Consumer, Family & Advocate Final Report
Iowa Mental Health & Disability Services System Redesign

Source: Iowa Department of Human Services
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Iowa is committed to improving the current mental health and disability service system. While in many cases the system and services are working well for people receiving services and their families, in other areas the system is broken and peoples' needs are not being met. But it doesn't need to be this way. With the Olmstead principles as a beacon, and best practices as a foundation, Iowa is in the process of improving mental health and disabilities services system (Redesign) that will enable all Iowans to achieve the quality of life they desire.

More than 100 Iowans from around the state – from doctors to counselors, consumers to family members, CPCs and psychiatrists, brain injury experts, and more – met in Des Moines, in Workgroups weekly for nearly three months. Their goal: create a new mental health and disability services system that is based on a foundation of values and principles that will guide the development of consistent and equitable services that lead to meaningful outcomes for consumers and families.

In addition to the Workgroups, the Department of Human Services (DHS) Director, Charles Palmer, attended Listening Post meetings with consumers, family members and advocates throughout the state. The goal of these meetings was to learn from those using the services regarding what is working well and what services need to be improved or added. More than 800 people participated in nine Listening Post meetings from September 9, 2011 through October 17, 2011.

While these meetings gave DHS the opportunity to communicate about the Redesign process, more importantly, the meetings gave DHS an opportunity for consumers, family members and advocates to share their personal stories, triumphs, failures, hopes, and concerns.

This process is just beginning. Over the next several years, DHS will be working diligently to reach out to Iowans to ensure that as the new mental health and disability services system is transitioned consumers, family members and advocates do not "fall through the cracks." The goal is to invite them to take a personal role in creating the services system designed just for them.

Below are several themes that emerged during the Listening Posts and a sample of personal comments that were shared during these meetings. Any case specific materials that were provided publicly were done so by either the consumer or a family member. Department responses provided to the consumer and/or family member as a follow-up to a question asked during the meeting are confidential.

Jail Diversion Programs: There were dozens of concerns about persons with mental health disabilities ending up in jail due to symptoms and behaviors related to their disability. It was further expressed that jail or the correctional institutions are not the appropriate setting for these individuals to receive the support needed. Therefore, it is important to have jail diversion programs to appropriately provide needed services.

- *A grandmother of a consumer in Iowa City tearfully shared that her grandson has a mental illness and was incarcerated due to mental health challenges. She suggested the need for crisis stabilization and the court's better understanding of mental health.*

- *The aunt of a16 year old nephew who is in prison requested consideration given for transition from youth to adult so that they are not placed in jail.*

- *A Sioux City advocate stated Individuals who don't receive services today end up in the corrections system and this is the wrong place for them.*

I**ndividualized Treatment:** It is understood that people have unique and individualized needs. As such, it has been requested that services broadly meet individual needs rather than a set of services being prescribed or made available based on a diagnosis. In the case of mental health, intellectual or developmental disabilities, "one size fits all" does not work.

- *A parent of a child in Cedar Rapids with a Brain Injury stated, "Make sure individual needs are considered. I need Respite Care. Don't make it one size fits all. Keep the individual in mind not the diagnosis."*

- *A Sioux City advocate believes there is a need for transitional services from youth to adult that are targeted for the individual.*

Peer Support Services: There is a growing recognition regarding the value of peer support as an aid to navigating the system and in recovery. Many people expressed peer support should be included in core services particularly around crisis intervention, treatment support and employment services. It was also stressed that family/peer support can be an effective tool for families as well.

- *A person in Cedar Rapids reported there is a lack of peer support services in her area and they are wanted.*

- *A person in Dubuque talked about the value of peer support and crisis intervention and how helpful her experience has been with peer support. She is concerned that peers will be overlooked and the same medical system will be emphasized in the Redesign.*

- *An Iowa City mother with two children with mental health issues thanked those responsible for Reinvestment dollars to pilot peer to peer services and feels that this is a wonderful innovation.*

- *A Council Bluffs advocate shared the big challenge of recruitment of credentialed staff in their area. Peer support could be useful.*

- *A person in DeWitt indicated peer support is one way to get people back into recovery.*

- *A person in Sioux City believed peer support needs to be a core funded service and one that is available 24 hours per day, with transportation.*

Housing/Workforce: Persons with disabilities often lack safe, affordable housing and viable employment. This negatively affects treatment efforts and progress. Therefore, it has been recommended to provide housing and employment options for all persons with disabilities.

