have a significant amount of money left over to use for its purposes. This would seem to be a win-win situation. If the state's greed, however, continues to drive decision-making, the "well" will dry up for everyone concerned - most importantly, for those currently receiving care that isn't offered anywhere else.

PROPOSAL: Amend Wis. Statutes s. 49.45 (6u) to read:

Notwithstanding sub. (6m), from the appropriation under s. 20.435(5)(o), for reduction of operating deficits, as defined under criteria developed by the department, incurred by a facility, as defined under sub. (6m)(a)(3), that is established under s.49.70(1) or that is owned and operated by a city, village or town, the department shall distribute to these facilities at least \$72 million in each fiscal year...

Diversion of ITP dollars from counties (in millions)





4011 W. CAPITOL DRIVE, MILWAUKEE, WISCONSIN 53216, (414) 449-0805

TO: State Legislators
FROM: MICAH
RE: Money for AODA Treatment in the state budget

MICAH (Milwaukee Innerscity Congregations Allied for Hope) is comprised of 36 congregations, of ten different religious denominations, in the Milwaukee area. Our combined membership totals more than 30,000. For many years, MICAH has fought for the funds that are needed to provide treatment for uninsured people who suffer from drug and alcohol addiction.

MICAH has been joined by other organizations in the struggle to have sufficient money put into the biennial budget so that treatment can be made available. The statement on the back of this page has been endorsed by the Interfaith Conference of Greater Milwaukee, Wisconsin Citizen Action, the Milwaukee Substance Abuse Services Network and the Women in Poverty Initiative. Other organizations are in the process of deciding on their endorsement.

We ask for your help for two reasons:

** As people of faith, we implore you to see the human tragedy of addiction and to recognize that there is hope to restore people to dignity and health with effective treatment.

** As citizens, we call on you to recognize that treatment is far less expensive than prison. AODA treatment is essential if W-2 is to be a success and if we are to reduce crime. We do not ask you to just "throw money" at the problem, but to include a serious process of review and evaluation so that Wisconsin can truly be a leader in the effort to seriously address this tragedy.

\$10 Million Needed in State Budget for AODA Treatment for Uninsured Individuals

We are a consortium of community, business, social service and religious organizations. We call upon the State of Wisconsin to include at least \$10 million in the annual budget for AODA (Alcohol and Other Drug Abuse) treatment for uninsured people. Ten million dollars is needed in Milwaukee County alone to restore funding to the 1993 level.

The tragedy of drug and alcohol addiction is taking a devastating toll on individuals, families, communities, and our society as a whole. Untreated addiction can only end in crime, death and further overcrowding in our prisons. This human catastrophe does not need to be as severe as it is: waiting lists for treatment centers continue to grow. Hundreds of people are ready and willing to enter treatment programs, but are turned away for lack of funding.

The magnitude of the addiction crisis is staggering. Governor Thompson has estimated that 66% of the remaining W-2 participants suffer from drug or alcohol addiction. Even more have dropped out of W-2. Conservative estimates are that 85% of Wisconsin's prison inmates are in need of AODA treatment. It would be far more cost-effective for Wisconsin to offer treatment before people have committed serious crimes and have been sent to jail.

Serious treatment options are needed to deal with serious addiction problems. Many underfunded programs have failed because they have not offered enough time. Short-term programs and outpatient services tend to become a "revolving door". Long-term treatment does work. We need to make a serious investment in people if we expect positive results. This is not inexpensive, but the alternative is far more costly. We cannot afford more prisons, and we cannot afford to have a large sector of the population rendered incapable of making a contribution. And, we cannot afford more crime and more broken families in our community.

Therefore, we urge Governor Thompson and the state legislature to include AODA funding for uninsured people in Wisconsin's budget. At least \$10 million of that funding is needed in Milwaukee County. This initiative should include a serious study of the effectiveness of various treatment options. In the end, this money will save Wisconsin's taxpayers many more millions, as we add people to the ranks of the self-sufficient rather than to the rolls of W-2 or of our prisons.

JOINT FINANCE PUBLIC HEARING
Case High School, Racine, WI
Thursday, April 8, 1999
Statement by Rose Stietz, O.P.

I come before you as a resident of central city Milwaukee and a former resident of Green and Lafayette Counties in southwestern Wisconsin. My primary issues today are lack of funding for uninsured people addicted to alcohol and other drugs and insufficient funding for public transportation in the city of Milwaukee.

I speak on the AODA issue as Chair of the M.I.C.A.H. Neighborhood Safety and Drugs Task Force and a member of the AODA Committee.

I understand there may be a line item in the budget that speaks of \$1 million related to TANF funding. This is welcome. However, it will in no way ameliorate the problem of miniscule funds for uninsured addicts.

At least 9 people have died by homicide in central city Milwaukee as a direct result of alcohol or other drugs since January 1, 1999: David Sanchez (age 25) shot by his brother after a night of partying; Lafayette Clarke (age 17) shot in a possible attempt to steal a drug dealer's money (two of his cousins were executed inside a drug house six years ago); Lykele Hood (age 17) shot by his older half-brother--a convicted drug dealer; Chris Brantley (age 16) shot after dealing drugs for quick cash; Rocarldo Chalmers (age 24) shot--had a misdemeanor conviction for cocaine possession; Lonnie Ragsdale (age 20) shot by crack-selling partner for not splitting proceeds fairly; Laquann Baker (age 18) shot because she was with Ragsdale; Christopher Loggins (age 30) and David Beasley (age 30) shot in a bar by a bar patron. Twenty-seven others have lost their lives in escalating violence --many of which will eventually be tied to alcohol or other drugs.

Governor Thompson is proposing \$6.2 million to be made available in loans and grants for taverns whose business may be hurt by another business--the Indian casinos. Uninsured people who are ready for and need extensive treatment can't get help because small providers are not given enough funds to treat clients adequately; then these providers are penalized for not offering successful treatment. This is a double standard. Is it because Governor Thompson has a brother in the tavern business but no uninsured family members?

WE NEED \$10 MILLION IN THE STATE BUDGET FOR TREATMENT OF UNINSURED PEOPLE IN MILWAUKEE COUNTY. We need the sniping at each level to stop and sufficient treatment made available to solve this serious medical problem.

Secondly, adequate Public Transportation must be funded in the city of Milwaukee--just as highways are funded outstate. Over three-fourths of the gas taxes raised in Milwaukee County leave the county to be spent on roads Milwaukee drivers will never see. Yet Governor Thompson has stated that no State funds can be used for people in Milwaukee County who have no cars even though this saves millions in highway construction and automobile pollution. Trolleys are a brain child of tourism--not a solution (permanent or temporary) to the needs of people in central city Milwaukee. Suburban trains are useful, but as stated in the 3/31/99 issue of the Milwaukee Journal Sentinel, they draw the well-to-do who already have vehicles to take them from place to place.

In the 1980s I visited New York City, Boston, Washington DC, Chicago, and San Francisco. My friends taught me how to navigate the public transit systems and I managed quite well going from city to suburbs to airports, etc. In the 1990s I was able to do the same in St. Louis. In Milwaukee, in 1985, I was able to make most of my stops during a three-hour transfer. Now, I can't always get to my first destination before my one-hour transfer expires--requiring me to pay a second fare just to get where I'm going. Unless I can find a friend to drop me at the airport, it costs a minimum of \$8.00 to take United Limo and much more by taxi. In the above cities, I could get to the airport for the price of a subway token or a city transit fare.

