



## Deinstitutionalization Toolkit: **STRATEGY – inDETAIL**

This section of the Deinstitutionalization Toolkit includes the supportive detail on the subject of Strategy. The research and detailed information are intended to provide background for the Deinstitutionalization Toolkit.

➤ **STRATEGY – inBRIEF**

### **Getting There: Strategies That Work**

Making systems work for people is not an easy task, but it can be done. Closing an institution is not one act—it is a series of incremental steps and decisions made over time, consistent with the community’s vision and plan to transform how the state or community serves, supports, and protects its citizens with intellectual disabilities and developmental disabilities (ID/DD). These steps include—

- Identifying possible allies, partners, groups that have differing perspectives and others
- Developing strategies to move the work forward
- Creating a robust community system of care and a commitment to quality assurance

In this section, we discuss these three components of a successful closure movement. For an analysis of closures and additional information of specific examples of different state closure plans, see Section 7 of the Deinstitutionalization Toolkit.

➤ **CLOSURE – inBRIEF**  
➤ **CLOSURE – inDETAIL**  
➤ **CLOSURE – inDEPTH**

### **Identifying the Stakeholders**

The stakeholders in this effort represent many different interests, points of view, and concerns. It is important to identify the broadest base group possible and to engage individuals and groups that initially may not share the goal of closing institutions and creating community living opportunities for people with ID/DD.



### ***Allies and Partners***

It is important to complete an environmental scan and to identify allies and partners that could work together as a coalition. In our review, potential allies and partners include the following:

**Protection and Advocacy (P&A) Organizations:** The P&A system is a national network of congressionally created, legally based disability rights agencies in each state that provide legal representation and other advocacy services to people with disabilities. People with developmental disabilities are served through the Protection and Advocacy for Persons with Developmental Disabilities (PADD) program, funded in part by the federal Administration on Developmental Disabilities. Although the impact of the organizations varies by state (see National Council on Disability, 2011), PADD has investigated complaints of abuse and neglect, and filed, joined, or intervened in class-action lawsuits that have alleged inappropriate care and treatment, including abuse and neglect of residents, the rights of people with a disability to live in the least restrictive environment, and breaches of statutory and constitutional rights. PADD also advocates for community options at a systemic level.

**State Council on Developmental Disabilities:** Most state councils are state or quasi-governmental agencies that are in a position to influence state policy and promote an agenda of inclusion and institutional closure (see National Council on Disability, 2011). Councils across the country have engaged in deinstitutionalization efforts through a variety of advocacy, capacity-building, and systems change activities.

**Self-Advocacy Groups:** Self-advocates are the best voices for deinstitutionalization, and several states have financially supported self-advocacy in order to give people with ID/DD a voice at the state level. National groups such as Self Advocates Becoming Empowered (SABE) and People First, as well as their state and local affiliates, include former institutional residents and can be a powerful voice to speak with decision makers as well as groups that do not support deinstitutionalization. Self-advocates have participated in the closure process in several capacities. For example, People First of Tennessee filed suit to close the Cloverbottom and Arlington Developmental Centers, and reached a settlement in 1996. The institutions closed in 2010. Self-advocates



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worked with the State of Maryland to describe the benefits of community living to parents who did not support the closure of the Rosewood Center.

**Parent Advocacy Groups:** Organizations such as United Cerebral Palsy and The Arc advocate for strengthening the community-based system. In some cases, they have joined in lawsuits to affect change on behalf of people with ID/DD.

**Independent Living Centers:** Centers for Independent Living (CILs) are grassroots, advocacy-driven organizations run by and for people with disabilities. They focus on civil rights, the independent living philosophy, and inclusion (National Center for Independent Living Web site, n.d.).

**Private Human Service Providers (Residential and Day Training):** Human service providers and the associations that represent them are in a unique position to understand how, and at what cost, the needs of people with ID/DD can be met in the community. However, because they will benefit financially by getting paid for the services they provide to people who move from the institution to the community, their motives are sometimes questioned.

### ***Decision Makers***

As you continue to identify partners and allies, it is important to consider the position of the following individuals and groups and to ascertain, as early as possible, their position, the support they could give your cause, and the roles they might be able and willing to play.

**DD Agency Leadership:** Within the constraints set by the legislature, the DD agency leadership is in the position to set a vision for the state's policy for citizens with ID/DD. It can develop community-based options and encourage people to choose community options to reduce new admissions, or it can support the status quo.

**Governor:** Committed leadership from a governor can change the tenor of the debate from whether an institution will close to how it will close. Each state has a DD Council with members appointed by the governor and funded by the Administration on Developmental Disabilities. The agencies are charged with advising the governor.



