

Founded in 1999

SB231 386

# People First Wisconsin

August, 2001

Dear Honorable Member of the Wisconsin State Legislature:

My name is Cynthia Bentley. I am employed by People First Wisconsin, which is a statewide advocacy group for people with disabilities. I am writing to you today because I am very concerned about the State Centers for the Developmentally Disabled. I am a survivor of the State Centers. I lived there for 26 years and they were the worst. I now live in Milwaukee and just celebrated 17 years being out of the Center and doing well. I believe it is time for all people with developmental disabilities to live in the community and have the chance at a real life.

I am sending you a folder of information about the state centers that People First Wisconsin has put together. I would like you to take a serious look at how much money is spent on the State Centers. The cost is \$400 a day for each person. This is too much money and if you read the folder you will also see that the care and support people get at the State Centers is not what it should be. It is time for a change. If I can live in the community with the supports I have, I think the people living in the State Centers can also live in the community with the right support. Nobody thought I could make it in the community when I left the State Center but look at me now.

Please read the folder. Please support the bill that has been introduced to create a taskforce to look at the future of the Centers. Please call me at People First 414-483-2546 or toll free 888-270-5352.

Yours truly,

Cynthia Bentley  
Self-Advocacy Specialist

**We're Here.  
We're Here To Stay!**



**People First Wisconsin**

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Self-Advocacy Specialist

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**People First Wisconsin**

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Value All Wisconsin Citizens!

Leave no person's door to the future  
locked in State Centers.

Close the Centers.

Use the 30 million dollars in savings to  
build stronger community services.

A message for Wisconsin Legislators from People First Wisconsin, a statewide self-advocacy organization made up of people with disabilities, many of whom are former residents of the State Centers. For more information, please contact People First Wisconsin at (414) 483-2546 or 3195 S. Superior Street, Milwaukee, WI 53207.

## Closing Wisconsin's Three State Centers Human Rights Fact Sheet

- 844 people with developmental disabilities still live in these institutions.
- They are separated from their home communities and their families. They are cut off from the world.
- They are denied many rights and opportunities the rest of us have.
- These Centers are not safe places to live, where residents get better care than they could get in the community.
- People who have lived in the Centers talk about how they were treated badly when they lived there, and how they had no rights at all.
- Department of Justice investigators found many, many problems with the care being provided at the State Centers.
- Some people say the residents of the State Centers can't live in the community. That is not true. The Department of Health & Family Services believes that all residents of the State Centers can live in the community. There are people with the same needs who are living good lives in Wisconsin communities.
- 10 other states have closed their state institutions, including Minnesota. If they can do it, why can't Wisconsin?

U.S. Department of Justice Report on the State Centers  
September, 1994

Summary of the Findings

- There is excessive restraint usage.
- The environment fails to meet the needs of residents – it has no stability, is non-stimulating, is unsafe and is overly restrictive.
- Residents are subject to harm due to inadequate supervision.
- There are inadequate behavioral programs.
- Training programs are inadequate and do not facilitate individual growth, independence, & functional skills.
- Emergency care is lacking and critical care is deficient.
- Medical record keeping is seriously deficient.
- Administration and monitoring of psychotropic medications are grossly deficient.
- There is deficient monitoring of seizure disorders.
- Diagnosis & treatment of illness does not meet professional standards.
- Monitoring & follow-up of medical care received at hospitals are insufficient.
- Psychiatric services are inadequate.
- There are shortages of trained medical staff.
- Psychological services do not meet professional standards.

# Natural Environments For All!

The Birth to Three Program for infants and toddlers with developmental disabilities is a wonderful program that Wisconsin legislators have rallied around.

One of the key principles of the Birth to Three Program is a requirement that infants and toddlers with developmental disabilities receive services in natural environments.

The federal government made this a requirement of the Birth to Three Program to ensure that segregation and institutionalization would not be an option.

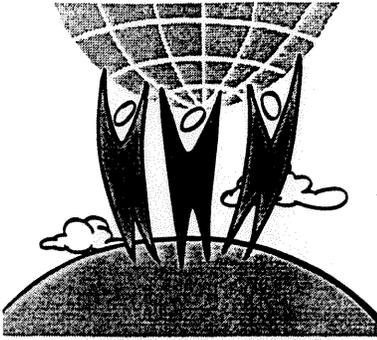
People First Wisconsin wants this philosophy to run through all programs for people with developmental disabilities. No matter what their age, we believe people with developmental disabilities have a right to receive services and supports in the same places everyone else gets them - in the community!

In the Birth to Three Program, if people do not wish to receive services and supports in natural environments, they have the option not to participate in the program. The same should apply to adult services.

Long ago, we realized that segregating people of color was wrong. It is time we recognize that segregating people with disabilities is just as wrong.

**Apply the Principle of Natural Environments to  
All Publicly Funded Programs for People  
with Developmental Disabilities.**

Building Leadership  
Around Wisconsin



Working Together  
For Change

Founded in 1999

# People First Wisconsin

More Reasons  
than You Ever Needed  
for Why the State Centers  
for People with Developmental  
Disabilities in Wisconsin  
Need to Close

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Marian Center, 3195 South Superior Street, Milwaukee, WI 53207  
Voice (414) 483-2546 Toll Free 1 (888) 270-5352 Fax (414) 483-2568  
<http://www.peoplefirstwi.org>

## Reason 1. The Dollars & Cents Story

844 people with developmental disabilities still live in the State Centers. We think that is 844 too many, but we also know that this is just 2% of all people with developmental disabilities who get services in Wisconsin.

This 2% costs 123 million dollars a year. The other 98% who live in the community cost 330 million dollars. This means 27% of the total money spent is spent on only 2% of the people. Some will tell you this is because this 2% have high needs but a big chunk of the cost is due to the fact that these people live in the State Centers rather than in smaller living arrangements.

It now costs an average of \$400. a day for a person with a developmental disability to live in a State Center. This means that each year, it costs \$146,000. for one person to live in a State Center.

The Department of Health & Family Services knows that 90% of all the residents of the State Centers could live in the community at a cost of \$300. per day. That means if these people lived in the community instead of living in the State Centers, it would save taxpayers 27.7 million dollars each year!

But the Department of Health & Family Services will tell you it costs more - not less - for people to move to the

community. That is because they won't make a plan to close the Centers. So every time someone leaves the Center, even though it costs less for that person to live in the community, the State must keep paying the Center \$200. a day or \$73,000. a year for that person, even though he or she doesn't live at the Center anymore!

If the Department would make a plan to close the Centers, then all that money paid to the centers for people who don't live there anymore would stop once the Centers closed. After that, taxpayers would save 30.8 million dollars every year, which they would have been paying if all 844 residents kept living in the State Centers.

