



Mental Health and Disability Services Redesign 2011

Children's Disability Services Workgroup Child & Family Outcomes – Working List¹

Goal I: Welcoming Communities that promote the full participation of Iowans with mental illness or disabilities.

- Youths' Perspective
 - I am not broken and recovery is possible.
 - I am safe.
 - I have friends.
 - I can come back (to services) when I need to.
 - I know where to go and what to do when I need help.
 - I have people who understand me.
 - They don't kick me out when I have a bad day.
 - I don't have to be cured, I can be proud.
 - People are willing to accept my disability.
 - I have supports to be successful at a job.
 - I know where to enter the system and access it.
- Parents' Perspective
 - I am not alone.
 - I feel supported rather than blamed.
 - My community is accessible.

Goal II: Increase access to information, services, and supports that individuals need to optimally live, learn, work, and recreate in communities of their choice.

- Youths' Perspective
 - I know that the system is working for me.
 - There are the right kind of services at the right time to help me.
 - I can access information that is easier to find.
 - Technology is working for me to access the services I need.
 - I don't have to go to the hospital/court to get help.
 - People listen to me and I get the services I need vs. the services that are available.
- Parents' Perspective
 - I can go anywhere and get information, and there is no wrong door.
 - I can identify someone who is knowledgeable.
 - The resources are in formats and language that makes sense to me.
 - I don't have to hear about services from other parents. I can hear about services from the system.

¹ Though parents are represented on the Children's Workgroup, the goal of this exercise was not to speak "for" parents and children. The resulting "working list" of outcomes is neither complete nor final. It simply serves as a reminder to the workgroup of the kind of outcomes that matter to children and families.

Goal III: A full array of community based services and supports that is practically available to all Iowans.

- Youths' Perspective
 - I can access services with ease. I don't have to drive far and can use telemedicine.
 - I have services in my community/home.
 - I don't have to miss time away from home or friends to get services.
 - I have a school that is part of my team.
 - If there is an emergency, someone is there.
 - I can access services/have medications adjusted 24/7
 - If I need medicine changes, I know that I can access services.
 - I know that my service providers are competent and talk to each other.
 - I know the services I need are affordable.
 - I help identify and design the array of services.
 - The services are respectful of my culture, values, priorities, family
 - I know that I will have a safe place to live.
- Parents' Perspective
 - There is evidence the system is working.

Goal IV: High quality services and supports

- Youths' Perspective
 - Direct care workers are well-trained.
 - I am part of a community; I belong and am not living a parallel life—I have wholeness of life.
 - I know the services are making a difference.
 - This service that I being provided to our family has proven to be effective.
 - The services that I need are available to me no matter where I live in the state.
 - The supports and services are simple and easy to access/understand.
- Parents' Perspective
 - I am seen as an expert re: my child. This validates that my being there is just as important as a professional's.
 - I can make choices, give input and set priorities for my family.
 - I am encouraged to give feedback.
 - I feel better and have a hopeful future.
 - The workers that come to my home are consistent (low turnover) in being there.
 - I matter.
 - Service providers understand the "lived experience" and respect the "lived experience" of parents who have a child with a disability.

Goal V: Clear accountability for achieving service results for Iowans that support individuals to live, learn, work, and recreate in communities of their choice.

- Youths' Perspective
 - At the agency, I am engaged and they demonstrate cultural competence in service delivery.
 - They don't give up on me
 - I receive regular communication in writing of my progress and goals.
 - I can find information about the system.
 - I can be maintained in the home.
 - I am on grade level, attending school, and working towards graduation.

- I am not picking up criminal charges
- I graduate with the skills I need.
- When I am referred to another specialist or PCP, I don't have to tell my story over again.
- My ability to have friends and engage with the community is important.
- I have peer supports when I need them
- If something in the plan isn't working, there is a commitment to developing a new plan
- Parents' Perspective
 - I know that the system providers are looking at data, and constantly proving themselves.
 - I have a seat at the table before decisions are made.
 - "Nothing about me without me"
 - I have peer supports when I need them
 - There is a system for measuring customer satisfaction that matters.

Pros/Cons of Potential Coordinating Entities

1. A part of/co-located with multi-county Regional Entities

- Pros
 - Focus on developing Systems of Care across the lifespan.
 - Can concentrate skill sets better in regional areas versus by separate counties.
 - Helps other community partners to understand the structure across the state.
 - The needs/funding/volunteers/supports of families and folks can better understand from a single point of coordination.
 - Consistency in approach that you can capture for youth ~ decision making about services.
 - Same array of core services.
 - Easier for community funders to understand the array of services, general populations and their needs
- Cons
 - CPC experience is with adults and not youth.
 - Will youth get the same priority status as adults?
 - Waters down the specialty care of youth.
 - Doesn't respect the specialties of providers.

2. Child Protection Services

- Pros
 - Know the youth service system
 - Able to balance a family's needs along with provide help.
 - Some experience in creating balanced plans for the youth/family.
- Cons
 - Not particularly skilled in Mental Health or Developmental Disabilities.
 - Seen as a crisis agency versus a long term care agency.
 - Stigmatizing to access services through Child Welfare.
 - Parents feel they lose control.
 - Let's the local community off the hook as it relates to ownership.

3. Private Providers

- Pros
 - Experts on provision of a youth's treatment.
 - Experience working across Child Welfare systems ~ community engagement, volunteer networks, boards.
 - Reduces the duplication of "leads"--roles/plans/communication.
 - Opportunity to do coaching and service delivery.
 - Develop capitated funding systems.

- Infrastructure exists with licensed professional staff; could deploy more quickly with enhancements. Integrated with education systems.
- Could capitate at provider level
- Cons
 - Some may not be experts in “systems”.
 - How do I know who to go to?
 - Lack of availability across the state.
 - Conflict of interest if serving as care coordinator and helping family find treatment/placement provider.
 - Building it within existing infrastructure can be a disadvantage and making a new system would be better.
 - Active staffing level.

4. Systems of Care Entities

- Pros
 - Understand the elements for success in a System of Care.
 - Demonstrated success in two geographic areas.
 - Efficacy has been well-researched nationally.
 - Are keeping kids out of placement.
 - More likely to recognize the need for community transformation.
 - Designed to be flexible and to be evolving.
 - Adept at constantly changing, measuring, and evolving.
 - Are serving children in foster placements currently and those at higher risk.
 - Already using family navigators, natural supports and community connections.
- Cons
 - In limited geographic areas at this time.
 - The service seems harder to do and less well defined—it doesn’t follow existing formulas.
 - Large scale collaborative are hard to sustain.
 - Adherence to the model is difficult.
 - Need to adapt the model to fit the particular community.