



New Level of Care (Exceptional Supports) Survey Results

Completed February 5, 2019

43 Residential Provider Agencies Responded to This Survey

Q1 How many participants do you currently support whose needs cannot be safely met with waiver services?

Total: 170

Q2 Of this number, how many do you receive exceptional supports for?

Total: 50

Q3 Totaling all participants you support with intense needs, regardless of exceptional support approval, how much are you subsidizing or "going in the hole" each week for, in non-reimbursed costs?

Total: \$35,880.75 per week in non-reimbursed costs

Q4 In the past 12 months, have you turned down an admission referral due to the participant's support needs exceeding what the waiver could reimburse you for?

88% of providers responded Yes

Q5 If you answered "yes" to the above question, how many referrals have you denied for this reason in the past 12 months?

Total: 405

Q6 Are you in favor of the Cabinet establishing an additional (higher) level of care or distinct service package to provide waiver services that would bridge the gap between waiver and ICF?

100% of providers responded Yes

Q7 In the past 12 months, have your staff had to call the police to help with dangerous behaviors because crisis services are not covered by the waiver and are generally unavailable in your community?

79% of providers responded Yes

Q8 How many participants have you sent a 30-day involuntary termination notice for that no one would accept?

Total: 61

Q9 If you have specific situations of intense/unmet needs of people you're supporting you'd like to briefly comment on (anonymously and protecting PHI), please do so here:

24 residential providers took the opportunity to respond to this question. Here, in their own words, are some of their concerns:

"Recently, I had someone with high medical needs that could not be supported by one staff. I had to pay another staff to come in and provide extra support during key times. No one would take this person. She eventually went into a nursing home. Huge strain on budget."

"Most individuals that this situation applies to are related to intense behavioral needs that directly relate to mental health needs."

"We have two participants that should receive exceptional supports but we have not requested exceptional supports. Last year our surveyor from DDID the QA/surveyor spent 13 hours reviewing that particular record. The way that they explained how we were to bill for the exceptional support it was absolutely ridiculous. We had to break down every employee's hourly rate (no overtime) and only bill that rate. Meaning that we would break even just on the rate and obviously lose money. We were expected to prorate the exceptional rate if the participant was here for 22 hours instead of 24 hours. I think there needs to be another level of care but it does not need to be so complicated it is difficult or impossible to bill correctly. How the exceptional rate was rolled out and how DDID monitored it were two completely different things. By the way the 13 hours spent reviewing the exceptional support record was a waste of time for DDID. No problems were noted. I am a nervous wreck about my billing audit which is due now. No telling what has changed or "new rules" have been developed and not communicated. "

"We serve a lady who was admitted for AFC services several years ago. While her placement initially went well, she had a period of crisis related to her co-occurring MI/ID that resulted in her losing multiple AFC placements. Her family/team (CM and behaviorist) requested/demanded that we provide her with a 1:1 residence arrangement, believing she could not "live with other people." Although we had previously removed the SR model from our business model no longer offered the service, we reluctantly agreed to

provide a temporary arrangement while referrals were sent to other agencies. This was over 4 years ago. Since that time the family/team has refused to consider any other agencies that would not provide 1:1 staffed residence within our region. Needless to say no other providers are willing to take on that losing proposition. To date, we've lost literally hundreds of thousands of dollars serving this one participant."

"I question the eligibility of some people. I think we support a number of people that their intellectual disability is border line to do environmental situation when the real issue is their Axis 1 diagnosis."

"serve a person 1:1 in a home by herself, due to physical aggression toward other individuals. Her aggressive behavior toward staff results in an average of 2 staff per month in turnover rate. She has sent 3 people to urgent or emergency room care in the past three months. Many of the seven people that we serve with exceptional supports results in a call to emergency services on a weekly basis."

"Categories of intense/unmet needs include Mental Health (psychological and behavioral), Physical Health (disease processes and intensive physical support/accessibility), Aging, and Criminal activity. Consequently, multiple levels of care in multiple fields and settings will be needed in order to provide person centered supports. It will require the ID/DD field to work collaboratively with law enforcement, the medical community, the mental health system, aging services, and others. The cost to providers is critical, as well as the cost to the community and to the individual whose needs are not being met. While providers cries for help are falling on deaf ears, the state demands that providers continue to keep individuals in these dangerous and inappropriate circumstances, the consequences of which considerable, up to and including death of the individual."

"T requires 1:1 staffing during awake hours for significant behavior concerns including self-injury, aggression and elopement. There have been numerous ER visits, sometimes more than 1 in a day, as well as police involvement and trips to Eastern State."

"L requires 1:1 staff at all times and 2:1 staffing during awake hours. She lives alone and has significant behaviors to include self-injury, physical aggression and property destruction, including destroying neighbor's vehicles."

"S requires 1:1 male awake staff at all times due to history of elopement, physical aggression and sexual behaviors. Has been incarcerated for sexual encounters in the community and has attempted to perpetrate against roommates."

"There is no support for mental health related crises. If someone is in need they are turned away due to "not meeting criteria". At this point I don't believe there is any criteria acceptable for admission into a Crisis Stabilization Unit or transfer to a mental health hospital. Residential agencies are left to fend for themselves without support from anyone."

"After several attempts at harming self, two vehicles stolen and driven several hours, multiple police interventions and court appearances, the state guardian insisted on 24 hour awake eyes on. This required 2 staff on throughout the night and three staff on during awake hours so that he was eyes on at all times. This was the staff needed to provided for his health and safety although this was a staffed residence."

"1 individual requires behavior supports, but that has lapsed and requires 1-1 due to behaviors, however is currently not approved for ES due to already providing the supports without the increase in pay."

“We have one individual that is so intense and so severe that she in no way should be in a community setting. She must wear a helmet because of her very physical destructive behavior to herself, staff, and property. She has to live alone because her behavior is so severe she could not possibly be safe having a roommate, and the roommate would not be safe either. She really requires a much higher level of care that we can provide. Finding staff even capable of handling her is very difficult and if anything ever happened to the staff she has, our agency would be severely impaired from keeping this individual safe.”

“1 individual who requires 2-1 but often 3-1 staffing ratio. She is required to have a 4th staff when she is having behaviors that require emergency situation. She has a history of jumping out of the van, she requires a 5-point harness and no one is able to be transported for her. The guardian demands that we train staff to do physical restraints on her, but the regulation for SCL requires us to have policies ensuring a restraint free environment. She has set fire to the van, pulled a toilet out of the floor, has hit staff with a fire extinguisher, causing a TBI.”

“There are several who have such great needs and had at least 6 people look at vacancies in that house and did not take it because of the behavior of the individual -- we are losing money here as well-- the system is a mess all around- not just needing another level of service—”

“We often pay for clothes for participants. We often pay for vacations for participants. In addition to the extra staff costs reflecting in question #3”

“Individuals with self-mutilation requiring 1/1, Intense Explosive Disorder requiring 1/1, MPW has no Exceptional Supports rate, intense behavioral issues from a person out of ICF and now in staffed residence. Several referrals have been turned down due to past experience with DDID and their lack of support when there are severe issues. Their idea of “you said you could support them so you have to do so no matter what the cost or consequences to staff and others”. Lack of supports and options has kept us from accepting some new referrals.”

“we currently support 3 people who stay home during the day = services/time that we cannot bill for.”

“Limited help available through state hospitals and comp care crisis centers. Literally desert of mental health supports around the state