



Deinstitutionalization Toolkit: **CASE STUDIES – inDETAIL**

The State Experience: Introduction

This section of the Deinstitutionalization Toolkit reveals the state’s 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: in**BRIEF** is an introduction to these case studies that provides information about the methodology, key questions, topics, and discussion threads used in the evaluation of Oregon and Georgia. The Deinstitutionalization Toolkit: Case Studies – in**DEPTH** explores the experiences of individuals directly affected by the deinstitutionalization process. These voices and reflections are of eight individuals with intellectual disabilities and developmental disabilities (ID/DD) who are most affected by the move from state institutions to the community.

- CASE STUDIES – in**BRIEF**
- CASE STUDIES – in**DEPTH**

The State Experience: Closing Institutions and Building Community Support Systems

Oregon

“Our system of community-based supports is not perfect. It remains underfunded, provider wages and training are inadequate, and we must improve client safety in the system. However, Oregonians with disabilities have some things today they didn’t have 30 years ago at Fairview: freedom, dignity and a sense of belonging.”

—Sara Gelser, Oregon State Representative

Oregon is a national leader in this field and currently has no large state institutions. This effort began in 1987; the last institution was closed in 2007, and the final activity required by the Staley Settlement was completed in 2011. Below is a timeline for the



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Oregon Institutional closures and the development of a robust community-based services system:

1987 – State Developmental Disabilities (DD) office creates Diversion team. The goal is to prevent people from entering Fairview. At the time, the state was averaging 11 new admissions a month. At the end of the first year, this number had dropped to one to three admissions a month. Within two years the institution had zero admissions.

1990 – Fairview was decertified and got funds turned back on by agreeing to a Plan of Correction and Reduction. The institution made commitments to staffing ratios at Fairview and agreed to move 300 people over two years (1991–93). At that time, it housed about 1,200 people.

1991–97 – Continued with approval to move another 600 people, increasing community capacity to support people with significant support needs.

1996 – Long-Term Planning Team convened. Work teams formed to look at issues related to labor, family with relatives at Fairview, unmet needs in community, and community capacity required to support all individuals in community. Plan completed and delivered to Oregon legislature in 1997.

1997 – Legislature agreed to close Fairview. This act required moving the last 300 people to communities.

1999 – Legislature reinvested \$10 million from Fairview closure to increase direct care wages by \$1.00/hour, create capacity in counties to respond to people in crisis (add staffing and funds for short-term diversion needs), and increase funds for family support from \$3 million to \$8 million.

1999 – Legislature passed Fairview Trust Fund bill. Directs department to sell Fairview property for market value and establish a trust. Interest from trust is to be used to make housing modifications for people with ID/DD living in their own home or a family home.

February 2000 – Last person leaves Fairview.



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2000 – Disability Rights and Arc Oregon filed class action suit (Staley Settlement) claiming that individuals in community have been waiting too long and not getting access to Medicaid services.

2001 – Staley Settlement was agreed to. Settlement establishes entitlement of adults with ID/DD to support service benefit. Benefit capped at \$20,000 a year. Individuals will self-direct, hire/contract. Support Brokerages established to provide personal agent support and serve as fiscal intermediary.

2005 – Oregon Legislature directed Department to determine impact of closing the last Intermediate Care Facility for People with Developmental Disabilities, Eastern Oregon Training Center. Planning groups look at labor issues, costs of services, client needs, and community capacity.

2007 – Oregon Legislature approved closure of Eastern Oregon Training Center.

October 2009 – Last person moved from Eastern Oregon Training Center.

June 2011 – Staley Settlement successfully completed. In 10 years, the number of people enrolled in community-based services went from 0 to 7,000 people.

Time and Place

In May 2010, a focus group was conducted in conjunction with the National Council on Disability's (NCD) conference in Portland, Oregon. This group brought together the key players in the decades-long effort to close all institutions and develop and maintain a robust community system of services and supports. Below is a summary of this session, identifying the participants and using the voices of participants to tell Oregon's story.

Participants

This focus group was made up of professionals primarily, with some advocates included.