This is unconscionable in 1999. People who cannot afford a car, elderly people who should not be driving, drivers who have had their licenses suspended for whatever reason, workers trying to get to jobs on time, and mothers and fathers trying to shop or get to medical facilities or child care are held hostage by legislators who ride comfortably in their several cars on highways that never seem to run out of funds. Perhaps if every legislator parked his or her car(s) for two weeks, the urgency of this problem would take on new clarity.

ram van Kampen, RD, CD. I am a Registered Dietitian employed w/ the Northern Area Agency on Aging. I want to ask for your support for the following issue statement. Thank you.

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Statements Supporting the Health and Financial Importance of Adequate Nutrition
Intervention For The Elderly

- ◆ Health care professionals who specialize in geriatrics and the people who run America's hospitals, nursing homes and home care agencies, agree on the cost-effectiveness of routine nutrition screening and treatment both for their own patients and as part of the health care system for the elderly population in general. (Hart & Associates, National Survey on Nutrition Screening and Treatment for the Elderly, 1993)
- ◆ In 1990-1991 in a 16-week longitudinal study of frail elderly women eligible for Home Delivered Meals, 73% showed an increase in weight and anthropometric and body mass measures with their receipt of 5 to 10 Home Delivered Meals per week. (Kordish, Clearfield, PA – Reported Nutrition Screening 2, 1993)
- ◆ An Area Agency on Aging program using liquid supplements for frail elderly had 100% of the participants report improved personal health through their positive anecdotal responses about increased performance of activities, improved weight gains, increased appetites or other physical and psychological improvements. Physicians reported 66% of program participants gained needed weight, 22% stabilized their weight and 33% were thought to have avoided unnecessary hospitalization or nursing home placement. (Siudarta, Oakland and Macomb Counties, MI – Reported Nutritional Screening 2, 1993)
- ◆ Among hospitalized adults, it cost \$5,575.00 more in the cost of treating a malnourished surgery patient and \$2,477.00 more in the cost of treating a malnourished medical patient. (Reilly, 1988)
- ◆ From a study done in two hospitals, patients with the likelihood of malnutrition had over three times the number of major complications, stayed in the hospital 2/3 longer and were four times more likely to die. (Reilly, 1988)
- ◆ Each reduction of one month in the average period of dependence (of the elderly) means a savings of up to \$4 billion in health care and custodial costs. (Califano, 1988)

Joint Finance Testimony- 4/8/99

My name is Eugene Dunk. Thank you for this opportunity to speak. I am the Vice President of the ARC of Racine, an advocacy organization for individuals with developmental disabilities and their families. I am also the parent and step parent of 7 children. The youngest in our home is a delightful fun loving 14 year old , Dan who also has Down Syndrome. This involvement in the ARC has awarded me an opportunity to redeem myself. Over 30 years ago I remember being in school and a young woman with developmental disabilities walked into our class to deliver a note to our teacher. One child yelled out here comes Debbie Mental and all the children, including me, hid underneath our desks. Like society, I am learning every day about the respect all Gods children and our citizens deserve as a birthright. My shame remains as do my obligations to help eliminate the barriers to communication and understanding.

We recognize the tough job you have deciding among many deserving programs all needing additional funding. I am here to remind of the difficulties families and individuals with disabilities have often without a voice to express them. As you know most individuals with developmental disabilities now live, work, and receive services in the community. We applaud these successes and thank the State and the legislature for helping turn inclusionary ideals into reality. Also please consider the cost savings of de-institutionalization when you look at community service costs.

Community Aids are essential to full democratic functioning and a quality of life for these citizens in our state. The federal governments failings need to become a state priority. The counties need continued assistance in providing these essential services.

Respite Care- there is a new respite Care program seeking state funding. This cradle to grave program would allow family caregivers temporary relief providing normalcy and enhancing the quality of care by reducing stress. We urge your support.

Finally, Family Support- This wonderful program provides funding for families to retain disabled children in their homes. Families with a county caseworker are able to determine the services most needed and the state provides up to \$3000 in annual funding.

As a parent of a teenager this program has proven invaluable. The funding has allowed my son proper after school and summer supervision and has provided opportunities for recreational therapy and social support. This has allowed both my wife and me to work and contribute back to the state. I am grateful and thank you for providing this funding. I only wish all families with the need could also have this opportunity. There is a large waiting list for services in Racine and around the state. Approximately \$3 million are needing to serve eligible, waiting families in need.

Most of you know the challenges parenting brings- congratulations and good wishes to Senator Plache and her new baby. Parenting a child with disabilities adds to these challenges. And yet Daniel's step-father is perhaps the most rewarding factor in my life. He gives out true unconditional love. I urge your support of programs for our state residents most in need and least as likely to have benefited from the economic growth and prosperity in our state.

Eugene J. DeF...



Birth Defects Surveillance and Prevention

Position Supported by the March of Dimes Birth Defects Foundation.

Background

Each year in Wisconsin approximately 2,000 babies are born with birth defects. Although a state statute exists for birth defects surveillance, Wisconsin's system is not adequately funded or staffed to track these babies. Wisconsin must invest in a *comprehensive* system which can be used to:

- Provide data on the incidence and prevalence of birth defects
- Develop baseline data for research on long-term effects of birth defects
- Target public health resources
- Evaluate public health programs and services

Economic Impact of Birth Defects

Birth defects cost billions of dollars per year for health care and special education services in the United States. A state investment in birth defects surveillance would work to reduce future state health care costs through birth defects prevention. Some facts about birth defects:

- Children with birth defects account for 25-30% of all pediatric hospital admissions.
- The National Centers for Disease Control and Prevention (CDC) cites birth defects systems (and resulting targeted prevention/education services) as a leading contributor to reducing birth defects.
- Accurate data are essential for estimating the economic impact of birth defects.

Cost Savings of Preventing Birth Defects

How Folic Acid Can Prevent Some Birth Defects

Each year, approximately 4,000 pregnancies in the United States are affected by a defect of the spine (spina bifida) or brain (anencephaly), also known as NTDs (neural tube defects). The B-vitamin folic acid can help to prevent **40 to 70 percent** of these birth defects every year. However, according to the Centers for Disease control and Prevention (CDC), most women do not consume enough folic acid daily to protect against these serious birth defects. Public health education is needed.

Lifetime Cost for Neural Tube Defects

Based on a lifetime per patient cost of \$294,000 for spina bifida, the 31 Wisconsin cases reported in 1995 would cost \$9,114,000. While aggressive public health education is needed to prevent neural tube defects, Wisconsin lacks a surveillance system that would aid in monitoring and evaluating the success of such an effort.

Preventing even one case of spina bifida annually would pay for an active birth defects surveillance system in Wisconsin.

Birth Defects Surveillance and Prevention in Wisconsin

The Past

Wisconsin's Birth Developmental Outcome Monitoring Program (BDOMP) was established by law in 1988, based on the 1984 Healthy Birth Task Force recommendation to "strengthen current efforts to collect, analyze and utilize maternal and child health data." In the ten years since Wisconsin's BDOMP was established, the state has not fully invested in this important program.

