

REAL STORIES OF REAL PEOPLE

Waiting for Services in Jefferson County

Mark* 30 years old

Needs Partnership for Hope Waiver for Personal Assistance

Mark is a 30 year old man who has severe intellectual disabilities, a seizure disorder and is non-verbal. He lives with his brother and father. His brother also receives service coordination and has developmental disabilities. His father suffers from Agent Orange syndrome as well as PTSD from serving in the war. His father and brother are his main caregivers. They all rely on disability benefits. None of them can work due to their disabilities. Mark and his family do not go out very often and currently their only car is broken down. They are relying on their other brother who lives 30 minutes away to come and take them shopping, to doctors appointments and anything else they may need outside of the home. They live in a trailer park and have had many issues with the home. They rely on local charities to help out. They recently had to have their home bug bombed. They had to move out for several days while this was being done. Mark is in need of personal assistant services. He is on the waitlist for a Medicaid Waiver slot. He cannot complete his daily hygiene routine on his own. He needs assistance. He relies on his father and brother to make all of his meals and give him his medications. His father is becoming overwhelmed taking care of both boys on his own. The Dept. of Health and Senior Services has been involved with Mark and his family as well. The landlord has called the hotline due to the conditions of the home and the fact that his father is the single caregiver of the home. Dept. of Health and Senior services contacted the DD Advocates Service Coordinator asking why he is not receiving in-home services. The waitlist was explained to them. The Personal Assistant would be able to help Mark maintain his health and his area of the home. Mark and his family do not have anyone else they can turn to for help.

Sarah* 20 years old

Needs Partnership for Hope Waiver for Day Habilitation

Sarah is a 20 year old young woman who lives with her mother. Sarah attended high school and graduated at the age of 19. Sarah went through Vocational Rehabilitation during her last year of school. Their recommendation for Sarah was to volunteer in order to work on her soft/hard skills. The transition after high school has been difficult for Sarah; she was a very sociable young woman, made friends easily and she always happy. Since graduation, Sarah has regressed and her depression has gotten worse. Sarah's mother believes a large part of his depression is from a lack of socialization and not being more involved in her community. This is where the Day Habilitation services would benefit Sarah. Sarah has been on the Department of Mental Health wait list since the October 2019 waiting for a Partnership for Hope Waiver slot. Sarah is involved with leisure services through an agency, but she really needs Day Habilitation to work on her skills to hopefully gain employment in the future.

Noah* 52 years old

Needs Partnership for Hope Waiver for Community Integration

For more than 30 years, Noah had his own apartment, a job, and a good life. Two years ago, he was moved to an assisted living facility, due to some health issues. This move took him from his community and circle of friends, and into an entirely new city. The transition has been difficult for Noah, who is a very sociable gentleman, making friends easily and helping others out along the way. Since his move, he had become depressed, attempted to elope, and has refused to unpack any of his items with the hope that he can return to his old apartment. A large part of his depression is not knowing what his new community has to offer and how he can be involved. This is where the Community Integration services would benefit Noah. However, he has been on the Department of Mental Health Waiting List since the Fall of 2019; waiting for a Partnership for Hope Waiver slot. The agency that formerly worked with Noah has agreed to support him in his new community and to strive and give him the best quality of life possible... but for now, his quality of live will have to wait.

Esther* 69 years old

Needs Partnership for Hope Waiver for Transportation

Esther was approved for the Partnership for Hope Waiver for transportation and placed on the waiver waitlist on 11/6/2019. Esther volunteers twice a week with Meals on Wheels at a senior center. She has volunteered with Meals on Wheels for several years. Esther does not drive or own a car. She does not work. She lives in an Assisted Living Facility (ALF). The ALF is not able to assist her with transportation and her father is very elderly and not able to drive her to the senior center to volunteer for Meals on Wheels. She has asked other participants that volunteer with her if they could assist in driving her but her home, the ALF, is very rural and they are not able to drive her because they cannot afford the gas to pick her up and drop her off. Esther feels very connected to her community through volunteering and through the friendships she has made with Meals on Wheels. She is 69 years old and does not feel she is able to work but volunteering gives her a sense of purpose. She feels very discouraged being on the waiver waitlist. She knows that people at the senior center/Meals on Wheels count on her as she is a dependable volunteer.