- Mary Lee Fay, administrator, Office of Developmental Services
- Jack Morgan, former deputy administrator, Office of Development Services
- George Braddock, president, Creative Housing Solutions



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- Bob Clabby, former superintendent, Eastern Oregon Training Center
- Judy Cunie, self-advocate, former resident of an institution
- Kathryn Weit, executive director, Oregon Council on Developmental Disabilities
- Gary Blumenthal, NCD board member
- Joan Durocher, NCD staff
- Barbara Butz, facilitator, Daniels & Associates
- Steven Allen, technical coordinator, Daniels & Associates

The Discussion

Topic 1: The PEOPLE Factor—Relationships and What Made Them Work

(1) Stable Leadership

“We have longevity in all of our roles. Even when we retire, we don’t really go away. We have leadership that has survived multiple governors. Partially because the program is low enough in the governor’s work that it can fly under the governor’s radar.

“As architects, we had a lot of opportunities to correct things as we go. We didn’t have to wait until everything was in the perfect shape at the beginning. We are OK with good enough to get started and then make changes. “

“We had a guy that could lay out that vision—James Toews. We kept increasing the staffing because we were under the consent decree. James Toews was superb at laying out a vision. “

“...The attorneys said you have to do it (deinstitutionalize). They could articulate it in a way that we could not. And they had the credibility that the state service agency didn’t have. That got it moving. If we have to do something...how best to do it. We had people in the community service system that were ready to expand. Had relationships, a lot of pent up demand and frustrations. Readiness and eagerness to show that things could be done in the community. There was a lot of excitement and easy collaboration.”



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(2) Managing Displaced Workers

“...we worked with groups from employment division, people could go to training, looking for other jobs on their work time, and the governor did a hire-first policy.”

(3) Training is key to making the transition

“Before people left the institution, the staff who would be working with them had to spend at least two weeks in training...often living at the institution. We did it because it was cheap for the provider, but it turned out to be really insightful.”

“As a support person, with all the different organizations that support people with disabilities...challenge in hiring, training and retaining workforce is a challenge.”

Topic 2: Vision and Values

(4) Really Listening to Families

“So the debate wasn’t ‘should we.’ We didn’t look for compromise but we had to really listen. When families said ‘we don’t want to,’ we would end up translating it to mean, ‘I’m afraid of quality assurance. How will I know? Can I show up anytime I want?’ When you got past the conversation of ‘No, you can’t close the institution,’ you got to reasonable demands. We had a family-directed volunteer that would do reports. I don’t think it changed the quality of services, but it helped buy-in.”

“It’s easier to serve people in the community and they deserve to have community life. It is pretty sad that you are put in prison because you have a disability. It has been proven over and over—what people can do if they are given the opportunity. There are so many things that we can contribute, and we deserve to be a part of our community. We will always need to work on convincing people that we are of value to the community and that we deserve every opportunity that we can get.”



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"We didn't have a high-powered, well-funded parent group (VOR) against closure. ...once we went through a very individualized process with the parents, parents saw the staff and providers as their friends."

(5) Leveraging Stakeholder Interests

"...when we talked to political groups we talked about the finances. But why we were doing it...it was values. Someone else said economics played in a big way. We have our attorneys to thank for that... They said we have to do it. That got it moving. If we have to do something...how best to do it."

"We had people in the community service system that were ready to expand. Had relationships, a lot of pent-up demand and frustrations. [There was a] readiness and eagerness to show that things could be done in the community. There was a lot of excitement and easy collaboration."

"...disjointed incrementalism. As long as you keep the vision...you can keep going in the right direction. Persistence, they had a vision of closing the last institution 20 years ago."

"Important that one or more people that really count need to believe that it needs to happen. It doesn't necessarily have to be the governor."

"...if it wasn't a civil right, it was based on an understanding that people needed to be in the community."

Topic 3: Strategies and Program Structure

(6) Understanding capacity

"We are not a private market. In the aging world, only 30 percent of the money is Medicaid. In our world, it is much more. We have to be very precise because a provider can't build and then wait for people to fill the slots. We are building and doing at the same time."



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Oregon started a state-operated, community-based program. This program is designed to serve only those individuals for whom there was no other option.

“We had started this in 1990 when we were closing institutions for kids because we had two populations that the community system wasn’t ready to take care of—people with significant medical needs (ventilator dependent) and people with significant behavioral issues. Throughout every downsizing period, we added one to two group homes. There were three to five people ranged within a 100-mile radius. Same as other group homes, but run by state staff. We now have 136 people. We have a lot of families that say ‘I want State Ops,’ but it is based on need. Now it is mostly a safety net. Only a few people stay there for a long time (but it is because the needs continue). We have very few medical homes; it is now mostly behavior support needs. Most are now coming in from criminal, corrections, forensics psychiatric review boards, and with co-occurring mental health issues. State Ops can’t say no. There are people with the same challenges in the community...but one of the criteria is that we have exhausted looking for a provider who would agree to support them. 138 out of 10,000 are in State Ops.”