The Present

BDOMP currently resides in the Division of Public Health within the Program for Children With Special Health Care Needs with GPR funding for one FTE position. Work is underway to rewrite the current legislation to more adequately meet this growing public health need, however, a major financial commitment must be made to ensure that state public health planners have accurate data for health prevention and service planning to prevent birth defects.

The Future

An active case-find Birth Defects Surveillance system would require a total staff of 6-8 to support data collection, analysis, data quality improvement, and education and prevention activities. Also needed are enhanced computer hardware/software including notebooks for personnel reviewing medical records at hospitals on-site, funding professional consultation and technical assistance.

March of Dimes Recommendation - Commit \$400,000 - 500,000 in the state budget for birth defects surveillance to support data collection, analysis, data quality improvement, and education/prevention activities.

For more information contact:

Russell S. Kirby, Ph.D., MS, Associate Professor and Coordinator of Research

University of Wisconsin Medical School - Department of Obstetrics and Gynecology

Sinai Samaritan Medical Center - Milwaukee - Phone: 414-219-5610 Email: r-kirby@whin.net

Amy L. Richardson, March of Dimes - Phone 414-886-8977 Email: amymod@aol.com

Congenital Anomalies

In 1997, reported congenital anomalies included:

Total Births With Reported Anomalies	1,038
Central Nervous System, Head	49
Anencephalus	7
Spina Bifida/Meningocele	19
Hydrocephalus	16
Microcephalus	5
Other Central Nervous System	9
Heart, Circulatory, Respiratory	142
Heart Malformations	110
Other Circulatory/Respiratory	37
Gastro-Intestinal	82
Rectal Atresia, Stenosis	10
Tracheo-Esophageal Fistula	11
Omphalocele, Gastroschisis	44
Other Gastrointestinal	18
Genito-Urinary	233
Malformed Genitalia	128
Renal Agenesis	14
Other Urogenital	92
Musculoskeletal/Skin	448
Cleft Lip, Palate	75
Polydactyly, Syndactyly, Adactyly	115
Club Foot	63
Diaphragmatic Hernia	23
Other Musculoskeletal/ Integumental	196
Malformation Syndromes	65
Down Syndrome	43
Other Chromosomal	22
All Other	98

Notes: These numbers reflect only those congenital anomalies that can be discerned at birth and are reported on the birth certificate. Many are not detected before the newborn is discharged from the hospital. Since more than one anomaly may be reported for each infant, the column does not add to total. This table is not comparable with congenital anomalies data published prior to 1989; see Technical Notes for explanation.

Testimony on Birth Defects Surveillance
Wisconsin Joint Finance Committee - April 8, 1999
presented by Amy L. Richardson, Associate for State Public Affairs
March of Dimes Birth Defects Foundation

Senator Burke, Representative Gard and members of the committee.

My name is Amy Richardson. Thank you for the opportunity to present testimony today on behalf of the March of Dimes Birth Defects Foundation. As you know, the March of Dimes is a national voluntary health organization with a mission to improve the health of babies by preventing birth defects and infant mortality. I am here today to speak on the issue of increased state funding for comprehensive birth defects surveillance in Wisconsin.

But first – speaking of babies --I would like to congratulate Senator Kim Plache on the adoption of her baby daughter Eve. And while Senator Plache's baby was not born in Wisconsin, every year approximately 65,000 healthy babies are born in our state. That's the good news. The challenging news is the number of babies born with birth defects and the Wisconsin's limited capacity to collect and use that information for prevention.

Consider these facts:

- Birth defects are the leading cause of death and disability among children of all races and socioeconomic status.
- While we know what causes some birth defects, such as substance abuse, environmental factors, and poor prenatal care, 65% of all birth defects in the country are of unknown origin.
- 150 Wisconsin babies die each year with birth defects as a cause
- It is estimated that 2,000 babies are born with birth defects each year in Wisconsin. I say the *estimated number is 2,000* because the truth is, as a state we simply do not know.

What does that mean - to have a comprehensive birth defects surveillance system? We are talking about data. Collecting the data and using the data as an investment in prevention. A strong birth defects surveillance program would include:

- active surveillance of some or all areas of the state
- routine analysis of data
- investigation of clusters
- use of information in planning prevention and treatment services
- published reports to share with others
- provision of information to families and communities

What is the current status of the program which is called the Birth and Developmental Outcome Monitoring Program? The program was established by law in 1988. It is underfunded and understaffed with only one full-time staff position. In fact, twice the state has applied for CDC grant dollars for surveillance, and twice we were turned down due to the

weakness of our existing program. The March of Dimes supports the proposed language revision for this program in the state budget which strengthens the program; however, without funding this work is dependent upon information collected on birth certificates - which is not specific enough and cannot account for those babies diagnosed following hospital discharge..

In the recently released report entitled Wisconsin Birth and Infant Deaths 1997, on the page listing congenital anomalies, there is a disclaimer at the bottom of the page stating that "these numbers only reflect those anomalies that can be determined at birth and are reported on the birth certificate. Many are not detected before the newborn is discharged from the hospital." It is tough to hold report writers responsible for this lack of information; but we must hold the state accountable for not providing funds to support this important, baseline data collection and analysis.

Wisconsin is clearly behind the 40 other states who are making birth defects surveillance a priority. There are model programs that show how surveillance and research can be combined to study the relationship of birth defects to factors such as nutrition, tobacco use, occupational hazards, and toxic substances in the environment. Only quality state birth defects surveillance system will accurately identify birth defects and provide data that can be used to study causes.

The parents of children born with birth defects want answers. They don't ask "why me," but why did it happen. Until causes are known, prevention strategies cannot be developed and the cost to you, to the families affected by birth defects and to the residents of Wisconsin will be significant, both financially and emotionally. For \$8 per birth, we could fund the Wisconsin program and begin to collect and use this data.

In closing, I would like to give you an example of how an annual state investment of \$400,000 - \$500,000 could result in cost savings. As you can see, this is a stalk of broccoli - a great source of folic acid. Research shows that folic acid consumed prior to conception and during the first weeks of pregnancy can reduce the incidence of neural tube defects by 40 - 70%. That's spina bifida and anencephaly (born without all or part of the brain) Furthermore, women who have one child with a neural tube defect are many times more likely to have a second. A conservative estimate for the lifetime cost of a child born with spina bifida is in the vicinity of \$300,000. In 1995, the 31 Wisconsin babies born with spina bifida will have a combined lifetime total cost of \$9,114,000. If we could save just one family from this tragedy, we could just about pay for one year of surveillance. And with a comprehensive surveillance system, we would be in a position to identify clusters of such birth defects and prevent them. It happened in Brownsville, Texas. It could happen here.

The March of Dimes urges you to protect communities throughout the state with first-class birth defects surveillance and research program. Additional funding is needed to get Wisconsin where we need to be.. The March of Dimes thanks Senator Plache for her

4/13/99

Dear Members of the Joint Finance Committee:

I am speaking today to ask your support for an effort to promote a stable, consistent, quality respite care system in Wisconsin through the provision of the Lifespan Respite Care Bill.