John* 27 years old**Needs Partnership for Hope Waiver for Behavior Services**

John is 27 years old and has intellectual disabilities and Attention- Deficit Hyperactivity disorder. He lives with his father and brother. His brother also has developmental disabilities and therefore John has a lot of responsibilities in the home. His father suffers from Agent Orange and PTSD from being in the war. John is responsible for helping his brother with his needs. His brother is also on the waitlist for services. John has behaviors that need to be addressed. These include but are not limited to money management concerns. John and his family rely on disability income. At this time they cannot work due to their disabilities. John gets his monthly disability check and he immediately spends it at thrift shops or pawn stores. He will not listen to his father. His family needs this money for food, other household supplies, and the trailer they live in is in need of repairs. John does not understand this. If his father tries to spend John's money on things they need, John throws a tantrum. John has had issues with running out of the home yelling and screaming. This has resulted in police involvement. When the police came out they called Dept of Health and Senior services due to the condition of the home and the other family members living there. His DD Advocates Service Coordinator was contacted, and the waitlist was explained. As his father is worried about him running from the home, he does not confront John about the money anymore. So, the family is not able to rely on John's money to help. John needs a behavior assessment and behavior services. He cannot get these without a Waiver slot. John is in need of services to live a healthy and successful life.

Miriam* 35 years old**Needs Comprehensive Waiver for Residential Services**

Miriam is a young woman in her early thirties, who has developmental disabilities. She resides in a skilled nursing facility at this time, as she waits to receive a Comprehensive Waiver slot. The Comprehensive Waiver will provide her funding to be able to live in a home amongst peers who have similar needs as herself. Miriam was placed in a skilled nursing facility in January of 2020. Miriam's mother passed away suddenly in 2018. Her grandmother was unable to meet her daily needs, due to her declining health, so Miriam's sister began caring for her after her mother's death. After caring for Miriam for over a year, it became too much for her. Miriam's sister was moving, and unable to take Miriam with her. In order to keep Miriam from becoming homeless, Miriam had to be placed in a skilled nursing facility, with people whom she is 40-50 years younger than, as she waits to receive the waiver slot. The last update is that Miriam is number 69 on the wait list.

Peter* 21 years old**Needs Partnership for Hope Waiver for Pre-Vocational Training**

Peter was approved for the Partnership for Hope Waiver for pre-vocational training. He was placed on the waiver waitlist on 12/3/2019. He is very driven to work and have as much independence as possible. He lives with his mother and several siblings. He would like to get a job and live in his own apartment someday. Peter is not able to find meaningful employment without supports. He did try Vocational Rehabilitation services but he was not successful in the program. Peter requires pre-vocational training to assist him in developing the skills he will need to find community employment. He needs to develop skills in the areas of taking direction, independently following through with tasks, having socially acceptable interactions with customers, employers and fellow employees, waiting for others to finish speaking, and not using curse words in the workplace. He will need help following a work routine. Peter also requires assistance in finding employment such as filling out applications and interviewing skills. He is waiting for the Partnership for Hope Waiver to start on his employment path.