However, the extent to which the governor accepts their recommendations varies by state (NCD, 2011).

**Legislators:** The legislature can be a powerful ally, and in most states the final decision on institutional closure will involve the legislature. However, the legislatures and, most important, legislators representing the districts in which the facilities planned for closure reside may want to protect the jobs of their constituents and avoid any action that may negatively affect the economy of their district.

### ***Individuals and Groups with Differing Perspectives***

Another important piece of the environmental scan is to identify the individuals and groups that might not support the closure of institutions in your community. It is important to try to identify their issues, understand their motivation, and determine what strategies can be used to engage them if possible—and if that is not possible, how to refute their arguments and deflect their influence. In other communities, these individuals and groups have included the following:

**Unions and Staff:** Unions in a number of states represent the state employees of the large institutions who might lose their jobs when an institution closes. Whether or not in a union, staff members generally resist any move that appears to jeopardize their jobs. Institutional closure represents change and uncertainty for their futures.

The Service Employees International Union (SEIU) has broken ranks with public employee unions that do not support deinstitutionalization, and has expressed public support for community-based living. SEIU is also working to unionize home care workers (Taylor, 2008).

**OTLarge Private Residential Providers:** Private Intermediate Care Facilities for the Developmental Disabled (ICFs/DD) are protecting themselves against closure.

**Some Parents of Institutional Residents:** For many residents, the institution has been their home for many years, and the possibility of change may be daunting. Some parents not only have similar feelings, but also may have taken comfort in an expectation (common in the past) that state institutional placement was permanent.



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On a national level, the Voice of the Retarded (VOR) represents parents and family members opposed to institutional closure, and is the only national organization lobbying for the preservation of large state institutions. The exact size and membership of VOR is unknown. If compared in size with organizations that promote deinstitutionalization, such as The Arc with 100,000 members and 1,000 local chapters, VOR seems to have influence on policymaking that far outpaces its size.

For example, in opposing the closure of institutions in Virginia, VOR argues that facilities have better oversight, services are provided as “wrap-around,” medical staff are on site, and facilities are stable (permanent) and contribute significantly to the local economy. These assertions, although they are not supported by fact and ignore the civil rights of people with ID/DD, and can be persuasive if not challenged effectively.

### ***Other Groups That Impact Strategy***

As you review all factors in the environment that will affect your strategy and your desired outcome, it is also important to consider the role of the following groups and to determine how you could engage them to work with your group. These groups include the media, the Department of Justice (DOJ), courts, court monitors, and the Centers for Medicare and Medicaid Services (CMS).

**The Media:** The media, using both editorials and investigative reporting, help to shape public opinion. Today’s media focus on stories to which they are guided by key stakeholders. In covering institutional closures, the press often focuses on long-term residents of the institution and fails to report on people with ID/DD who are successfully living in the community. For example a 2010 Associated Press story about the potential closure of an institution in Washington State begins, “Larry Butts first set foot in the Rainier School campus the day it opened in 1939, when he was just 6 years old. Seventy-one years later, he could be forced out of the only home he’s ever known if lawmakers decide to close the Buckley facility he shares with nearly 400 other developmentally disabled patients.”

In some cases, the media can be a powerful force for institutional closure. Several well-known exposés have been credited with prompting major changes. For example, Geraldo Rivera’s 1972 investigative report exposed neglect, abuse, and a lack of



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programming at Willowbrook, a state institution for people with ID/DD on Staten Island. This exposé prompted the closing of that institution and the creation of P&A organizations. In another example, in 1978 a *Detroit Free Press* series of stories of abuse at the Plymouth Center in 1978 helped close that institution.

Although not common, this type of investigative reporting still occurs. For example, Mary Beth Pfeiffer has published a series of investigative reports in the *Poughkeepsie Journal* about the slow pace of deinstitutionalization at the Wassaic Campus of the Taconic Developmental Disabilities Service Office, the high cost of institutional care in New York State, and the role that Medicaid overpayments play in maintaining the status quo (Pfeiffer, 2010). The *Chicago Tribune* has run a series of stories about unexplained deaths of children with disabilities at Alden North, a 93-bed privately run nursing home providing ICF/DD services to children near Chicago, Illinois (Hopkins and Roe, 2010).

**Department of Justice (DOJ):** The 1980 Civil Rights of Institutionalized Persons Act (CRIPA) gives the attorney general the right to conduct investigations and litigation relating to conditions of confinement in state or locally operated institutions (the statute does not cover private facilities). DOJ negotiates with a state to develop a settlement agreement.