My husband and myself are parents of a 13-year boy with C.H.A.R.G.E. Syndrome, which involves physical and mental disabilities. Since our son's diagnosis shortly after birth we have known that this child would remain in our home. Regardless of everyone's inability to predict his abilities and Dr.s' warnings of a limited capacity for mental and social development we wanted our son, Toby, to be as much a part of our family and community as our other child and his peers. We did this because we believed then as we do today that persons with disabilities have the right to be fully included in their communities. We did not know that it would save the State of Wisconsin \$60,000 dollars a year, the estimated cost of out-of home placement.

There however, has been a price to pay for our decision and our son's basic rights for love and happiness from people that know him best. Throughout his thirteen years Toby, our son, has presented many challenging periods from severe head-banging and other self-abuse to continual sleepless nights where he cried or yelled. For years we needed to get up with him to calm him with backrubs or singing. For years we operated on 2 to 3 hours of sleep a night and every night we went to bed not knowing if it would be a night where we would get a full night's sleep or if one of us would need to get up. We also needed to "sleep" with one ear open as Toby began to learn skills like opening his windows and crawling outside. Sometimes we needed to remove all furniture except his mattress and blankets as his frustration or fear or emotions that we will probably never know escalated and he caused damage to any item within reach. Daytimes presented another set of challenges.

Some people have told us that we were chosen by fate or God to care for Toby which gave us little comfort as we rose weary from our bed to care for a child who screamed and arched his back at every new experience, even eating, and didn't like to be touched. Others called us Saints. We assure those that label us as such that we are very human and require relief.

Through our sons' thirteen years we have had funds put in his County Support plan but have had inconsistent Respite opportunities in our rural area. We have had over thirteen providers in thirteen years, each that we've had to train and then schedule when they could provide it. Sometimes not when we really needed it.

By the mid-90's we began to acknowledge that sleep deprivation and stress had had effects on our family. We realized that through a combination of pride and denial we had not been aggressive enough in getting the RESPITE we needed, the Care for the Caregiver. We accepted our situation and suffered consequences. Soon we found ourselves facing severe financial hardships as my husband, working two jobs, fell behind on his paperwork for his business. I also had two part-time jobs besides caring for my family and began to experience muscle weakness, which I still have, and chronic back pain. Our youngest sibling was referred for a psychological examination as her behavior became concerning, and our oldest daughter found support in her peers when needed as she "didn't want to bother us".

Relief or RESPITE when we received it was lifesaving and has been invaluable to us as constant care providers.

As we began to get more respite our coping skills re-emerged. We were able to get a chance just to think, to examine our priorities and ourselves. We turned the attention on to our younger child and we funneled our oldest daughter's attention into appropriate after-school activities-an opportunity she hadn't had before as we had to count on her constantly for providing after-school care to her brother.

Unfortunately the consistency of RESPITE was short-lived. A wonderful provider we found was hired elsewhere. Another retired. Another became overwhelmed with our son's recent experience with puberty and had to retract her offer of services. Today we again find ourselves with no RESPITE even though the money is in our son's plan.

Recently I met parents of children with hearing and visual impairments and cognitive disabilities from all over Wisconsin; Appleton, Madison, Superior, and Bear Creek. They related similar stories of the high levels of physical, emotional, and financial stress and their difficulties in finding adequate RESPITE. Some reasons for difficulty included lack of providers, some lack of funds in their counties, and some were put on waiting lists for funding for respite through the Family Support Program. This successful parent-centered program has no new rate increase proposed in this budget yet has over 2,000 families on waiting list. Most use family members for RESPITE and then find themselves excluded from family events when their child is too physically involved to attend. As families coping skills are stressed some families have turned their frustrations to the school systems.

I shared the news about the new bill being proposed to the Governor's Budget, the LIFESPAN RESPITE BILL, that will provide the first steps toward a coordinated respite care system in Wisconsin, as well as additional funding to increase the availability of respite throughout the state.

The funds needed by the State to get valuable relief for families is \$75,000 for 1999-2000 and \$450,000 for 2000-2001 for start-up costs and maintenance. The bill will establish a statewide vehicle to coordinate efficient, consistent, quality respite care in Wisconsin. The access to lifespan respite care could be available to all that need it, regardless of age, disability, or income. RESPITE would be established for any primary

caregiver of an individual with special needs. Not only would parents of children with disabilities benefit but also would families supporting an elderly parent in their home, spouses caring for another with Alzheimer's and care past age 21. Again saving the State money as opposed to costly out-of-home placements.

We need to support our families by increasing accessibility to funding, qualified providers and respite services in Wisconsin, a State that has had a vision of long-term care and family-directed services.

RESPITE needs to be viewed as essential to families' support systems, not begged for or only received while under crises.

By funding the LIFESPAN RESPITE BILL, the vehicle to a stable respite care infrastructure, you are supporting families as they most need it, consistently.

At times we question our fate if we had chosen the other path, the road not taken, the decision we didn't make because of our beliefs that person's with disabilities should be fully included in their communities. The decision that would have left the State a \$60,000 a year bill, and left my son without a family and community base and all that encompasses.

Thank you for your time and your consideration of support of the LIFESPAN RESPITE BILL,

DEANNA YOST
WASHBURN, WI
715-373-5000

LIFESPAN RESPITE CARE

.....

ISSUE STATEMENT:

Respite Care is care which is provided to a person with special needs in order to give temporary relief to the family or primary caregiver of that person or care provided when the primary caregiver is unable to provide care on a temporary basis. A special need means the physical, behavioral, cognitive, emotional or personal need of a person with a condition which requires care, supervision or both in order to meet the basic needs of the person. Respite is a primary support service consistently requested by parents and other primary caregivers of individuals with special needs. Demand for respite in Wisconsin far exceeds available funding, programs, and qualified providers. Service access and funding are inconsistent throughout the state. In many counties respite programs have waiting lists or are non-existent, or. Some families have access to funding but cannot find skilled providers, while others have providers but no funding. In addition, Wisconsin lacks an efficient means to coordinate respite care statewide, resulting in fragmentation of resources, duplication of efforts, and inconsistencies. There is no set of statewide standards and guidelines, or means to promote quality assurance .

