



Employment and Community First CHOICES Program
Group 4
Family Feedback and Recommendations

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Introduction

A Doctoral Occupational Therapy student from Belmont University has partnered with the Tennessee Disability Coalition on a feedback initiative for families in group 4 of the Employment and Community First CHOICES Program. Over the past several weeks, families have shared their experiences using this Program through phone interviews and online surveys. The following report contains families' feedback on the Program's strengths, weaknesses, and suggested recommendations. Of note, several families were in the first round of enrollees and thus have experience spanning the entire length of the Program.

Program Strengths

Families reported several strong aspects of the Program.

- All families receiving the Family Caregiver Stipend reported the funding as beneficial, protecting and supporting them financially.
- Prior to the impact of Covid-19, families reported the funding for community and employment supports was valuable.
- Many families greatly appreciated when they had support coordinators that went above and beyond in supporting them.
- Having consistent and dependable services and workers was highly valued among families.
- Those who have received respite care said that the supports alleviate or lessen caregiver burnout.
- Tennessee families are grateful for the possibility to have assistance, funding, and support for their loved ones with special needs.

Impact of Covid-19

The impact of Covid-19 on families has been dire. Due to the need to contain the spread of the virus, all community integration services have been cancelled and in-home supports have become next to impossible to safely use or find. Prior to the outbreak of Covid-19, the direct support professional (DSP) crisis had been ongoing but now is magnified dramatically. Families had already been struggling to find qualified providers or workers and now find it extremely difficult or cannot risk their loved ones' health by introducing new people into their homes. Families reported that they have lost their worker(s) or have had to discontinue Consumer Direction (CD) services due to this concern. In some cases, they are unable to work full-time due to being the sole caregiver for their child. This has led to loss of income and career opportunities at this critical time. Being a full-time caregiver and receiving the stipend does not make up for this loss of income. Families reported that the stipend does not replace the CD worker, as it is 25% less than what a worker makes through CD. During the Covid-19 crisis, families report that funding in their budgets is unable to be used due to severely limited providers and/or community services. Some describe feeling unknowledgeable about new ways to utilize funding or are unable to use other services. The rigid design of the ECF CHOICES program limits families' options to utilize benefits during this time. The current either/or policy is not beneficial to families. For example, families must choose between CD or the family

caregiver stipend. Similarly they can receive respite care or a personal assistant, but never both. Based on families' feedback, the following recommendations have been put forth for review:

- *Allow the parent/caregiver to be considered and paid to be the DSP, at least during the international health crisis.*
- *Increase flexibility of the Program's benefit options.*
- *Increase the stipend, to recover and survive through the impact of Covid-19.*

Providers & Service Delivery

As mentioned before, there continues to be a DSP and provider crisis. Finding a provider that meets individuals' needs can be extremely difficult, even more so if the individual has significant behavioral needs or is rurally located. One family who participated in an interview reported that there were zero providers in her rural town. She became a full-time caregiver for her child and was then unable to financially support her family. This led to the loss of their home, and they were forced to relocate to a more urban area to obtain services. Another family mentioned that families worry about whether or not they can work enough to support their families and if not, that they could lose their child to foster care. Families frequently talked about putting their careers on hold indefinitely or losing income to work part-time or from home in order to be the sole caregiver. Their options become severely limited and in the case of single caregivers, situations can become dire.

The field is not attracting or retaining qualified, competent workers due, in part, to non-competitive pay scales. Skilled workers are being lost to jobs that pay more competitively and have less risk of exposure. One consequence has been high turnover rates at provider agencies. This has significant negative consequences for the member, often in the form of increased behavioral issues, as well as for the family. 100% of families who have utilized CD recommended increasing DSP pay.