In October 2010, DOJ entered into a comprehensive settlement with the State of Georgia, which requires that the state cease new ID/DD admissions within nine months, transition all people in state facilities to community settings within five years, create additional Home and Community-Based Services (HCBS) Waiver slots, provide support for people with ID/DD living in the community to gain access to needed services, provide respite to families, establish mobile crisis support teams, and provide reasonable oversight of the community-based service system (Galbraith, 2010). In announcing the settlement, DOJ indicated it will be “a template for our enforcement efforts across the country” (Miller, 2010), indicating that DOJ actions affirm the Supreme Court’s decision that state budgets cannot be an excuse for not fulfilling its obligation to implement the *Olmstead* decision.

In another instance, DOJ brought suit against the Conway Human Development Center in Arkansas, claiming that residents were not being given enough of a chance to move



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to less restrictive community-based settings—such as group homes or family dwellings with professional assistance—and alleging dangerous practices (Matthews, 2011).

The priorities of the federal government establish DOJ priorities and determine how strongly DOJ can advocate during settlements. DOJ has not always focused settlement agreements on community living. In some cases, it has focused on addressing improvements to the institutions. For example, in 2008 DOJ intervened in a case regarding abuse in a large residential facility in Texas (the “fight club” case), and asked the State of Texas to spend \$150 million to hire 1,100 staff to upgrade the quality of care in state institutions. Although the DOJ Settlement Agreement with the State of Texas includes a reference to the *Olmstead* decision and contains language in support of personal preference and community integration, its main focus was on improving institutional care and was not balanced by equal attention to ensuring that the state’s citizens have the community supports and services necessary for real choice between living in an institution and living in the community (NCD, 2011).

**Courts:** In addition to judging cases directly affecting institutional closure, courts may need to rule on related issues. For example, some local courts have upheld zoning laws allowing discrimination against small group homes; others have upheld the rights of people with ID/DD (Parish, 2005).

**Court Monitors:** Court monitors are charged with ensuring that the state is in compliance with any consent decrees. Thus, the extent to which the court monitor supports home and community-based services is based on rules laid out in the consent decree.

**Centers for Medicare and Medicaid Services (CMS):** CMS provides funding for institutions through the ICF/DD program. It has the ability to withhold that funding if the institution does not comply with its standards. For example, by decertifying the Howe Developmental Center in Illinois because it did not meet the quality standards, CMS made the institution ineligible for federal match, costing the state approximately \$2.2 million per month (\$73,000 per day). This was a major factor in the state’s decision to close the facility (Shannon, 2009).



## **Developing Strategies**

To accomplish deinstitutionalization and system redesign, advocates, family members, and self-advocates need to come together, identify their vision and values, and develop a concrete plan that will move the state or community toward the identified goal.

Research supports the idea that community-based services have significant advantages over institutions in terms of quality of life outcomes and cost. Nevertheless, those are rarely the factors leading to a successful closure. According to the stakeholders we interviewed, most successful closures were based, at least to some extent, on clarifying the group's values and sharing a commitment to community living. A statement of values might include these types of statements:

- A state should not unnecessarily restrict a person's quality of life, social interactions, or basic human rights based on disability status.
- The social environments of people with ID/DD should be as much as possible like those of their nondisabled peers.
- An individual should not be required to give up the right to live in the community in order to receive needed services and supports
- People with ID/DD should be allowed to make decisions about their own lives to the maximum extent possible
- Research supports the fact that community settings result in improved quality of life in areas such as opportunities for integration and social participation, participation in employment, opportunities for choice-making and self-determination, quality and duration of services received, contact with friends and relatives, adaptive behavior, and other indicators of quality of life.
- The community is for EVERYONE. This includes people who have medical or behavioral issues that complicate their care and support.



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### ***Develop a Broad-Based, Well-Organized Coalition***

*BE IT RESOLVED by the Legislature of the State of Minnesota on behalf of the citizens of the state that the state apologize publicly to all persons with mental illness and developmental and other disabilities who have been wrongfully committed to state institutions, acknowledging that it regrets this history of institutionalization of persons with those disabilities, and that it commits itself in their memory to move steadfastly to help Minnesotans with those disabilities who in the future turn to the state for services to receive them in the least restrictive manner.*

—H.F.168/S.F.1135

The coalition can start with a base of key membership groups, providers, family members, self-advocates, the DD Councils, legal aid agencies, and P&A agencies that join around expanding community-based services, stopping admissions to the state hospitals, and ultimately closing hospital beds and entire facilities.