“Fairview had 3,000 in 1987. First thing that we needed to figure out is crisis response. Who went into the institution because there was no other option? Before we had good crisis response, 10 people a month were entering institutions...six years later it was zero.”

(7) Process of Closure

Three key teams did a tremendous amount of work:

The Housing team, which was in charge of staff, timing, and logistics.

The Development team, which developed person-centered plans for everyone. That is how Oregon did community designs—one person at a time. They focused on understanding individual needs, compatibility, what community they have family in. They tried to ensure that doctors and supports were in place, and so on.



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The Transition team, which took the lead on ensuring that individuals are up-to-date with physicals, and so on. They also initiated a series of transition meetings with individuals, parents...everyone involved.

Topic 4: Housing

(8) Separating Housing from Support Services

"...separated housing ownership from the selection of provider. This has turned out great because we can stop licensing a provider and people don't have to move because the house was not owned by the provider."

(9) Getting the Right Expertise

"We brought people in who really know housing. Our state housing agency provided the funding. Several advantages: They knew the issues, they had the resources. They could talk effectively with the legislature. They could deal with housing much better than a service provider. We hired people in the housing industry. Housing was owned by organizations that specialized in owning and managing property rather than the service providers. They knew what needed to be done to maintain housing/property values. Those people were the intermediaries..."

"Contractor was point of entry for neighbors who were scared. They thought property values were going to tank. They were most concerned about cars and staff. They were OK with diversity, even weird diversity. They were worried about staff coming and going, playing their boom boxes, flicking cigarette butts, taking all the parking spots on the street. We taught our contractors to really talk to the neighborhood. In one case, the church adopted the house and it really helped create community."

"In a couple of cases, we used local housing authorities. Housing staff in the agency was really important. They knew the business. They knew the DD housing needs and the type of things that housing authorities usually build."



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(10) Thinking Through the Financing

“Paying attention not just to staffing, also housing, affordability, how to make it work. Took advantage of other financing options.”

Topic 5: Strategies That Paid Off

Design focused on conforming to the “look and feel” of the neighborhood—structure and paint had to blend in with what existed.

Landscaping was seen as important and they did not attempting to cut costs by omitting landscaping, a big issue for the neighborhood.

Confronting county fears was also seen as a priority—the state government defines programs and provides funding. Counties must administer the programs. Counties had concerns about taking care of “these folks” (people with ID/DD who are leaving the institution) and having them in the community. They were concerned about whether funding would be adequate. The projects are compared to the downsizing in corrections and mental health where there was not enough funding in the community and it was not done well. Fear of personal safety and of property value was also a factor.

(11) Litigation

All of the participants in the litigation process regularly and informally communicated with each other. State Attorneys General came and went—most of them were seen as people who wanted to do the right thing. The DD agency did not get to pick its attorneys, but it could convince them that they should represent the DD agency as the customer.

*“If we fight this and win we will have a very expensive institution and will have spent millions of dollars to get this.” **[[I don't understand the relevance of this quote.]]***

Part of the role of litigation was keeping focus, and over time the group felt it was very important to maintain a focus on individuals and their rights. Litigation made it clear that serving a small number of people in institutions took a large



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percentage of resources both in terms of financing and in terms of staff time. For 10 years, a huge percentage of the energy of the staff had been used for the people in institutions.

Every place is different. Strategies around Eastern were very different than those used at Fairview. Oregon had begun person-centered planning with its DD clients. Staff saw closure as a completion of their job. The vision never changed. The vision combined two elements—closing the facility, but doing it in a way that would strengthen the community system. Calculated planning was used to align resources to strengthen the general DD system, but also could be used to strengthen services that former residents were going to use.

Closure of Fairview was completed and then the next lawsuit focused on access to home and community-based services. The timing was perfect. Some states see a lawsuit as a personal insult. Other states can see it as an asset in getting the resources that they need.

“We didn’t start out with a closure plan. We started out with a downsizing plan. We could move down the path, gave us some experience. People didn’t have to make an enormous decision. At the same time the economics are working on your side. As you downsize, the cost per person increases with no end in sight. By the time the legislature actually went to close the institution, half the people were already gone.”

