



**A REPORT
ON FAMILY EXPERIENCES
DURING TRANSITION YEARS FOR YOUNG ADULTS
WITH BEHAVIORAL HEALTH NEEDS**

Summer 2018

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Maryland Coalition of Families for Children’s Mental Health
North Carolina Families United
Oregon Family Support Network, Oregon
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Wisconsin Family Ties, Wisconsin
Youth and Family Peer Support Alliance, Illinois

DEDICATION

To the children, youth and families who struggle with behavioral health challenges and the service providers who strive to help them.

AUTHORS

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ABOUT FREDLA

The Family-Run Executive Director Leadership Association (FREDLA) is a national network of family-run organizations across the United States. FREDLA works to build leadership and organizational capacity of family-run organizations. FREDLA grew out of the family movement and has a vested interest in ensuring that the family-run organizations are strong, and every family member’s voice is heard throughout the system.

FREDLA has grown to become a respected source of information and technical assistance to states, communities, and family-run organizations. FREDLA is a partner with The National Training and Technical Assistance Center for Children’s Behavioral Health facilitated by the University of Maryland School of Social Work and funded through the Substance Abuse and Mental Health Services Administration (SAMHSA).

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INTRODUCTION

There is a crucial need to better understand families' experiences during their children's transition from the child mental health system to the adult mental health system. This transition typically occurs when youth are 18 to 25 years of age and coincides with developmental milestones for emerging adults, as well as changes in legal status that affects parental rights. Due to the lack of research on the benefits of involving family members in services during this transition, there are also few recognized best practices regarding parental involvement. Service delivery approaches in the adult system typically do not emphasize family involvement as a key component of treatment. Thus, there is a need to provide guidance to the field on family engagement for young adults with behavioral health needs transitioning to adulthood.

In March 2018, FREDLA held an expert convening of six major technical assistance centers, four local and statewide family-run organizations and three national family organizations to identify research and resources on this topic. As a follow-up to this effort, FREDLA worked with ten family-run organizations across the country to organize discussion groups with parents and caregivers of youth between 18 and 25 years of age who have behavioral health challenges.

Family members who participated in the discussion groups had youth and young adults with a variety of challenges, including youth and young adults on the autism spectrum, severe depression and suicidal behaviors, substance use, homelessness, and justice involvement. A total of 67 individuals participated in the discussion groups. Of those who provided information about their child's system involvement, more than half identified that their young adult was involved 2 or more systems (see Appendix A). Families represented both urban and rural areas as well as families with children on Medicaid or applying to get Medicaid and families with private insurance. Some families had their young adults living at home with them while others reported their young adults were living in residential settings, were homeless, or incarcerated.

The terms "youth" and "young adult" is used throughout this report. Youth refers to youth 14 to 18 years who are approaching transition, whereas the term "young adults" refers to young adults 18 to 25 years in the process of transition to adulthood.

HOPES AND DREAMS

“ Our kids want what everybody wants at this age.”

For any young adult, the transition to adulthood involves multiple biological, cognitive and psychosocial changes and decisions. These changes and decisions are compounded when a young adult also struggles with behavioral health needs. When parents were asked to define successful transition to adulthood for their young adults with behavioral health needs, parents responded that they want their children **to reach their goals and to be as independent as possible**. They said that their young adult children wanted to feel independent and able to do things on their own, despite their challenges. Their children wanted what all young adults their age do--to get a driver's license, have a job, or go to college, live on their own and socialize with peers and develop healthy relationships.

While parents acknowledged that their young adults wanted to feel independent and capable of making their own decisions, parents also voiced concern that their young adult children may face challenges that their peers without behavioral health challenges do not. Some parents commented that their youth and young adults with behavioral health challenges seemed to mature more slowly making them at risk of making poor or impulsive decisions that could have dire long-term consequences. Parents' primary worry was about their children's safety. Their young adults also had social and emotional issues that tended to isolate them from peers.

“ Successful transition means learning the essential life skills to be able to make it with minimal or no parental support.”

Parents expressed a strong desire to help their children take on as much of the decision-making role as possible in ways that support their self-efficacy and safety. As one mother poignantly explained her primary goal is to prepare her child for the day that she will no longer be there to support him. For her, this meant coaxing her son to take on new challenges, when he was reluctant to do so, and helping him gradually develop the life skills and confidence to pay his

SUCCESSFUL TRANSITION:

“A successful transition into adulthood would require that the youth be able to live independently, secure employment, and provide for themselves some sort of income, have the life skills necessary to find themselves transportation, further education or whatever they need to get into the next phase of adulthood.”

“Basically, they need to be able to move out and live on their own.”

“Successful transition from childhood to adulthood would be having my kids go out into the world without being arrested or going to jail.”