Another area to address is service delivery of respite care. Families need more providers qualified for respite care of young children. Historically respite providers worked with adults or the elderly. Agencies have told families that young children pose a "liability" and, therefore, they do not provide services to that population. On a related topic, it was mentioned that sending families to providers to interview was not ideal and that having a list of high quality providers to choose from would be more beneficial. Based on families' feedback, the following recommendations have been put forth for review:

- *Increase DSP pay to a competitive rate and recognize the profession with professional associations or certifications.*
- *Strengthen the provider network in rural areas.*
- *Address the need for pediatric respite providers, competent in providing such services to young children.*
- *Increase benefit hours, particularly for single parent/caregiver situations.*
- *Provide families with a list of providers to choose from that have good ratings or information to help inform their decision.*

Consumer Direction & Public Partnerships LLC

The majority of families that used CD reported significant dissatisfaction. The concept of CD is very appropriate and has benefited many families, but some areas of the Program need improvement. The lengthy and difficult-to-navigate onboarding process with Public Partnerships LLC (PPL) is a prominent area for growth. As one family put it, “people apply when they want to start working but it takes a month, out-of-pocket expenses for trainings, [has] a very stringent online application, [and] is very precise and gets kicked back due to errors,” leading to increased time for onboarding. This laborious process costs parents out-of-pocket as they pay for various trainings and supplemental pay in order to retain good workers. Application and onboarding takes well over a month to complete, and families are losing potentially good applicants due to this.

Families provided feedback on their experiences with PPL's support brokers, describing them as “not overly helpful”, “not personable” and having “poor communication skills”. Additionally, families said they experienced difficulty coordinating between the worker(s) and the support broker. Based on families’ feedback, the following recommendations have been put forth for review:

- *Decrease the time it takes to approve and pay new workers.*
- *Cover the cost of required trainings and certifications.*
- *Provide customer service training to PPL support brokers.*

Communication and Customer Service

Good communication is vital to the success of any program, and respondents highlighted ways in which all aspects of the ECF CHOICES Program could improve. Families are faced with an immense amount of paperwork from various organizations related to their ECF CHOICES benefits. This is overwhelming and confusing when each organization (TennCare, DIDD, MCOs, PPL, provider organizations) uses a different set of terminology and processes. In order to decrease confusion, families need the ECF CHOICES staff to understand each programs’ terminology so that policies and procedures that are interrelated within the various agencies can be clearly explained and understood. A prominent example is the title of the Employment and Community First CHOICES Program. Families were confused by this title and initially thought their child was not appropriate for the Program because their child was not old enough to be employed at the time of application.

In order to provide families with the highest quality customer service, each organization within the Program would benefit from staff trainings so that confusing, absent, or incorrect information is not shared. Staff who are knowledgeable about the various programs and their interactions and can share that information in a way that is understandable have a significant positive impact on families’ lives. Alternatively, poor communication can negatively impact families’ lives in many ways. One example involved a family that was told for 14 months that they were not allowed to leave the home if the worker was present with their child. This led to increased caregiver burnout and increased difficulty performing everyday tasks outside the home. With repeated calls, this family was able to resolve the issue but was also told “No one

told you this information.” Another family was told that they were unable to be reimbursed when they took over conservatorship of a loved one, only to find out later that they missed out on eligible funding for their child due to incorrect information shared by ECF CHOICES employees. These two examples highlight the need for improved communication and customer service in the Program.

An experience shared by one family as they moved from another state into Tennessee highlighted an opportunity for collaboration between state’s Medicaid programs. This family had a difficult time discovering and obtaining services for their child, a process that took more than two years. To ensure top tier support to families and continuity of care for individuals, state Medicaid Programs could assist families in their transition by identifying the next point of contact for transitioning service from one state to another. Based on families’ feedback, the following recommendations have been put forth for review:

- *Provide collaborative trainings between each ECF CHOICES-related agency in order to cross train on terminology and processes.*
- *Create a more user-friendly way to deliver better, more detailed explanations of the Program and available services, with less jargon.*
- *Rename ECF CHOICES to provide clearer communication to families what the Program potentially offers.*
- *Address state-to-state collaboration among Medicaid agencies to assist families in identifying the next point of contact for families in their new state.*