The group saw this as “overcoming opposition by articulating a simple vision.”

Topic 6: What’s Next?

(12) What Is Left to Be Done?

The self-advocate said “Attitudes.”

Now that Oregon has a community-based system, it becomes a question of what people are doing in the community.



(13) Employment Policy Shifts to Employment First

Oregon needs a better employment policy. For a while when it was closing Fairview, it had capped the number of people in sheltered workshops, but then the focus shifted to final closure. There was an idea that the culture had changed enough so it would just happen and also when they moved to person-directed services people would be demanding jobs...but that didn't happen. The team has kept data. They are now focusing back on expectations about employment. They are training to an "employment first" policy. The Medicaid Infrastructure Grant is providing funds. They have nine training teams. They need to set rates that have the right rates to support the outcome they want but doesn't leave people vulnerable.

(14) Quality Assurance and Systems Shifts after Closure

The nature of the conversation changes after closure. Moving people out of institutions is a different conversation than when people are not in the institution and they don't plan to go in. That's the conversation that Oregon is in now. You move on really quickly. It is no longer a battle over the institution. Still have battles...but different battles—quality assurance questions.

The group felt that systemic change is necessary so that the system does not go backward. The team is seeing people slide back to segregated classrooms. It was felt that there should probably be more focus on early education.

The group suggested that Oregon doesn't support families in a planned way. It has some waivers, but there needs to be more investment in families. There is a growing awareness that the state needs to be thinking more holistically. Most of the same things that you do for the support provider systems you need to do to support family providers (such as backup systems).

Health care and access to health care is an ongoing issue.



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(15) Education Issues

Moving backward into self-contained classrooms feeds into what they need to deal with in an adult system, such as a need for cutting transition programs and getting employment on the radar screen. DD needs to pick up where the education system drops off and needs to be more aggressive as a system to take on the education system.

They don't have nearly the structure or sense of what they are trying to accomplish with children that they have with adults.

They have 5,000 kids enrolled in case management but they don't do a very good job.

School districts are aggressive in pushing back. Lawyers find it lucrative to get contracts with school districts.

In the DD system, they did a good job changing pediatric nursing homes. In the past, an adult's average stay was four months; for children it was seven years. Now they're backsliding.

(16) New Housing Trend Issues

Gated communities represent a new type of segregated housing situation. People with resources are setting these things up because they don't see the services they need in the community. In Oregon the state is pushing back against a group that is trying to set something like this up. But they don't know if they are on firm legal ground in their pushback. The state established rates that would make it difficult to sustain something like this. They do not want there to be a financial incentive to group people together.

Self-advocates said they are working on getting younger people involved so they can say they don't want this. They want something different in their lives.



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(17) Quality Assurance

They are concerned about how to make sure people get the services they need when they are spread out.

Quality assurance (QA) is a challenge. It is hard investing in infrastructure when individual needs are not met. The counties are statutorily involved in running the system. On the aging side half the programs are state run, half counties. It is unclear which is better.

“I don’t have a lot of faith in the county system. A lot of attention on excluding people from work who have certain conditions, etc. It all depends on the staff. Need staff that buys into the system.”

“Depends on leadership. Not sure what the best system is. It is a challenge when you have 32 different entities.”

For QA, the system is dependent on case managers. They are using them to promote individual goals and look for incidents that indicate poor quality. The team is less into quality improvement than in the past. They use abuse information, serious event reports, licensing data, and customer surveys but that doesn’t give you a complete picture. Their approach is more protective now. As they train on person-centered strategies and positive interventions (rather than physical intervention), they lay the groundwork for higher expectations. The team has the groundwork built but they don’t have the full QA system in place as they envision it.

Topic 7: Advice to another state

(18) Advice

Close the front door.

Get some rest.



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Georgia

Georgia was selected because it had recently signed a statewide Settlement Agreement with the United States Department of Justice (DOJ) providing community alternatives to institutionalization for people with developmental disabilities and mental illnesses. DOJ has indicated that this settlement agreement will serve as its template as it works with other states. The agreement also provides services for people at risk of institutionalization to prevent future admissions to state hospitals. The negotiation process with DOJ and the State of Georgia was heavily influenced by stakeholder groups including the Georgia Developmental Disabilities Council and Georgia Advocacy Office (the Georgia protection and advocacy agency).

