



P.A.D.S.
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November 17, 2011

To: The Honorable Terry E. Branstad
Governor of Iowa

Mental Health and Disability Services Study Committee

- Senator Jack Hatch, Co-Chair
- Representative Renee Schulte, Co-chair
- Senator Joe Bolkcom
- Senator Joni Ernst
- Representative Dave Heaton
- Representative Lisa Heddens
- Senator David Johnson
- Representative Linda Miller
- Senator Amanda Ragan
- Representative Mark Smith
- Senator Pat Ward
- Representative Mary Wolfe

Charles M. Palmer, Director, Iowa Department of Human Services

Thank you for your on-going efforts to maximize stakeholder input into the redesign of Iowa's mental health and disability service system. PADS is a non-profit grassroots organization, run by and for people with disabilities, that works to improve the lives of Linn County residents with disabilities. A majority of the Board of Directors, including the President and Vice President, are people with disabilities. As we stated in our remarks at the public meeting on redesign in Cedar Rapids on September 16th, the most important thing that policy-makers can do at every stage of redesign is listen to what people with disabilities have to say about the service system that profoundly affects the quality of their lives. For us as PADS members, these issues are very, very personal.

At the September meeting, we expressed our position on a number of important issues. Some, but unfortunately not all of them are addressed in the Interim Report. There is much to praise in the recommendations of the workgroups, and we would like to point to some specifics, as well as to some major concerns.

1. **We need to bring Iowa into compliance with *Olmstead* principles.** We are glad that the Iowa Legislature required (in SF 525) that the design of the new system should be based on *Olmstead*, and it is very encouraging that those principles are stated so

"Peer Action Disability Support (P.A.D.S.) is Devoted to Improving the Lives of People with Disabilities Through Peer Support and Community Activism"

explicitly in the Interim recommendations. There are many facets to Olmstead. Here are a few:

- At the September meeting, we stated that the services that people are able to access should not depend on where they live, or their diagnosis, but rather on their needs. A system developed in line with the recommendations in the report would advance this idea in some ways. Requiring that a set of core services be available in every region in the state is a big first step. Expanding eligibility for the ID Waiver to all people with developmental disabilities will help thousands of people and also bring Iowa into greater compliance with *Olmstead*.
- We strongly support these important redesign components, but *this can only become a reality if the system is adequately funded!* We join our voice to the chorus of consumers and family members, advocates, providers and Iowa counties that call for the Legislature to begin to live up to its commitments to the mental health and disability service system.
- We strongly support the recommendation that core services be evidence-based, produce the outcomes desired, and be consistent with good stewardship of taxpayer dollars. And so we are opposed to including, in the array of core services, *existing* residential services like ICFs/MR, day programs and sheltered workshops. These do not produce the outcomes we want, they are not cost effective, and most important, *they are not consistent with Olmstead*. We understand the concern that sheltered workshops are the only option currently available in many areas, particularly rural areas, and we support the idea of a gradual but steady transition, over a defined and limited number of years (five at most), in order to avoid leaving people with no service options at all. But it is time for Iowa to take its place among the many states that have moved away from facility based services to a system that supports full community inclusion while slowing the growth of state long term care expenditures. As you know, failure to do so invites litigation and risks a finding of non-compliance with *Olmstead* by the U.S. Department of Justice. *People with disabilities do not exist to serve the interests of the administration and staff of outmoded services that do not respond to our needs and preferences! The time for change is long past!*

2. We support a system that creates individualized budgets and individualized service plans.

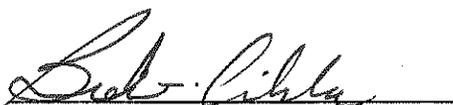
- We support the recommendation for adoption of the Supports Intensity Scale assessment tool, because when properly used it is thorough, objective and focused helping individuals achieve their personal goals. But we believe all disability populations, not just ID/DD, should have service plans that are based on functional assessments that are consistent and fair, as stated in the DHS State Olmstead Plan. This would include adults with significant adult onset disabilities such as MS, spinal cord injury, ALS, etc.
- We think that requiring each region to ensure that an array of core services is available needs to be coupled with the opportunity to access flexible funding similar to what is currently offered under the Consumer Choices Option and the children's system of care in Northeast Iowa. A truly individualized budget and service plan may have to include nontraditional supports, including supports from family, neighbors and friends and the purchase of items "off the service menu."

3. We need a system that is focused on keeping us at home with the supports that address the continuum of our needs, including nontraditional supports.

- We need to include supports for accessible housing and transportation as a vital component in implementation of Iowa's Olmstead Plan. For example, the Iowa Finance Authority's HCBS Waiver Rent Subsidy program needs to be adequately funded to meet the demand by people trying to remain in their homes and communities. Iowa's transportation brokerage system needs to be much more effectively marketed, and be served by a consumer advisory council.
- We need a service system that responds to the pressing needs of people who are not Medicaid eligible.
- We need a service system that keeps us from falling off the service cliff because of changes in our eligibility status.
- We need timely access to services when we are at risk of costly and otherwise unnecessary institutionalization.

The development of these consensus recommendations in such a short period of time shows that there is a broad areas of agreement on what Iowa needs to do. We support many, many of these recommendations, and we deeply appreciate the contribution of so much time and talent by work group members, the quality of the technical assistance, and the Department of Human Service's very open dialogue with stakeholders. Consumers and families have been asking for real change for so long. Now it is up to our legislators to determine whether this will be a point of real progress, an answer to our hopes and dreams, or whether this important opportunity will be squandered. Failure to move in the right direction hurts not just the disability community but all Iowa taxpayers.

Sincerely,



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cc: Linn County delegation, State Senators and Representatives