



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

April 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 parents, family members and individuals with disabilities that we hope will provide helpful information to task force members.

Responses from Parents, Family Members, and Individuals with Disabilities

Survey Participant Profile

- 81% Parent
- 14% Family Member
- 5% Individual with a Disability
- 75% Age of Person with the Disability 6-40 years old
- 37% Autism Diagnosis
- 37% I/DD Diagnosis
- 86% Receive Medicaid Waiver Services
- 8.5% One Medicaid Waiver Waiting List
- 53% Receive Services through Family Supports Waiver
- 32% Receive Services through CIH Waiver
- 78% Receive Waiver Services in Family Home

Comments

If Medicaid Waiver Services are provided in a residential program, what do you like about where you or your loved one lives?

- Allows him to be more independent and responsible and part of the community.
- The staff are friendly and care about my son.
- The ability to have his own home with roommates.
- Involvement with community activities, meaningful work, and volunteer opportunities.
- I live on my own because of my services and I like that I have that right.
- The assistance lifts a tremendous burden off me and gives my son a smile and a purpose.

Comments

If Medicaid Waiver services are provided in a residential program, what do you not like about where you or your loved one lives?

- Not enough staff for him to go to events his roommate does not want to go to.
- We don't always have full communication from staff about issues at the house.
- Staff turnover, poor training programs, lack of access to his form of communication.

- The staff is from a different country. They do not speak English well and even medical professionals fear this could cause a medical problem. They have not understood nutrition and we need my son on a diet to keep his weight under control. He has gained 40 pounds in 6 months.
- Lack of staff, in both number and quality. Unprofessionalism. Lack of respect.
- Location.
- Staffing shortages.
- Too many staff changes.
- Would prefer she remain in family home.
- Competitive wages in Hamilton County keep provider from fully staffing site at current DSP wage rate.
- Have to adapt to the state or company's rules instead of having a life of their own. Example – my son hates taking a bath in the morning, but the company wants him to take a bath in the morning because it is more convenient for staff. He hates it and that is just one problem.
- It is difficult for the agency to hire enough staff ... to provide that each of the three housemates can go to different activities at the same time. Also, by the state changing from daily rate to hourly rate, our children and their provider agency cannot access all of their designated funds to provide these additional staff ... the inaccessible funds are not able to be used to pay for other need services either ... we parents have to pay for music therapy, which he loves and his is helping him immensely. Yet, money is returned to the state for the times we take him on vacation or he comes home for a couple of days.

If services are provided in a group home, was a group home the first choice for residential services or would you have preferred receiving residential services through a Medicaid waiver?

- 71.43% Preferred Medicaid Waiver
- 28.57% Preferred Group Home

Do you or your loved one receive day program services?

- 36.30% Yes
- 63.70% No

Comments

Please comment on your day program experience.

- It's a place to go where he is safe, and he enjoys going.
- My daughter needs a place with high functioning individuals, peers, where she can meet people and make friends. Community integration is great, except she needs peers for real friendships and potential romantic relationships. I think this would do a lot for her depression. Most of us would be depressed without peers.
- I toured a number of programs and some seemed like they were warehousing people without much in the way of activities. Our current program is pretty large, but it also has a lot of floor space and many rooms to allow clients to pick and choose where they want to spend time.
- Staffed by poorly trained staff who presume my loved one incompetent simply because of his autism-related communication and motor differences. He does not have support for his method of communication. The activities and childish and boring.

- Our daughter has been working for 24 ½ years. Monday through Friday, 7am-4pm. She has developed great work ethics ... We are extremely pleased with our workshop. As all things it is not perfect but continues to be a place she wishes to be a part of.
- We do not like the ratio, so our sons attend a program two days a week that requires private pay.
- Our daughter loves it and would like to attend more than two days a week, but her funding does not cover that.
- They (the provider) are the only place in town that provides group day program services ... I don't think there is a lot of incentive for them to provide better services.
- Does not receive day services. Family did not feel it was a good fit due to size of space, the mix of participants, activities available for functional level and personal interest.
- My child is fortunate to have 1:1 staff, otherwise daycare would be a poor choice for her day, especially when short-staffed. I've worked in a day program and have seen the difficulties DSPs face when providing care that allows for a good life for those who have great physical and emotional needs.

If you receive day program services, would you like the opportunity to receive community employment supports?

- 50.77% Yes
- 49.23% No

Comments

Why or why not would you like the opportunity to receive community employment supports?

It is difficult to find meaningful employment situations. Volunteer opportunities could also be meaningful and productive.

Transportation.

I am tired from the rejection from programs. I have tried 4 programs. She would "progress" so much with any one of the four, but for some reason she has been rejected 4 times.

My son is quite capable of employment, but he needs a job that is a good match with his skills/strengths. Most jobs previously presented were highly dependent on reliable motor control, which my son does not have. They wanted to put him in the available "box" instead of finding a job, based on his needs/interests.

Unfortunately, vocational rehab has such a bad reputation among the other parents I know that I'd rather use our behavior therapist for community employment supports. She is more qualified than most of the voc rehab people I hear about.

If we apply for employment supports, then she will lose hours for community and home health.

Need wheelchair transportation ... his power chair seems to create lots of roadblocks.

I can do many things.

Do you or your loved one receive community employment supports?

- 19.55% Yes
- 80.45% No

Comments

Please comment on your community employment experience.