Under the agreement, the state stopped admitting people whose primary diagnosis is a developmental disability into state hospitals in July 2011 and instead, placed them directly into community services. The settlement agreement builds upon the work of the Georgia Children's Freedom Initiative, which was launched in 2005 to focus advocacy and action on moving all children in state institutions into community-based settings. The coalition formed to advance the Freedom Initiative had immediate success by getting House Resolution 633 passed by the Georgia House of Representatives, which urged the State of Georgia to develop a plan to serve all children in community-based settings focusing on family reunification. The coalition did not stress budget savings because it stated, "it may not be cheaper to serve people in the community." The coalition argued for the human and civil rights to live in the community and worked on building a consensus around these concepts. For example, the coalition held a summit of more than 100 participants during the first year (2005) to raise awareness, discuss alternatives, and build political will. The coalition worked closely with parents reluctant to move their children to community-based settings. It organized tours of community placements, which proved to be very successful in convincing parents of the possibility of community placement. Parents universally wanted to see that the people who were going to serve their children could make a significant commitment, rather than just shifts of strangers rotating through.

The initiative has been successful in closing the state hospital beds for children. There were about 45 children in state hospital beds when the initiative began. About five or six children are left due to parental concerns. The coalition documented all the stories of



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the children who came out of the institutions in a video. The coalition reported that challenges remaining include capacity in rural areas and parental rights issues for children still in the institutions.

The state has stopped admissions to the state hospitals for all children under 18. Crisis respite homes are being set up in the community in response to the DOJ settlement. The crisis teams will be able to respond anywhere in the state within a 90-minute time frame. Because of the DOJ settlement, individuals leaving the hospital will get priority. Everyone in state facilities is guaranteed a waiver slot. Thirty slots were set aside for youth aging out of foster care.

The coalition has continued its legislative advocacy, conducting informal presentations to groups of legislators around the state. It has been educating legislators about the DOJ settlement. A tour for legislators is being planned. The biggest challenge the coalition sees for the future is ensuring that there will be appropriate community capacity.

Everyone interviewed during the site visit in Georgia stated that the impact of DOJ is very important. It has had an impact on the Governor's staff and agency staff—DOJ is driving the conversation. The DOJ settlement has focused on where people sleep, not how they live. Without the DOJ settlement, the pace of closure would have been much slower. Community capacity would not have increased and there would not have been a moratorium on admissions. Some legislators fought closure for economic reasons. Now those legislators have been neutralized.

The parents and guardians who attended the focus group expressed their strong support for their children living in the community and out of institutions, though each (self) advocate deals with the system in a different way. They faced enormous challenges, and it took a lot of finagling to get it right. Georgia has some exemplary providers, and they are under pressure to expand. They recognize the need to find ways for them to help others create similar programs. However, they see rates paid to providers and program infrastructure as huge hurdles to expanding quality services.

The State of Georgia has increased the monitoring, quality improvement, and control of community-based placements. The state officials said one of the things that helps states



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be successful is to develop a “healthy obsession with quality.” The state needs to be clear about what it is and is not willing to fund. When Georgia has an unsuccessful transition, it conducts a root cause analysis to figure out what went wrong. The state is also expanding the quality improvement process to provide technical assistance to providers through the Quality Improvement Regional Councils staffed by the Delmarva Foundation, under contract with the State of Georgia. Additionally, providers who have already participated in a Quality Enhancement Provider Review can ask Delmarva to come and provide additional technical assistance in a specific subject area such as documentation, policy and procedures, or developing person-centered supports and services. Georgia providers are requesting additional training and technical assistance. Providers, family members, and staff officials know that adequate capacity and infrastructure is not available at this time, so the state is exploring bringing in national providers in order to increase capacity. Access to services is a problem, particularly in rural areas, but statewide as well. The state has been conducting a needs assessment—mapping out where individuals are and how many are more than 10, 20, or 50 miles from the nearest provider.

In summary, the DOJ settlement has moved the Georgia deinstitutionalization effort to high gear with a rapid rollout. Challenges include ensuring a uniform standard of quality of services throughout the state and making certain that there is adequate capacity to serve people where they want to live.

Time and Place

On May 24, 2011, a focus group was organized with the help of the Georgia Developmental Disabilities Council in Atlanta, Georgia. This group, convened at The Shepherd Center for Rehabilitation in Atlanta, brought together the key players in the effort to close institutions for individuals with ID/DD in Georgia. Below is a summary of this session identifying the participants and using the voices of participants to tell Georgia’s story.