Luke* 21 years old**Needs Community Support Waiver for Day Habilitation**

Luke is an extremely routined person and anything out of sync for him will send him into a downward spiral. Luke is going to be hard to transition from high school which is why his family took the time to find the right day program for him. Being told at this point that he's going to be put on a waitlist and may not be able to transition right away has them panicking. Both parents work and cannot afford to lose income. They have 2 teenage daughters who will be home during the summer but they are not capable of taking care of Luke when he becomes violent or destructive which WILL happen if he's not kept on a structured routine. Luke is not capable of being left unattended for any amount of time. He becomes "bored" and that's when the destruction/violence begins such as.....he has broken the front door by slamming it backwards, he has broken both door handles in the backseat of a car, he has ripped and frayed several cords (fire hazard), he has placed a plastic bowl on a hot griddle melting the bowl, he has cut apart his mattress down to the springs, he has taken out his bedroom window and thrown things onto the front lawn, he will take apart anything he can get his hands on, he has hit, punched, and kicked his sisters.....the list goes on and on and that was under parental supervision. They do not have family help either as he has become too much for grandparents to handle. With Luke being completely non-verbal they cannot leave him with just anyone as no one would know how to communicate with him and the family cannot trust that his needs would be met. The day program they found has people that know how to communicate with him and they have a 1:1 ratio which is what Luke needs. He cannot "wait" for this service upon graduation in May.

Current funding levels are expected to leave more than 800 people waiting for services this year.

Nicholas* 55 years old**Needs Comprehensive Waiver for Residential Services**

Nicholas has intellectual disabilities and dementia and his memory is deteriorating at a fairly rapid rate. Nicholas requires 24 hour supervision at this time due to ongoing health and mental issues. He currently lives in a provider ISL home, however is paying rent due to not having the appropriate waiver. He currently receives 16 hours of personal assistant services however this is not the appropriate oversight he needs at this time. Nicholas's overall health has declined drastically as he needs supports in all areas of daily living and developmental skills as well as oversight at night. For this reason, Nicholas needs the Comprehensive waiver in order to remain as independent as possible in residential placement. He needs oversight and assistance to complete his hygiene routine, meal prep and every day chores. Nicholas needs assistance with all business correspondence and scheduling appointments. It should be noted a symptom of Dementia could be hallucinations or paranoia - Nicholas has experienced both of these as of recent. He is also now scared of the dark. Nicholas will make statements that are untrue and requires an individual assistant when socializing. Nicholas no longer awakes at night when his bed shaker goes off for emergency purposes. This poses concerns as he would need staff oversight to get him out of bed in the case of an emergency. He will often get up around 3 am, eat breakfast and get ready for the day. Should Nicholas receive a Comp waiver he would stay in the ISL home he is currently in, however have the appropriate oversight that is currently greatly needed.

Paul* 24 years old**Needs Comprehensive Waiver for Residential Services**

Paul is a 24 year old man that lives with his mother and step-father. Paul has several positive attributes and his mother describes him as a great person; funny, intelligent and caring when he is not exhibiting negative, dangerous and violent behaviors. He graduated high school at age 21 (with an IEP) and now spends his days with mom at home and his evenings and weekends with his mom and step dad. He is fond of his grandparents, but they are elderly and unable to defend themselves from him in the probable event he becomes violent. His mom, like most middle class families, needs to work but, unlike most families, had to quit her job because Paul cannot ever be by himself and no one else is able to “handle” him. Services and strategies have been sought but there is either no availability, or providers do not believe they can provide the level of support he needs in his home to be successful, or strategies and services tried have been unsuccessful. Paul not only has a significant intellectual disability but he also has several mental health issues. This results in him targeting his parents, pets (he has injured a dog so badly it had to be euthanized) and aggressively assaulting them. They live in fear in their own home and are often walking on eggshells to not upset him. They express that the system has failed them. Paul has been hospitalized for behavioral health 6 times in the past 12 months with law enforcement often involved. One hospitalization lasted for nearly two months. He also has been out of home in a crisis respite home for 90 days (max allowed) so he could increase his skills and for his family to get a break from the near daily, constant trauma they experience. Paul’s needs for specialized residential placement are compelling and an agency has agreed to provide these supports; but he does not have the funding for this. This family is on the verge of relinquishing their guardianship of him in the belief that their only hope to have a basic, decent life and family relationship is that they should “turn him over” to the state. They have expressed that the consequences of this action would be better than the possibility of them having to be hospitalized or worse due to the aggression/assault they experience from him. They also believe he needs to be successful in life. They love him dearly, but are absolutely no longer able to provide him the specialized care he needs. Paul has been on the waitlist for a comprehensive waiver slot/funding for the services since its inception in July 2019. He and his family have, as any prudent person would consider, a dismal quality of life and this is despite all community /home based interventions that have been tried.

