

I am both the Executive Director of The Arc of Mississippi, and the father of a child with developmental disabilities. And after reading the article by Peggy Matthews (Residential community for retarded adults eyed) December 31, I feel compelled to respond.

I believe those working to create Son Valley have good intentions, but they should have learned years ago that segregation is not a viable option in America. Housing people with disabilities in segregated communities, no matter how new and spacious, is outdated and unacceptable. Segregation hurts not only our older neighbors and people with disabilities but also every single person who will be missing out on the opportunity to get to know them and learn from them. Almost every study done on segregation of people with disabilities shows they fare better when included in regular places, not segregated in special places.

If Son Valley becomes a reality, how often do you think that your children and grandchildren will have the opportunity to interact with the people who live there? Don't you think that you would have a much greater chance of meeting, interacting, and befriending a senior citizen with disabilities if he or she were residing in the same setting as your grandmother? Or do you even want to meet and learn from them? Is a diverse community important to you? Should longevity be punished by removing older people from society?

The Arc, as well as the rest of the disability advocacy field, has been tireless in its efforts to move our society forward, to eliminate the isolation of places like Son Valley and the stigmatization of individuals with disabilities. The Arc believes freedom and equality are unattainable in segregated environments. Son Valley would represent a giant leap backward for our society, back to a time when some members of our communities were worth less than others.

We MUST take advantage of the services and programs that organizations such as The Arc have worked so hard to supply in our state. We must keep all of our citizens with disabilities and our elderly citizens close to us. We must stand beside them, and learn from them, and appreciate them for being unique individuals. We cannot lock them away in segregated villages!

If you would like to discuss this further, please do not hesitate to call.

Matt Nalker

The Arc of Mississippi
7 Lakeland Circle Suite #600
Jackson Ms 39216
982-1180
matt@arcms.org



The Arc of the United States

*People First, Visionary Leadership,
Community Participation, Diversity, Integrity and Excellence*

Reply to:

1010 Wayne Ave., Suite 650
Silver Spring, MD 20910
(301) 565-3842 (301) 565-3843 Fax

Reply to:

1331 H St., NW, Suite 301
Washington, D.C. 20005
(202) 783-2229 (202) 783-8250 Fax

October 7, 2003

The Editor
State Journal Register

Re: Lincoln Developmental Center

To Whom It May Concern:

Your article on Lincoln Developmental Center Initiating a new era for LDC presents information out of step with today's realities for people with intellectual and developmental disabilities.

The article tells only part of the story of institutionalization and presents an impression for your readers that institutions may enjoy broad support. They do not!

It's likely that very few of your readers have ever actually been to an institution for people with developmental disabilities. Lincoln Developmental Center represents a concept whose time has past. In Illinois today, there are dozens of competent and caring service providers who are, daily, providing quality community services for people just like those at institutions like Lincoln. There are also thousands of people with developmental disabilities living in our communities with their families, many of them with aging parents, who need those and want same community services.

Deinstitutionalization has been taking place in the United States for the past three decades. In the 1990s alone there was a 44 percent decline in the number of persons in state-operated institutions. It's critical to note that primarily potential cost savings did not drive these reductions. Indeed, if cost were the only consideration, then we as Americans wouldn't enjoy many of the freedoms that make ours the greatest nation on earth. In many cases during the deinstitutionalization process, states "matched" someone leaving the institution with someone at home waiting for services. These institutions closed and others are continuing to close because it is the right thing to do.

Most of those providing services to people with disabilities in Illinois are not-for-profit agencies. Most rely on the generosity of donors and corporate partners to supplement the reimbursement that the state provides and do so for far less than the cost of state operated institutions.

As for cost, most studies show that while the cost of providing services within the community is the same or less as institutionalization, cost is not the reason to move people from institutions. Almost every study following people leaving institutions has demonstrated – by every quality of life indicators – that they are happier, healthier, and their families are more satisfied. The private (non-profit) sector can and does provide these services better than government. Government should stick to what it does well: funding, monitoring, and regulating service provision.

There are also significant resources in Illinois for training and technical assistance. Truth be told, most of the expertise and capacity is in the community, not at Lincoln. This is just a ploy to keep an outdated and outmoded facility open. Building small homes on the institution does not fool anyone, it is still an institution and is still a top-down state government program. Much less flexible than what is done daily, across Illinois, by the private sector.