The Department currently proposes relocating 35 people each year of the next biennium. At this rate, it would take 24 years or until 2025 for the Centers to close. This is too long!!!

If the Department won't close the Centers, we figured out what it will cost for one person to live in the Center in the future, based on the Department's relocation rate (35 residents each year) and the current Center reduction rate (\$200. per day, per relocated resident) that the Department is proposing. (Please turn to next page.) Remember, the cost of these same people living in the community is \$300. per day or \$109,500.

Reason 2. People don't need to live in the State Centers.

It is a myth, a lie, and an old wives tale that the size and location of the building someone lives in determines the amount and type of care they receive from support staff.

The fact is that any amount of assistance and supervision can be provided in any setting, as long as the money to pay for that assistance and supervision is available. We have many stories of people with complex needs for assistance and supervision who are living good lives in small community settings.

Reason 3. People Who Have Lived in the State Centers are Passionate About Them Closing Because of What They Experienced There.

People First Wisconsin could pull in over 100 of its members to tell you stories about the abuse and neglect they have witnessed or experienced while living in the State Centers. It doesn't just happen in Wisconsin's institutions, it happens all over the world.

History tell us that it is when these stories end up in the newspapers that states or countries make policies to close these institutions. But when these stories end up in the newspapers, it is too late for the residents who have suffered.

Cost Per Person Who Lives In State Center

	<u>Per Day</u>	<u>Per Year</u>	<u>How much more than community</u>
Year 2003	\$427.	\$155,887.	\$46,387.
Year 2005	\$447.	\$163,113.	\$53,613.
Year 2007	\$469.	\$171,185.	\$61,685.
Year 2009	\$494.	\$180,310.	\$70,810.
Year 2011	\$522.	\$190,530.	\$81,030.
Year 2013	\$555.	\$202,575.	\$93,075.
Year 2015	\$595.	\$217,175.	\$107,675.

By the year 2015, it costs twice as much for a person to live in a State Center than it does for that same person to live in the community.

By the time all residents would move out of the State Centers, this is what it would cost:

Year 2023	\$995.	\$363,175.	\$253,675.
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This is over three times what it would cost for a person to live in the community!

We hope the State of Wisconsin will start listening to the stories that ex-residents of the State Centers have to tell, and that they will believe these people. We hope the State of Wisconsin won't wait for things to come out in the press before they act to close the State Centers.

It has been proven that people are safer living in community settings because there are more people who see them everyday, especially other community members and family members who can notice when something is not right.

No matter how many rules and regulations are made for institutions, the likelihood of abuse and neglect doesn't go away. The problem is the institution itself...and the fact that the community has little or no contact with the people who live there.

Reason 4. Living in the State Centers is Not a Right.

Institutions for people with developmental disabilities have only existed for the last 200 years. Wisconsin's State Centers are 106 years old. For at least 1,600 years before that, people with developmental disabilities did not have the "choice" to live in an Institution. Just because we have had State Centers in Wisconsin for the last 106 years doesn't mean that the State must provide this option for eternity.

If people with disabilities, their families & their communities survived without the option of institutions for 1,600 years and more before these institutions were built, they can survive without these institutions again.

The Olmstead decision concluded that the ADA could not be used to forcibly remove people from institutions. However, it did not require States to offer institutions as an option. There are 10 states that no longer have any people with developmental disabilities in state institutions. The Olmstead decision did not say they had to build institutions again so people in those states could have that placement option.

The Olmstead decision stated that institutions "may" remain open without violating the ADA. The decision did not say that states "must" keep institutions open (if they have them) in order to comply with the ADA.

The Olmstead decision also said that people with disabilities do not have the right to insist that the State pay for them to get service in a certain way, if the State cannot afford the cost of that service. Surely this decision must also apply to State Centers as well as community placement.

If a state decides that its Centers cost too much, they have the right to choose to close those Centers.

The Olmstead decision allowed "comparative placement cost" to be a factor in determining whether people be placed in institutions or the community. People First Wisconsin believes it is time for the State of Wisconsin to compare the cost of the State Centers and decide they are not a fiscally responsible option for people with developmental disabilities. The Centers already cost 31 million more dollars than it would cost to serve the 844 residents in the community. That works out to \$36,500. more per person, per year.

At current relocation rates, by 2025, placement in the State Centers will cost \$253,675. more per person, per year.

Reason 5. The Employment Rights of One Citizen Should Never Be Given Priority Over the Human Rights of Another Citizen.

We know that many people who work in the State Centers belong to Unions. They will not have jobs at the State Centers if they close. We don't want these workers to be unemployed. But we also know that Wisconsin state government is very big, and there are lots of jobs working for the state that people could have if they didn't work at the State Centers. Plus, there are more than enough personal care jobs waiting for them in the community.

The most important thing is that the State of Wisconsin should never put the employee rights of one citizen above the human rights of another citizen. And the decision to keep people with developmental disabilities in state institutions denies those people their human rights more than it could ever advance the employment rights of the people who work at these institutions.

Reason 6. The Federal Department of Health and Human Services Has a Goal that People Should Not Have to Live in an Institution if They Can Live in the Community with the Right Support.

*Voice of the Retarded* is trying to convince people that the residents of state institutions around the country are extraordinary people who can't live in the community, even with lots of support. VOR members are saying that no matter how much money is available, these people could never live anywhere but in these institutions. There's an old saying, "Never Say Never...".

How does *Voice of the Retarded* know this if they won't give these people a chance to try living in the community? If we can find ten people with similar needs who are living in the community, why isn't this enough proof that these individuals in the institutions can live in the community, or at least should try it?

*Voice of the Retarded* is cashing in on the fact that legislators and other citizens don't really know these people who live in State Centers. VOR members are counting on you believing them without questioning them.

Reason 7. Wisconsin Can Build Stronger Communities Only By Including All of Its Citizens Within Them.

Some people who talk about the Olmstead decision say that we can't end institutional settings for people "unable to handle or benefit from community settings." Again, what did they do before the 1800's, when there were no institutions to put people in? What they did is work together as a community to include and support people with special needs. They didn't just abandon their fellow citizens in exchange for paying a few more dollars in taxes!

If there is one thing that is true about people with developmental disabilities, we always go beyond what everybody expects of us. This is especially true for people who have left the State Centers. We show that the impossible in people's minds can become the possible in our lives.... All we need is an opportunity and support from our fellow citizens!

We'd like to point out one last thing (you can hang the next page in your office):

If there really is  
a  
"voice of the retarded",

WE -  
self-advocates  
and  
People First -  
are that voice,  
and we say NO to  
institutions!