Joseph* 30 years old**Needs Community Support Waiver for Personal Assistance**

Joseph is a thirty year old man who currently lives with his mother. Joseph is diagnosed with moderate intellectual disabilities. He also has cataracts that are inoperable so his vision is very limited. Joseph was born without one leg and without some of his fingers. He uses a prosthetic leg to walk, but he requires assistance with tasks that require dexterity in his hands, such as cutting foods or grasping larger items. Joseph needs assistance for household chores, completing hygiene tasks, and going out into the community. Joseph also needs supervision as he is very friendly and does not understand stranger danger. Joseph’s mother has been providing around the clock care and supervision for him to meet his needs. His mother has been unable to work or even leave the home on her own as Joseph cannot be left alone. Joseph is in need of a personal assistant to come into the home and meet his daily care needs. Without the care that his mother has been willing to provide without pay, Joseph would require a placement with around the clock care. His mother is in her sixties and may not be able to provide this care much longer. A personal assistant would give her the break that she needs in order for Joseph to remain in his home longer.

** Names have been changed to protect identities and comply with HIPPA regulations. If you’d like further information or to visit with the people on this list, please contact us to make arrangements.*

This unfortunate situation will eventually end up costing taxpayers more money.

The mission of Developmental Disability Advocates is to provide resources to create opportunities for individuals with developmental disabilities in Jefferson County to live full and enriched lives.

Jefferson County Developmental Disability Advocates

2020 Legislative Priorities

Adequately fund services for people with intellectual and developmental disabilities (I/DD)

- There is a direct support hiring and retention crisis as a result of inadequate rates, which affects our ability to provide adequate services (the increase in Missouri's minimum wage will only increase this urgency)
- Adequately funded service rates and eliminating the waitlist will save on costs associated with crisis supports.

Ensure ALL Missourians have the opportunity to work in a competitive, integrated setting

- Establish "Employment First" legislation
- Fully fund Vocational Rehabilitation
- Support Medicaid-funded employment through DMH-DD

Safeguard existing programs, funding and services from Managed Care entities, which have been proven to be ineffective with I/DD services in every state where they have been introduced

- Continue to collaborate with DMH-DD, MoHealthnet, legislators and other stakeholders to create a more efficient framework for delivery of long-term services and supports (LTSS) that produce successful outcomes that matter most to individuals with I/DD
- Design a system to include the following core values:
 - ◇ Prioritize people with I/DD
 - ◇ Provide stability and sustainability
 - ◇ Provide ease in administration
 - ◇ Preserve and strengthen local control
 - ◇ Provide positive, measureable outcomes
 - ◇ Comply with the Medicaid Home and Community Based Services Final Rule
 - ◇ Ensure TCM stays at the local level, is independent of the Managed Care Organizations and is not conflicted



Administrative Office

998 E. Gannon Drive, Suite 230, Festus, MO 63028
Mailing address: P.O. Box 427 Herculaneum, MO 63048
N. line: 636-282-5500 N. Fax 636-282-5501
S. line: 636-933-3300 S. Fax 636-933-3301

Service Coordination Office

1615 Vine School Road, Herculaneum, MO 63048
N. line 636-282-5510 N. Fax 636-282-5511
S. line 636-937-6946 S. Fax 636-933-3311



For more information, see our website and social media sites.

www.ddadvocates.org



@ddadvocatesjeffersoncounty



@ddadvocates_jc



ddadvocates