The disability field has, over the past three decades, learned to separate “level of care” from real estate. They are two separate issues. Where the needed supports for a person take place and the frequency, intensity, and duration of those supports are two separate issues. There are no services available in large buildings that can't be provided more effectively in our neighborhoods, among family and friends.

The Arc as well as almost two hundred other organizations are part of a national movement to promote the “Community Imperative.” The “Community Imperative” states, in part:

- *All people have fundamental moral and constitutional rights.*
- *These rights must not be abrogated merely because a person has a mental or physical disability.*
- *Among these fundamental rights is the right to community living.*
- *All people, as human beings, are inherently valuable.*
- *All people can grow and develop.*
- *All people are entitled to conditions that foster their development.*
- *Such conditions are optimally provided in community settings.*

In fulfillment of fundamental human rights and in securing optimum developmental opportunities, all people, regardless of the severity of their disabilities, are entitled to community living.

Does it make sense to label and categorize people on the basis of some characteristic and treat them as if the condition they have is the most important thing about them? So important, in fact, that it is a legitimate interest of the state to offer alternatives for the provision of needed care and support that, in fact, force people to trade their human and civil rights for services? Doesn't our nation's Constitution have something to say about this?

If it is agreed that people should not have to essentially leave society in order to receive the basic support they need to live their lives, then it does not make sense to offer needed supportive services outside of the community setting. Again, this is not an issue of cost; it is an issue of civil rights. Other than in the criminal justice system, there is not another situation where such restrictions take place in our country, nor one that tolerates the effective control of one group by another.

Lincoln should be permanently closed. The people who lived there, with close cooperation of families or advocates, should be given choices of places to live in the wonderful communities of Illinois. The time has come.

Sincerely,



Steven M. Eidelman
Executive Director

October 15, 2003

The Honorable Robert Ehrlich, Governor
State House
Annapolis, Maryland 21401

Dear Governor Ehrlich:

The Arc of Maryland applauds the legislative directive requiring a report from the Department of Health and Mental Hygiene for closure of a state residential center operated by the Developmental Disabilities Administration. We eagerly anticipate the Department's recommendation so that the civil rights of individuals living at these centers can be restored by responsible action to end the segregation that exists because of these institutions.

The Arc's national and state position statements call for the right of all persons with mental retardation to live in their community, with responsible closure of state institutions that includes individualized planning for quality community supports. Study after study concludes that the vast majority of individuals with developmental disabilities are living fuller, more socially interactive and productive lives in their communities than those in institutions.

As you know, Maryland closed Great Oaks Center seven years ago. Despite heated political debates, Great Oaks was closed. Individuals with complex medical needs who require ongoing medical and nursing attention moved to small community settings, supported by a network of community agencies and medical supports in local communities.

The Arc opposes "Community Resource Centers" located at state institutions for respite care, recreation, and medical services for people with developmental disabilities living in the community. Public dollars should not be spent repackaging segregated centers. Maryland rejected this concept thirty years ago and instead wisely chose to invest in building the infrastructure needed in the community. Public funds must be invested to strengthen the community infrastructure and supports, not for segregated, disabled-only centers.

The Arc advocates for responsible public and fiscal policy. However, public dollars should be invested in those human services that are cost-effective and reflect contemporary best practices, not in furthering or expanding large institutions. The state must not shirk its responsibility to make reasoned public and fiscal policy that balance the needs of people waiting for services with the demands of a few who either do not know what is possible for their loved one or reject their adult family member's right to new opportunities.

We offer our support and assistance to your Administration in your leadership efforts to ensure that all persons with mental retardation currently residing in state institutions have the opportunity for a quality life in the community.

Sincerely,

Ed Worff
President

Cristine Marchand
Executive Director

November 12, 2001

Mr. Nelson,

I appreciate your taking the time to respond to my letter of October 31. It's clear that you are giving the Lincoln Developmental Center issue a great deal of consideration. But I take exception to several points made in your column.

First, you state that your premise is "don't close the facility, fix the problem." The Arc believes that *the facility is the problem* – closing the facility is the only way to fix it. Scholars at Syracuse University have developed the Community Imperative, which The Arc endorses wholeheartedly. The Community Imperative states that all people are entitled to a full life within the community, *regardless of the level of disability*. No matter how idyllic a portrait you may paint of life at LDC, it is not life in the community. It is life apart from families, friends, and neighbors – and that is unacceptable.

