

Introduction

Youth with intellectual disabilities often face challenges when preparing to leave school settings to move into life in their communities. These young adults may experience high rates of unemployment, increased rates of poverty, and involvement in service systems that do not have the resources needed to provide quality services for all who need them.

To address this uncertain future, there have been many “systems change” efforts in recent years. These efforts may be funded by the federal government, states, or foundations, and are aimed at helping to change outcomes for people with significant disabilities.

Systems change projects often take place on the state level, and involve consortia of state agencies serving people with disabilities. These agencies work together to examine why people with disabilities struggle, and identify how potential changes in policy and practice can improve quality of life outcomes. In this brief, “consortium” is used to indicate a group of professionals working on a systems change project. This might include steering committees, advisory councils, task forces, or leadership groups.

For consortium members like us, family members of youth and young adults with disabilities are important allies who could offer valuable insight, energy, and commitment into systems change issues. Unfortunately, these family members are often left without a seat at the table. Sometimes this is due to the structure of the projects calling for a prescribed list of participants, usually consisting of state-level professionals. It could also show an inability to effectively mobilize and engage parents in the effort.

This brief will highlight the reasons why parents and families are essential partners in any systems change

effort. It will describe the importance of the family’s perspective, and how their experiences should be used to shape policy recommendations. It will offer strategies on how to engage parents and families in systems change efforts, and how to promote family involvement to state-level partners.

Why Should Families Be at the Table?

For decades, families have been leading the charge to improve the lives of their children with disabilities. Concerned parents have been the driving force that led to federal laws entitling all youth to a free and appropriate public education in this country. Families struggled for humane living conditions for their loved ones with profound disabilities, and groups of energized parents formed highly influential disability advocacy organizations, many of which still play an important role. Today, families continue to advocate for quality employment and opportunities for economic self-sufficiency.

Any disability-focused systems change effort that seeks to incorporate a range of stakeholders and experiences must actively and meaningfully involve families and caregivers. Often it is families who know the most about their children and the impact disability has had on their lives. Families have experienced multiple service systems, and have attempted to untangle a complex web of regulations in order to access services and supports. For families of youth with significant disabilities, their exposure to outside interventions came very early, making them seasoned experts on how services operate. In short, families know how services and supports are supposed to work, understand where they tend to fall short, and often have ideas on how to make them better.

Families also lend a perspective on systems change that professionals and administrators do not have. Family members tend to see things from a functional

lens (is this working for my son or daughter?), rather than a policy lens (how will this fit into our funding structure?). Sometimes, the essential point of supports (to assist the person with a disability to function as independently as possible) gets lost in the process professionals think they must follow. Families and caregivers help bring the focus back to what is important.

Finally, families are great allies in generating the political will needed to impact systems change. Family testimony can have a profound influence on legislators and other governing bodies. Legislators in particular want to hear from their constituents. Letters, calls, emails, and personal testimony from a family on how a certain agency or service is helping or hindering their son or daughter can be powerful and effective.

Acknowledge Experiences, Fears, and Hopes

Some government-based systems change efforts struggle to engage families. One reason could be that families don't feel they have a place within the activities. They may feel like everything is happening "above" them, and that their perspective is inconsequential.

If a systems change effort seeks to include families, it must first acknowledge the experiences, fears, and hopes that come with having a child with a significant disability—in particular, the experiences families have when navigating and interacting with various service systems.

Some families have had difficult experiences with education systems and service providers. These systems can be confusing and seem to work at cross purposes. This can breed frustration and weariness on the part of families, who can also feel overwhelmed by how difficult it appears for their son or daughter to work or to have safe and supported housing.

These experiences, fears, and hopes need to be validated, and seen for what they are: illustrations of where a system might be failing, and what the ideal outcome might be in the eyes of those who care for the individual with a disability. Families may feel more comfortable engaging in a systems change discussion if they perceive that their hopes, fears, and frustrations are being heard and their opinions respected.

Convey High Expectations

Every parent has hopes and dreams for their child. These may be modified if the child has a significant disability, but they still exist. Generally, families want their child to grow up safe, healthy, happy, and connected to their community.

Unfortunately, many parents' hopes and dreams are worn down by years of limiting messages about what others feel their child can accomplish. In the worst case, this can lead to families who have very low expectations of what their child will achieve. If families voice low expectations, others (including educators, service providers, and employers) may be inclined to do the same.