- *A Cedar Rapids father requested more extended vocational services. He indicated that his son is involved with Options Prevocational Rehabilitation program. This program is limited to one year for on-the-job readiness, but his child won't be ready in one year and needs more time and service.*

- *A mother in Cedar Rapids indicated that her daughter is a little higher functioning than the "Options" program, but lower than competitive workforce. She is worried about the program getting cut, which allows her to get out in the community.*

- *A person in Council Bluffs was concerned with the gap between mental health services and vocational rehabilitation.*

- *A person in DeWitt diagnosed with bi-polar disorder said he was a very active participant like the last Redesign. Noted that everything you say seems like last Redesign that did not change much. We want recovery oriented services and peer support and wrap services. These were excluded from the last Redesign. They need to be in this Redesign. Please help those with mental health problems become taxpayers. Another huge issue is employment. Companies are not hiring people with disabilities right now. Recovery oriented services get people to work.*

- *A Sioux City Advocate stated there is a need for vocational rehab services and employment for consumers.*

Adequately Funding Services: There is concern from consumers that current services will be reduced or underfunded rather than improving and expanding needed services. Funding of not only the current system, but the expanded system is a critical issue and one that is shared by all. The legislature will be responsible for appropriations; however, your advocacy helps in setting priorities.

- *A Cedar Rapids mother of two special needs children indicated that the community is the first place money should go. She is against money going to institutions. Her children lived in her home when experts said they couldn't.*

- *A person in Iowa City had a concern with the present system cap on the dollar amount for services. He hoped that each Region could provide "core plus" and that each county would offer more than expected by the Region.*

Transition: Attention has been brought to assure consideration of what would happen to people when transitioning from a County System to a Regional System. Consumers are afraid of losing services and/or being left behind. They are worried that they will lose access to current case managers or family navigators that are helping them. In addition, consumers are also concerned about the transition from youth to adult services and want more attention and communication spent in this area.

- *A Cedar Rapids community member voiced concerns about what will the larger counties have to give up in the Redesign? Will counties lose all of their funds?*

- *A person in Waterloo shared concerns that he has had the same case manager for 20 years and people don't want to go to new case managers. Please look at not having to move to services that would require new case managers.*

- *A Council Bluffs advocate admonished to be sure not to change one problem for another and creating more bureaucracy and administrative paperwork in the Regional Redesign.*

- *A person in Council Bluffs was concerned about the loss of local support and wanted to be sure to keep in mind that local support is important to consumers.*

These comments represent the themed comments DHS heard during the Listening Posts. However, many other individualized concerns were brought to the attention of the Department of Human Services. Family members shared concerns about how their loved one had fallen through the cracks in the "Waiver Programs" and Medicare system,

etc. Consumer, advocates and providers shared their frustrations in navigating through services and being frustrated trying to meet all the requirements necessary to receive services. It also became clear that “practice patterns” within treatment differ among county and/or service areas.

You can read the full comments from all nine Listening Posts here: http://www.dhs.state.ia.us/Partners/Partners_Providers/MentalHealthRedesign/Public%20Comments.html.

DHS, along with the workgroup members and the members of the Mental Health and Disability Services Study Committee (Legislative Interim Committee) are sensitive to these issues and taking them into thoughtful consideration.

DHS is dedicated to involving consumers, families and advocates in solutions for a better mental health and disability service system. Therefore, a Consumer & Advocate Group has been established and is meeting with DHS on a regular basis to assure the voices of those who are served are heard.

If you have additional input that you feel is critical to consider in the redesign process, please email your comments to: DHS-MHSRedesign@dhs.state.ia.us.

If you would like to learn more about the Redesign process and follow the progress of the workgroups, visit: http://www.dhs.state.ia.us/Partners/MHDSRedesign.html.