As for your comment that I have "no clue about the resident population at LDC," I respond that I don't need to know anything other than that they have mental retardation or related developmental disabilities, and are therefore The Arc's constituents. It matters not one iota whether their disabilities are profound or whether they are functional enough to meet your acceptable standards. You argue that some of the population with mental retardation has been granted release from the institution. That's not good enough. LDC and other institutions like it should be closed, period. People who need a lot of supports can get them in the community. The level of support a person receives is not related to the size of the buildings in which they live. Anything you can do in big buildings, you can do in family-scale environments.

And incidentally, I am the parent of a son with a diagnosis of severe mental retardation, who has lived in his community with family and friends for his entire life. I feel that I do indeed "have a clue" about these matters. I have been a special educator for more than 20 years and have seen many institutions in those years. Being president of the largest volunteer-based advocacy organization for people with mental retardation has given me the opportunity to see programs across the United States in which people with mental retardation are living full and rich lives in their communities.

I'm pleased to learn that your newspaper employs several of our constituents. That's a good start. The next step is to school yourself in people-first language. You write about "retarded people" and people "impaired by mental retardation." The acceptable language in this day and age is "people with mental retardation." They are not "impaired by" or "afflicted with" or "suffering from" the condition. Please visit our web page at www.thearc.org and read through the Press Room section, where you'll find helpful language guidelines.

Lastly, the reason why my e-mail address is not listed in the staff directory on The Arc's web page is because I am not part of the staff. As president, I am a volunteer, as are the members of our board of directors and members of the boards of many of our state and local chapters. For those wishing to contact me, I can be reached at info@thearc.org.

Sincerely,

Karen L. Staley, President
The Arc of the United States

October 29, 2001

Dear Editor,

As president of The Arc of the United States, I read with stunned disbelief your editorial on the proposed closing of Lincoln Developmental Center (*Would We Close a Prison?*). The theme of the column – comparing people with mental retardation to criminals sentenced to prison – is so extreme and outdated that it could have been written at the beginning of the last century.

I take issue with a number of the specific points mentioned in the editorial. First, it is not a valid argument to say that people with mental retardation should remain institutionalized because “there is nowhere else for them to go.” This is reflective of a perverse “I don’t want them in my neighborhood” mentality that has led to years of discrimination and bigotry toward people with disabilities.

It is true that some people need full-time supervision and round-the-clock care, but you are confusing real estate with the need for support and care. There is nothing that is magic about big, old buildings. Anything that you can do there can be done better in highly individualized places near where families reside. We should be allocating resources to create community living opportunities where these services can be provided. The new jobs created in ensuring these services should allay your columnist’s fears about losing the jobs provided by the institution. The institution existed to serve people and we now have a better way of doing that. It never existed to be an employment program or a market for vendors in the community.

Study after study shows that people who leave institutions fare better than those who remain. When done properly, reuniting people with mental retardation and their communities is a thing of beauty. In fact, Illinois lags behind most states in the move toward community living and the people of Illinois should be outraged that so many of their sons, daughters, sisters, and brothers remain institutionalized.

Citing the impact of an institution on the local economy is as illogical as it is outrageous. Plenty of illegal activities – drug trafficking, prostitution, weapons sales – have been outlawed in this country despite the “jobs” and billions of dollars they generate. Institutionalization of people with disabilities is not a financial or economic issue. It is a question of each individual’s right to a full life in the community and the right to enjoy the freedoms our nation promises its law-abiding citizens.

In addition, the argument that residents of LDC would only be moved to another institution reflects the narrow thinking that has perpetuated institutionalization as a viable option for people with mental retardation. Ten states have no institutions at all, and the residents of those states are no more or less disabled than the people now trapped at LDC.

I can imagine no other explanation for supporting the continued operation of LDC than an irrational fear that people with disabilities might one day live in our neighborhoods. It

is that sort of bigotry that contributes to racial and ethnic discord in our country and others. Why is it assumed that the only other option is another prison-like institution? Why would residing in the community not be considered an option?