Close Wisconsin's State Centers Now!!!

# WISCONSIN

Wisconsin State Journal

Tuesday, February 27, 2001 • B3

## Close three state centers, disabled advocates urge

By Kelly K. Spors  
Wisconsin State Journal

A group of people with disabilities is asking the Wisconsin Legislature to close three state institutions, claiming they often mistreat their residents and that better care is offered on the community level.

People First Wisconsin, a statewide advocacy organization of people with disabilities, says closing the institutions is not only better for the residents, but will save state dollars as well.

The three institutions are located in Madison, Union Grove and Chippewa Falls.

"I didn't get the skills I needed to live on my own when I was at the center," said Christine Mayer, who lived at the Southern Wisconsin Center for the Developmentally Disabled in Union Grove for eight and a half years. "Now I live in a structured house by myself and can come and go as I please."

Mayer was one of several people who spoke out during a three-day convention for people with disabilities. On

Wednesday, several members of the organization plan to meet with state legislators and push for closing the centers.

Howard Mandeville, program and policy adviser for the Wisconsin Council on Developmental Disabilities, said the cost of running an institution is much more than the cost of helping people living in the community.

"Especially in the time of a tight (state) budget, it's more prudent to move people into the community," Mandeville said. "There could be some substantial savings by closing these centers."

Jim Malone, spokesman for the state Department of Health and Family Services, said the department had wanted to close the center in Union Grove a few years ago, but the Legislature would not do it. "There are many different viewpoints out there - parents who have loved ones in these places, politicians," Malone said. "Without the support of the state Legislature, it's impossible to close one center, much less three."

# OPINION

Wisconsin State Journal

A8 • Friday, March 30, 2001

## GUEST COLUMN

### Disabled will benefit from transfer of resources

By Lisa Mills

In response to Dennis Boyer's guest column March 8 regarding the future of the State Centers for the developmentally disabled:

On an icy cold day last November, scores of people from the Office and Professional Employees International Union Local 39 and People First, the self-advocacy movement among people with disabilities, braved the weather to march in protest of CUNA Mutual Group's abrupt and unfair firing of Steve Erstad, a union member and disabled man. It was a day where the rights of workers and the rights of people with disabilities were unified in the name of justice.

For those of us who call ourselves disability rights activists, it seems like only yesterday we were building a strong alliance with the labor movement. Yet now, AFSCME, the state employees union, and People First are squared off in conflict over the future of Wisconsin's three state centers for the developmentally disabled.

Why did we go from allies to seeming enemies in a matter of months? Because AFSCME leaders are convinced closing any of the centers will undermine their rights as workers.

Boyer, AFSCME government relations coordinator, cites Minnesota as a state to which Wisconsin can model its efforts. Minnesota closed all of its state institutions. But they also preserved the rights of their state employees through a nine-page memorandum of understanding drawn up early on in the closure process. People First knows this, and has studied the Minnesota deal in detail, because contrary to how Boyer portrays us, we don't want anyone to suffer as part of a closure process.

Then let's turn to the reasons why the centers need to close. These reasons are much more than the "inflammatory charges" Boyer says we "swagged" into Madison with. The facts are not something People First invented. They are facts any citizen can find at the Department of Health and Family Services, which is responsible for administering the centers. The critical facts are these:

1) The state centers currently serve 2 percent of people with developmental disabilities, but spend 38 percent of the budget for people with developmental disabilities.

2) The Department of Health and Family Services has gone on record that every resident of the centers could live in the community, if the money available to the centers were made available to create alternative support and living arrangements in the community.

3) By the department's own calculations, a savings of \$30 million could be captured for the community service system, if the centers were closed.

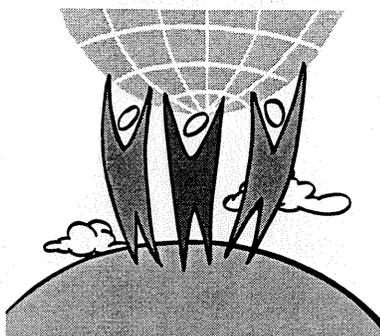
4) More than 40,000 people with developmental disabilities rely on and prefer our community service system. They represent the overwhelming majority. And they are currently depending on a system that is grossly underfunded.

People First wants to see a single system for people with developmental disabilities, rather than two separate systems, which compete for resources. With 40,000 choosing the community and only 844 still residing in centers, there is overwhelming evidence that the single system should be a community system.

We would gladly work with the unions toward a closure plan that protects quality of life for all involved. The question remains: Will legislators back away from closing the state centers because they fear loss of union support at election time? If so, once again people with developmental disabilities will be short-changed.

*Mills, of Deerfield, is the administrator for People First Wisconsin and a consultant to the community service system.*

Building Leadership  
Around Wisconsin



Working Together  
For Change

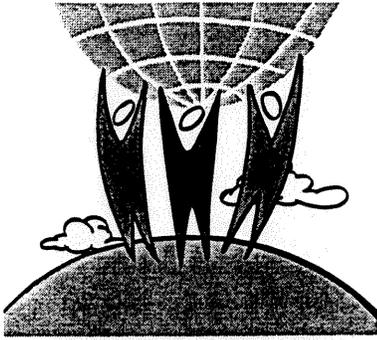
Founded in 1999

# People First Wisconsin

## Why We Are Here

- To help people with disabilities in Wisconsin to speak up for themselves, and to speak up for those who can't speak for themselves;
- To provide opportunities for people with disabilities in Wisconsin to speak up and be heard.
- To educate people with disabilities in Wisconsin about their rights, including kids with disabilities.
- To help people with disabilities in Wisconsin to figure out what they want to do with their lives, and how they can make these dreams come true.
- To educate the public about the rights & strengths of people with disabilities and what we need from the public to be successful.
- To help local self-advocacy groups to get started, get stronger, and figure out what they want to do and how to do it.
- To help individuals with disabilities and local self-advocacy groups get to know each other, learn from each other, and work together.
- To work toward closing all institutions in Wisconsin and making life in the community a human right for people with disabilities.

Building Leadership  
Around Wisconsin



Working Together  
For Change

Founded in 1999

# People First Wisconsin

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## MEMBERSHIP APPLICATION FORM

People First Wisconsin is the new statewide self-advocacy organization for people with disabilities. In addition to enabling people with disabilities to have their voices heard, the mission of People First Wisconsin is to:

- ❖ Educate people with disabilities, including kids with disabilities, about their rights;
- ❖ Assist people with disabilities figure out what they want to do with their lives, and how to make these dreams come true;
- ❖ Educate the public about the rights and strengths of people with disabilities, and what they need from the public to be successful;
- ❖ Help local self-advocacy groups to get started and get stronger;
- ❖ Help individuals and local self-advocacy groups get to know each other, learn from each other and work together;
- ❖ Work toward closing all institutions and making life in the community a human right for people with disabilities.

