



Deinstitutionalization Toolkit: **STRATEGY – inBRIEF**

Getting There: Strategies That Work

Making a system work for people is not an easy task, but it can be done. Closing an institution is not one act; it is many pieces of work coming together to create the opportunity for a community to rethink how it serves and supports its citizens with intellectual disabilities and developmental disabilities (ID/DD). This work includes the identification of allies and partners, the development of strategies to move the work forward, and the identification of the roles of each partner and ally. Creating a comprehensive community system of care and a commitment to quality assurance as an ongoing process involves a diverse group of stakeholders.

Identifying Allies and Partners

It is important for advocates to complete an environmental scan to identify allies and partners who could work together as a coalition. In our review, these individuals and groups include protection and advocacy agencies, state developmental disabilities councils, self-advocates, parent advocates, private human service providers, and the state developmental disability agencies.

State legislators and governors play a pivotal role in creating the political will to close institutions, and their support is imperative if the initiative is to succeed. Additional decision makers that have roles in the discussion and in the process of institutional closure include the Department of Justice, the courts, and their court-appointed monitors if there has been a court ruling in support of closure.

The scan must also include individuals and groups who may oppose the move to close institutions. Specific strategies should be developed to engage these groups in discussion and to identify objections and concerns so they can be addressed as the plans move forward. These groups may include staff of institutions, the unions representing them, and some parents of people who would be affected by the closure.



The Basics: 10 Strategic Steps to Pursue

1. Develop a broad-based, well-organized coalition.
2. Explore legal remedies
3. Become experts in Medicaid, the federal Medicaid Home and Community-Based Services Waiver, and the Affordable Care Act.
4. Build your case with faces, not facts.
5. Line up leadership.
6. Analyze the political environment.
7. Seek out groups or individuals with different perspectives.
8. Use timely and targeted communication, public education, and media relations.
9. Advocate for quality assurance standards to protect health and safety of people living in community-based settings.
10. Include specific implementation steps in closure plans

Strategies That Have Worked for States: A Review.

Based on a literature review and examination of the closure activities in Georgia and Oregon, we identified strategies that have worked in individual states. Some of these strategies focus on engagement of key stakeholders; others are specific strategies that the coalition may develop and use to move their work forward.

An important starting point is the issue of “framing” the debate. Advocates generally agree that the focus of the debate and discussion should not be “if” closure will take place, but rather “when” and “how.” This framing changes the discussion and creates a problem-identification and problem-solving environment.

It is important to maintain cohesiveness of the advocates. A Georgia advocate said that they have been able to avoid having the discussion become an “us” and “them” discussion. Individuals who have different points of view must be respected and listened to so their concerns can be addressed. The focus on “when” and “how,” and not “if” enable this discussion to move forward in a less adversarial manner.

Another key strategy is to be clear that living in the community is a civil right. The individual with a disability and his or her right to an independent life outside the



National Council on Disability

Living, Learning & Earning

An independent federal agency committed to disability policy leadership since 1978

institution should drive this conversation, not the numbers or the economic impact on a community. Again, this changes the tone and direction of the discussion and debate.

“Faces, not facts” are important drivers of the discussion and the community’s support. The issue should have a “face”—personal stories, individual self-advocates, and parents who support the closure are all important influencers. The media must have access to these individuals and their stories and be encouraged to share them.

Other strategies that have been successful in helping initiate closure and ensure its success include the following:

- Building community capacity
- Developing creative person-centered housing options
- Building quality assurance programs that include parents
- Drafting model legislation
- Engaging the justice system and the courts

Implementation and Building Community Capacity

Deinstitutionalization is a process. It begins with the acknowledgment that institutional care may provide adequate services and supports to people with ID/DD, but it falls short by not extending the right of an individual to live in the least restrictive environment while receiving the necessary services and supports. For that to change, the process of deinstitutionalization must include the development of a system of community-based services and supports, ensuring that people with ID/DD can access basic and specialized services and supports within their community.

Creating this community-based system of services and supports is a challenge. Successful deinstitutionalized states have modeled systems that deliver these services in ways that meet or exceed the level of service provided in the institutional environment. They have also established quality assurance programs working to maintain and improve these systems that serve people with ID/DD living in a community. A robust system of community-based supports and services with a quality assurance program is an achievable objective for the deinstitutionalization process, and its development is an integral part of the strategic plan.