“They need to graduate from high school or get a GED or [some other training] so that they are able to learn how to provide for themselves.”

“A good transition would be if I knew what the plan was going to be fore my child when he turned 18. What life was gonna look like without me.”

“It would be for the young adult and their support system to truly understand what's expected of them from different providers so that the transition is handled smoothly.”

own bills, keep a job, and live on his own. Other life skills that parents mentioned included being able to take public transportation, schedule medical appointments, keep a job, go to vocational training or college, and have healthy peer relationships. Parents want their young adult children to be able to advocate for themselves. Most importantly, they want services and supports in place to ensure their safety and well-being.

PLANNING FOR TRANSITION

“Successful transition may look different for different young adults depending on their needs and challenges.”

Federal law requires that transition planning begin for students in special education by the child’s 16th birthday. However, many students with behavioral health needs do not have an IEP, therefore transition planning is not mandated. Parents reported that transition planning often starts around 17 years of age, which does not give families enough time to get services from the adult system in place before their child’s 18th birthday. As services and supports from the child service system end, parents must search for resources that are available from the adult system and complete the necessary paperwork to get services and supports in place. There usually is little time to do this, causing parents to feel stressed and gaps in services to frequently occur. Parents who had private insurance said that transition planning was basically non-existent.

ELIGIBILITY

“My child didn’t quite fit the criteria.”

Eligibility and access to appropriate services was a major topic of discussion. Eligibility criteria in the adult service system are often significantly different from the eligibility criteria in the children’s behavioral health system. As a result, youth who may have received services and supports for many years as children may face a reduction or discontinuation of services and supports around their 18th birthday. Many of the parents reported that their young adults met some but not all the criteria for eligibility and were therefore denied services that could have benefitted them. They described their young adults as being in a “gray area that nobody knew what to do with them” or that they had “fallen through the cracks.” This was particularly true for young people who had diagnoses “not otherwise specified” or NOS. Another related problem occurred when the young adult did not have a diagnosis as a child.

An inability to qualify for services or the lack of developmentally appropriate services in the adult service system may result in serious consequences for young adults. For example, one mother explained how her daughter ended up homeless when she couldn’t

qualify for services. Other parents talked about their adult children languishing at home, getting in trouble with the law, or becoming suicidal.

SILOED SYSTEMS

“Each partner agency has their own policies and sometimes those policies clash.”

Parents noted major differences from the child-serving system to the adult system. These differences include: different ages for transition, a different array of services and different eligibility criteria. All these differences make navigating transition complex, confusing and challenging under the best of circumstances. If youth are involved in multiple systems, transition planning can be more challenging because the process varies across systems and availability of services may vary across geographic regions even in the same state. A parent explained that his son was involved with the special education, child protective services, and the juvenile justice system. The timelines for transition started at 14, 16, and 17.5 years respectively and there was little coordination between the systems. Parents stressed that consistent ages for transition across systems would afford more time for this multi-faceted and complex process.

ACCESS AND AVAILABILITY OF RESOURCES

“We can’t get the resources we need.”

While states and communities have built a robust array of services for children and for adults, parents reported a lack of appropriate services for youth and young adults transitioning from the child service system to the adult system. Likewise, parents raised concerns about the limited number of services that are covered by private insurance. As one mother explained, the out-of-pocket costs of services are

YOUNG ADULT SERVICE NEEDS:

“There are resources out there, but the child and the family really have no idea what they are and how to access them.”

“Adult service providers have not been trained how to motivate [our kids] or even what services and supports are available.”

“Oftentimes individuals have services when they are children and all of a sudden they’re gone because people have not figured how to access those same services under the adult system.”

“There are things out there for high functioning kids, but for kids who are transitioning out and low functioning there are not enough programs.”

“Just letting someone go after 30 days is irresponsible. No kid is able to walk out of rehab after 30 days and have the tools to stay clean if they were in deep before they went to treatment.”

“My son deals with wandering and it’s a safety issue...I need to make sure there is someone who can do the one-on-one support.”

“Sometimes finding programs that actually go beyond job placement is definitely needed.”

“The child and adult service systems are siloed.”

expensive, and she “fears the day when her daughter turns 26 years old and falls off her insurance.”

Parents identified a variety of services and supports that they felt would benefit their young adults as they transitioned to adulthood. The most frequently cited were basic life skills (e.g., learning how to pay bills, schedule appointments, and problem-solving), transportation (e.g., help getting a driver’s license or learning how to use public transportation), vocational training and job assistance (e.g., writing resumes, interviewing, job coaching), educational support (e.g., academic accommodations in college or training programs), peer support, and housing assistance (i.e., finding housing that incorporates the supports for that young adults with behavioral challenges need to live independently).

The process of qualifying for Medicaid or other services from the public sector can be complex and confusing. Parents struggled to get information and felt that some providers were not knowledgeable about ways to assist families to access services and complete the necessary paperwork.