### Four types of memberships are available:

- Self-Advocate / Individual with a disability \$1.00 per year
- Self-Advocacy Group affiliation No Charge
- Friend of People First Wisconsin \$10.00 per year
- Corporate Membership financial/in-kind donation of \$100.00 per year  
{for organizations wishing to support People First WI}

**PLEASE TURN OVER**

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Marian Center, 3195 South Superior Street, Milwaukee, WI 53207  
Voice (414) 483-2546 Toll Free 1 (888) 270-5352 Fax (414) 483-2568  
<http://www.peoplefirstwi.org>

## Benefits of Membership:

No matter what kind of member you are, you'll receive a copy of every issue of ***On The Move***, People First Wisconsin's statewide self-advocacy newsletter. Corporate members will get a discount if they'd like to advertise in this newsletter. Self-Advocacy groups affiliated with People First Wisconsin that want to publicize their activities in ***On The Move*** can do so free-of-charge.

Self-advocate members will be given special priority for attending the bi-annual statewide self-advocacy conference sponsored by People First Wisconsin. Once People First Wisconsin is going strong, all self-advocate members will be able to vote for the person they want to represent their area of the state on the People First Wisconsin Board. Self-advocate members will also be able to vote on big issues at the bi-annual conference.

Self-advocacy groups affiliated with People First Wisconsin are able to call on People First Wisconsin staff for technical assistance (e.g. general advice, help with recruiting advisors, problem-solving, strategic planning, assistance with fund-raising, and help with organizing local self-advocacy events). All members will receive information about People First Wisconsin, the work it is doing, and how members can be actively involved.

## To Become A Member Of People First Wisconsin, tell us:

Your name: \_\_\_\_\_

Your address: \_\_\_\_\_  
\_\_\_\_\_

Your telephone number or email: \_\_\_\_\_

What kind of member you want to be:

- |                          |  |   |
|--------------------------|--|---|
| <input type="checkbox"/> | Self-Advocate / Individual with a disability | \$1.00 per year                                 |
| <input type="checkbox"/> | Self-Advocacy Group affiliation              | No Charge                                       |
| <input type="checkbox"/> | Friend of People First Wisconsin             | \$10.00 per year                                |
| <input type="checkbox"/> | Corporate Membership                         | financial/in-kind donation of \$100.00 per year |

Last but not least, enclose a check for your membership fee and return this form to:

**People First Wisconsin**  
**3195 S. Superior St. Milwaukee, WI 53207**

\*If you'd like to make an in-kind donation, please call Lisa Mills at (414) 483-2546.

# We Need Your Help!

Support Wisconsin Taking a Serious  
Look at the State Centers!

**Support AB 473 and SB 231**

These bills would create a  
taskforce to develop a plan for  
the future of the State Centers.

A message for Wisconsin Legislators from People First Wisconsin, a statewide self-advocacy organization made up of people with disabilities, many of whom are former residents of the State Centers. For more information, please contact People First Wisconsin at (414) 483-2546 or 3195 S. Superior Street, Milwaukee, WI 53207.

## Closing Wisconsin's Three State Centers Dollars & Cents Fact Sheet

- The 3 State Centers cost taxpayers 30 million dollars more than what it would cost if the 844 residents lived in the community. This saved money could be used to help with waiting lists and paying direct support staff in the community better wages.
- We can only get the savings if the legislature decides to close the Centers.
- The reason the Centers cost so much is because every time someone moves out of a Center, the state has to keep paying that Center \$73,000. a year for that person, to cover the overhead costs of keeping those big buildings open.
- We know community services for people with developmental disabilities don't have enough money. We know this State budget is really tight. So closing the State Centers now is the right thing for Wisconsin and for people with developmental disabilities.
- The cost to the State for closing the 3 State Centers is around 4.5 million dollars over 10 years. Over that 10 year period, the net savings to the State is 55.5 million dollars. From the 11<sup>th</sup> year onwards, the savings for the state is 15 million dollars every year. If you add to that the federal match money, the total savings is 30 million dollars every year.
- We need legislators to find the courage to joint together to close the State Centers and spend funding for people with developmental disabilities more fairly and wisely. Closing the Centers will bring back many millions in savings for Wisconsin.

# End the Institutional Bias in Wisconsin

## What is the institutional bias?

Right now, the state will pay \$400. a day for someone to live in a State Center; but the state will only pay \$200. a day if that same person wants to live in the community.

This is an institutional bias that means over 800 people with developmental disabilities are denied the right to live in the community because their support services cost more than \$200. a day.

## Why does this blatant institutional bias exist?

Because Wisconsin continues to value institutions more than community services, even though federal laws and policies and court decisions repeatedly tell us that people with disabilities should have an equal right and opportunity to live in the community.

Because Wisconsin values institutions more than community services, it spends 27% of all funds for people with developmental disabilities on its state-run institutions, but these places serve only 2% of Wisconsin citizens with developmental disabilities.

According to Department of Health & Family Services data, the residents of the State Centers could live in the community at a cost of about 30 million dollars less than it costs for them to continue to live in the State Centers. The institutional bias not only denies choice, it wastes precious tax dollars.

## How to End the Institutional Bias:

Fund all services for people with developmental disabilities at the same daily rate. Set that rate based on individual need. Stop under-funding community services and over-funding institutional services.

# What Do The State Centers Have To Do With Building Stronger Community Services for People with Developmental Disabilities?

- The community service system is millions of dollars short of what it really needs to support people with developmental disabilities to live good lives in the community.
- If the State budget is tight, we need to be looking for other ways to find that money.
- The State Centers cost \$30 million dollars more than what it would cost to support the 844 residents to live in the community.
- Closing the State Centers is the only way to capture those savings for community services.
- Money is not the only answer to building a stronger community service system. The other thing Wisconsin must do is recognize that we will never have a strong community service system as long as we have an institutional service system competing for our time and resources.

**If we make the community service system the only service system for people with developmental disabilities, we can focus all of our energy and resources on making it the best it can be!**



Wisconsin Survival Coalition

## STATE INSTITUTIONS

### 2001-2003 Proposal for the State Centers for the Developmentally Disabled

Moving Toward a Single, Community-Based System for All

For more information contact:

Lisa Mills at 414-483-2546; [lmills@peoplefirstwi.org](mailto:lmills@peoplefirstwi.org)

*Just 844 people with developmental disabilities now live in the three State Centers for People with Developmental Disabilities. This population continues to decrease every year, as the community service system that Wisconsin has developed repeatedly demonstrates the capacity to support these individuals to live in ordinary communities, close to other citizens and with opportunities for a multitude of life experiences that were otherwise denied as the result of living in the State Centers.*

Over 35,000 people with developmental disabilities now receive supports through this community-based system. Yet Wisconsin continues to maintain the State Centers as a separate institutional system that now costs \$30 million more than what it would cost to provide comparable support in the community for the 844 Center residents. The only way to reduce this significant waste of precious tax dollars is to close the State Centers.

