WASHINGTON STATE UNIVERSITY

THE WILLIAM D. RUCKELSHAUS CENTER

UNIVERSITY OF WASHINGTON

I/DD 2019 Recommendations Progress

(Plain Language Introduction & Summary)

What is this project about?

- The state Legislature asked the Ruckelshaus Center to interview people to find out what they think about the progress of the 2019 Intellectual and Developmental Disability (I/DD) workgroup's 20 recommendations. This work also explored:
  - Issues preventing I/DD progress.
  - I/DD programs in other states that aren't offered in Washington.
  - How people can work together in the future to improve I/DD services and supports.

What we did

We shared interviews and listening sessions with more than 135 people, including:

- Individuals with I/DD and self-advocates.
- Parents and guardians.
- Advocates.
- People who work in the I/DD community.
- Unions.
- Residential Habilitation Center residents and people who live in communities.
- Developmental Disability Administration (DDA) workers and leaders.
- Legislators, the Governor's advisor and staff.

People told us what they think of I/DD program progress – what is going well and what needs improvement.

We summarized these conversations into a report.

What we understood before we did the interviews

- We heard how hard it was for people with I/DD (and their families) to get through COVID. How difficult it was to get access to many services and supports, especially in the community. How many felt like they were alone. And how hard it was for care givers to help people get through the worst of COVID.

- We heard how angry some people were, especially self-advocates and community providers, about being left out of the 2019 I/DD workgroup. Some people were especially upset about the Fircrest nursing facility recommendation. We also heard that a good thing that came out of this was a stronger self-advocacy movement.

- We heard about changes in leadership over the past four years. Changes at the Arc of Washington State, the Washington State Developmental Disabilities Council, People First of Washington, DDA and other places. We heard people hope that positive relationships will grow, including fresh ways for everyone to be heard and understood.

What this report is

- It's a mix of what different people told us. Their feelings about progress and barriers. Their thoughts on relationships and trust. What they believe are the most difficult issues facing the whole I/DD community and system. And some new suggestions on what can be done to improve the way that people can work together moving forward.

What this report is not

- This is not a report about who is right or wrong.
- This is not a review of I/DD program numbers. There are plenty of other reports that do that.
- This is not a report on <u>how</u> to fix things. Fixing big problems is a group effort, where diverse voices can be heard and understood.

What we heard: Key points

- Some people are happy with their supports and services. Others feel that they aren't listened to, and that their needs are often ignored. Or that they have to wait too long to get services they need.

- People with I/DD told us that they often get stuck – between a system that was built for health and safety, and their need for choice, independence, and personal rights.
- Most people with I/DD live in their homes with their parents or other family members. Everyone is getting older, including caregivers. This is a big problem - families cannot take care of their loved ones forever.
- More and more people, including those with I/DD also have behavioral issues. Direct care staff and others need the right experience to work with people who have challenging behaviors. It's hard to find, train and hold onto direct care workers, when pay rates are low compared to other jobs. Both of these issues – behavioral challenges and keeping the right types of direct care workers to support people with I/DD are big issues.
- Housing is very expensive – finding places that people can afford is another big issue.
- In order to solve these big issues, people and organizations need to work together – to build stronger relationships and trust. It's going to take a bigger team effort to continue to make progress and solve difficult issues.
- People asked for better communications between DDA, advocates, individuals, self-advocates and other I/DD system partners. Many want to be part of the planning and decision-making process. They want their experiences included and understood so that better planning and decisions can happen.

What we heard: 2019 recommendations progress

The 2019 workgroup came up with 20 recommendations that fit into four areas. The Legislature continues to fund many of these areas, and DDA continues to work to turn that funding into services and supports:

- **Improve community residential services**
  This includes improving how community services are measured, and how services are expanded. People told us that more state-operated living alternatives are being set up. Crisis stabilization facilities are coming online in communities, but the process is slow. Staff wages have been studied, and recommendations have been made to improve rates. Case management is improving since COVID, but there are still too many clients assigned to each case manager. More families need respite care, beyond what is available. Many people feel that progress is slowly happening, and that much more work needs to be done to expand choice and access.

- **Improve system coordination**
  This looks at how well people are working together to create new I/DD workforce and training opportunities. What's being done to expand housing options. And if

RHC doctors and specialists can give services to people in the community. Some people were happy that DDA is teaming with other state departments to create new housing. Some felt that more work is needed to partner with universities and others to get more people trained to learn how to support people with I/DD. Others believed that there are too many barriers preventing RHC doctors, dentists and other staff from serving people living in the community. Many would like to see continued progress in these areas.

- **Invest in state-operated nursing facilities**
  The big issue is people aging - people with I/DD and their family caregivers. The second issue is the replacement of nursing beds at Fircrest RHC. Self-advocates and some advocates have been opposed to Fircrest and would like to see that money used to expand community services.

- **Change Intermediate Care Facilities (ICFs) into short-term crisis intervention and stabilization services**
  The federal government changed the way that people get services in the ICFs. DDA is letting people know these ICF stays are shorter-term. More people with I/DD and their families (and guardians) are experiencing transitions out of the ICFs, as long as community providers or others are willing to support them. Challenging behaviors have become a barrier to community choice and placement. DDA and partners are trying to work through those and other barriers, but people sometimes have to wait for months or longer to find willing community providers with the right staff.

What we found: Other states' ideas

Washington state is moving forward with housing flexibility, behavioral health options, and other systems improvements. Other states have moved forward with:

- Different types of community crisis homes models.
- Specialty hospitals.
- Higher pay rates for greater coordinated care efforts.
- Community-based residential care for medically fragile adults.
- Positive behavioral support and intervention to support challenging behaviors.
- Community-based ICFs with clinical, dental, specialty, vocational and habilitation services.
- Family care homes (owned by caregivers).
- University partnerships to train new doctors and nurses to work with I/DD.
- Housing developer organization models.
- Special care community dental clinics.
- Mobile crisis services.

- Enhanced Behavioral Support Homes.

These are a few examples in other state programs. Some of these ideas have been explored by DDA and the Legislature.

What We Heard: Teamwork and Trust

Many people told us that trust between people is slowly building. We heard that some people appreciate DDA's efforts to hear from others who have not always been heard. Many people want to see faster progress. Others said they hoped to see advocates work more closely together, with fewer arguments. Self-advocates and others focused on the need to be understood, and part of the planning and decision-making process.

DDA has the burden of program development, oversight and improvement. RHCs want to provide the right services and effective transitions into the community. Community providers want to provide supports and services with the right staff. And everyone wants to find better ways to communicate back and forth.

The full report is at:
https://s3.wp.wsu.edu/uploads/sites/2180/2024/02/Ruckelshaus-Center_Perceptions-of-2019-I_DD-Workgroup-Recommendations-Progress_-February-29-2024.pdf