Transition can be one of the most difficult and daunting times for young adults and their families. Parents felt that this transitional period should be a time when supports and resources are augmented rather than being reduced or eliminated.

CONFIDENTIALITY AND COMMUNICATION

“ The adult system is not equipped to be able to address things from a family perspective.”

For parents in the discussion groups, communication is a safety issue. Parents in the discussion groups felt that HIPAA and providers’ concerns for confidentiality creates barriers to families staying involved and at times can put their young adults at risk. Parents said they felt that adult service providers are often reluctant to involve family members in their young adult’s care due to confidentiality concerns. Parents sensed that providers were supporting the young adult’s developmentally-appropriate need for independence and providers felt that involving parents would foster dependence. Parents were frustrated by provider’s lack of understanding about how family involvement could be an asset to supporting their young adult’s care and fostering independence.

“It is frustrating to watch your 18-year-old get into the adult system and crash because services and medications have not been transitioned.”

Many of the parents described situations where providers either did not engage families or had minimal communication with the family even when releases of information were in place. They felt that adult providers did not understand the developmental needs and behavioral health concerns of their young adults, who mature more slowly, and how it ~~can~~ can affect their ability to meet age appropriate expectations. Parents were concerned that young adults can become discouraged and disengage. At the same time, parents understood and supported their young adults being given more authority to make decisions. However, they expressed concern that the systems and providers did not fully appreciate the detrimental consequences that could occur if the young adult were to make a poorly informed decision like discontinuing medications. Parents felt strongly that their input would be beneficial when it comes to critical decisions that may put their young adult’s safety at risk. In many instances the parents were the safety net if and when things went wrong and yet they had little input in the decision-making process.

“Communication is key.”

Parents identified several things they would ask from providers to facilitate better communication including:

- ***Encourage young adults to involve their parent/family members in their care:*** Young adults have a right to determine the degree to which their families are involved, and involvement can look different based on the individualized needs and preferences of the young adult. Providers have a critical role in encouraging young adults to involve their families in their care. Some young adults may want or need their family involved in their

PARENTAL INVOLVEMENT:

“I cover my son’s insurance, but I am excluded from the decision-making process regarding his services.”

“There should be specific policies to allow the family to be part of treatment planning.”

“Despite all the consents she signed, they still don’t contact me.”

“There has got to be a way to get some family member legitimately included in the contact information, in appointment scheduling, and whatever follow-up is needed.”

“He needs to interact with his own peer group, but he needs his family support to feel comfortable there and to get him there.”

“You don’t want to take away their independence, but guardianship is needed because they are making decisions that can be a safety concern and detrimental to their health.”

treatment decisions; others may want or need their family involved in financial matters or navigating transportation needs. It would be helpful for providers to discuss options for involving families in a positive light as well as revisiting the topic from time to time as the young adult moves through transition.

- ***Training on HIPAA & confidentiality:*** HIPAA need not be a barrier to communication with families. Providers should be knowledgeable about options, such as release forms and advance directives, in which families can be appropriately involved in their young adults' care.
- ***Recognize the value of family involvement:*** Family involvement in appropriate ways should be an essential component of services for young adults. Parents want to work with providers to provide information about their young adult's unique needs and how to motivate them. At the same time, parents can support young adults in keeping appointments and encouraging them when they are finding it difficult to remain engaged.

WHEN IT WORKS

"I am grateful that the organization listened."

When communication with parents is open, providers can better meet the service and safety needs of young adults. Some parents gave examples when providers listened to their concerns and involved them in the care of their adult children. One parent described a very positive experience with a provider who honored the decision-making authority of the young adult, but at the same time discussed with him the benefits of involving family members in his care. The young adult chose to involve the parent and they collaboratively defined the parameters of parental involvement. Other parents gave examples of how open communication with schools and residential facilities allowed them to respond to their adult children's behavioral health needs and ensure their well-being and safety.

RESOURCES AND SERVICES THAT SUPPORT FAMILIES

Parents reported feeling overwhelmed by the transition planning process and having to learn how to navigate the adult behavioral health service system. Parents identified resources and services that would be supportive as they navigated the transitions process with their young adults. These included:

- ***Centralized information and resources about adult services and supports:*** Parents expressed a need for one centralized place to get information about services and community resources for both the child and adult service systems.

Currently, parents felt that information is “scattered” and “difficult to obtain.” Parents said that when their child was young they had to learn how to navigate the child serving systems to obtain services and supports. As their child becomes a young adult, everything they have learned about how the child serving systems becomes obsolete and they must learn how to navigate an entirely new system--the adult service system that involves new processes, protocols, and different eligibility criteria.