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Participants

This focus group was made up primarily of (self) advocates with some professionals included.

Sam Trogdon, parent of Susannah Trogdon

Allison Peters Whittle, guardian of Nicki Raisler

Nicki Raisler, self-advocate

Susan Jamieson, Mental Health and Disability Rights, Atlanta Legal Aid

Eric E. Jacobson, Georgia Council on Developmental Disabilities,

Anna Watson, Georgia Diagnostic Classification Center

Victoria Richbourg, Serenity BHS and a parent

Daniel Crimmins, Center for Leadership in Disability, Georgia State University

Nancy Vara, parent

Nola Sayne, self-advocate

Eddie Towson, lead on Quality Assurance, Georgia Developmental Services

Renita Bundrage, parent

Ruby Moore, Georgia Advocacy Office

Barbara Butz, facilitator, Daniels & Associates

Ellen Piekalkiewicz, facilitator, Daniels & Associates

The Discussion

Topic 1: Personal Experiences of Self-Advocates and Parents of Children with Developmental Disabilities

Self-advocates and parents and guardians who attended the focus group expressed their strong support for individuals with ID/DD living in the community and out of institutions, though each (self) advocate deals with the system in a different way. They faced enormous challenges, and it took a lot of persistence to get it right. There are some exemplary providers, and they are under pressure to expand. The participants recognize the need to find ways for them to help others



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create similar programs. They see rates paid to providers and program infrastructure as huge hurdles.

“Many of us don’t live in institutions but lead institutional lives.”

One parent’s son is still residing in a nursing home in Alabama, where he was placed as a child. She is working with the State of Georgia to get her son back and into a community-based setting.

The Georgia Protection and Advocacy (P&A) agency was working with families and the State of Georgia to determine where people were located in nursing facilities. Their data are not complete and not every person was accounted for. There are Georgia children in Alabama.

One self-advocate’s sister is still in a group home, but she wants her to come home. She is blocked from moving because she is in a different program. Ultimately, the goal is to have the sisters to live together with the self-advocate’s guardian as a family unit.

One self-advocate attends a day program and is trying to get a job.

One client is home after a bad experience. She had never lived in an institution but did briefly live in a group home. She did not do well in the group home and she was not thriving. Her father now reports that she is doing well enough with him but worries about what will happen to her once he gets too old to care for her. She is on a waiting list for a waiver.

One focus group participant was a mother who is a behavioral service provider. When her son came out of high school, she was fortunate enough to have him go into her program.

“I was hoping he would be able to move into an apartment but they reduced the daily rate for apartment living at a level that was not financially viable to staff. So now they are taking people out of their own homes and putting them back into group homes.”



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A parent reported that her son has a micro board that is supported by the State of Georgia. Micro boards apply to become licensed service providers for one person.

Getting the right services is often a long, bumpy road. Advocates and parents banded together and went straight to the people with the purse strings. They invited local legislators and senators to their homes.

“So [my son] moved to Athens and lives independently with supports in his own home. He has not been hospitalized again in nine years and he has a job. When he was in the institution they said, ‘He won’t make it.’”

Topic 2: The PEOPLE factor. Direct Care Workforce: Availability and Training

“There is a critical need for direct care workforce.”

“How can we make sure the person with the most extreme needs is addressed in a thoughtful, competent way?”

“Those are the individuals that people make the argument about that the institution has to exist. Presumptively we think those people’s needs are being met in this congregate setting...they are not.”

A number of years ago, a state program spent millions of dollars training state workers. When individuals were transferred to community-based services, the advocates wanted the training dollars to be spent on the community workers. But the state would no longer pay for the training because the workers were not state workers.

The Developmental Disability Council created a values-based curriculum. It is now in 13 colleges around the state. The course is co-taught by someone with a disability. As the funding concludes, the Council will not be able to keep it going.

Providers are saying they need additional help. The division of DD is expanding its in-house training program and quality improvement process to provide technical assistance to providers. It has been collecting data and now is trying to use the data for continuous quality improvement—new processes. It used to be



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“You’re doing badly; you figure out how to fix it.” Now, it is putting processes in place to bring providers up to at least a certain level. Currently, the infrastructure is not there. It is looking at bringing in some of the national providers in order to increase capacity. Access to services is a problem, particularly in rural areas, and statewide as well.

