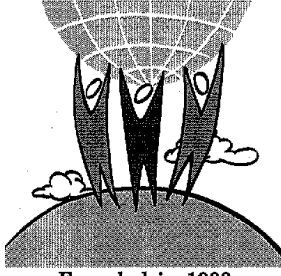


Building Leadership  
Around Wisconsin



Working Together  
For Change

Founded in 1999

# People First Wisconsin

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

## 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.

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!

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.

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!!!

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

Over 800 people are still lodged at the three State Centers for people with developmental disabilities. **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. (YOU MAY WANT TO CHECK THIS WITH MARY GREEN – THE NUMBERS KEEP CHANGING)** 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 **(I TOOK OUT THE WORD CURRENT)** resident of the Centers.

Over 35,000 people with developmental disabilities rely on and prefer our community service system. This group includes many people once deemed to be in need of institutional care. This overwhelming majority of Wisconsin citizens with developmental disabilities depend on a community support system that is currently under-funded. **(YOU MIGHT WANT TO MENTION THE 6,000 ADDITIONAL FOLKS ON THE WAITING LISTS TOO – AGAIN NOT SURE IF 6,000 IS THE RIGHT NUMBER)**

### **The Problem**

The State Center system is funded and operated as a distinct system separate from the county-administered community support system. Although the community system serves many more people--including people with support needs similar to residents of the Centers--the community system is significantly under-funded. Evidence of under-funding is documented by long waiting lists and low-wage jobs. 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. When a Center resident moves out, \$190.00 a day is available for the cost of community support. The remainder, \$210.00 a day, stays in the Center budget despite the fact that the person no longer generates costs to the Center. The budget proposed by the Governor makes a very small adjustment in this formula. It would increase the amount available for community support (CIP 1A) to \$200.00 a day and reduce the amount retained by the Centers to \$200.00 a day. Half the money would be used to cover actual costs of support; the remaining half would stay to pay for buildings and staff the person no longer uses.

### **The Solution**

The Wisconsin Council on Developmental Disabilities, the Survival Coalition, **AND CAPOW** 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. **(THIS IS STATE/FEDERAL MATCH COMBINED)** 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 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.

## 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?

# 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.

# 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.**



## STATE CENTERS INITIATIVE

# People Can't Wait to End the Institutional Bias Favoring State Centers

**ISSUE LEADERS:** Lisa Mills, People First of Wisconsin, 414/483-2546, lmills@execpc.com; Steve Verriden, ADAPT, 608/249-4308, adaptsteve@charter.net

*The number of institutional closures continues to rise dramatically across the nation. Thirty-eight states have closed or begun to close at least one large state-run institution for people with developmental disabilities. Ten states have closed all such facilities. Wisconsin doesn't even have a plan to close any of its three State Centers.*

### ISSUE:

**Just 800 people with developmental disabilities now live in the three State Centers.**

- The Centers' population continues to decrease every year because our community service system can now support people with significant disabilities to live alongside other citizens in our communities.

**The daily cost for residents in State Centers has skyrocketed, currently averaging \$477 per day or \$174,100 per year.**

- This is \$53,000 more per person per year than the national average spent on this type of institutional care, and \$80,000 more per person per year than the average spent on Wisconsin's alternative community program, CIP1-A.

**99% of the State Center residents could live in the community for an average rate that is less than the \$477 per day the state spends to keep people in the State Centers. Most could get services for much less.**

State law must change to make sure people are not unnecessarily kept in the State Centers, and that enough of the money being spent on them in institutions can follow them to fund their community services. To make this happen, more efforts must be made to down-size and close the State Centers. If the Centers were closed, projected savings could be used to provide desperately needed increases in community service funding.

Moving out of the State Centers and being served in the community under the CIP 1-A program has been proven to be the right thing to do. While only 75% of State Center guardians are satisfied with the placement of their loved one in a State Center, 96% of guardians for individuals who have moved out of the State Centers are satisfied with the quality of the community services they are receiving through the CIP 1-A program.

### GOAL:

*Start a process that will move Wisconsin toward a single, high quality support system for people with developmental disabilities. This system must be community-based, with adequate funding and an adequate workforce. Stop running three State Centers as a separate - and very high cost - system.*

### 2003 - 05 ACTION PRIORITIES:

- 1) Direct the Department to develop a plan to **close Northern and Southern Center in 3-4 years**, and transfer \$23.6 million in savings to community services.
- 2) Direct the Department to **create a downsizing plan for Central Center**, which ensures that residents' needs are met.
- 3) Level the playing field between the State Centers and community services and make community a real choice. **Increase the CIP 1-A rate to \$325 per day.**
- 4) **Increase the CIP 1-A rate in a way that is cost neutral to the state.** Fund the CIP 1-A rate increase by increasing the Center Reduction Rate to \$325.
- 5) When a person dies in a State Center, the Center currently has the option to keep the entire rate (\$174,100/year at present) in its budget. **Adopt a policy that would require that at least 75% of these funds be used to help others move out or to prevent people from moving into the Centers.**
- 6) **Put safeguards in place so people moving to the community have all the supports they need to succeed.** CIP 1-A rates should be adjusted periodically to ensure that rates match costs of placements.

*For more information about the Survival Coalition or other Survival Coalition issue papers, visit the DAWN website at: [http://www.dawninfo.org/co/sc/survival\\_coalition.cfm](http://www.dawninfo.org/co/sc/survival_coalition.cfm)*

**DECEMBER 2002**

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.

# 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!**

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.

# 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.

There is an institutional bias in funding for people with developmental disabilities: the 2% that live in the State Centers for the Developmentally Disabled get 27% of the funding while the 98% that live in the community get only 73% of the funding!

Despite this, we are very worried about the care people are getting at the State Centers.

We believe all people should be able to make their own choice of where to live.

People living in the community can realize their dreams. Community members' lives are enriched by living alongside people with developmental disabilities.

Allow all people with developmental disabilities to live near their family and friends. Support the State Centers Taskforce Bill (Senate Bill 231 and Assembly Bill 473) and move toward closing the State Centers.

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