Families may be more likely to become involved in systems change efforts if they feel those efforts are rooted in high expectations—namely, that people with significant disabilities can be meaningfully employed and become valued members of their community. Leaders of systems change projects should convey to families that the intention of their activities is to improve service systems so they can provide the supports needed to help people with significant disabilities achieve their full potential.

Tips for describing your systems change project to a parent or family member:

- » Consortium members should be careful about the language they use to describe programs and outcomes.
- » Beware of the negative tones that tend to creep into systems change conversations. Remember, when you discuss the population you work with, you are talking about somebody's son or daughter, sibling or friend. Avoid broad generalizations or characterizations of people with intellectual disabilities as being difficult to care for or a burden on the system.
- » If families become involved, they will do so because they want to make the lives of their son or daughter, and those of other individuals with disabilities, better. They also want to believe that the people who work for large service agencies feel the same way.

Effective Outreach and Communication

One common challenge your systems change consortium may encounter is identifying parents of youth with significant disabilities who are willing to serve on advisory groups and can be effective doing so. There could be many reasons for this:

Your consortium is not looking in the right places to recruit parents. When consortiums look for parent representatives, where do they look? Do they ask state agency members if they know of any interested candidates? Do they post openings on websites? Are they using methods that get them in close proximity to groups of parents? There are many knowledgeable and energetic parents who may find it interesting to serve on advisory groups, but these opportunities are often unpublicized or presented in ways that are less than attractive.

- » Your consortium may not be asking for help where it is readily available. Does your systems change project enlist the help of parent centers or other disability organizations to help identify parent representatives?
- » Parents of youth with disabilities are busy. Many work during the day and don't have the option to leave work to attend meetings.
- » Participation may not seem worthwhile to parents, given the bother of having to leave work or use their free time to participate.
- » Parents feel disconnected, or believe that they can have very little impact on what a service system does.

Here are some tips that might encourage more families to become involved:

- » Enlist the help of local service providers, parent organizations, or disability advocacy groups to find parents willing and able to be a part of the effort. These groups have direct access to parents, and parents might be more willing to participate if the opportunity is presented to them by a trusted source.
- » Communicate the purpose of the systems change effort so families know what's at stake and how they can help. Avoid overly technical

explanations of project goals and activities. Also, avoid acronyms or overly specialized language during meetings. Parents often have to play catch-up with the information that is being discussed, and the use of jargon may leave them feeling frustrated.

- » Be clear about what you'll ask parents to do and how you will incorporate their participation into your activities. Many family members feel underused and underappreciated when they attend advisory groups. Their participation is likely to be more effective if they have a clear understanding of their role.
- » Make sure parent representatives are considered as equals to the other members of the group. Be flexible with meeting times and locations to accommodate parent participants.
- » Offer stipends for family members who serve on advisory boards and attend meetings, and reimburse them for travel expenses.
- » Explore innovative ways parents can be involved without having to physically attend every meeting. Use technologies such as teleconferencing, video conferencing, or podcasting audio so families can get information if they can't be there in person.
- » If it's not feasible for family members to be part of the advisory group, consider soliciting their feedback in other ways. This may include asking a small group of parents to review materials that are generated by the project, or to conduct listening sessions with families of youth with intellectual disabilities to gather their experiences and perceptions about employment.

Messaging to Families: The Issues are Important and Your Story is Critical

Families of youth with significant intellectual disabilities feel the impact of that situation on a daily basis. However, they may not be aware of the ongoing systemic issues and challenges that could impact their children. To engage families, you need to make the issues relevant: how will the issues affect them and outcomes for their son or daughter?

Without being alarmist or overwhelming, let prospective parent representatives know that there

are serious issues with employment and income supports for people with significant disabilities in this country. Explain that there are efforts underway to address those challenges, and input from parents is needed if these efforts are going to be successful.

While having family members closely involved in advisory groups and project activities is vital, not every parent is going to be able to participate. One important way parents can assist systems change efforts with minimal time commitment is to share their story with key individuals and groups. Some parents may be more comfortable submitting their stories in writing, while others may be willing to share their experiences in various public forums. To share their stories more effectively, family members may need to be coached on what to include and how best to communicate their experiences.