Self-advocates are the best voices for deinstitutionalization. This text is from the resolution passed by the Minnesota Legislature and signed by Governor Pawlenty on May 25, offering an official apology to Minnesotans with ID/DD and their families, who were harmed by the experience of institutionalization in the state reaching back as far as the 1800s. The resolution is the result of decades of work by activists—especially the Remembering with Dignity (RWD) project based at Advocating Change Together (ACT)—who have sought to close institutions, create more community and family living options for people with disabilities and mental illness, remember those who lived and died in Minnesota’s institutions, and acknowledge that part of the state’s history.

Self-advocates worked with the State of Maryland to describe the benefits of community living to parents who were opposed to the closure of the Rosewood Center. In Maryland, if opposition by the individual, family member, or guardian is identified, a peer mentor (self-advocate or individual with an ID/DD living in the community) may be introduced to and paired with a resident to expose the resident to community living experiences.

State supported self-advocacy link: <http://ici.umn.edu/news/fyi/jun10.html>



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### ***Set a Vision and Comprehensive Agenda***

As discussed previously, having a clear vision based on shared values is critical to all of the work you do as a group, including the establishment of a comprehensive agenda. This agenda should include the key stakeholders, identification of stakeholders who are not yet at the table but should be, consensus on leadership of the group and the group's structure, and the basic goals and objectives in all areas of work. This would include creating the political will to close institutions, developing specific strategies, creating community capacity, and building a quality assurance plan that engages parents and other stakeholders in the process.

**Stay focused on the goal:** Begin with the most comprehensive vision of system of care in the community for people in state institutions and on waiting lists in the community. In establishing this comprehensive vision of the system, do not compromise on the vision or the values you have established; the political process tends to modify and cut down. You may need to compromise at some points in the process on “detail” or “timing,” but the vision must remain clear.

Create a written, consistent deinstitutionalization platform and outline of principles. The objective is that people with ID/DD have the right to live in the least restrictive setting. Strong communications, including written position papers and a deinstitutionalization platform that can help keep the coalition unified and anchored, are critical. The platform can serve as a “major educational tool” with lawmakers and the media. An excellent example was developed by The ARC of Connecticut in its *Platform for Reform*, which included concepts such as person-centered self-determination, full empowerment of families, self-advocacy, implementation strategies to effect real inclusion, and a commonsense plan for reform.

<http://www.arcct.com/858>

Several key strategies, including the following, have worked well in states that have closed institutions or are in the process of closing them:

**Frame the Debate:** It is important that vision and values frame the debate. This action directs the focus on the individual and his or her rights, and away from the self-interests of other groups.



**Focus on Closure as a Civil Right:** This strategy shifts the discussion to a legal one and focuses the debate on the rights of the individual with disabilities—not the numbers, the economic benefits to the state, or the impact on the economy of the community that houses the institution. The individual is the core of the litigation surrounding institutional closure.

**Define the Choice; Not “If” but “When” and “How”:** Based on the legal issues involved and the rights of the individual, the state can choose to frame the discussion in this way and to focus the community’s attention on the important issues that surround the closing of an institution: capacity building, developing a quality assurance process, and so forth. This allows the process to include all stakeholders and can create an environment of inclusion and ownership in the success of the closure and the transition of people into high-quality, person-centered living situations in the community.

**Close the Front Door:** States using the deinstitutionalization strategy of shutting off new admissions have generally faced less opposition than states that close the doors in the beginning of the deinstitutionalization process. To accomplish this, state officials and stakeholders must identify the pathways leading to institutionalization and work to provide alternatives. Some states (e.g., New Hampshire, Georgia, Michigan) using this strategy have chosen to focus on children first, and then move on to adults. However, in Missouri, with no admissions in more than two years, the state still has six state-run institutions. Representative Scott Rupp introduced legislation to close the facilities within five years.

<http://www.columbiatribune.com/news/2010/dec/14/bill-calls-for-closure-of-state-run-institutions/>

### ***Consider Legal and Legislative Strategies***

Coalitions around the country have utilized or benefited from a legal strategy with the involvement of the State’s P&A agency, legal aid organizations, and/or DOJ. Federal policy and programs are evolving to support more people with ID/DD living in community-based settings. In July 2011 DOJ released a technical assistance guide to the Americans with Disabilities Act (ADA) and the *Olmstead* decision. It is an authoritative guide that advocates may want to use as part of their campaign. The guide might be useful to quote in briefs in court, in meetings with government officials, in



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letters to the editor, and in opinion editorials. It represents the official position of the highest law enforcement agency in the country.