The state's Department of Health and Family Services has acknowledged that Center residents' support needs could be met in the community, and that only a handful of residents would require a rate equal to or higher than the \$400 average daily rate currently being paid to the Centers for residents' care.

When funds are available to adequately support a person in the community, Wisconsin law and the *Olmstead* Supreme Court decision require people to be placed in the community. Ten other states, including Minnesota, have closed their State Centers and strengthened their community systems.

For financial, legal, programmatic and humanitarian reasons, the time has come for the state of Wisconsin to move from a dual service system, with a costly institutional bias, to a single, community-based system. The state should invest the savings achieved from this transition to strengthen the community system for all persons with developmental disabilities.

#### ***Legislative Initiatives:***

- Close Northern Wisconsin Center and Southern Wisconsin Center within five years.
- Provide sufficient funding for quality support in the community by increasing the CIP 1A rate beginning July 1, 2001, to \$300 per day. Continue to increase the rate over the next budget periods as needed to ensure the efficient transfer of Center residents to supported community settings.
- Retain the savings achieved from Center closings to strengthen the community-based developmental disabilities service system.
- As each Center is closed, residents should move to the community settings that meet their support needs and not simply be transferred to a remaining State Center or other institutional setting.
- Increase the CIP 1-A rate for people currently living in the community to \$160 / day.

## ***The Survival Coalition***

The Survival Coalition is the statewide coalition of disability organizations. Survival monitors the progress of state agency and legislative proposals that affect people with disabilities and educates legislators about the needs of people with disabilities.

Survival also sponsors the biennial Disability Awareness Day rally at the State Capitol. The "People Can't Wait" rally on April 25, 2001 will focus on the waiting lists for community services for both people with disabilities and the elderly.

## ***Leadership***

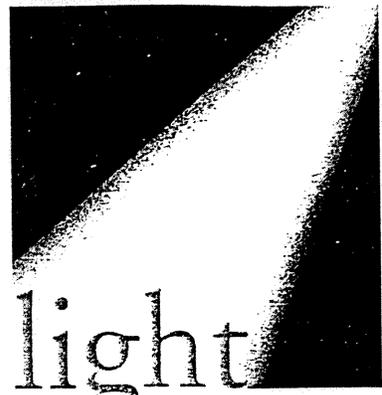
Michael Blumenfeld, Co-Chair  
16 N. Carroll Street, Suite 800  
Madison, WI 53703-2726  
(608) 257-1888  
blumk@aol.com

Lynn Breedlove, Co-Chair  
Wisconsin Coalition for Advocacy  
16 N. Carroll Street, Suite 400  
Madison, WI 53703  
(608) 267-0214  
lynnb@w-c-a.org

For further information visit [www.wcdd.org](http://www.wcdd.org) and click on "DAWN", the Disability Advocates Wisconsin Network website.

## ***Survival Coalition Participants***

- Access to Independence
- ARC Milwaukee
- The Arc-Wisconsin Disability Association
- The Arc-Dane County
- Autism Society of Wisconsin
- Autism Society of SE WI
- Board on Aging and Long Term Care
- Brain Injury Association of WI
- Brotoloc Health Care
- Citizen Advocacy
- Coalition of Wisconsin Aging Groups
- Community Alliance of Providers of Wisconsin, Inc. (CAPOW)
- Community Living Alliance
- Council for the Deaf and Hard of Hearing
- Council on Blindness
- Easter Seals of Wisconsin
- EBTIDE
- Epilepsy Foundation of South Central Wisconsin
- Family Assistance Center for Education, Training and Support (FACETS)
- Great Rivers Independent Living Services
- Independence First
- KindCare, Inc
- Kuality Kare
- Learning Disabilities Association of Wisconsin-Dane County
- Lutheran Social Services
- Mental Health Association in Milwaukee County/Office of Public Policy
- National Alliance for the Mentally Ill – Wisconsin (NAMI)
- Options for Independent Living
- Parent Education Project (PEP) of Wisconsin
- Prader-Willi Association
- Rehabilitation For Wisconsin, Inc. (RFW)
- Society's Assets
- Spinal Cord Injury Association Madison Area Chapter
- State Independent Living Council
- United Cerebral Palsy (UCP) of WI
- UCP of Southeastern WI
- Wisconsin ADAPT
- Wisconsin Alcohol, Drugs & Disability Association (WADDA)
- Wisconsin Association of the Deaf
- Wisconsin Association of Family & Children's Agencies
- Wisconsin Association of Residential Facilities (WARF)
- Wisconsin Client Assistance Program
- Wisconsin Coalition for Advocacy
- Wisconsin Coalition of Independent Living Centers (WCILC)
- Wisconsin Council on Children and Families (WCCF)
- Wisconsin Council on Developmental Disabilities (WCDD)
- Wisconsin Council for People with Physical Disabilities
- Wisconsin Family Ties
- Wisconsin Occupational Therapy Association (WOTA)
- Wisconsin Personal Services Alternatives (WPSA)



# The Spotlight

The Newsletter of the Wisconsin Council on Developmental Disabilities

Volume 7, Number 1  
Spring 2001

## Closing State Centers Could Help Under-Funded Community Services

In the last 15 years thousands of Wisconsin citizens with severe disabilities have moved out of the three State Center institutions and have built happy, productive lives in the community. Talk to any former Center resident and you will hear a testimonial to the value of community—the place for friends, family, work, play, and involvement. Former Center residents have a remarkable record of successful transition to the community even though they also must cope with an under-funded community system. None who have left the Centers are interested in going back. None supported by community services are on a waiting list to enter the Centers.

Over 800 people are still lodged at the three State Center institutions. The State Center system uses 38% of the available funding for disability services to serve 2% of the total population of Wisconsin citizens with disabilities. The state agency that administers the State Centers reported that every current resident could be supported in the community if the money available to the Centers could be used to fund community-based supports for these individuals. The Department of Health and Family Services estimates that only a small number of residents would require the average daily rate of \$400.00 currently being spent on each resident of the Centers.