Background :

Parents and primary caregivers who are responsibly trying to raise their children with a special need or care for a family member at home search for the appropriate services and supports to help meet their respite care needs. Sometimes this search forces parents or primary caregivers who have exhausted all their own financial , emotional and physical resources to place that individual with a special need in an foster home, nursing home, or institution. This practice is the consequence of inadequate funding of respite care services. Lack of incentives and statewide coordination to develop flexible community based respite to help keep individuals of all ages with special needs at home, in their schools, jobs, and communities also contributes to the problem

SPONSORING ORGANIZATIONS

ARCH - Association for the Rights of Citizens with Handicaps, Inc, Waukesha
Catalyst Home Health, Madison
Child Care Connection R&R Agency, Wausau
Children's Trust Fund, Madison
Have a Heart Farm , River Falls
Independence First, Milwaukee
Interfaith Partners in Caring, Sinsinawa
Juneau County Committee on Aging , Mauston
La Causa, Inc, Milwaukee
La Crosse Aging Unit, Lacrosse
Lifespan Respite Care Committee, Wausau
Marathon County Commission on Aging
Omatayo, Milwaukee
Piccadilly Place Respite / Child Care, Beloit
Parents Education Project (PEP) - West Allis
Rehabilitation for Wisconsin, Inc, Madison
St. Agnes Hospital, Respite Care, Fond Du Lac
South Central Respite, Inc, Pardeeville
St. Ann's Adult Day Care, Milwaukee
St. Ann Center for Intergenerational Care, Milwaukee
Special Needs Adoption Network, Milwaukee
The Arc of Wisconsin, Madison
The Respite Care Association of WI, Inc, Green Bay
United Cerebral Palsy NCW., Wausau
United Cerebral Palsy SEW., Milwaukee
United Cerebral Palsy of SCW., Janesville
United Cerebral Palsy of Wisconsin, Madison
Wisconsin Family Ties, Madison
Wisconsin Coalition for Advocacy, Madison

These practices:

- Increase the risk of out of home placement by 50%
- Lead to a 4 times higher risk of abuse and neglect
- * Lead to an 80% divorce rate
- * Put the health of the primary caregiver and siblings at high risk . 65% of primary caregivers will develop chronic or life threatening illness i.e. depression, lupus, cancer, muscular dystrophy, multiple sclerosis. 45% of siblings develop serious emotional disorders
- * Force parents or primary caregivers to make an otherwise unthinkable choice between retaining responsibility for and the relationship with the individual and giving decision making authority and control to a state agency by severing legal ties to the individual with special needs in order to obtain the help they so desperately need - In many counties CHIP(children in protective custody) petition has to be filed before families are eligible for respite
- * Waste public funds by placing an individual with special needs in an out of home placement when their basic needs could be provided by their families who love them
- * Force individuals into out of home placements rather than supporting families and promoting the development of community based respite service

Position:

The Lifespan Respite Care committee, and numerous organizations statewide are seeking to increase the availability of respite to Wisconsin citizens as part of a comprehensive service system to all individuals with special needs . Adequate respite care is critical in our efforts to ensure a full continuum of support services for families and primary caregivers. The Lifespan Respite Care committee, along with numerous organizations statewide, and direct service organizations supports a policy of consumer-driven respite care services in which all Wisconsin families and primary caregivers have access to flexible, affordable, and quality respite - regardless of disability, income, or age. Consumers have a right to adequate resources for respite care; a right to choose whether to have respite in their home or elsewhere; and to choose who provides it. Respite should be provided in a variety of settings with a variety of support models, and be flexibly designed to fit the unique circumstances of each person. Consumers should have the option of time-limited respite as an alternative to a more restrictive and long term living arrangement, including out of home placements.

Action Required:

- 1) The Lifespan Respite Care committee supports the following legislative initiatives:
to provide GPR funding of \$525,000 for the 1999-2000 biennium to increase availability of respite services and to develop a consumer-driven, well-coordinated, and ready-to-respond respite care delivery system in Wisconsin.
- 2) Contact your Senator and Assembly Representative to indicate your support for Lifespan Respite
- 3) Urge your Senator and Assembly Representative to co sponsor / support The Lifespan Respite Care Bill

Talking Points on the Lifespan Respite Care Bill

For further information on the Lifespan Respite Care Bill please call:

Nancy Olson WCDD Project Coordinator Lifespan Respite Care @ (715)355-1522

The Wisconsin Council on Developmental Disabilities (WCDD) @ (608) 266-0979

or your local FCI coordinator

1. Respite care is a key support to families and caregivers.

Research and families tell us that respite care helps to:

- Reduce stress in families/caregivers lives
- Strengthen family's/ caregivers ability to care for their children at home
- Help older adults remain at home
- Reduce residential , nursing home, foster care, and institutionalization
- Reduce risk of abuse and neglect
- Enhance family/caregivers coping skills
- Increase feelings of depression
- Increase community and peer contacts for children with disabilities
- Increase family social activities and interactions
- Allow families to spend time with siblings and other family members

Respite Care is a highly requested Family support service. Yet Wisconsin lacks a stable respite care infrastructure.

Wisconsin is taking important steps toward flexible, family - centered services (Examples include Family Support Program, Children Come First, wrap around services. family support and preservation, ect) When families identify their own needs and strengths, respite care is often one of the most frequently requested service. However, Wisconsin's lack a stable respite care infrastructure means that respite resources are fragmented, some families have access to funding but cannot find adequately skilled providers, while others have providers but no funding. Many families receive no respite services at all. Each county is different there are no statewide standards/guidelines, consistency, or quality assurance.

Wisconsin Communities have demonstrated a commitment to respite care.

Some Wisconsin communities have worked hard to develop respite care for local families/caregivers. Most of these efforts are dependent upon time limited grants or inconsistent funding. While this money is essential, it does not provide the stable, consistent and non categorical respite care infrastructure needed by families and caregivers. The lifespan respite care bill would provide that stability. Local efforts can then focus on direct assistance to families.

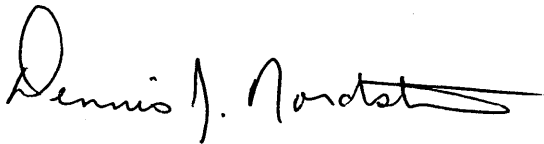
4/12/99

To: Joint Finance Committee

I would like to go on record as opposing several of the governor's proposals for the planned budget. Specifically, the Vocational Rehabilitation base allocation, the Community Integration Program and the Community Options Program are all inadequately funded. I will be brief, but let me explain why.

I am a public school, special education teacher. I work with cognitively disabled young adults, transitioning them from school services to adult services. To be succinct, the last few years have been extremely difficult for our students. Services that were formerly available to them are slowly disappearing. Practically, what this means is that a large portion of our students are struggling to make it in the world outside of school. Reducing or freezing funds that have already been compromised is unconscionable. I can safely say that if funds are neglected in these areas, many handicapped individuals who are capable of successful community integration will be put at risk. At some point finances will be needed to deal with the negative results of a lack of funding. Perhaps money would be better spent on the front end, rather than waiting until problems develop.

Thank you for your help.

A handwritten signature in black ink that reads "Dennis J. Nordstrum". The signature is written in a cursive style with a long horizontal flourish at the end.

Dennis J. Nordstrum
Teacher, Lincoln High School
Wisconsin Rapids, WI

4/12/99

To: Joint Finance Committee

I am the mother of a young boy with Downs Syndrome. He is a very special person, he is happy, loving and very determined, however; he is the kind of person in need of funding for supported adult living arrangements and supported employment. My husband and I love our son very much but; there will come a time when we will not be able to care for him. We do not want our other children to be forced to take on the responsibilities that would come along with our son. Housing options and job supports are very limited and in time many of us as parents will need care for our children, if they are not being productive and constructive they will find something else to do with their time. The something else could be nonconstructive and is not an option. We need this committee's support and understanding to keep funding programs for our children.