- After 6 months with a job coach, I found a job for my child.
- We haven't worked with voc rehab because of all the horror stories we have heard from other parents. We use our behavior therapist for this, and it works very well, but we can only get an average of an hour per week.
- The service provider is wonderful but limited in providing transportation. Because our son's job is outside Marion County he cannot take IndyGo thus parents must drive – also only receives 5 hours a month so parents must assist with other 5 hours for him to keep a job.
- VR has been excellent and so has her job coach.
- Assistance with initial employment was fine. What is missing is help to progress beyond entry level job. That would require more education and one on one support.

Comments

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

- Great staff, job coach and behavior specialist.
- Have been with our provider since he was targeted.
- We are using a "one stop shop" which allows integration of home activities and day services.
- The access to private ABA services transformed our family.
- The general diploma, which keeps the door open to jobs and at least some postsecondary ed and training for students with disabilities.
- The very fact that the services are available is something we are truly grateful for. As much as we love and support our sons, we could not begin to allow them the opportunities without the help of the waiver. Having two children with severe disabilities takes a toll in many ways. I have no doubt our health and financial situation would be significantly worse if not for the services offered our family. We are grateful.
- The ability to have options for what is best for our loved ones. We have several tools that can help benefit and support the natural supports that are in place. Our system is also very responsive when there is a concern.
- The opportunity to live in own apartment with another disabled individual with 24-hour staffing.
- Choice and the variety of services and providers.
- We have a good case manager and that is important. There are not many options for young adults who are high functioning, but not high functioning enough for full employment or independence.
- I think First Steps is an excellent program. My son made excellent progress and I wish we had the option to continue services past 3 years old.

Comments

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

- Multiple similar comments regarding staffing:
 - Lack of staff is a huge problem everywhere.
 - Better pay for waiver service providers so they are able to hire more people.
 - Qualified, well paid staff.
 - More stability and not so much turn over in staff so relationships can bond.

- Improved training for people supporting nonspeaking individuals in the community and in residential settings.
- Shorter waiting time to receive waiver.
- Clearinghouse for service providers, allowing comparisons of all options, assistance finding roommates.
- It would be great to have a centralized online website to contact prospective providers instead of having to go through the pick list. It would also be great to get reviews of agencies from other families.
- Better transportation for those in wheelchairs.
- Access to practical, convenient, reasonable priced transportation. (Multiple comments regarding transportation.)
- There needs to be more educational programs and parents need to know what services are provided and why.
- The ID community needs to welcome those individuals with ID and mental health issues. Their needs are unique.
- More digital record keeping to minimize family and social worker time spent on paperwork.
- Work with colleges and universities to make use of their unused dorms and apartments in the summer to give higher functioning young adults customized, supervised independent living and learning experiences.
- Fix the application and eligibility process. Working with the DFR is an extremely humiliating, degrading experience.
- Indiana is deferring to the feds – Social Security – to make the eligibility determination, so Medicaid is unavailable to many, many families, who file multiple appeals. Many give up. Some hire attorneys. We're now awaiting a hearing which is expected to take 18 months to 2 years due to the backlog of cases. My son could be 26 by the time he receives supports.
- Give the "team" more ability to make choices that will best serve the individual instead of "fit" into the system.
- More person centered. Budget to be utilized as needed instead of "in pots."
- More social events, things to do in the community.
- While I understand the need to have set requirements these get in the way of doing what is best for our loved ones. For example, I do not need someone to be with me when I take my loved one to a doctor's appointment, but since that is the DSP's shift, they come. When I need assistance to modify the home to allow for continued and increased independence that funding is not allowed.
- Include disabled people in decisions more. Don't treat disabled people as fragile.
- There is not equality when an adult must live with their parents indefinitely. Allow people to move out of family home and into the community.
- As (my son) ages, it would be nice to have more choices for retirement activities. Remember the aging process and the changes needed for other services.
- Need more residential options that don't require you to give up your waiver services to get in a group home. We need both.
- I would like to see the waiver fund alternative therapies to ABA for children with autism. I would like swim lessons and water safety classes accessible across the state and fully funded. I would like the cost of sensory supports funded, including weighted blankets, and sensory diet supports.

Comments

Additional Comments

- I am a CAN/HHA trying to financially support my daughter and myself on \$10.40 an hour. I am being told it would be better to put her in a group home than to find housing that can support the both of us.
- I have been lucky to be able to stay home and manage my son's care. My husband earns just enough for us to get by on one income if we live simply and frugally. The day to day demands of keeping up with all the extra details in a disabled person's health and life is exhausting. I am so grateful for waiver services, but I am worried about my son aging out of school in 2018 and being able to keep enough direct support professionals on staff to keep him meaningfully busy as an adult.
- Stop forcing people into institutionalized group homes.
- The day programs in my county are so short that it makes it impossible for a parent to work.
- Pull down every federal cent that can be found.
- Age 80 for parents is MUCH too old for consideration of emergency services.
- I find the process for accessing services to be challenging to understand. There are a lot of good programs and supports available, but it is not easy for family members to understand the options and apply.
- I was told that my child would have to be arrested, hospitalized multiple times, or hospitalize other people multiple times to even be considered for the CIH Waiver. Most weeks, she does not need the CIH Waiver. A "middle size waiver" based upon need, especially behavioral needs, is needed.