### *The Problem*

The State Center system is funded and operated as a distinct system separate from the county-administered community support system. The community system is under-funded as indicated by waiting lists and low worker wages. The Center system is not under-funded but is budgeted based on actual costs. The average cost to house one person at a State Center is \$400.00 a day. In the budget proposed by the Governor, when a Center resident moves out, \$200.00 a day is available for the cost of community support (CIP1A program). The remainder stays in the Center budget despite the fact that the person no longer generates costs to the Center. Half the money will be used to cover actual costs of support; the remaining half will stay to pay for buildings and staff the person no longer uses.

### *The Solution*

The Wisconsin Council on Developmental Disabilities and the Survival Coalition endorse the closing of Northern Wisconsin Center and Southern Wisconsin Center within five years. People First Wisconsin calls for closing all three Centers within ten years. The state should budget sufficient funding for quality support in the community by increasing the CIP1A rate to \$300.00 per day. These increases should continue in future budget

periods as needed to insure the efficient transfer of Center residents to supported community settings. For each Center closed, the state will net a projected savings of \$10 million a year in state and federal funding. These savings should be used to strengthen the community support system. As each Center is closed, residents should move to the community settings that meet their support needs and not simply be transferred to a remaining State Center or other institutional setting.

Closing the Centers is a controversial issue. Some guardians are opposed to any move that would threaten the future of the Centers. The union representing Center staff wants to protect their workers. With the number of Center residents progressively dwindling, the union recognizes that the Centers may be a diminishing resource for their employment. WCDD is committed to constructive collaboration with guardians and workers to develop a plan for closing the Centers that meets the guardians' concerns for the well-being of Center residents and the union's concerns for its members. The foundation of WCDD's position on Center closing is based on the strong message coming from those who know first hand the difference between institutional support and community support—the people who have moved from the Centers to productive lives in the community.





**Wisconsin  
County  
Human  
Services  
Association**

**In Reply, Refer to:**  
**Michael J. Tiber, President**  
Iowa County Department of  
Social Services  
109 W. Fountain St.  
Dodgeville, WI 53533  
Phone: 608-935-9311  
Fax: 608-935-9754  
Email: m.tiber@jobcenter.org

August 6, 2001

Mr. Dan Remick  
People First Wisconsin  
3195 South Superior Street  
Milwaukee, WI 53207

Dear Mr. Remick:

Please excuse the delay in responding to you on this matter. Somewhere in the transition from the former to the current officers of the Association, this response to you was delayed. Hopefully this response will not be too late to be of help to you.

This letter is to inform you that the WCHSA Executive Committee voted, at their June meeting, to support WLC:0142/2 as you requested. This bill establishes a task force to develop a plan to close at least one of the state centers. In addition, it is our hope that the dollars savings realized by closing a center would be reinvested in community services.

WCHSA is happy to be able to partner with People First in the important endeavor.

Sincerely,

Michael J. Tiber, President  
WCHSA

cc.: file

*To Promote Positive & Professional Relations in the Field of Human Services*

6/1/01

### **Mattie Conway's Success Story- From Institution to Life!!!**

It is difficult to put into words the type of impact Mattie has on anyone. Once you meet Mattie and observe her for even five minutes, you become amazed as you realize all of the abilities she displays. **Mattie is a perfect example that having a disability, does not mean you are disabled from leading a "normal, full, productive life!"** Mattie was born in Arkansas in Jan. 1966. Due to congenital rubella, she was born blind, deaf, and with a cognitive disability. She lived with her family until she was 13 yrs old. Sometime during those first 13 yrs, Mattie moved to the Wisconsin area. When she reached 13 yrs old, her family felt unable to continue caring for her and placed her in Central State Center.

When Mattie was 15 yrs old, she began working with a teacher, Alice, who would eventually become her legal guardian. As a part of Mattie's school program, she received on the job training in a variety of Madison businesses during her high school career. They included a hotel, three hospitals, and a university. Her duties ranged from washing and folding towels, collating, stamping and stuffing envelopes, to counting and bagging medical supplies. In 1988, Mattie graduated from Memorial High School in Madison.

In 1988, Mattie moved to the Underwood Group Home located in Cudahy, WI. She had her own bedroom, was able to help with household chores, and had the opportunity to enjoy community outings. Some things she enjoyed doing were camping and going to the WI Dells.

Also in 1988, Mattie began a position at a hospital. Her job was to attach inventory labels to hospital supplies. Unfortunately, her employment ended due to budget cuts.

In Oct. of 1991, Mattie began working with CEO, Inc. who assists individuals with disabilities in obtaining and maintaining community employment. It was during this same month, that Mattie became employed at Pizza Hut with the help of CEO. Mattie was hired as a prep assistant. Over the years, Mattie has had a variety of job duties there, such as washing windows, making pizza sauce, coffee prep, emptying garbage, and folding pizza boxes. She continues to work there today part time, 5 days a week.

Besides working, Mattie also has lived since the mid 1990's in a supported apartment setting with one roommate. She still enjoys recreational activities. One of her favorite activities is to go to the YMCA and enjoy the whirlpool. She also enjoys lying in the sun, swinging, sliding, making cookies, working with clay, and having monthly massages!

Mattie is an inspiration, and great fun! Many times people are amazed by what Mattie can do, but then will say, "I feel so sorry for her." But, Mattie has a wonderful home, a job she enjoys, time for fun and people who care...she leads a full and happy life!!

This is one of my favorite songs.

### **We Can Make A Difference**

Some say we shouldn't be heard  
We've got something to say.  
Some say we are lost  
We can find the way.  
Some say we don't care  
We've got love today.  
We can make a difference.

*Refrain:*

*We can make a difference in everything  
we do*

*We can make a difference  
It's up to me and you.*

*Children of the light,  
the Spirit shows us how.*

*We can make a difference now.*

He needs someone to lean on  
It just takes one shoulder.

She has a lonely heart

Just takes one to hold her.

They're afraid to take a chance

Just takes one who's bolder.

You can make a difference.

*Refrain:*

*We can make a difference in  
everything we do*

*We can make a difference*

*It's up to me and you.*

*Children of the light,*

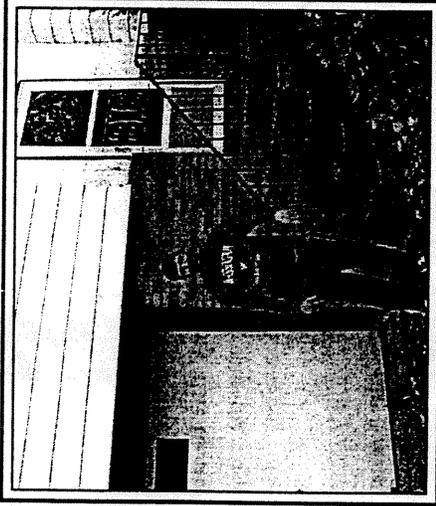
*the Spirit shows us how.*

*We can make a difference now.*

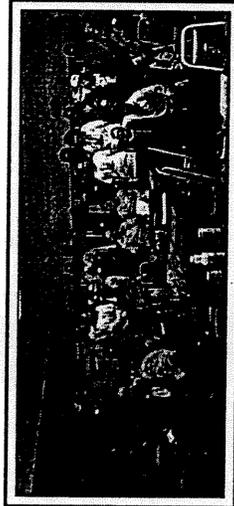
Copyright 1989 Dakota Road Music, All Rights Reserved, used by Permission.