Tips for families on sharing their perspectives with policymakers:

- » **Be brief and be clear.** Remember that time and people's attention are both limited. Work on your story so it is concise and free of confusing acronyms or jargon.
- » **Start with the basics.** Briefly describe yourself, your child, their disability, and what your life is like at the current time.
- » **State the problem.** Outline the problem or issue. What exactly isn't working, and what is the impact on your child's education, employment, or independent living prospects? Why does this problem exist as far as you can tell? Give specific examples.
- » **Offer a solution.** Given your experience and knowledge of the problem, what do you think will help? Testimony is much more effective if you come with a solution.
- » **Offer your assistance.** Let policymakers know that you are willing to help solve the issue in any way possible. State that you look forward to hearing from them if your help is needed.
- » **Coach your son or daughter to testify as well.** Hearing directly from youth can be very powerful. Help your son or daughter speak for themselves to the greatest extent they are able. Help them use multimedia or written testimony if that is easier.

Messaging to Professional Partners: Families Can Help Us Meet Our Goals

Another barrier to family engagement is the perception of professionals that including parents is complicated and awkward. Some agency staff may feel that a high-level systems change effort is not the place to try and incorporate families. There could be a feeling that having parents at consortia meetings may be risky in some way, or that people may not feel they can speak freely with parents present. Overall, there may be the perception that "this is our work, and we will bring in the families when we need them."

To overcome these tendencies, consortia leadership needs to send a clear message to its members that family input and participation is not only welcome, but crucial if the project is going to meet its goals. Family members offer a unique perspective and investment in the issues impacting youth with intellectual disabilities. They are essential partners in any systems change effort.

Using Partners: Parent Training and Information Centers

Over the years, parents have united to create a network of organizations that advocate for the needs of families of youth with disabilities. In addition to The Arc and the National Down Syndrome Society, there is a nationwide network of Parent Training and Information Centers and Community Parent Resource Centers (often referred to collectively as Parent Centers) supported by the U.S. Department of Education's Office of Special Education Programs.

These organizations could serve as valuable partners in any state systems change effort. They are often staffed by parents who have children with disabilities, and those parents use their experience to help other parents understand how to advocate for their children. Parent Center staff are professionals who give trainings and take phone calls from families on a daily basis, and who understand the main issues in education, transition to adulthood, and a variety of other topics.

These advocacy and training organizations conduct leadership programs so that parents can learn how

to become effective advocates for other families. They are often asked to take state-level leadership roles, serving on crucial advisory committees and task forces, and are a great place to start if a project is seeking family input.

There are Parent Centers in all 50 states and the U.S. territories. Many states have more than one Parent Center. To find one near you, visit Parent Information and Training Centers Network: www.parentcenternetwork.org

Parent Training

Another way to engage families is to think about what materials you generate or services you offer to them. Create family-friendly handouts, webinars, or videos that highlight best practices in employment for individuals with significant disabilities. To provide information in a more personal manner, try conducting workshops in partnership with Parent Centers on topics your project is working on. This tends to be an effective strategy for conveying information in a way that allows parents to ask questions directly of experts and parent trainers.

Using Partners: Disability-Specific Organizations

In addition to the Parent Centers, there are many strong national and local disability advocacy organizations. These groups may be able to help systems change projects conduct effective outreach to parents and recruit them to participate in the process.

Many of these organizations, such as The Arc, the National Down Syndrome Society, and the Autism Society, have both local and state chapters. These groups were built upon the idea of parents mobilizing and advocating for people with intellectual disabilities, and they have a wealth of expertise in the area of systems change. See the “Resources” section for more examples and contact information.

Summary

Our society’s expectations of what youth with significant intellectual disabilities are able to achieve is increasing. Many states have systems change projects that aim to eliminate barriers to education,

employment, and independent living for these youth. For such efforts to be truly inclusive and successful, they must incorporate the experiences of parents and family members in a meaningful way.

Finding parents to participate may be a challenge, and adjusting old ways of doing things may take some new strategies. In the long run, however, partnering with families and using their experience and expertise can lead to major changes, and improved outcomes, for people with disabilities.

Resources

Minnesota Employment Policy Initiative Policy Brief on Employment and Transition-Age Adults and Their Families

www.mn-epi.org/docs/FinalPolicyBriefonEmploymentandTransitionandFamilies.pdf

PACER Center

www.pacer.org

The ARC

www.thearc.org

National Down Syndrome Society

www.ndss.org/

Autism Society

www.autism-society.org/

Parent Information and Training Centers Network

www.parentcenternetwork.org

TASH

www.tash.org

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ThinkWork!



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www.ThinkWork.org