Resource guide: [http://www.ada.gov/olmstead/q&a\\_olmstead.htm](http://www.ada.gov/olmstead/q&a_olmstead.htm)

### Create a Legal Strategy

In almost all states where deinstitutionalization has occurred, litigation has played a strong role and is often the initial impetus for closure or downsizing. Litigation continues to be among the strategies used to require states to cease alleged violations of federal Medicaid law, the ADA, Section 504 of the Rehabilitation Act, and the U.S. Constitution. Litigation has been successful in improving access to Medicaid home and community services by decreasing waiting lists for community placement, downsizing institutions, and challenging restrictions on the scope of services so people with ID/DD can live in the most integrated settings.

The legal consensus developed over years of litigation and currently being enforced by DOJ is that people have a fundamental right to live in the least restrictive environment that meets their needs. Legal remedies have accelerated the pace of deinstitutionalization. In recent years, federal intervention through DOJ lawsuits and formal and informal settlement agreements is pushing states to move more quickly in their efforts to deinstitutionalize people with ID/DD. Under general rules governing lawsuits brought by the Federal Government, DOJ may not file a lawsuit unless it has first attempted to settle the dispute through negotiations. The *Olmstead* decision has often been called the *Brown v. Board of Education* of the disability rights movement. In June 2009, in commemorating the anniversary of the *Olmstead* ruling, President Obama stated:

*"The Olmstead ruling was a critical step forward for our nation, articulating one of the most fundamental rights of Americans with disabilities: Having the choice to live independently. I am proud to launch this initiative to reaffirm my Administration's commitment to vigorous enforcement of civil rights for Americans with disabilities and to ensuring the fullest inclusion of all people in the life of our nation."*



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[http://www.whitehouse.gov/the\\_press\\_office/President-Obama-Commemorates-Anniversary-of-Olmstead-and-Announces-New-Initiatives-to-Assist-Americans-with-Disabilities/](http://www.whitehouse.gov/the_press_office/President-Obama-Commemorates-Anniversary-of-Olmstead-and-Announces-New-Initiatives-to-Assist-Americans-with-Disabilities/)

In developing a legal strategy, several tools and recent court decisions may be helpful. DOJ has recently posted a legal rights resource guide on the ADA page of its Web site.

<http://www.ada.gov/cguide.pdf>

In October 2010, DOJ entered into a comprehensive settlement with the State of Georgia which requires the state to cease new ID/DD admissions within nine months, transition all people in state facilities to community settings within five years, create additional HCBS Waiver slots, provide support for people with ID/DD living in the community to gain access to needed services, provide respite to families, establish mobile crisis support teams, and provide reasonable oversight of the community-based service system. In announcing the settlement, DOJ indicated that it will be “a template for our enforcement efforts across the country,” indicating that DOJ actions affirm the Supreme Court’s decision state budgets cannot be an excuse for fulfilling its obligation to implement the *Olmstead* decision.

<http://georgiadojsettlement.blogspot.com/>

In another instance, DOJ brought suit against the Conway Human Development Center in Arkansas, claiming that residents are not being given enough of a chance to move to less restrictive community settings—such as group homes or family dwellings with professional assistance—and alleges dangerous practices. The court, however, sided with the State of Arkansas, and the Conway Human Development Center will remain open.

<http://www.arktimes.com/ArkansasBlog/archives/2011/06/08/judge-dismisses-suit-over-conway-human-development-center>

In Illinois, a groundbreaking consent decree in *Ligas v. Hamos* was finalized June 15, 2011, in the Chicago federal district court. The decree gives people with ID/DD, who currently live in large private but state-supported facilities known as ICFs/DD the choice to move into small community-based settings with the necessary supports. It also



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requires that an additional 3,000 people with ID/DD who are currently living at home be provided with community-based services.

[http://www.equipforequality.org/news/pressreleases/june\\_15\\_2011\\_ligas.php](http://www.equipforequality.org/news/pressreleases/june_15_2011_ligas.php)

DOJ has filed a motion to intervene in *Steward v. Perry*, a class-action case brought on behalf of approximately 4,500 people with ID/DD who are living in Texas nursing facilities and are being denied the opportunity to live in integrated community settings and receive active treatment while confined in these facilities. The State of Texas has recently filed an opposition to the DOJ motion.

[http://www.ada.gov/briefs/steward\\_interest.pdf](http://www.ada.gov/briefs/steward_interest.pdf)

For more information about legal issues, see Section 2 of the Deinstitutionalization Toolkit.

- LEGAL – in **BRIEF**
- LEGAL – in **DETAIL**
- LEGAL – in **DEPTH**

### Develop a Legislative Strategy

In several states, advocates have worked with state legislatures to pass reform. This involves building relationships with legislators through one-on-one meetings and using personal stories. As the examples below illustrate, legislative work can focus on many different strategies: clarifying state values and intent in regard to compliance with federal law, studying the issue and making recommendations, and engaging in the financing and budgeting aspects of service expansion and institutional operations.