I would like to express my extreme concern with the tragedy of cuts and decreases in the Community Integration Program, the Vocational Rehabilitation based allocation and the Community Options Programs. These programs need to be reconsidered and funded more now than ever before. At one time our children were institutionalized, we have made great gains in society with helping our children stay in their homes and showing them what love, responsibility and employment are all about. We do not want to take steps backward and be forced to have institutions again. Our children can be productive members of society with support. We all need to help this happen with more money being allocated to the programs mentioned above which support employment and housing.

Thank you for your support.



Mary Gillette

4606 Huser Rd.

Vesper, Wv. 54489

April 12, 1999

The Joint Budget Committee:

Dear Sir or Madam:

Mark and I are the proud parents of a kind and loving young man named James Robert Grundman.

Jim is fourteen years old, has Down Syndrome and is currently in Jr. High School in Wisconsin Rapids. Jim is completely dependent on my husband and I for all of his needs. He cannot be at home alone, at any time because his current mental state is that of a four to five year old. I am employed by the Wisconsin Rapids School district, so that I will be home when Jim gets home from school. I have to be here for Jim because there is no day care for a fourteen-year-old. I am not complaining but, what will happen when Jim graduates from High School, and there is no funding for housing, jobs, or career training, because our Governor has decided to decrease monies going into programs for handicapped people such as CIP and COP.

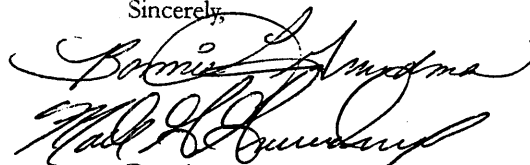
Do I have to quite my job and become a full time, stay at home mom again?

And what about Jim?

He has an older brother and sister who have grown and have gone off to school. He knows the natural progression of things and wants to work and live on his own someday just like his brother and sister. Jim wants to live his life as independently as possible, but that will not happen unless we get support from our government.

In closing, I think it is a real shame that we house, feed, clothe, educate and entertain people that are currently in our jail system, yet our children who have never hurt anyone, do not even get a place to live and a chance at a normal life. If this child is not supported, he will live with us, but what happens when we die? If he has no career skills or living skills the government will have to support him then anyway. So, please help give our son a chance to be all that he can be. He is a warm and wonderful human being who deserves a chance in life too.

Sincerely,

The image shows two overlapping handwritten signatures in cursive. The top signature is for Bonnie Grundman and the bottom one is for Mark Grundman. Both are written in dark ink.

Bonnie and Mark Grundman
3531 Coach Lantern Drive
Wisconsin Rapids, WI. 54494

Ps. Remember you could be in his shoes, you never know what tomorrow brings.

TESTIMONY OF
ROBERTA JOHNSTON, 2702 Thornapple Rd, WAUSAU
IN SUPPORT OF ONE PERCENT
FOR PREVENTION. I represent Healthy Families,
a home visitation program for first-time families. I share
with you some SUCCESS STORIES (June 1998) from a first-time
family whom I visit.

(John and Mary are the parents of a nine month old child. They
(Not real names)
continue to grow by increasing their understanding of child
development. The mother completed the Ages and Stages to measure
the gross and fine motor skills, and the social and problem-solving
skills of their child at four, six, and eight months. Their
child's development is on target. Both parents look forward to
learning about their child's development. This knowledge has
improved their ability to provide for his physical and emotional
needs.

The mother had questions about introducing solids. She
learned about when to introduce various foods by placing food
models to match the appropriate month from birth to one year. She
reviewed what she learned by reading a hand-out about the same
topic.

The father and mother began a book of pictures from magazines
for their son. They placed the pictures behind plastic on a photo
album page which they cut in half. Finally they joined the pages
with yarn.

The family has a medical home. Their child's immunizations
are up to date. The parents have talked with a marriage counselor.
The mother also talked with a psychiatrist and started medication.

John and Mary have participated with the Healthy Families
Portage County Program for nine months. They continue to visit or
call the family home visitor and to learn more about the healthy
development and nutrition of their son.

SUCCESS STORIES (September 1998)

In September John and Mary reached a long-term goal. They moved into their own apartment! It has two bedrooms, a kitchen, dining room, living room and a bath. They plan to take their son to the park nearby. Before the move they were living in a small two bedroom apartment with Mary's parents. The living arrangements were very crowded.

John attained a personal goal. He works full-time at a local plant and is very busy during canning season. Mary tracks their spending and manages the checkbook. She also contributes to the family income when she babysits for relatives.

Their son reached a developmental milestone with their support. He is now walking! He is also eating table foods with them. John and Mary have many books for him, and he enjoys turning the pages of cardboard books.

Mary continues to see a psychiatrist and take medication. She asks the family home visitor to take her to her appointments.

A highlight of the past three months is the one year birthday of their son! The parents gave a party for relatives and friends. Mary says that they are satisfied with the Healthy Families Program and benefit from the support.

Joint Committee on finance Public Hearing
Tuesday, April 13, 1999
UW - Stevens Point
University Center -- Alumni Room
1015 Reserve Street
Stevens Point, WI

My Personal Story:

I sit in on Committees that involve County agencies, School Administrative
Personal.

I organize and facilitate meetings for parents of special needs children.

I have been made aware of the many families who are struggling with the lack of support - for supporting their children within their homes . The question is often how can we make people understand us without sounding like we are whining complaining or feeling sorry for our selves?

Very often we are required to purchase or adapt specialized equipment to make it physically easier for our children to be safe, mobile and independent. We need computers that promote learning, communication, and independence . We need to adapt or homes to promote safety, accessibility and again independence. We as parents are responsible for providing daily therapies to keep our childrens bodies and minds from turning into a spastic nightmares. We as parents are responsible for making sure our children have a healthy diet which can be more then a little difficult if you are dealing with a child on a special diet or one which refuses to eat. Have you priced ensure or glucerna lately? How about diapers? Don't forget the wipes and laundry for those "accidents! We won't get into poop painting or vomiting.

How do we reach you, to make you understand the financial and emotional impact our beautiful children have on our household. We love our children and are willing to do what ever we can to give them happy full productive lives.

Our love for Dani and her love for us is our greatest light!

Personally, I plan on living forever to take care of Danielle

But.....the reality wether we want to face it or not is.....

Who will love and care for our children when we simply can't do it anymore? I know parents who are battling cancer and aging that are at crisis stage because their adult child is bigger than they are and after more than 20 years they simply can not do it anymore! Where will their child live, work and play? Who will watch over our children when we are gone? Who is Responsible??????? In Wood county their are waiting lists for everything.

It is our plan to keep Dani with us to eternity. To always be able to provide for her. But what if we turn into those other families - we get sick, old - die. How will Dani move on to a happy healthy environment in which people love her. Will she continue to learn and grow? Who responsible? What community supports are there?

Why, when we as parents accept and are responsible for the new direction our children have taken our lives, must we be put on waiting lists in some cases for years, instead of supported so we can continue to work, make and encourage a better life for ourselves and our children.

Families need The Family Support to be funded to its full potential. Giving children and their families supportive choices and opportunities to have the best life possible, should be the goal each and every person in this room.

I encourage you to ^{send} do what ever it takes to get schools ^{to} help us teach our children that they are a great value and can be an active positive person in their community.

Continuing education to work funding resources (DVR) is as key to our child's goals as it is to any other young adult.