Georgia did a huge rate study that concluded that providers are getting paid too much. If the analysis is acted upon, it may close many providers. Everyone gets the same rate regardless of their needs. That is changing now.

“We wanted to show how much it costs us and it backfired. The people that work for me get paid about minimum wage even after 25 years. They have to work two jobs to survive.”

“Some folks simply have no family to count on.”

“Most of the people I serve don’t have family or the family rights have been terminated.”

Topic 3: Vision and Values

In Georgia, only some believe that it is no longer a matter of “if and when” closure will happen. They are trying to figure out how to serve people. Georgia still has a private Intermediate Care Facility. Most agreed, however, that there is momentum now, but they are struggling to make sure people are landing safely.

Georgia does have examples of what it looks like when it is done really well—Georgia Options. Why is Georgia Options head and shoulders above other providers? Other providers provide residences, not necessarily homes. Strong leadership. One person at a time. Micro boards. Transparency around abuse and neglect.

“They know what home is. It is a sanctuary, it’s your own space, and you get to say who comes through the front door. The individual is afforded a lot of autonomy and dignity and respect that is elevated to a cultural norm. Unfortunately, that is not the norm.”



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Topic 4: Strategies and Programs

There was a consensus among the group that it was too tragic that you have to get the entire legislature to your house. Many are not going to be able to get the legislature to their homes.

"The system is dysfunctional."

Parents have valid concerns. You need to show them how it is done well in Georgia in order for them to agree to let their family member go.

"The problem is that people can't see how it will work."...The Children's Freedom Coalition and the Georgia Developmental Disability Council (GDDC) sponsor tours that help families 'see' how this could work for their loved ones."

Georgia began tours to highlight community living options and services available in the community. This has proved very successful. One of the mothers participating in the focus group had participated in one of these tours and that is the reason she was able to make her mind up to bring her son home from an institution in Alabama.

"The parents' concerns were: I want to know that my child is safe, having a good life, and that there is some possibility that people who serve him can make a significant commitment to him so it is not just shifts of strangers rotating through."

In the institution, up to 40 percent of residents have dual diagnoses. People seem focused on the behavioral issues. The community programs are not up to par for people with dual diagnoses. These folks have real mental health diagnoses. They have behavioral issues which overshadow the mental health issues.

"You can't just throw meds at them."

Professional and dental services are provided at the institution. Georgia is down at the bottom in dental care. State agency officials are trying to push advocates to bring this issue to the legislature. Every year there is a battle in the legislature



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over dental services funded by Medicaid. It is the first thing they cut. Right now, they are just trying to keep it as a covered service.

“I have a waiver and I live on my own. I have had trouble getting dental care. Nobody takes Medicaid. They will not do a root canal.”

Topic 5: Quality Assurance

One of the things that helps states be successful is to develop a “healthy obsession with quality.”

The state needs to be clear about what it is and is not willing to fund.

Georgia has started doing needs assessment, mapping out where individuals are and how many are more than 10, 20, or 50 miles from the nearest provider. The state is beginning to know where it needs to build these services.

Topic 6: Successful Transitions and Safeguards

The people who are coming out now have the most needs.

When transitions to the community are not going well, the whole transition team meets with the provider, hospital staff psychiatrist, case expeditors, regional staff, and state staff to take action if there are behavioral issues. They had a protocol in place that is used if anyone had to return to the hospital within 60 days. Now they do it for any unsuccessful transition.

“When we have an unsuccessful transition, we are doing a root cause analysis to figure out what went wrong. Unfortunately, we have found that when we bring everyone to the table, people are not being forthcoming as to what needs to be said.”

The role of the parent in the root cause analysis discussion is still evolving. Unless people who truly care about the person are involved, there cannot be long-term resolution.

“When I am sitting with providers, I hear that the families ‘don’t get it.’ That really gets my blood pressure up. Don’t tell me I don’t get it. I’ve



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raised my kid...I understand and I've been at IEPs, I've been to PTs. I've been there for the long haul, etc."

Topic 7: Litigation

It took years and the Federal Government for things to turn around. At the same time, expectations were rising. It took the rising expectations and the DOJ settlement to get the state to move.

The DOJ settlement will not be successful unless the system can address individual problems. Until there is a way to respond to individual concerns, especially where the problems were so easily identified, progress is stymied.

"We are all looking for systemic change, but there is no way to solve individual problems. It takes three weeks to get to the right person to talk to."