In the spring of 2005, the Georgia General Assembly passed House Resolution 633 (HR633), a resolution drafted by Georgia Children's Freedom Initiative. It urged the state to develop a plan to identify, assess, and plan appropriate community supports for people under the age of 22 who live in nursing facilities, ICFs/DD, and private and public hospitals.

<http://georgiacfi.org/cfi/files/f0/f0c9b6f6-1626-4774-83b6-75b959080a72.pdf>



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In Kansas, advocates were successful in getting the Developmental Disabilities Reform Act passed in 1995. This act established the policy of the state “to assist persons who have a developmental disability to have: (a) Services and supports which allow persons opportunities of choice to increase their independence, productivity, integration and inclusion into the community; (b) access to a range of services and supports appropriate to such persons; and (c) the same dignity and respect as persons who do not have a developmental disability.”

In 2009, the Washington state legislature passed HB 1244, directing the Governor’s Office of Financial Management to conduct a study of the feasibility of closure of state institutions. The study looked at such questions as the following:

- a) Maintain quality of care: Will people and families receive equal or better services and supports than they are currently receiving?
- b) Future service demand: Are there people in the future who will need these services and supports?
- c) Regulatory and policy environment: To what degree are there federal and state regulatory and policy pressures for various alternatives?
- d) Financial impact: What are the current and projected future fiscal impacts of various alternatives?

### ***Become Medicaid Experts***

It is important to know how the current system operates and what options are available within it that support individual choice and community living. It is best for someone from legal aid or the P&A agency to take the lead for the coalition in this area, but it is important that all advocates educate themselves so they can articulate what exists and what is needed as they speak to their legislators and others who can influence the closure decision.

### ***Build Your Case***

Provide cost data and the numbers of people who could be served in the community, as well as on the quality of life and health outcome benefits of living the community instead of in state institutions. Provide information on *Olmstead* and the ADA. It is important to



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debunk the many myths out there and to replace them with facts and a clear understanding of the civil rights issues at the core of this discussion.

During periods of budget tightening, some states are considering closing institutions in order to save money. This approach has several drawbacks:

- It leads opponents to claim that the state is not willing to commit the resources needed to care for vulnerable citizens.
- It leads politicians and policymakers to conclude that savings from institutional closure can be used for other state priorities. Advocates should ensure that any savings from closure continue to be dedicated to supporting people with ID/DD in the community. This will allow the state to develop a more robust community system, invest in quality assurance, and serve people who are on the waiting list.
- It is easier for legislators to hold their ground against opponents when the legislators believe that closure is “the right thing to do” rather than “the least costly thing to do.”
- It allows states to lose sight of the fact that the goal of institutional closure is community integration. It is not enough to close an institution and move people to another large institution or even another institutional setting, even if it is a smaller institution in a “community setting.”

For more information about community, see Section 4 of the Deinstitutionalization Toolkit.

- COMMUNITY – in **BRIEF**
- COMMUNITY – in **DETAIL**
- COMMUNITY – in **DEPTH**

### ***Line Up Leadership***

Advocates need to gain support for their reform platform from the state agency, the governor, and key legislative leaders and staff. The coalition cannot proceed with its agenda without this vital step. Make sure that this engagement is bipartisan. To engage leaders, families must personally visit and share their stories.



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Within the constraints set by the legislature, the DD Council leadership is in the position to set a vision for the department. It can develop community-based options, encourage choice of community to reduce new admissions, or support the status quo. In Oregon, advocates worked very closely with the DD commissioner, who put a moratorium on admissions to the state institutions and eventually closed all ID/DD institutions in Oregon.

It is also important to engage other DD core partners such as the P&A agency, the University Center for Excellence in DD, and the DD agency in your area.

### ***Understand and Work Within the Political Environment***

It is important to understand the political environment and the interests and position of all stakeholders on these issues. Many factors are at play in the closure of an institution, including the fiscal environment of the state, the economic impact on communities, and the emotional needs of family members who are concerned about making changes that will affect their loved one.

### ***Seek Out Individuals and Groups with Different Perspectives on the Issue***

Hold informal meetings with local businesses, families, union representatives, and legislators for the purpose of information sharing, negotiation, problem solving, and potentially engaging them in the design of the deinstitutionalization plan. Avoid a bunker mentality and do not assume that simply because you do not engage individuals and groups with different positions they will not pay attention to system redesign or oppose deinstitutionalization. Have an open-door, problem-solving approach with these individuals and groups without compromising on principles. Families must be shown real examples (not just data and examples from other states) of individuals just like their family members who are living successfully in the community. Communicate with families about their specific concerns, which could include access to regular health care and dental care, safety, and continuity and quality of care.

