



“Our Voice in Missouri Redesign”

Survey and Listening Sessions: Response Summary

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Prepared by

Michelle C. Reynolds, Ph. D., Katharine Ragon, M.S.E.,
Megan Birzer, M.S.W., and Rachel Hiles, B.A.

University of Missouri-Kansas City Institute for Human Development
A University Center for Excellence in Developmental Disabilities
Kansas City, Missouri

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Introduction

The Missouri Department of Mental Health has created a Redesign workgroup with the task to “*design and implement an efficient, flexible, locally based system so people with developmental disabilities receive the supports they need when they need them.*” (For further information on the work group, please visit <http://dmh.mo.gov/dd/DDSystemWorkgroup.htm>). To ensure that the voices of self-advocates, families and other stakeholders is provided in the Redesign activities, the Missouri Developmental Disabilities Council (MDDC) developed a process of information gathering using both Regional hosted Listening Sessions and an on-line survey. The goal of these activities is to (1) to increase awareness about potential changes to the state developmental disability services system, which has been named Missouri’s Redesign and (2) to understand what is working well and what could be improved in terms of the functions of the disability service system.

MDDC contracted with UMKC IHD to host the survey electronically, develop a free standing website providing an overview of the DDC involvement in the Redesign activities including a link to the survey, and organize the responses to surveys and listening sessions for dissemination. The survey consisted of demographic and open-ended questions. All questions were optional and the identity of respondents is confidential. Respondents were provided opportunities to provide additional feedback on the survey.

This Summary report highlights key responses from the Compilation and Comprehensive reports. For Section 2 (Self-Advocates and Family Needs) the responses were summarized in full, while Sections 3 through 9 only include highlights from the recommendations. This report is designed to provide stakeholders with an overview of the responses. For readers who seek a deeper understanding of the responses, including the responses from what is and is not working from each section, the Compilation and Comprehensive reports are available online by visiting <http://www.moddcouncil.org>.

Section 1: Overview of Demographics

A total of 1,115 surveys were completed between June 25, 2014 and August 31, 2014. As a companion to the survey, Listening Sessions were hosted in the ten different DDD regions. These sessions were hosted as open forums that allowed for feedback and comments regarding the state service system functions. Each session lasted approximately 2 hours in length. Sessions were held from July 8, 2014 through August 27, 2014 with approximately 463 in attendance. These attendees included 159 family members, 39 professionals, and 25 self-advocates who self-identified their role.

Section 2: General Self-Advocate & Family Needs

- **Awareness of how to access DD services:** Self-advocates and families indicated that there was a need for greater awareness in how to access DD services and provided recommendations for transparency and dissemination of information including partnering with medical providers, explanation of paperwork, what is available, and eligibility requirements.
- **Publication or website about disability resources:** Families also recommend publications or a website to “empower the family/individual with more information on what is available and make suggestions when the family/individual is unsure of what to ask for.” Families and professionals express that a website would be useful that “explains everything for various life stages” and are “family friendly.”
- **Assistance with “navigation” of complex services & support:** Families indicate a lack of knowledge and frustration in navigating systems and services. Families and professionals recommend a clear process and “less cumbersome paperwork.”