Program Design

A one-size-fits-all approach has been taken while creating the ECF CHOICES Program, and families are not always able to find providers or services that fit their child’s needs well. The supports and services this Program provides assist individuals to fully participate in their community, the value of which cannot be overstated. Individuals with disabilities can develop independence and gain skills through this Program. However, in its current state an initial financial investment is required and some families cannot afford that. In several cases, families report having to pay out-of-pocket for costs associated with their benefits. Reconsidering the reimbursement-only policy would alleviate this financial strain on families as they utilize benefits, such as the family education and training funding. On a similar issue, families report that when using the benefits to attend community events, expenses such as hotel, transportation, food, etc. are not covered. Families recommended increasing the available funding for community events in order to cover associated costs with event attendance. A related issue is the lack of inclusive community programs and services available to families. Ideally, families would be able to find and participate in non-segregated programs and services but currently such programs are rare. The community has not caught up to the ideal of inclusive design yet and until such time, ECF CHOICES members deserve to be able to access community programs.

Community supported living is another aspect of the program that families would like to see funding expanded. One family expressed that “... The adults in the ECF CHOICES group 4

Program deserve the opportunity to live independently in their community with supports, if they so choose.”

A stronger behavioral services component to the Program is needed for those with behavioral needs that are long-term. One family reported that her child was unable to utilize most benefits available to them due to her child’s significant long-term behavioral needs, which were not able to be met in group 4. Another family had to seek advocacy help when their child’s placement in the Program was threatened due to not using benefits because of ill-fitting services and providers. This left the family feeling that they were being chastised unfairly for a poor provider network or provider fit, something well beyond their control. Based on families’ feedback, the following recommendations have been put forth for review:

- *Develop more options for inclusive activities and services in the community.*
- *Increase funding available for community events, to cover hotel, transportation, food, costs.*
- *Increase funding for community supported living.*
- *Allow for funding to be used for therapeutic equipment as well as assistive technology.*
- *Accept and pay purchase orders or invoices directly for parent education and training allowance, as opposed to reimbursement.*
- *Provide a more comprehensive behavioral services component to the ECF CHOICES program in order to more fully serve those with long-term needs.*
- *Provide a more robust Mobile Crisis Service with expertise in the I/DD population.*

Managed Care Organizations (MCOs)

The overwhelming majority of respondents used BlueCare and reported a high rate of satisfaction, particularly highlighting timely responses and high level of support from their support coordinators. Many felt that their support coordinator was very helpful and supportive but appeared unknowledgeable on the Program, increasing time needed to solve problems. The Member Advocate position was only known by two respondents, both of whom served on regional advisory councils. Only one of those families reported any interactions with her Member Advocate, saying that she had received excellent support. Some families reported differences among their MCOs and how benefits were allocated or how processes worked. Families expressed the need for clear, transparent communication about why processes are different or why benefits may differ from others in a similar situation across all 3 MCOs. Based on families’ feedback, the following recommendations have been put forth for review:

- *Increase awareness of Member Advocate position to families not on advisory councils.*
- *Provide training to support coordinators regarding the ECF CHOICES Program.*
- *Address low provider acceptance rate with UnitedHealthCare.*
- *Provide clear, transparent information to families about the way the MCO delineates benefits.*

Enrollment

Many families that provided feedback were in the first round of enrollees to the ECF CHOICES program and stated that they were able to enroll in-person. One family described this as having “made all the difference.” Another family stated that the online application was “very frustrating” due to irrelevant questions such as child’s income when the child was too young at time of enrollment. Having access to a live person when encountering difficulties enrolling is very helpful for families, as communication via phone or email was described as “much more difficult.” Based on families’ feedback, the following recommendations have been put forth for review:

- *Provide live person assistance during online application and enrollment.*
- *Prioritize in-person enrollment for improved customer service experience for families.*

Conclusion

To conclude this report, the families that participated in this feedback survey would like to share their gratitude for the Program and the services and supports it provides.

We respectfully submit this report and recommendations for your consideration as you continue to refine the Program to be even more responsive to meeting the needs of the individuals served.