Lastly, and perhaps most incomprehensibly, the editorial states: “Would the state close a prison over similar allegations? Of course not. Because prisoners need to be in prison. It’s the same with LDC residents.” It’s hardly necessary for me to point out the foolishness of that statement. It is stated very clearly: People with mental retardation should be treated as criminals. And in fairness to prisoners in Illinois prisons, I would trust that “life-threatening conditions cited by state and federal inspectors” would indeed result in a discussion of whether or not to move those prisoners to another location.

I look forward to your next editorial. Here are a few suggested headlines: “Suspending Civil Rights – Why It Makes Sense”; “It’s Time To Arrest People Different From Us.”

Sincerely,
Karen L. Staley, President
The Arc of the United States

Voice of the People
Chicago Tribune
435 N. Michigan
Chicago, IL 60611
tribletter@tribune.com

As president of The Arc of the United States – an organization whose mission is to advocate for full inclusion in all communities – I am writing in response to an editorial submitted by Voice of the Retarded supporting institutionalization (December 16). That editorial contains the usual misleading assertions put forth by those who would keep people with disabilities locked away from their families and our communities.

The most glaring falsehood is that the population in institutions has “fallen under the radar.” To the contrary, this population is at the center of The Arc’s advocacy and has not for a moment been forgotten.

It’s likely that very few of readers of the Chicago Tribune have ever actually been to an institution for people with developmental disabilities. Even so, all Americans can appreciate our right to live in any neighborhood we choose, as equals. Assertions that institutional care has improved over the years are highly suspect, but more importantly, they are irrelevant. None of us would want to live in a “country club prison,” even if we were assured the accommodations were comfortable. Freedom means choices, and institutionalization bars even the most basic of these.

Deinstitutionalization has been taking place in the United States for the past three decades. In the 1990s alone there was a 44 percent decline in the number of persons in state-operated institutions. It’s critical to note that primarily potential cost savings did not drive these reductions. Indeed, if cost were the only consideration, then we as Americans wouldn’t enjoy many of the freedoms that make ours the greatest nation on Earth.

The Voice of the Retarded submission to Voice of the People questions the motives of those of us who want to reunite people with disabilities and their families. As a nonprofit organization, The Arc clearly has no financial motive. Our motive is to fulfill the mission of inclusion dictated by our constituents, the very people whose lives are in question here. Indeed, our motive is to work toward the day when an advocacy organization like The Arc is no longer necessary. We hope to one day work ourselves out of business.

In the interest of accuracy, here are a few facts: no person with a developmental disability has become homeless due to moving from an institution or from the closure of a group home; we advocates view occasional closures as a good sign, as it’s appropriate that those failing to deliver quality services are forced out of business; state institutions continue to operate regardless of their performance – and without regard for the families that have been torn apart by institutionalization.

The Voice of the Retarded also raises the issue of cost, another favorite argument of those supporting institutionalization. The truth is, most studies show that while the cost of providing services within the community is the same or less as institutionalization, cost is not the reason to move people from institutions. Almost every study following people leaving institutions has demonstrated – by every quality of life indicator – that they are happier, healthier, and their families are more satisfied. Why use taxpayer funds for services that families don't want, which produce poor results, and are outdated?

The disability field has, over the past three decades, learned to separate “level of care” from real estate. Where the needed supports for a person take place and the frequency, intensity, and duration of those supports are two separate issues. There are no services available in large, old buildings that can't be provided more effectively in our neighborhoods, among family and friends.

If Americans can agree that people should not have to essentially leave our society in order to receive the basic support they need to live their lives, then it does not make sense to offer needed supportive services outside of the community setting. Again, this is not an issue of cost or motives; it is an issue of civil rights. Other than in the criminal justice system, there is not another situation where such restrictions take place in our country, nor one that tolerates the effective control of one group by another.

Freedom is priceless and the desire to be free is a motive that cannot be questioned.

Sincerely,
Lorraine Sheehan, President
The Arc of the United States

**Joint Letter from The Arc
For Legislators, Governor and Media**

October 15, 2003

Dear :

We write as volunteer and staff leaders of The Arc at the national, state, and local levels in Maryland. Many of us are parents of individuals with mental retardation and related developmental disabilities.

