



Deinstitutionalization Toolkit: **CASE STUDIES – inBRIEF**

Case Studies: Introduction

The Deinstitutionalization Toolkit: Case Studies: *inBRIEF* is an introduction that provides information about the methodology, key questions, topics, and discussion threads used in the evaluation of two states that are at different stages of the deinstitutionalization process.

The Deinstitutionalization Toolkit: Case Studies: *inDETAIL* reveals the states' experiences of the closure process from the perspective of advocates and leaders involved in closing institutions and building community support systems in Oregon and Georgia. The Deinstitutionalization Toolkit: Case Studies: *inDEPTH* explores the experiences of individuals directly affected by the deinstitutionalization process. These voices and reflections are of eight people with intellectual disabilities and developmental disabilities who are most affected by the move from state institutions to the community.

- **CASE STUDIES – inDETAIL**
- **CASE STUDIES – inDEPTH**

The Oregon and Georgia Experiences

Oregon has been working on these issues since 1987 and closed the last state institution in 2007. Georgia, by contrast, began work on closing institutions in 2005 by committing to closing admissions to children; but its process was escalated by a Department of Justice intervention in 2010, with a settlement that outlined a five-year plan starting in 2011.

These two state experiences give a glimpse into the factors that affect success, the necessity of working with all stakeholders, and the importance of building community capacity and shifting the focus of service from large groups to individuals, thus ensuring a richer and more diverse life in the community than is possible in even a small institutional setting.

As part of this project, the research team conducted two focus groups in person, one in Georgia and others in Oregon, and 20 interviews, which included 26 individuals,



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including self-advocates. Representatives of the respective state Developmental Disabilities Councils, the state Protection and Advocacy Agency, the state University Center for Excellence in Developmental Disabilities, and the state legal aid groups were included in the interviews examining the implementation of deinstitutionalization around the country and specifically in Georgia and Oregon.

The interviews and the in-depth state studies focused on the political genesis of deinstitutionalization in Georgia and Oregon and the specific implementation elements.

Methodology

Key Questions

All interaction centered on a set of key questions:

Tell us about your specific experience with institutional closure.

Based on this experience, what do you think are the most important keys to successfully closing an institution?

What were the key barriers to successful closure in your opinion?

If you were to advise advocates who are working on this issue, what would be key recommendations?

How can quality be assured in the community? What are the best plans you have seen?

How do you talk about the cost savings of closure?

Selection of Interviewees and Focus Group Participants

Individual participants were chosen because of their knowledge and experience with the closure of institutions. In some cases this knowledge was personal, and in some cases it was professional. The list of participants includes the leadership of all the key national organizations related to this issue, a former judge, state officials who have participated in past closure issues or are currently participating in closure activities, service providers, parents, and self-advocates who have lived in institutions.



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Key Topics Discussed

- Dealing with the concerns of parents
- Creating new person-centered housing options in communities
- Strategies for separating the provider of housing and the provider of services
- The cost savings of community living versus institutional living and the best way to talk about this
- Identifying and overcoming barriers presented by groups that are opposed to closure of institutions
- Identifying the key elements of good transition planning
- Identifying key elements of an effective quality assurance plan
- The role of the community—parents and advocates in plan monitoring
- Continued development of community resources
- Funding of community resources in these financially challenging times

Key Discussion Threads

The following thematic trends emerged from our interviews:

Closing institutions does save money, but most successful states did it because “it was the right thing to do.”

The allocation of resources is a major issue—serving a relatively few people living in institutions consumes resources that could serve many more individuals in the community.

The most powerful action a state can take is to make the decision to “close the door” and not allow new individuals to become institutionalized. This changes the entire debate to not “if” but “when” and “how.”

Parents’ needs and fears must be identified and discussed. Helping parents actually see and experience individuals with disabilities like those of their child living in the community is a powerful tool. This can and has been done successfully.



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Success is a process, not a single event—it takes time to build the community capacity and the oversight systems that are necessary to ensure that individuals' needs are met.