I know families that have supported and done all the right things to make sure school goals and work training all went off so there would be no gaps, skills wouldn't be lost...there made sure their child had a variety of work skills/experience.....funding ended and after two years of sitting home, that child will need all new training.

Realizing that high paying jobs will never be in their future. The need to expand slots and funding for CIP and Cop so that our children are able to be integrated in their community is vital to promoting self worth, and acceptance. I believe in the "Village" concept.

I want you to think of your own situation as a young couple just starting a family. How overwhelming would this financial responsibility be to you and your spouse! I want you think all the emotions and stress you have experience at the death of a person in your own life who has died way before their time. The happy healthy life we for saw our child having is gone - dead. Someone told me that 80% of our families are broken with divorce. Is it a wonder?

Debra + AF's school care for special needs children.

* no child care for these children 8-21 yrs
Thank you!

State graduation test -

I have a child that totally
screws on test!

44 yrs

Pam I consider
parent - mom
6011 North Park Rd
Wisconsin Rapids WI
915-433-7188

I would like to thank the Joint Committee
on Finance for holding this ~~the~~ hearing
and giving parents like me, the opportunity
to share & support some of the terrible
things we have had happening in Wisconsin
Danielle at 5 months of age

bial ancephalitis (at 5 months)
parent Olegon's Dorex Gaustant
(severe ^{uncontrolled} seizure disorder)
^{I carry a pager cell phone}

\$300,000.00 med. bills ~~paid~~ in
just 6 months

Katie Backet
A remove stress of ^{unknown} future
med. ~~cost~~ cost.

Danielle is
1 1/2 years now
COS school
program

I am here in support of
Family Support
CIP

COP

long term care design

* Currently work on a program for before
& after school care for special needs children
- looking into ~~the~~ Adult Day Care & Housing
needs

Pam Ironside

6211 North Park Road
Wis. Rapids, WI 54457
715-423-7182

Parent Co-ordinator of
Parents Helping Parents
of special need children

New address as of 4/23/99
Craig & Karen RAHM
5248 Crocus Ct.
Stevens Point WI 54481
(715) 343-1902

Name:
Craig & Karen RAHM
2511 6th St So.
Wis. Rapids WI
54494
(715) 423-1439

We are the parents of three sons, Levi - age 10, Josiah age 8 and Isaac age 6. Levi and Isaac have been diagnosed with Autism/Pervasive Development Disorder. After receiving the required MMR (measles, Mumps, Rubella) shot, both boys' speech literally disappeared. They became locked in their own worlds of silence and they developed behaviors because of their inability to communicate. Both boys received services from Birth to Three and Early Childhood through our school district. Levi had difficult years but has made remarkable progress - his speech returned in small chunks, ^{and is fluent now,} and currently is in the 4th grade receiving support services ~~for~~ 40% of his day. Autism is the most severe learning handicap.

Isaac has been another serious matter. At 6 1/2 he is basically nonverbal - has delayed development - ^{no sense of danger,} and is not potty trained and ^{has} poor communication skills.

Our main target is family Support funding - ^{which is frozen.} We believe ~~it~~ it is not funded to the fullest extent and not everyone who is qualified is on the program - some basically for lack of the knowledge of the plan's existence.

Our family is moving from Wood Co. to Portage Co. because of the educational program available in Portage Co. As a result we will no longer be able to receive

Family Support not because my children don't qualify but there is an approximate 3 year waiting list. My boys will lose approximately \$6,000 of support over the next 3 years.

These monies were used for the following areas:

A) Respite care

B) Educational materials, seminars and educational resources to understand Autism and the different learning styles these children have.

C) Sensory items for their deficits such as having textile touch problems - sensitivities to light and sound.

D) Cost of materials is always much higher:

i.e., - Specialized Swing \$180⁰⁰

tricycle \$150⁰⁰

books | videos \$35 - \$50 each.

F) Other medical care not covered by insurance.

E) YMCA programs to meet their fine and gross motor needs.

Isaac's pullups alone has cost the family approx.

G) Fence, \$150 mo. forcing us to seek the Katie Beckett program home alterations & modifications a form of Medical Assistance. We feel the Committee to insure needs to insure those families who have been receiving the safety benefits continue even if they move to another of these special needs county for better educational programs and Children Services for their families.

Thank You

To the Joint Committee on Finance

Our daughter, Megan Isensee, turned 18 this year. Megan is mentally and physically disabled. She will be eligible to remain in the school system for the next three years and will be living with us during that time. From an early age, we have instilled in Megan the expectation that she would be moving on with her life after she completed school, just like her siblings.



We are willing to give Megan a helping hand to get started with her adult life. Our vision is to have Megan lead a full life, which includes having a decent place to live, a job, and recreational opportunities. Because of her disabilities, this will be impossible for Megan to achieve without some assistance beyond that which we can provide.

Will that help be there, or will it take a crisis – such as the death of my husband or I – for society to help Megan live a complete life? The waiting lists for the programs that could help Megan are already hopelessly long. The bureaucracy associated with getting into these programs is disheartening.

Please help. There are thousands of handicapped adult citizens like Megan already on waiting lists who need support beyond which they themselves, and their families, can provide. Like Megan, these citizens need assistance now, not when a crisis occurs. We need programs that are user-friendly. We need adequate funding for services. We urge you to fund these programs to meet the needs.

Pauline Walker

**Pauline Walker
2831 Piney Avenue
Wisconsin Rapids, WI 54494**

Testimony
Joint Finance Committee
April 13, 1999

Lucille Weiler
440 17th St. S.
Wisconsin Rapids, Wi. 54494
715-424-1638

I am speaking here today as the mother of a very wonderful young man who happens to be cognitively challenged. My son Travis is nearly 20 years old. He has received special education services through the schools since he was 3. Travis has always been a very social person. He loves to bowl and play softball on regular city recreational leagues. He also likes to earn his own money. Although he went through the high school graduation ceremony last spring, he has returned to school this past year in order to receive more job skills training, as this has not been available to him through the adult services system. He is currently working at a pet store, which he loves. When he began working there he needed one to one supervision. Once he began learning his job, the job coach backed off gradually, and he is now able to do his work independently. Unfortunately, this job is only available through the school as a training site for students. As of yet, the people in supported employment have not been able to find a job site for him. Apparently it is difficult to find employers who are willing to hire people with disabilities, even though funding for job coaching and training are presently available through the Division of Vocational Rehabilitation. (DVR). I have been optimistic, however, that it will be just a matter of time until the right match is found, and Travis is able to be productively employed. Unfortunately it is my understanding that the Governor's Budget proposal includes a decrease in funding for the services of Vocational Rehabilitation. Travis is capable of being a productive worker once he is placed in the right job, and given the intensive training available through the DVR funding. If funding is cut, the possibility of this happening will be seriously jeopardized for him. I may be politically naive, but it makes no sense to me that an administration which claims to be invested in putting people to work would cut funding for an agency designed to give people the support and training they need to be successfully employed.