The Arc applauds the legislative directive that calls for a report from the Department of Health and Mental Hygiene regarding closure of a state residential center operated by the Developmental Disabilities Administration. We eagerly anticipate that Maryland's legislature will recognize that the civil rights of the individuals now living at these centers can be restored by responsible action to end the segregation that exists because of these institutions. The Arc's national and state position statements call for the right of all persons with mental retardation to live in their community, with responsible closure of state institutions that include individualized planning for quality community supports.

But some voices in the public today advocate for the continued support of these same institutions. These voices express concern that being allowed to live in the community will compromise the safety and well-being of their family members. In contrast with their concerns, we offer the following data and observations.

Study after study concludes that the vast majority of individuals with developmental disabilities are living fuller, more socially interactive and productive lives in their communities than those in institutions when they have competent staff and receive appropriate supports. All of the studies published in 1990 or later reported significant improvements in challenging behaviors of individuals who moved from institutions to community settings. The research overwhelmingly concludes that adaptive behavior was almost always found to improve with movement to community settings from institutions. Moreover, family members, who were often as a group initially opposed to deinstitutionalization, were almost always satisfied with the results of the move to the community after it occurred. (Larson & Lakin, 1991). Studies based on over 2,600 subjects demonstrate strongly and consistently that people who move from institutions to community settings have experiences that help them to improve their adaptive behavior skills. People living in community programs funded by the Maryland Developmental Disabilities Administration have lower mortality rates than persons in the general public and than persons in state-operated institutions.

But we don't need to look further than Maryland to see this in practice. Seven years ago, Maryland closed Great Oaks Center, the state residential center located in Southern Maryland. Despite the anguish and heated political debates at the time, Great Oaks was closed. Individuals with complex medical needs that require ongoing medical and nursing attention moved to small community settings, supported by a network of community agencies and medical supports in local communities. Today, the Riderwood Retirement Village exists on the property, employing local workforce and contributing to the economy of the local community.

No parent really chooses to put his or her child in an institution. It is only when no other options are presented that a family “chooses” to take this heart-wrenching step. And no person with mental retardation “chose” to go to a state institution.

Many of us were told to forget we ever had a child with disabilities and to place them in an institution. Instead, we took our child home and raised him or her (typically with little or no public support or services), formed The Arc and got federal and state laws passed to educate our children in public schools. We sued for our children’s right to a public education. The Arc went on to get legislation passed for vocational rehabilitation, community services, Medicaid home and community programs, housing, and nondiscrimination and rights protections.

The 2000s are a different time for people with developmental disabilities. Thanks in large part to The Arc’s national, state and local advocacy, people with developmental disabilities and their families today have many more promising options. **Today, with a wide array of community alternatives, no parent has the right to deny an adult son or daughter the right to greater opportunity, growth and inclusion in our society. Moreover, the state acts irresponsibly – and violates the fundamental civil rights of people with disabilities - if it is coerced by a small, vocal group of parents to keep people in state institutions in the name of “parent choice” when appropriate, less restrictive community supports are possible.**

There are nearly 10,000 people with developmental disabilities waiting for services funded by the Developmental Disabilities Administration. What about “parent choice” for these families – many of whom have no choice but to wait for years for some help? It would be outrageous to allow a small number of parents or family members (with the support of institution employees who believe their current jobs are at stake) who are demanding their “choice” for institutions to force the state to admit people who are now living in the community with no services into an institution.

The Arc opposes the development of “Community Resource Centers” located at state institutions. Proponents of such centers want to locate respite care, recreation programs, and medical services for people with developmental disabilities living in the community at the state institution’s Community Resource Center. Public dollars should not be spent repackaging segregated centers. Maryland rejects this concept for such centers thirty years ago and instead wisely chose to invest in building the infrastructure needed in the community. Public funds must be invested to strengthen the community infrastructure and supports, not for segregated, disabled-only centers. Why should an individual be offered segregated, disabled-only recreation programs at a state institution when locally sponsored community leisure and recreation programs are available closer to or in people’s own neighborhoods? And why should a person go to a state institution for their medical care or treatment given the wealth of knowledge and experience that exists at facilities such as Johns Hopkins and the network of physicians and clinics throughout our communities?

