



Report to the Task Force for the Assessment of Supports and Services for People with Intellectual and Developmental Disabilities

May 2018

The Arc of Indiana conducted a survey to gather input from parents, family members, individuals with disabilities and providers for the Task Force for the Assessment of Supports and Services for People with Intellectual and Developmental Disabilities. Following are highlights of responses from providers that we hope will provide helpful information to task force members.

Responses from Providers

Survey Participant Profile

- 24.6% Provider of Disability Services
- 34.6% Direct Support Professional
- 41.8% Professional in Disability Field

If you are a provider or DSP, what type of services do you provide?

- 47.73 % Medicaid Waiver
- 15.15% Group Home
- 40.15% Day Program Services
- 37.12% Other

Comments

What Barriers, if any, have you come across in providing services?

- The lack of income for DSPs is requiring me to rethink my vocation.
- Staff turnover.
- Ability to recruit and retain quality staff.
- Trying to assist families navigating through the different agencies to obtain waiver supports, Medicaid and Social Security.
- Accessibility to employment services.
- Vehicle cost of transporting individuals into community. Transportation issues mentioned in several comments.
- Lack of communication between providers to provide continuity of care to individuals.
- Low reimbursement rate for music therapists that results in difficulty to hire quality MTs.
- It is extremely challenging to serve the number of children who desire to have music therapy services, as music therapists are not allowed to provide music therapy through the Medicaid waiver in public schools.
- Lack of ability to work with school / educational providers.
- Indirect requirements such as documentation that eats into time that could be spent working with the individual directly on skills.

- We are expected to be getting our individuals into the community upwards of 30 hours a week. Though we do serve many individuals who are fully capable to maintaining packed full days like this, we also serve several who cannot do this. We are running into barriers of trying to assist multiple individuals at a time with mobility, lunch services, and person care needs while not leaving anyone alone at the same time. This is difficult to maintain.
- School personnel not having a full understanding of the program.
- WIOA rules have made it impossible for younger people to access earn while they learn work skills.
- Employers in the community do not have a good understanding of the services available when employing individuals with disabilities, or they have mistaken ideas about individuals with disabilities in general.
- Not enough psychiatry services for people with disabilities.
- Several people noted “behaviors.”
- Limited day service options.
- Families unwilling to change.
- Rural communities lacking options.
- Getting in network with insurance / Medicaid.
- Residents do not have enough money at times to adequately supply themselves with what they need.
- I have several folks on the FSW with very high behaviors. I have worked with them to apply for the CIH Waiver, but each has been denied. I even had a homeless individual denied after her father died and her mother remarried and moved away. There has to be a better way to triage the needs.
- Lack of hours or ability to move hours around service to service to best support an individual’s needs.
- Providers who do not seem to understand the concept of choice.
- Long wait lists from providers.
- Extensive wait list for therapies.
- Need for crisis services.
- VR changing to order of selection.

Comments

What currently works well in the service system for people with disabilities?

- All of the different services that are provided for individuals with disabilities in our area means that they are able to participate in a large variety of different programs.
- The fact that there is a choice of providers.
- Clients on Medicaid waiver seem to receive appropriate funding to fill their needs. Group home individuals are being left behind.
- Working in small groups vs large groups.
- There is a system for clients to make a lot of choices of services.
- People with disabilities advocating for themselves instead of expecting something because they have a disability.
- Offering a choice of social outings of interest.
- Individuals with disabilities are becoming more engage in community events and activities.
- The staff who have a great heart for service delivery.

- I run a workshop. They really enjoy their co-workers, making a paycheck, and feeling like they are a productive part of society.
- Thinking outside the box, opening our eyes to what marginalized individuals can accomplish.
- People have choice, but there are long waiting lists (for services).
- Working toward more individual planning and goal setting by the individual and/or families.
- Improved FSW application and timeline for services.
- Having a portal like Advocare that all providers can access across services and providers.
- Group home funding is consistent and allows for a reliable funding stream for providers if the group home is close to full occupancy.

Comments

What changes do you recommend in the service system for people with disabilities.

- Initial level of care that is sufficient unless there is a change in status or need to re-enter services.
- Improved referral process from First Steps to BDDS and DOE to BDDS
- Higher wages for staff to reduce turnover rates that cause the people we serve undo stress. They do not understand why their “friends” are not longer around, or why this new person is who is giving them a shower.
- Utilize Uber for transportation.
- Explore more options geared toward children.
- Eliminate Order of Selection by having providers assume some of the responsibilities that currently overwhelm VR counselors.
- Portal for parent / caregiver access.
- Consistent training and communication for all providers.
- Better training for parents and DSPs.
- It is my belief that as sensory difficulties and communication orders are addressed by certified therapists, behaviors decrease naturally. (Under the Daniel’s administration) paperwork requirements were changed making it almost impossible (for therapists) to be paid ... many therapists stopped being waiver providers. As a result, I saw an increased dependence on behavior consultants and a huge increase in dollars on budgets that were allotted to behavior. I would love it if the needs of therapists were addressed and a recruiting effort began to bring those professionals back into waiver teams.
- Less red tape and paperwork.
- A database of staff who are found to commit abuse, neglect and/or exploitation.
- A state-wide plan that is strategic and targets businesses to educate and inform them about the benefits of employing individuals with disabilities.
- Residential options for people with I/DD with significant behavior issues.
- The cap on CHIO hours from a single provider is limiting to clients wanting to out in the community,
- There needs to be people designated to educate families on the waiver, how it is used and what it can be used for. It should not be left to service providers with a narrow focus to ensure that families know everything there is to know about services.
- FSW consumers are asked what their dreams are and where they want to live, but it is extremely difficult, unless (there is) an extraordinary health and safety risk to move to a CIH waiver. A FSW clients day services takes up the majority of funding and leaves little PAC options for residential support.

- Advocate for the removal of WIOA restrictions regarding pre-voc entry for people under 25.
- Stringent rules to protect individuals from service providers who take over guardianship of individuals they provide services to for the sole purpose of controlling the choices they make.
- More connection between school and waiver prior to handoff.
- Create an Algo system that includes medical necessity and functional ability with which to determine service needs.
- Maybe an intermediate option between FS and CIH waivers. Lots of families with individuals still living at home struggle to find supports due to limited staffing and lack of funds.
- A positive change to this system would be for all providers to work together for the person receiving services – not get into turf wars over budgets.
- More trainings for case managers and behavioral specialist on self-advocacy and individual led meetings.
- Bundle day services so that people can experience greater array of experiences.
- Online training program/library for providers.

Comments

Other Comments

- Indiana should be working hard to ensure there is protection of individuals with disabilities receiving waiver services due to potential issues with federal funding i.e. block grants/per capita as it is very likely this population will be the first to fill the impact.
- Once people come off the waitlist for FSW, and go through Medicaid and Social Security, they finally get to select a provider for service only to be put on yet another waitlist.
- Sheltered workshops should be a choice ... people should be able to work in the community if they want to and if they do not, still have viable options to work along friends and make money.
- I had to pay tons of money to an attorney to figure out how to calculate the DSP bonus. This should have been an easy calculation, but it was made complicated by regulations.
- I wish the autism mandate for ABA services could be expanded to other disabilities who need this type of treatment.
- I have worked in group homes and supported living sites and I can honestly say, there is not enough regulations in place for supported living. Clients in supported living are often not being serviced in a way to reach their full potential due to the fact that they can refuse everything ... more needs to be done to help ensure they are making better choices.
- I believe we have come far in providing quality supports and opportunities for individuals with disabilities, but we have a long way to go.