



June 19, 2020 – As self-advocates, we have come together because we wanted to make sure our voices are heard loud and clear on the 2019 Ruckelshaus Recommendations report titled “Rethinking Intellectual and Developmental Disability Policy to Empower Clients, Develop Providers, and Improve Services”. Our goal in coming together was to report back our opinion to the Legislative Task Force who were tasked to make a plan on how to implement the 4 main Ruckelshaus Recommendations. Please read through our thoughts on each recommendation point. Also, please remember to have self advocates at the table from the very beginning, when you create new documents or policies that affect our lives. We want to work with you the Legislative Task Force to make sure those with developmental disabilities receive services in the least restrictive setting as possible.

1. Ruckelshaus recommendation #1: Increase community residential services

The self-advocacy coalition strongly believes the best way to keep people out of segregated settings like RHCs is having robust community support. This involves making sure community residential services are fully funded. First, all service dollars spent on individuals in any RHC setting right now should follow that individual into the community. Second, individuals should be able to receive all their services in the community and direct their case managers on what they should look like using person centered planning options. It is critical that individuals are given multiple options on where to live at. Individuals should be able to decide if they want to live on their own or in group settings. New community housing options may need to be created to support everyone. The creation of these new housing options should be created with the assistance of self-advocates. Individuals with I/DD service hours should not be dependent on your residential setting. Housing should not be dependent on support services.

It is key that DDA case workers explain these rights to all individuals especially those in segregated settings and actively help individuals look for community options. It is also key as mentioned earlier all housing options like State Operated Living Alternatives (SOLA), diversion beds, and other options are adequately funded based off of a rate study, so that people can leave RHC’s that are more restrictive to them personally, and costly to our State in the long run. Thirteen other states and the District of Columbia have all moved away from the old restrictive institutional model to the newer community residential model. The self-advocacy coalition believes Washington State should be next. Finally, we encourage our State to work with private businesses and organizations to find additional money for housing.

2. Recommendation 2: Improve cross-system coordination

The self-advocacy coalition believes that any cross-system coordination should be led by self-advocates who have first-hand experience of transitioning from institutional settings to community settings. We believe we have the expertise to work with all of our partners to find new and creative ways to serve the I/DD population in their local communities. We think peer mentoring programs can be used to assist people in transferring out of the institutions. We believe that we should work with all State and community partners that will help people move back into the community. This involves working with not only disability partners but also mental health services partners, housing partners, and other partners that will build up the community.

In regards to reforming guardianship we believe people should be able to make all the important decisions that affect their lives. When individuals require assistance to help make certain decisions, they should receive that assistance without giving up their rights to a Guardian. Instead individuals can be helped by supported decision making services. While we believe some workers at institutions may be able to support people in the community, we have concerns with everyone becoming community providers. This is because we feel it's generally easier to spot and report issues in the community. Therefore, those that do want to transition should be checked out first through a screening process. Lastly as the report stated we see a big need to increase affordable accessible housing in all areas of our State, which would help people with I/DD transition faster into their local community.

3. Recommendation 3: Invest in state-operated nursing facilities (SONFs)

The self-advocacy Coalition strongly disagrees with this recommendation. We believe this is a time to invest more in the community through adding and improving housing options. We believe individuals can and should receive most services in their communities. We think if there are enough affordable accessible housing options out there and that in-home care services and other services are set up better to work for the individual there would be less need for congregate nursing facilities. As the current COVID-19 crisis has shown people living in congregate settings such as these are at far higher risk of getting sick and dying than those in smaller housing settings. While some may need nursing level care in congregate settings, these settings should be used more as the last resort instead of a default choice. People should be able to transition out of these settings when they choose to.

Finally, Individuals should be able to receive most nursing home level care in their community. Some individuals may need more assistance in finding providers with a higher level of expertise. We need to make sure there is a higher level of provider with more expertise to do medical level tasks and/or mental health support.

4. Recommendation 4: Operate intermediate care facilities (ICFs) as a short-term crisis stabilization intervention

The Self Advocacy Coalition strongly believes Intermediate Care Facilities should not be used. DDA should instead try to avoid crisis situations by making sure caseworkers are able to respond within a week after an issue is brought to their attention. This will reduce the need for an out of the home placement. DDA should implement crisis support teams where a skilled support team comes out to clients' homes to help them deal with issues and avoid

larger crises. This team may need to include a Behavior Health Therapist that can help clients and their providers work through issues they are having with each other. We feel when people with I/DD are taken out of their own home without a substantial medical or dangerous reason it leads to more problems for them in the long run as well as cost the State more money.

If and only if, after using the crisis team approach the situation still exists the Self Advocacy Coalition recommends DDA use local community Diversion Beds or local Hospital systems to help the client with I/DD resolve the emergency. Local Community Diversion Beds should be used temporarily, 90 days or less, and DDA should always have the goal of returning the person back into the community as soon as possible and should support the person in doing so. People who need crisis support should receive help from DDA and DSHS to maintain their current housing situation unless they want to move.

When Local Hospital systems need to be used we feel like their staff should respect the rights of the person with I/DD and treat them with respect as they do with others who use their medical services. We think by treating people in their local community, instead of ICFs in other areas, it will help reduce stress and keep them from further crises. As stated in the first recommendation each local area should have enough community housing options like diversion beds to support the I/DD population there. Finally, when people are placed outside the home temporarily people with I/DD should have access to organizations like the Washington State Developmental Disability Ombuds to help explain their rights.

We The Self Advocacy Coalition hopes you will consider our thoughts and opinions as you take the next steps to implement the Ruckelshaus recommendations.

Sincerely,

Self Advocates in Leadership (SAIL)
People First of Washington
Allies in Advocacy

Self Advocates in Leadership, People First of Washington and Allies in Advocacy together represent more than 1,200 Washington residents with developmental and intellectual disabilities.

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