The Arc has long advocated for responsible public and fiscal policy. The Arc at all levels has worked tirelessly and creatively to expand federal Medicaid revenues to states and particularly to the State of Maryland for DDA services. The Arc of Maryland is on record supporting tax measures, if necessary, to continue important services and programs. However, tax dollars should be wisely invested in those human services that are cost-effective and reflect contemporary best practices, not in furthering or expanding large institutions. The state must not shirk its responsibility to make reasoned public and fiscal policy that balances the needs of people waiting for services with the demands of a few who either do not know what is possible for their loved

one or reject their adult family member's right to new opportunities. It is inconceivable that this state would deny persons the opportunity for richer lives in the community by bowing to the wishes of a small vocal group of parents!

The Arc calls upon the Governor and State Legislature to fulfill the promise of existing Maryland State statute: "To promote, protect, and preserve the human dignity, constitutional rights and liberties, social well-being, and general welfare of individuals with developmental disabilities in this State." We offer our combined resources to provide any further information to you and invite you to visit people with multiple and profound disabilities living in your community.

Sincerely,

Lorraine Sheehan, President
Steve Eidelman, Executive Director
The Arc of the United States

Ed Worff, President
Cristine Marchand, Executive Director
The Arc of Maryland

David Rosenthal, Vice President
Kate Rollason, Executive Director
The Arc of Anne Arundel County

Eugene Mark, President
Fred Baughman, Executive Director
The Arc of Montgomery County

Ed Nolley, President
Stephen Morgan, Executive Director
The Arc of Baltimore

Steve Pyles, President
Mac Ramsey, Executive Director
The Arc of Prince Georges County

Tim Atkinson, Executive Director
Vikay Koontz, President
The Arc of Carroll County

Charles Reese, President
Harriet Yaffe, Executive Director
The Arc of Southern Maryland

Michael Shank, President
Joanna Pierson, Executive Director
The Arc of Frederick County

Roger Rima, Executive Director
The Arc of Talbot County

Nancy McKee, President
Tim Quinn, Executive Director
The Arc Northern Chesapeake Region

John Follet, President
Bob DeHaven, Executive Director
The Arc of Washington County

Tracy Eberhardt, President
Carol Beatty, Executive Director
The Arc of Howard County

Starr Todd, President
The Arc of Worcester County

"Draft letter to the editor written by Nancy Weiss of TASH in support of efforts to close an institution in Maryland."

Sample Paragraphs for a Letter to the Editor

(this letter would be too long for a letter to the editor but you may be able to use, or adapt parts for a letter that fits the situation in your state)

Dear Sir/Madam:

I've been closely involved in the efforts to close the Rosewood Center in Maryland. Recently, about 200 people took part in a rally to keep Rosewood open. About a quarter of the protestors were family members of Rosewood residents; more than half were employees and union members out to assure that their jobs remained secure; none were Rosewood residents expressing their own views on what the future should be for this institution.

I know hundreds of people with developmental disabilities and communicate regularly with many more. I don't know one person who lives in or has lived in an institution who would say that the institution was a good place. I know parents who want to keep their sons and daughters in places like Rosewood because it is what is known and what feels safe, but what is more important is hearing from adults with disabilities themselves. If it were true that the people who live at Rosewood choose to live there and don't want to move (as supporters for keeping the place open say) -- why have none of *their* voices been heard? You'd think at least a few residents who really want to see the place stay open might have been at the rally or have been interviewed since (because I don't believe that they are "too disabled to have a voice" as some people have implied).

A saying among advocates with disabilities is "Nothing About Me Without Me". Lots of people are happy to speak for and about residents of institutions. One group even calls itself "Voice of the Retarded" -- although not one person with a cognitive disability sits on their board or is represented among their leadership. No Rosewood resident was at the rally or has said since, "this is where I want to be". To me, that absence speaks volumes.

About half of the 200 or so people at the rally to keep Rosewood open were employees and members of the union (AFSCME). I suppose some employees may be fighting to keep Rosewood open because they truly believe it is what is best for the residents, but most of the employees made it very clear that they were there for their own interests, not those of the residents. The message of the union (and that of many of the politicians) was concern over the possibility of lost jobs. But as one State delegate said, "while jobs are important, lives are more important". It is indefensible to keep a portion of our citizenry locked up so that others can keep their jobs.