- **Training for self-advocates and families:** Self-advocates recommend ongoing training and education to support families and share knowledge about options available, especially at critical transition points.
- **A resource navigator:** Families indicate a “navigator” or person to reach out and guide through the process as a single point of contact would be beneficial, including understanding multiple systems, options and paperwork.
- **One stop resource center or statewide number:** Families request one place to access all agencies and phone numbers that is centralized with “an advocate that could lead us to resources available across state departments,” including assistance in rural areas.
- **Educate schools on disability services and supports:** Families and professionals emphasize the importance of educating and sharing resources with schools on working with children and the process for accessing supports. Educators lack knowledge about what is available for adult services.
- **Build capacity of natural & community supports:** Self-advocates, families and professionals stress the importance of learning to navigate the system and utilize community resources. Through organizational and individual networking self-advocates, families and providers can access inclusive, community-based activities including sports, summer camps, classes, etc. It is essential that supports and social connections are built where people live and social capital is developed.
- **Integrate multiple service systems and agencies:** Service systems must be integrated to “decrease the amount of ‘islands’ and systems/agencies that the person with a disability has to navigate.” Greater integration and “teamwork” benefit individuals and encourage independence, specifically the Developmental Disabilities System with Independent Living Centers, Educational system, and Behavioral Health, especially when individuals have “dual diagnosis.”
- **Connections to peer support & networking with self-advocates & families:** Peer support connections and networking are essential for families and self-advocates. There is a need to help isolated families develop a support network and work with the individual and families to ensure learning from family contacts, area CIL, relevant disability groups, and faith based groups. Families want to be connected with others in similar circumstances and access to training on providing services in their communities through natural support systems, barter and/or co-op systems for respite and transportation. Families desire more opportunities to network locally and regionally.
- **Financial support & funding of services to families:** Families need services and resources but lack the funds to access them. Families appreciate having a budgeted amount, but desire more say in how to use the funds as well as information about what their options are regarding the use of funds. Education is essential on accessing local supports and finding resources to decrease dependency on state/federal supports. In and out of home respite is important to families to be able to work and also to focus on the family as a whole, including other siblings.

Section 3: Recommendations for Self-Advocate & Family Voice in the System

- **More open forums & meetings with self-advocates and families are needed:** Questions and opportunities for feedback must be provided often across the state and in a variety of formats. It is essential that response is encouraged. “If you can’t measure what people are thinking, how can you solve any problem?” Host meetings so people can talk and be heard. Offer local/online town halls, focus groups, surveys, etc. Use the Regional Advisory Council to organize regional forums annually. Use social media/technology.
- **Listen better to what self-advocates and families have to say:** Individuals and families are the experts in supports that work for their families. Communication between individuals/families and service providers is essential to quality services and supports. “We need someone who will listen to what we have to say, and then that person can help us.” Take time to get input from families.

- **Sustainability is needed in the disability system:** Sustainability of the system is necessary. Gather national best practices and discuss with focus groups. Make your voice heard on behalf of the people served. “This is critically important when funds shrink but need expands.”
- **Disability system at all levels needs to be transparent:** Emphasize developing solutions, present resources. “There needs to be open source information.”
- **Self-advocates and families must be integral to systems change at all levels:** Self-advocate and family voice is critical to providing services in order that all people are “independent co-participants in society.” It is essential that the system remain “open to listening to our [individuals/families] requests...that will help our family members become more independent.”

Section 4: Services & Supports Recommendations

- **More flexibility of what is funded and how it is funded:** “Decide what is important and fund it.” Solutions are needed across the lifespan as children “are still in a critical ‘window’,” youth in transition need support, and aging individuals/families need “better solutions.” One size does not fit all, “funding needs to be used for a larger variety of services.”
- **Offer more individualized service options:** Services must “meet the individual needs of the person.” Services and funding “should focus on the person and family with the disability...in the local community.”
- **Offer services that foster self-determination and allow for self-directed supports:** Services need to truly be what an individual needs and wants as well as be “flexible and much more responsive to changing needs and circumstances.” Provide individuals opportunities to assume responsibility from the onset. “People need more choice and better options for quality supports.”
- **Supports should assist in creating a vision for the future:** Families would like a resource that “explains what our future options might be” such as a booklet, website, or guide to programs to start looking into. Support transitioning youth at the college level. Integrate community/school/work.
- **Transportation was identified as a major area of need:** The lack of transportation “paralyzes” families who cannot get to services and supports provided within the community and by the system. Transportation allows individuals to “live meaningful lives.” Without transportation individuals are “as isolated as they used to be in remotely located state hospital settings.”
- **Fund & provide specific services & supports:**
 - **Intense Therapies:** A family shouldn't have to advocate for intense therapies, to the point that their child now needs residential care. The right in home supports, shouldn't lead to this.
 - **Relationship building and valued roles:** The current "bureaucracy" is locked in models of the past. No longer should we have to see people with disabilities in "day wasting" programs and service land. People belong not only in the community, but should be a part of the community and experience social roles and value for who they are just like everyone else. Workers should be focused on relationships, and balance safety/security with it.
 - **Early childhood services:** I wish we had more resources for children between 3-6 because they are still in a critical "window".
 - **Respite:** More and better respite services are needed both in the home and at respite care centers to help keep consumers in the natural home when possible and to give care providers a much needed break.
 - **Personal care attendants and group homes:** We need more PCA care available and better group homes.