The second concern I have for my son, and many other people with special needs, is that of housing options. Because Travis has impaired judgment, he needs fairly close supervision to ensure his safety. A few years ago we had hundreds of dollars of electronics equipment stolen from our home, as Travis let people he thought were friends into our home while I was at work. The older he gets the more difficult it has become to find routine, affordable supervision for him while I am away. In addition, while Travis is usually fairly good natured, he has on rare occasion, lost his temper while playing with neighborhood children. I am 47 years old and a single parent. It is already difficult to provide adequately for his supervision needs. Once he is out of school he will be unsupervised for most of the day, especially if he is not able to obtain suitable employment. The most logical solution would be for him to gradually transition into a supervised living arrangement of some kind. The group

homes, however, charge from \$1500 to \$3000 per month to cover room, board, and supervision. Travis receives about \$580 a month in federal and state social security payments. Even though I work both a full time and a part time job, it would be impossible for me to make up this difference.

In the 1970's deinstitutionalization occurred, and people who were moved out of institutions and into the community with the goal of providing more humane, cost effective care, were fully funded to be cared for in the community. Unfortunately those same dollars have not been provided to care for those people with disabilities who have been raised from birth by parents in their homes. There are now 2 generations of people who are waiting at home for services, with more generations to come. The state has not kept good on its promise to keep people out of institutions by providing adequate funding for community care. The majority of funding still goes to institutions to provide care for the small number of people with disabilities still residing there. The current budget proposal freezes funding for CIP programs which are already underfunded. What counties need to be able to provide suitable living arrangements for people are increases in fully funded CIP 1B slots. While Community Options is another very good program, I have been told that the waiting list for COP has not moved in 10 years in our county. It will take major increases in COP dollars to even begin to meet the need.

I am aware that Long Term Care Redesign has been proposed as a way of simplifying the funding system for the elderly and disabled, but this program has a long way to go before it will be fully implemented. It is my understanding that no dollar figures have been released, and it is just being piloted for people with disabilities in a few counties. Numerous questions remain regarding how and if it will be able to meet people's needs. I just sat in on a Senate Committee Hearing in which Secretary LeAnn told committee members that people would have a choice about services, as long as they choose the least expensive option. Either I missed something important, or client choice is nothing more than political rhetoric. Even if the program is successful, it will be years before it is fully implemented. People with disabilities and their families need help now.

The situation that My son and I, and many other families like us are faced with is this: We will have to get along as best we can until a crisis occurs. If Travis gets hurt or hurts someone else, or if I die, law enforcement and social services will be forced to intervene. It doesn't make sense for anyone to have to live on pins and needles waiting for a crisis to occur to obtain services. I ask you to continue to fund DVR services, and seriously look at those options such as fully funded CIP 1B slots to make supervised housing available for people with disabilities.

Thank you very much for your thoughtful consideration of these issues.

June Price

3576 South 43rd Street, #32
Milwaukee, WI 53220-1550

Telephone & Facsimile: 414.541.2848
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Wednesday, April 7, 1999

Joint Finance Committee
Wisconsin State Capitol
Madison, WI 53702

Dear Finance Committee Chair and members:

For 19 years, I've lived on my own in a rent-subsidized apartment — despite needing to rely on others for all of my personal care and housekeeping needs. Without this invaluable help, I would be dead. No, that is not an exaggeration; it is fact.

My progressive physical disability — spinal muscular atrophy — results in my having a fragile body and highly specialized needs. I cannot be lifted or moved or helped by just anybody, with or without a certificate declaring their expertise. My workers must be trained in how to specifically help me without hurting me. One slightly wrong move and I suffer months of pain and immobility. Because of this, I cannot rely on most home health agencies that send just anyone — it must be someone specifically trained to assist me.

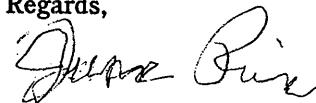
But these people are hard to hard — and the search is made much harder with the pathetically low rates these workers are paid. I've been told new workers cannot be found. Without this help, I'm forced to move to a nursing home. But in a nursing home, I'd never get workers specifically trained to help me; I'd get *just anyone*. Within hours, I'd be severely hurt; in days, I'd no doubt be dead.

The bottom line is that those of us with special needs are competing with McDonald's for help. Workers are faced with the choice of whether they prefer wiping someone's butt or flipping a burger when they're paid more to flip burgers.

Please raise the pay for personal care workers and others who provide this invaluable care of us citizens with the greatest needs.

Thank you.

Regards,



June Price

3576 South 43 Street
Milwaukee, WI 53220-1550
April 7, 1999

Joint Finance Committee
State Capitol
Madison, Wisconsin

Dear Committee:

We all live at Clare Woods Apartments, rent-subsidized apartments for people with physical disabilities. We rely on Personal Care Workers to help with all of our care including dressing, bathing, toileting, grooming, and feeding in addition to helping with laundry and light housekeeping. Without these workers, we would be forced to move into a nursing home.

It is becoming increasingly difficult to find and keep good workers because the pay is so low and there are no insurance benefits offered. We can't find workers and neither can the agencies helping us.

Please increase the pay for Personal Care workers to we can remain living in our apartment and not have to go into a nursing home!

Thank you.

<u>Name</u>	<u>Apartment #</u>
EGAN A BLACKLEY	# 16
Jean Anderson	# 26
Pennis Kelley	# 11
Gail Rodder jr	# 13
Lisa Burg jr	# 27
Janice Pucci	# 32
Richard S. Wianski	# 24
Nancy C. Moham	# 2

Name

Apartment #

William J. Arneroy

#30

do. J. P. ...

Roger Lassak #8

James Lee #29

Jain Finance Committee:

I have been working as a pcw for 2 years. Without my help the people I care for could not live at their home.

Many agencies have closed because they can't afford the cost of a pcw program.

The same is why good pcw's are quitting - we just can't afford to work at these wages.

The agency I work for has committed the increase in wages and benefits to the pcw's.

Please support the \$4.00 rate increase to agencies for MA personal care.

Date 4/6/99

PCW Signature:
Mikhail Sterenzou

Joint Finance Committee:

I have been working as a PCW for 7 years. Without my help the people I care for could not live at their home.

Many agencies have closed because they can't afford the cost of a PCW program. The same is why good PCW's are quitting - we just can't afford to work off these wages.

The agency I work for has committed the increase in wages and benefits to the PCW's.

Please support the \$4.00 rate increase to agencies for MA Personal Care.

Date: 04/05/99

PCW Signature: Tatyana
Sterenson

Joint Finance Committee:

I have been working as a pcw for 7 years. Without my help the people ± care for could not live at their home.

Many agencies have closed because they can't afford the cost of a pcw program. The same is why good pcw's are quitting. We just can't afford to work at these wages.

The agency I work for has committed the increase in wages and benefits to the pcw's.

Please support the \$4.00 rate increase to agencies for MA personal care.

Date: 04/06/99

PCW signature. L. Geif-

Joint Finance Committee:

I have been working as a PCW FOR 3 years. Without my help the people I care for could not live at their home.

Many agencies have closed because they can't afford the cost of a PCW program. The same is why good PCW's are quitting - we just can't afford to work at these wages.

The agency I work for has committed the increase in wages and benefits to the PCW

Please support the \$4.00 Rate increase to agencies for MA Personal Care.

04/07/99

Vitaliy Gorbelic