# **Jeffrey Johnson**

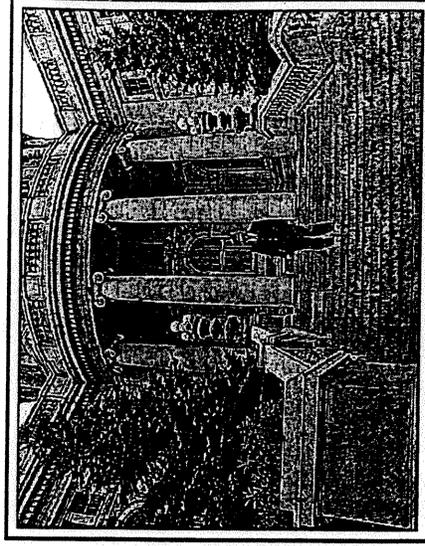
## **Taking Steps Toward My Dream**



**Jeffrey outside of his home in Madison, WI**



**Jeffrey at a People First Wisconsin Board Meeting on 10- 9-99**



*Of a life of my own  
where I make the  
choices and decisions  
about the things that  
are important to me.*

*For more information contact:*

**Jeffrey Johnson, FCI**

**Coordinator**

Access to Independence

2345 Atwood Avenue

Madison, WI 53704-5602

608-242-8484 ext. 19

E-Mail: [ati@chorus.net](mailto:ati@chorus.net)



Hi. My name is Jeffrey Johnson. I am the Self-Determination Advocate and Full Citizenship Initiative Coordinator in Dane County, Wisconsin. I am also the President of People First of Dane County.

Self-advocacy and self-determination are both movements to make sure that we the people that have the disability are able to stand up for ourselves and go forward with pride. Self-determination is the power we have and the rights. We want to be treated no different than anyone else.

Self-determination means we take control and we make the choices and decisions. The responsibility is ours and last but not least we have the money. The money gives us the power to do what we want to do. We know what is best for us. Please give us the chance to make mistakes. That is the way we all learn.

Can you imagine living in four institutions? I did that. When I lived in Southern Wisconsin Center I got into a fight with my peers. After the fight, I got fed up with the rules that weren't fair and made my first and very own choice. I did not care any more what they did to me. I did not care if they locked me up. I took my chances and I told them:

*You cannot tell me who I can talk to or not. I can talk to all of my friends and peers if I want to and I can sit anywhere I want to. I am putting my foot down. You are not my boss. I am my own boss and you cannot tell me what to do.*

That was the day I took my very first stand and stood up to them. From that day on is when I started to speak up for my self.

Some people from a place called Create-Ability in Madison, Wisconsin came to see me at Southern Wisconsin Center. This time I was part of planning my support plan. That is how it should be. I was a very lucky guy because they were willing to meet me halfway.

**Freedom means making choices, taking action, being responsible for my choices and myself and being a part of the community.**

*Jeffrey Johnson, October, 1999*

As years go by, self-determination grows in all of us. I think we just got to figure out how it works. I said to them, *I will show you how.*

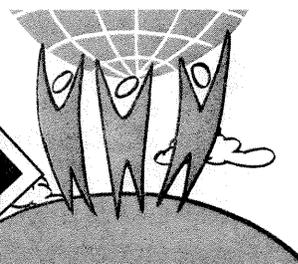
### **Jeffrey's Road To His Dream**

- 6-2-98 I moved out of Southern Wisconsin Center (an institution for people with developmental disabilities) where I had lived for over 7 years.
- 6-2-98 I started working at M.P.A. (A sheltered workshop) in Madison, Wisconsin.
- 9-25-98 I was hired as the **Full Citizenship Initiative Coordinator** for Dane County, Wisconsin..
- 2-14-99 I was elected **President of People First of Dane County.**
- 2-27-99 I helped create **People First Wisconsin**—the first statewide self-advocacy group in Wisconsin.
- 4-29-99 I received the **Outstanding Advocate of the Year** award from ARC of Dane County.
- 5-13-99 I quit my job at the sheltered workshop.
- 8-9-99 I was hired as the **Self-Determination Advocate** for Dane County, Wisconsin.
- 11-5-99 I was a panel member in a presentation at the AAUAP national conference in Washington, D.C.

People First Wisconsin

# On the MOVE

People First Wisconsin



Volume 3 ♦ Number 1 ♦ Spring 2001

## People First Wisconsin Fights to Close Wisconsin's State Centers

by Dan Remick, President of People First Wisconsin & Lisa Mills, Administrator

People First Wisconsin believes every person with a disability has a right to live in the community. This means we believe that no person with a disability should be locked away in big institutions, far away from friends and family, and with no chance to live a life

anything like all other citizens in Wisconsin.

100 years ago, lots of people thought the best thing for people with developmental disabilities was to take them away from their families and communities and lock them up. So Wisconsin built three State Centers. Back then, over 3,000 people with developmental disabilities were put in these

Centers. Times have changed. No more institutions are being built and ten other states have closed down their institutions. People

with disabilities who can speak for themselves (or who have committed advocates) are now fighting to get out of institutions. We can't find anybody with a developmental disability that has lived in a State

"Closing the State Centers will not only give these 844 people their freedom, it will also save the state 30 million dollars, that can then be spent to help with waiting lists, increasing the pay of support staff."

Center who says "I want to go back." Many people who have lived in these State Centers have terrible stories to tell about what life was like there and how little control they had over their lives.

But right now, 844 people with developmental disabilities still live in the three State Centers. People First Wisconsin is fighting for these people's freedom, and trying to make sure no person with a

Continued on page 2

On the MOVE

"On the Move" is for and about people with disabilities. It is intended to be read and shared by them, their families and the people involved in their lives.

"On the Move" is published by People First Wisconsin and made possible through a grant from the Wisconsin Council on Developmental Disabilities (WCDD). Any opinions expressed do not necessarily represent the position of WCDD.

"On the Move" invites your comments, ideas, and stories.