- **Aging supports:** There needs to be a better solution for the aging consumers to transition from the natural home to supported housing. Many are out living their parents, leaving their care to siblings or putting the burden on the taxpayers through the Medicaid system.
- **Child care providers:** Finding childcare providers that are able to care for children with special needs.
- **Independent supported living arrangements** are needed.
- **Ideas for changing state and legislative policy to increase funding for services:**
 - **Service delivery models** need to be examined to identify techniques and methods to reduce cost of service delivery. Example more collaboration with private not for profits.
 - **Comprehensive support waiver** update so providers get reimbursed for mileage even if the consumer is not in the vehicle. For example: Let's say a consumer wants to go visit family. If the provider drops the consumer off, they (the provider) should be reimbursed for the mileage on the trip back home.
 - **Administrative costs** at the DMH state level. How much of those funds could be better used redirected to client care? Our governor has made some extreme cuts. We, as caregivers, can't be making all the reductions. And, make those adjustments well known. If we are all working together, it improves morale and is motivating to all!
 - **Accept the Affordable Care Act's** provision for expanding Medicaid in Missouri.
 - **Find a designated source of revenue for the Dept. of Mental Health** just as the Conservation Dept. has so that services for the disabled are not dependent on the whims of the legislative process and the other demands on the General Revenue funds.
 - **Increase the taxes for DMH DDD.** Advocate for the clients and their families.

Section 5: Service Coordination Recommendations

- **Conflict of interest between support coordination and providers must be addressed:** Service coordinators are coordinating services for the individual/family. Ensure that this is the case and they are not “protecting or lining the pockets of the provider.”
- **Need to decrease high turnover of professionals:** Individuals/Families work with multiple case managers/ service coordinators, sometimes several in a short period of time. It is important to address turnover and build relationships with service coordinators and providers so needs are known and can be served.
- **Provide additional ombudsman and oversight for quality assurance:** Communicate with families regarding who can be contacted about concerns in their county. Communicate across departments. Providers must be held accountable and supported to meet the needs of individuals well. Provide an annual ombudsman (oversight certification).
- **Ensure qualified professionals and organizations that provide services and supports:** Consider the experience of service coordinators, not just education. People need training, skills, greater expectations, and investment.
- **Increase pay for direct-care workers:** There should be “a true minimum wage standard.” Train and pay direct care workers so that “people can live, work, and be successful.”
- **Create manageable workloads for support coordinators so they can focus on providing education and navigational supports:** Smaller workloads allow case workers to “give more time for their clients.” The ability to focus on the individuals on a lighter case load would increase quality and allow time for relationships.
- **Support an interdisciplinary team approach to implementation of services and supports that includes, doctors, schools, employment specialist, etc.:** “Working together as a team...helps the consumer to thrive and everyone is aware of what is needed, and who has taken the active role in

specific tasks.” Input from others on the team e.g., family members, doctors, or teachers would “enable toe service coordinator to see what services are available that would meet those suggestions.” The team should be “advocates for [her] potential and growth.”

- **Ensure choice of service coordinators:** “Each person with a disability should be given the responsibility of their case managers in specific detail. We are unsure of her role. And if we are assigned someone who lacks the follow thru, we should be allowed to be reassigned.”

Section 6: Training for Professionals Recommendations

- **Consistent training to ensure adequate, long term professionals:** Consistency and flexibility across counties with oversight to ensure the funds are helping individuals with disabilities is essential. Statewide training should be provided to service providers and coordinators. Professionals need “uniform, best practices applied to the process.” Trained staff across the state would speed up the process of eligibility and service provision.
- **Provide training, education, and coaching to professionals and support coordinators:** Provide training on what is available in the community. Service coordinators need to be familiar with resources available to meet needs. “There needs to be more coordination between agencies.” Statewide training needs to filter down to service coordinators and providers. “It would help if the Division would train all of its employees including fiscal personnel and nurses, in the idea that people with DD are still people entitled to live their own lives. The fiscal and medical requirements placed on people because they happen to need DD supports often sadly curtail their lives and choices.”
- **Utilize innovative delivery methods for training and education materials:** Information needs to reach those providing services and oversight. Staff are busy, use technology to train which would also ease costs related to travel and time. Allow service coordinators opportunities to network.