### **Engage and Include Parents**

It is important to recognize that some parents have extreme doubts about moving their son or daughter from the institution. Address the concerns with empathy, information, and honesty. The Georgia Children's Freedom Initiative has effectively worked with



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parents not only through clear communication and facts but with actual tours of community living arrangements. It now includes several involved parents who once had misgivings about deinstitutionalization.

Georgia Parent Journeys: From Fear to Fulfillment

<http://www.georgiacfi.org/cfi/files/f0/f0c9b6f6-1626-4774-83b6-75b959080a72.pdf>

In Oregon, state staff engaged the parents of people who were in institutions slated to be closed, listened carefully to their issues and concerns, then worked to engage them in the closure discussion and process. The Oregon advocates felt that it was important not to let the fears of parents dictate policy, but made every effort to address each parent's concern individually, to engage them in the discussions, and to ensure that they had a voice in developing the transition plan for their child. They also worked to engage parents in ongoing quality assurance activities after community placement.

### **Address State Employee and Local Community Issues**

The loss of jobs in a community is often a powerful obstacle to gaining legislative support for closure. At the same time, it is important to be clear that, ultimately, decisions about institutional closure must be based on what is best for people with ID/DD rather than the related workforce issues. States often use public education campaigns as part of their efforts to address community opposition to deinstitutionalization. However, states cannot wait until opposition has been resolved to implement deinstitutionalization.

Several approaches have been used to mitigate economic impact. Some states operate part of the community-based system, thereby allowing these states to transfer unionized public employees out of institutions and into community-based services. The American Federation of State County and Municipal Employees (AFSCME) reported, as of June 1996, that more than 40 percent of the states have maintained responsibility and a role in the provision of services in community-based settings rather than relying solely on the private sector for community services. AFSCME reported that 13 states—Arizona, Colorado, Connecticut, Louisiana, Massachusetts, Minnesota, Mississippi, Nevada, New Hampshire, New York, Oregon, Rhode Island, and Texas—operate small



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community-based residential facilities for persons with developmental disabilities. Other states, such as New Jersey and Iowa, do not own the community residences, but provide state employees to staff them.

States have also utilized aggressive retention and job placement for displaced workers. For example, when closing Rosewood, Maryland instituted an outplacement process for employees, including job training and placement at nearby psychiatric institutions. The DD agency reached out to other state agencies and private providers to obtain job placements for state employees. Oregon also was aggressive in providing outplacement services to staff affected by closures, and its governor at one point instituted a “hire first” policy for employees affected by the closing of state institutions.

With careful planning, some institution employees can work in the community services developed to serve former institution residents. Institutions are often located in rural areas. Although some former residents will continue to live in that area after the closure, others will return to a community closer to their families. As a result, some of the community jobs will be located in communities other than the ones in which the institution jobs were lost.

It is also important to address local community issues related to institutional closure, such as the economic impact of closure as well as future land use. Examples from other states include former institutional facilities that have been converted to use as business/industrial parks or condominiums with golf courses. Again, as with workforce issues, it is important to be clear that decisions about institutional closure must be based on what is best for people with ID/DD.

### ***Employ Timely, Targeted Communication, Public Education, and Media Strategies***

Proponents must mount a major campaign to confront the stigma, misinformation, and negative attitudes associated with deinstitutionalization. Proponents must confront and change attitudes while creating a broader understanding of the nature of community-based living through public testimony and personal conversations with legislators. The use of individual stories can often change attitudes, and having self-advocates tell their own story is the most powerful strategy of all.



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Myths and misunderstanding about how people can be served in the community and the effectiveness of community-based services can be difficult to overcome. Again, self-advocate and family testimony is a powerful tool, especially when the discussion includes national studies offering sound assessments of effective interventions, treatment models, and outcomes.

### **Effectively Using the Media**

Many advocates for deinstitutionalization have used the media to influence public opinion. To get the media's attention, advocates must utilize the same strategy of using personal stories faces, not facts. These stories must be about people who have left an institution and are living successfully in the community. Stories may also highlight people who are living in institutions and look no different from those living in the community. The Georgia Children's Freedom Initiative effectively used the media to highlight its campaign to close all children's beds in Georgia.