"On the Move" is also available on tape or in languages other than English. To request a copy in one of these formats, call Lisa Mills at 800-270-5352.

## CLOSING Continued from page 1

developmental disability will ever have to live in fear of being locked away in a State Center again. We believe that once Wisconsin's legislators understand our point of view, and once they hear our stories, they will be courageous and work with us to close the State Centers forever.

We can't find  
anybody with a  
developmental  
disability  
that has lived  
in a State Center  
who says  
*"I want to go back."*

Closing the State Centers will not only give these 844 people their freedom, it will also save the state 30 million dollars, that can then be spent to help with waiting lists, increasing the pay of support staff in the community, providing respite and many other things. Too much taxpayer money is being poured into the State Centers. The people living in these Centers could live in the community with the same amount of support and for a lot less money than it costs to keep them in the Centers. The Department of Health & Family Services has said this. We believe they have a right to live in the community with the rest of us.

We now have a grant to support our work to close the State Centers. If you would like to help, or if you would like a copy of our paper - "More Reasons than You Ever Needed for Why the State Centers for People with Developmental Disabilities in Wisconsin Need to Close," please call our office at 1-888-270-5352 or in Milwaukee, call 414-483-2546. ♦

## Working Together

by Joe Simon

**No matter what  
kind of disability you have,  
we all need to work together!**

by Joe Simon, **People First Wisconsin**  
Board Member, Richland Center

One of my goals has been to bring people with different disability groups together. I believe people with any kind of disability can understand what a person with a different disability goes through better than someone without a disability. I know this might not always be true but I think it is true most of the time. As a person, I have usually found greater acceptance from people who have different disabilities than from those without a disability. So I was really excited to become part of **People First Wisconsin** because this is an organization open to people with any kind of disability.

The Board of **People First Wisconsin** is made up of people with different kinds of disabilities. We work hard to respect each other and bring the disability groups together. I wish all local advocacy groups would think about ways they could bring people with different disabilities together to work on issues. We are stronger when we work together than when we work alone. I think NAMI and ADAPT and People First should find more ways to work together. When you get right down to it, we all care about the same things. Even though the service system divides us up, we shouldn't let that make us think we are too different from each other to work together. We are all people with disabilities and we all need equal rights and opportunities! ♦



Hello my name is Cynthia Bentley. I started at **People First Wisconsin** on November 1, 2000 and my title is Advocate Specialist. I serve on three boards: Special Olympics, DD Board appointed by Governor Thompson, and ARC Housing Board. I also volunteered for 11 years at Shadetree Family Resources Center.

I currently juggle seven baby-sitting jobs. I have participated in Special Olympics for 27 years. My hobbies include hanging out with my cat, shopping, watching a good program, or cutting out pictures from my magazines. I am very involved in my community and have lived in Glendale for the past 14 years. I am very pleased to be working at **People First Wisconsin**. I hope my talents and resources will help you.

If you have any questions or concerns, you can always call me 414-483-2546.

Thank you! ♦

## Staying Active Can Help With Finding a Job

by Daire Keane

My name is Daire Keane. I am the Secretary of the board for **People First Wisconsin**. I live in Greenfield. I was born in Milwaukee but my parents came from Ireland. I have two brothers and two sisters. I graduated from Pius XI High School in 1991. I have participated in Special Olympics. I played basketball and earned a bronze medal.

I attend Milwaukee Area Technical College. I take two classes there. This semester I am taking Applied Algebra and Modern American History. I am involved with the Milwaukee ARC. I am President of the ARC Consumer Council. We have meetings once a month on Thursday evenings at the UCP building on 76<sup>th</sup> St. and Oklahoma Ave. I am involved with the MATC Student Senate. I am also involved with People First. I have made some friends at school and work. I have also made friends at ARC, People First and Lutheran Social Services. I was junior Nurses Aid at Mt. Camel Healthcare Center. I was an Usher at the Marcus Center when it was called the Performing Arts Center (PAC). I used to work at the childcare



center at MATC as a Kitchen Helper. I have currently started looking for a new job or some volunteer work I would enjoy. It's important to stay active, even if you don't have a job. Staying involved in your community can help you find the job that is right for you.

I live with my parents right now. I plan to eventually move to my own apartment again. I am considering attending Alverno College in the future. I attended the ARC Conference in Milwaukee on September 15, 2000. I had a nice time there. I wrote a blessing, which I read at the dinner. I hope that people with disabilities will get the support that they need. Being involved in self-advocacy can help with this. It can help us meet people and learn important skills we can use at work. I encourage everyone to try it! ♦

People First Wisconsin  
Room 113, Rosary Hall, Marian Center  
3195 South Superior Street  
Milwaukee, WI 53207



We're Here To Stay!

Support the  
People First's Campaign to  
***Close the State Centers***  
and bring 30 million dollars in  
savings to community services.

Become a member of **People First Wisconsin** in the next 60 days and *we promise your membership dues will be used for our Campaign to Close the State Centers!*

Join Today! Fill out and return the membership form included with this newsletter.

If you are already a member, and would like to make a donation to our Campaign to *Close the State Centers*, please send your donation with a note that this is how you want the money to be used.

***Do you need  
a dynamic speaker for  
your meeting, conference  
or workshop?***

**People First Wisconsin** has trained over 30 self-advocates from around the state to be public speakers. They will be ready by spring 2001 to visit your group or organization and speak on a variety of topics. For more information contact Mary Clare at the **People First Wisconsin** office at 414-483-2546.

David

October 28, 2001

1266 S. Forest La.  
Prairie Du Sac, WI 53578

Re. Senate Bill 231

To: Senate Committee on Human Services and Aging

Dear Senator Robson, Chair,

I am strongly opposed to Senate Bill 231 which call for the deveelopment of a plan for the state centers for Devopmental Disabilities.

Since 1996 the DHFS proposed closing of Southern Wis Center with residents transfered to other Centers or community placement.

This plan was withdrawn after overwhelming opposition from parents, guardians and Senator Petrie.

In 1998 several bills on this matter were proposed and drafted but none enacted.

In 1997 the DHFS proposed placing residents in community facilities without family or guardian consent! Now the court has final authority.

Last year the Joint Legislative Council Special Committee on developmental disabilities recommended a task force to create future plans for the three centers.

There have been enough of these studies - a waste of our money and time.

I am the legal guardian for my brother, John Dirienzo at SWC. He is profoundly retarded and has multiple problems of health. He receives 24 hours care and supervision as well as care at three outside hospitals.

The high degree of professional care at SWC and medical care has kept my brother alive.

These are the reasons for my opposition to Senate Bill 231. I appeal for your help to oppose this Bill.

Sincerely,

Roland J. Di Rienzo