Section 7: Intake & Eligibility Process Recommendations

- **Intake, assessments and plans should be more person-centered and individualized:** The current questions do not allow for a clear picture of individual needs. Not everyone fits into a box and questionnaires are not always appropriate. Balance objective, standardized questions with descriptive information. Consider all factors for each individual. “Assessment and planning need to be discussed with the person’s strengths and weaknesses covered on a regular basis.”
- **Utilizing technology to make intake and eligibility process more efficient and transparent:** Use technology securely to provide information that “could flow into a tracking system.” Connect case managers via a central database. Streamline meeting by giving individuals/families an online form prior to the meeting and incorporate the information into the PCP. Send information via e-mail.
- **Streamline the process to increase timeliness of responses:** Develop a method to submit information once for all agencies and organizations and decrease repetitive paperwork. Consider the professional information provided by doctors and integrate into the determination for eligibility. Call families and update information electronically.
- **Create transparency regarding all processes of service delivery:** The process is not clear for families, use language families understand. Provide realistic expectations on what families can expect in terms of support.

Section 8: Person Centered Planning Recommendations

- **Plans should be driven by the needs and goals of the person with disability and their family:** Directly involve the individual in the process. Focus on abilities. Apply the principles of “person centeredness”

rather than just talking about it. The system exists for the individuals, diversify approaches, communicate on what works, needs, and preferences.

- **Individual should be involved in every step of the planning process:** “You will have more success with making sure their [the individual’s] goals are in the forefront and having others make suggestions but not making the final decision.” People need to put their own effort in their plans. Motivation increases if people feel in control of setting their own goals.
- **Family, sibling and others should be included in the planning process:** The Support Coordinator, the person and the person's close family/friends work together to create a plan to get the person's needs met. That being said, often the plan only involves the parent, person, and support coordinator. More people family friends need to be involved if willing. Families have little to no involvement in this process. Often problems are identified, but no help is given until it is a crisis.
- **Continuous and on-going planning sessions focused on outcomes:** Other than manage a case, service coordinators are limited as to what they can actually do. Provide a program that would actually give individual personal support. Focus on the preferences and goals of the individual.

Section 9: Quality Assurance Recommendations

- **Address conflict of interest when between state, county boards and service providers:** Eliminate conflict of interest as much as possible. Separate SB40s and providers of services.
- **Quality assurance must focus on life outcomes and evolve with the person across the lifespan and situations:** A persons needs and capabilities change across the lifespan, consider individuals. Use quality of life as the indicator for quality enhancement. Help families create “dreams” for their children and provide concrete examples.
- **Consistent implementation of policy, practices and quality assurance must occur across the state:** Walk the talk so individuals and families succeed. Study what is working. Ensure the standard is met. Be transparent to individuals and families. Ensure individuals/families are satisfied with services.
- **Improve monitoring and oversight of providers:** Make sure services are happening and are good, communicate, care, and use common sense. Discuss trends and best practices and support providers to implement best practices and address issues. Focus on people rather than emphasizing water temperature.
- **Ensure accountability of services provided:** Assist agencies to provide quality supports. Everyone will benefit. Hold everyone accountable and be consistent.
- **Increase communication and trust between all parties to ensure quality:** Outcomes can fall through the cracks, provide progress on a frequent and consistent basis to the family and their service coordinator, so that problems can be addressed quickly and adjustments can be made. Make sure there is communication between families, caregivers, etc. is vital. Connect agencies (i.e. a state wide system to where agencies and contract agents could look into medical records, approval process {to see when in the system the request may be}, phone numbers of contract agents, DMH personnel on the cases, etc.). Work towards a "common goal" with providers. Provider Relations does assist in this area. However, there doesn't appear to be enough staff in this area so that concentration can be made with any providers who are having issues/difficulties. Improving this process would mean adding staff to work with providers more thoroughly.

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