Here are examples of this strategy in action:

*Wall Street Journal* article: "Babes Among Elders: Nursing Home Kids"

<http://www.georgiacfi.org/cfi/files/38/382a05a1-df9f-4693-9a7b-735620f19ad4.pdf>

Through investigative reporting, the media have been credited with prompting major changes. For example, Mary Beth Pfeiffer has published a series of investigative reports in the *Poughkeepsie Journal* about the slow pace of deinstitutionalization at Wassaic Campus of the Taconic Developmental Disabilities Service Office, the high cost of institutional care in New York State, and the role of Medicaid overpayments in maintaining the status quo (Pfeiffer, 2010). The *Chicago Tribune* has run a series of stories about unexplained deaths of children with disabilities at Alden North, a 93-bed privately run nursing home providing ICF/DD services to children near Chicago, Illinois (Hopkins and Roe, 2010).

Finding parents who initially opposed deinstitutionalization and now are satisfied with the services their child is receiving in the community and who will speak to media about their experience can provide powerful testimony.



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For example, a mother and daughter find new life after deinstitutionalization in Illinois:

<http://southtownstar.suntimes.com/lifestyles/vickroy/4657312-452/mother-daughter-find-new-life-after-howe.html?print=true>

A Kansas mother describes her transformation from vocal opponent of closure to supporter:

<http://www.khi.org/news/2010/sep/10/parent-defends-closing-state-hospital/>

### **Creating a Community System of Care and a Commitment to Quality Assurance**

Getting a deinstitutionalization plan approved and funded is only half the battle; actual deinstitutionalization has its own unique challenges. The next step is for the stakeholders to demonstrate a commitment to individualized treatment care plans with strong quality assurance measures. A one-size-fits-all plan will not work, will not serve people with ID/DD well, and will not address parental concerns. To ensure the success of its goals, stakeholders must participate in the implementation plan, monitor its progress, and identify concerns, which can then be addressed with the state agency or other implementing individuals or groups.

#### ***Implementation***

It is important for the state have a plan for identifying how, when, and where the community resources will be identified to meet the needs of people with ID/DD living in the community. In Georgia, certain services and skills were not available in the state, and the state was recruiting individuals from neighboring states to serve Georgia while the state developed individuals and groups to meet these needs over the long term.

The availability of housing is another critical element of community capacity. Oregon took an important step of separating services from housing. One agency or organization provided services, and another distinct organization owned the physical property. This separation allowed the state to terminate the services of nonperforming providers while preserving the housing.



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Oregon also is a leader in the area of housing. The state made a conscious decision early in the process of closing its first institution to use housing professionals to guide its housing policy and programs. It enlisted builders, contractors, and other real estate professionals, along with housing authorities in the state, to identify, create, and manage the housing needed of people coming out of institutions.

Here are two specific approaches to creating community capacity in the housing arena:

One Oregon contractor has created a unique approach to the development of person-centered environments targeted to people with ID/DD. His company, Creative Housing Solutions, has completed more than 1,500 projects for this group.

<http://www.gbcchs.com/>

The ARC of King County in Seattle, Washington, also has a project called Creative Housing Solutions. On its Web site, it shares the stories of 20 people with ID/DD and their families and the creative housing solution that support their needs. Each of these stories identifies the unique and person-centered solution to an individual's housing and support needs.

<http://www.arcofkingcounty.org/creative-housing-solutions>

### ***Quality Assurance Programs That Engage Parents and Stakeholders***

It is important that the plan identify how the state agency will ensure that the standards of care identified in the plan will be monitored and what corrective action the state will take if it determines that people are not getting the care that was identified in the plan, or the care is not being delivered in a way that meets the state's standards. Some states, such as Georgia, have developed local, regional, or state Quality Assurance Councils to help the state in this important work.

This work includes identifying and addressing gaps in the community service system and ensuring that there is adequate funding for community services, including the availability of very intensive supports for people with significant medical needs or behavioral challenges. Oregon pursued this strategy while at the same time shutting off admissions, and eventually closed all state institutions.



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State Developmental Disability commissioners have realized that including people with ID/DD and their families in statewide quality assurance systems is a way to ensure the effectiveness of quality assurance mechanisms and help alleviate parental concerns about quality of care and safety issues.

The State of Georgia has contracted with Delmarva to assist in the staffing of five regional and one statewide Interagency Quality Improvement Committees composed of stakeholders, including self-advocates, family members, regional staff, the Office of Developmental Disabilities staff, provider representatives, and support coordinator representatives. Part of the Quality Improvement Committee's role is not only to generate quality improvement initiatives but also to assist in the evaluation of the state's quality management system.

Additional resources are available on the topic area of Strategy in the Deinstitutionalization Toolkit. These are external documents that may be accessed for a more in-depth review of the topic area.

➤ STRATEGY – in**DEPTH**

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