- **Family peer support:** Many parents described the unique and valuable support they received from parent peer support providers. They spoke about how helpful it was to have another parent who had navigated the transition process with their own young adult and who could assist them to understand how things worked. They shared how valuable it was to have someone who listened and understood what they were going through. Several of the parents also described the critical support they received from a family-run organization including peer support, education, support groups, trainings on navigating the adult service system, events and resources.
- **Tools and resources to help parents understand young adult development:** Several parents suggested that it would be helpful to have an easily accessible tool that described social, emotional, and developmental milestones for young adults. This information would help parents know what should be expected and assist in finding the best programming to make sure that young adults stay engaged and moving forward towards their goals.

FAMILY SERVICE NEEDS:

“I live in a rural community. A lot of our parents have no idea that there are services available and they don’t even know what they need.”

“Just having a central place where you can access resources and ask questions about how to navigate the adult system would be helpful.”

“As the sole provider for my child, I look for connection to other parents who understand what I’m going through.”

“As family members, we don’t go away after our child has turned 18.”

“We have the child and family team meetings which technically [coordinates services across systems]. The unfortunate thing is that it doesn’t carry over to the adult system.”

“It would be helpful to have tools to help parents understand the developmental milestones for young adults and how they are affected by different disabilities that our kids might have.”

- ***Trainings and access to expertise on legal and financial issues:*** In addition to information on resources, parents expressed a need to learn about legal and financial matters once their child turned 18. Parents reported they were discouraged from obtaining guardianship of their young adults and did not have the information about other options, so they could make informed decisions. They requested trainings on topics such as types of guardianship, power of attorney, ABLE accounts, and special needs trust funds to plan and make decisions for their young adult and family.
- ***Self-care:*** Finally, parents reported high levels of stress, frustration and anxiety related to their caregiving role. Those parents whose young adults live at home especially need support services so that they can take a break while knowing that their adult child is safe and being taken care of by a qualified provider. Caring for their children with behavioral health needs is difficult and often a life-long responsibility for parents. Parents need supports and resources for self-care strategies for their own physical and mental wellness. Because parents and family members will support young adults long after the service system programs are gone, it is important to promote and support caregiver self-care strategies.

POLICIES AND SYSTEMS THAT SUPPORT FAMILIES

Beyond services and supports, parents also identified policies and systems changes they think would improve services and supports for young adults and their families, including:

- ***Fund peer support for young adults and for families:*** Funding is needed to support both types of peer support during the transition years. Young adults need and value the support of peers their own age who can listen, understand, and support. Families also need support specifically around transition and navigating the adult service systems.
- ***Creating a flexible period of transition:*** A flexible transition period from 18 to 25 years when young adults could access services and supports from the child and adult services systems would accommodate the developmental needs of young adults. This would allow the youth to choose services from the child serving system while they gradually transition to the adult service system.
- ***Improve coordination of transition planning across systems:*** Requiring transition planning to start at the same age across child welfare, juvenile justices, intellectual disability/developmental disability systems would enable better coordination and strategic planning for youth and families who are involved in

multiple systems. Families felt creation of a web-based system for applying for services across different systems and providers would facilitate a more seamless process for young adults to access services. Moreover, using a teaming approach similar to child and family team meetings to bring youth, families, and child and adult service providers to the table to plan and implement care plans.

- ***Increase funding for services transition age youth and young adults:*** Parents felt that there is a great need to direct funding to the expansion of the supports, services, and care coordination for transition age youth, young adults, and their families. Since transition age youth have diverse needs and many young adults meet some but not all the requirements for existing services and therefore do not qualify for them e.g. NOS diagnoses, there is a critical need to develop a broader array of services.
- ***Provide training for adult providers and professionals:*** Training for providers and professionals is a step to helping providers understand the benefits and options for involving families in care of their young adults. Training could help change the culture of some providers who feel that families infringe upon a young adult's independence rather than support independence. Additionally, training on resources, options for family involvement through release of information or medical power of attorney would be helpful to ensure that providers, youth and families work together toward the same goal – independence for the young adult and achieving their goals.

APPENDIX A

PARTICIPANTS

Sixty-seven individuals participated in the discussion groups. Fifty-seven (85.1%) were women and ten (14.9%) were men. The majority were Caucasian (59.7%), followed by African-American (32.8%) and other ethnicities (7.5%). Fifty-eight (86.8%) were currently caregiving for a youth or young adult between 18 and 25 years of age, 3 (4.5%) had children older than 25 years of age and 2 (3.0%) had children under 18 years of age who were preparing for transition to adult services and one (1.5%) did not respond to the question. Two participants (3.0%) indicated during the discussion group that they had transitioned themselves.

Table 1.
Percent of Youth and Young Adults by Type of System Involvement,
FREDLA Discussion Groups on Transition,
Summer 2018 (N=65) ^{1, 2, 3}