Institutions are not good places, or in the case of most of them, even benign places. By necessity they are regimented and are run to meet the needs of many, rather than the needs of each person for freedom and recognition. I hear enough horror stories to know that very often they are inhumane places. I do not think for a moment that everyone who works in an institution is a cruel, inhumane person -- probably exactly the opposite. Most people who work in these places are likely caring people who want to

be helpful; then there's a portion of people who are neither caring nor cruel but just show up and do their job; and then there are some who get a thrill out of being in charge, bossing people around -- staff who lack the maturity to separate out what's personal and what's not personal when the people they are supposed to care for are difficult and even aggressive (and this kind of behavior is clearly caused by stifling environments that rob people of their ability to have impact on their worlds). Responses to challenging behavior in places like these are often coercive, restrictive, and serve only to escalate already difficult situations.

It is a sad paradox that the individuals who have the most severe disabilities are the most likely to be placed in environments that directly produce the types of behaviors for which they are then punished and controlled. The sad reality is, the more people dislike living in institutional settings and having every aspect of their lives regimented, the more likely they are to attempt to protest against such treatment. The more demonstrative their protest, the more likely it is that their behavior will be viewed as an expression of their continued need for institutionalization and the less likely it is that their protest will be heard. When will we realize that when you deny an individual basic respect and freedoms, he or she is given little choice but to rebel?

Some (albeit likely a small minority) of the people who work in these places do things to innocent people that would make you cry. People are locked in closets; denied food; hit and pinched; tied up for days on end; paraded naked; sprayed with hoses; left in the dark; taunted and tormented; denied the use of bathrooms; subjected to water spray to the face, jalapeno pepper sauce to the mouth, or ammonia to the nose; subjected to sexual abuse; humiliated and dehumanized -- and much of this in the name of treatment. These are not things that happened in the forties, or that happened once, or even rarely. They are things that happen when people are put in places in which they are isolated not only from the pleasures of life but from the public scrutiny that serves to protect vulnerable people

Bad stuff is done to people when they are hidden from the public eye. Institutions are not OK, not for awhile, not for some people, and not just until we have something better. They should be closed and resources and expertise shifted to community settings.

At the Fairview Developmental Center (a state-run institution) in Huntington Beach, California, a staff person killed a fourteen year old young man who had autism and mental retardation by rolling him inside an exercise mat in an effort to control his behavior. The staff person was arrested. Testimony showed that as punishment for "non-compliant behavior" she had put a diaper across the young man's face to block his vision, rolled him in the mat, sat on the folded end of the mat and kept him there for more than ten minutes until he stopped kicking. The staff person's attorney argued that lay people might consider her reaction "improper" but that a room full of autistic students is "a different world". "These are socially undesirable people" the attorney went on to argue, "sometimes what a person has to do may seem strange and distasteful to others". The judge dropped charges and dismissed the case saying that he had no doubt that the staff person had caused the boy's death but that her actions were "between her and her conscience and not something for a court of law".

Across the country, individuals with disabilities as severe and health care needs as complex as the individuals continuing to reside at Rosewood, are being well supported

in the community. Nine states have closed all of their state institutions and are providing quality supports to all of their citizens with disabilities, even those with significant behavioral challenges and complex medical needs, with a range of services in the community.

The movement toward community living started over thirty years ago and research is unequivocal regarding which type of support results in better lives. People with disabilities living in the community experience improved quality of life in areas such as:

- opportunities for integration and social participation;
- contact with friends and relatives, participation in employment;
- opportunities for choice-making and self-determination;
- quality and duration of services received, protection from abuse and neglect; and,
- other indicators of a quality life.

Prior to community placement, many parents oppose the move to the community -- change is understandably worrisome. But research shows that almost without exception, once their sons and daughters are living in the community, their parents report increased satisfaction with the quality of supports and support for community placement for their loved one.

There is no other example in this country of people being locked up and segregated from society – except for prisoners incarcerated for their crimes. It is not just or reasonable to deny people the right to real lives in the real world when the success of community supports has been demonstrated across the country.

It is one of our country's greatest shames that we continue to keep people in institutions and an even greater disgrace that we try to convince ourselves and others that this removal from society and denial of rights is in the best interest of the people still in these places. It is time to end this era of segregation and begin one characterized by valuing and including all members of our communities.

Nancy Weiss
Executive Director, TASH