Psychiatric Residential Treatment Facility Waiver Demonstration

Storytelling Project

Interviews and Stories by Harriet S. Bicksler, MA

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Section 6063 of the Deficit Reduction Act of 2005 authorized up to $218 million for a five-year demonstration, Community Alternatives to Psychiatric Residential Treatment Facilities (PRTF) from fiscal year 2007 through fiscal year 2011. The Centers for Medicare and Medicaid Services (CMS) awarded grants to nine states to develop and provide home and community based services and supports to children and youth with serious mental health challenges who met the level of care for treatment in a Psychiatric Residential Treatment Facility.

This Demonstration grant waiver program, often called the PRTF waiver, was designed to enable CMS to develop reliable cost and utilization data to evaluate the effectiveness of community-based service-delivery models, such as wraparound, whose goal is to reduce placement in institutional settings when implemented with fidelity to the model and within a system of care approach that includes the necessary array of services and supports. As part of the Demonstration, Congress included an evaluation component to answer two specific questions: 1) Did the Demonstration services result in the maintenance of, or improvement in, a child’s or youth’s functional status? 2) Did the waiver treatment costs, on average, total no more than anticipated aggregate PRTF expenditures in the absence of the Demonstration? In response to these questions, the nine states have clearly demonstrated that the children and youth are maintaining or improving their functional status at an average cost of less than a third of the cost of a PRTF.

The goal of this demonstration was to prevent or shorten stays in residential treatment settings while improving outcomes for children and youth with serious mental health challenges in areas such as education, family relationships, mental health and co-occurring disorders, and decreasing contacts with the child welfare and juvenile justice systems.

The following stories from each of the nine states give a more personal view of how and why this initiative has been so important in the lives of the children, youth, and families that have participated in this demonstration project.
Engaging Families Through Motivational Interviewing

Susan Mayer, Denali Family Services and Barbara Knapp, Alaska Project Director

One of the unique features of Alaska’s PRTF waiver is that all the children selected for participation are affected in some way by a Fetal Alcohol Spectrum Disorder (FASD). In addition, they have a mental health diagnosis and are at risk of placement in a residential treatment facility. The waiver provides another pot of money as a resource to serve these youth, whether through respite services for parents, therapeutic foster care, a mentoring program similar to Big Brothers-Big Sisters, or training for providers, which is how Susan Mayer became involved.

Susan was among those trained when the waiver provided the funding to bring experts in the Families Moving Forward intervention model to Anchorage, Alaska to train clinicians. Families Moving Forward is the only empirically supported treatment model for families and children affected by FASD. Children with an FASD were prenatally exposed to alcohol because the birth mom drank alcohol while she was pregnant. The alcohol causes a brain-based disorder which is permanent. Most of the time there are no outward signs of FASD (the “FASD face” occurs in less than 5% of youth with the disorder); therefore, interventions need to focus on finding ways to handle the behaviors that are typical of those with an FASD.

Children with an FASD are brought to a mental health center because of behavior issues such acting out, disobeying authority, impulsiveness, aggression, or making the same bad choices over and over that get them in trouble at school or with the law. They don’t “get better” with traditional therapies or behavior modification techniques. Psychological testing often paints the picture of a youth who is immature in appearance with normal intelligence. The youth may have some learning disabilities, slow auditory processing skills and a poor memory; he or she may also be a concrete thinker who doesn’t understand double meanings of words in jokes and who doesn’t read facial cues or body language very well. Bright lights, over-stimulating classrooms, and/or a chaotic home-life can precipitate even more negative behaviors. The youth wants to fit in and have friends. Teachers want the student to behave and stop interrupting the classroom. Parents want the youth to learn from mistakes so he or she will succeed and become an independent adult. But the youth can’t change the damage already done to the brain and doesn’t understand the reasons for the inappropriate behavior and inability to learn.

Because youth with FASD fall along the spectrum of the disorder, some experience small effects and some—like those on the PRTF
Waiver—experience FASD serious enough to prevent them from ever living independently.

As a clinician at Denali Family Services, Susan estimates that almost half of the caseload at Denali is affected by FASD, so being trained in an intervention model that specifically separates the externalizing behaviors of youth from the long list of mental health diagnoses that are so problematic for their parents has been very important. The program is in-depth and highly structured and cannot cure or fix the FASD, but does give families strategies that work with their child. The clinician meets with the family over nine months, often in the home.

Because the program is so intense, not all families are willing to make the commitment. Those who do find they are supported and given specific tools to help them deal with the frustrating behaviors of their children. Susan notes that the program is often more about the parents than their child; because parents are given “homework” (such as keeping track of how often, where and when certain behaviors happen), they feel like they are actually doing something and consequently feel less hopeless and helpless. At the beginning of the intervention, the therapist does a complete functional assessment with the parent and child to find out the triggers for behavior and how the child reacts to things in his or her environment. The assessment helps to determine patterns of behavior—for example, the child always has a problem when this happens but never when that happens. The therapist is able to do “fly-on-the-wall” observations of the child in his or her home environment, and then help the parent learn how to track behavior. While every parent may have a lengthy list of problem behaviors to address, the therapy often focuses on just three, ranking how often and when they happen. Once they start tracking a specific behavior, almost immediately the frequency starts to decrease, probably because the parent becomes more aware of what triggers the behavior and how to redirect the child prior to the trigger. At the same time, the child is also learning new coping skills. As parents feel more competent, and less helpless, the child’s behavior improves.

Amy is the birth mother of Tony and knows that her alcohol use during pregnancy caused problems for her son. Tony had significant impulse control issues and his behavior easily became violent. Family systems therapy didn’t help, and finally Tony ended up in acute care and a residential placement because he did not change or learn from his mistakes. As a condition of his release, Amy agreed to outpatient treatment—at this point she was willing to do anything to help her son.

Susan began working with Amy in her home and helped her understand how FASD affects behaviors and other mental health diagnoses. Based on the initial assessment Susan conducted with Amy and Tony, they created a plan that helped begin to bring about good changes. At a feedback session after four months, Susan evaluated Tony’s executive function, noting that he continued to have sensory issues, but his academic skills were on par with his classmates. Susan used this information to help Amy advocate for Tony at school during Individualized Education Plan (IEP) meetings. Finally, Amy is experiencing some relief from years of feeling like nothing worked for Tony.

The success with Amy and Tony is one reason Susan is so enthusiastic about implementing the training she received for working with children who have a mental health diagnosis along with FASD. Susan believes that the core technique of motivational interviewing creates families who are engaged and enthusiastic, and Susan has been able to develop the kind of therapeutic relationships that help families achieve success when so many other attempts have failed. Amy and Tony are proof of that.
Fifteen-year-old Sapphire spent a year and a half in a residential treatment facility thousands of miles away in another state. When she was released to come home to Alaska, her parents were concerned because she still had significant needs for intensive behavioral health services and they had two other younger children at home. As part of the “Bring the Kids Home” initiative to return children to Alaska from their out-of-state placements, the PRTF waiver program for kids with a serious emotional disturbance (SED) and a Fetal Alcohol Spectrum Disorder (FASD) was able to provide 40 hours a week of mentoring services for Sapphire.

Brenda Dow, a clinician at Presbyterian Hospitality House (PHH, a community mental health center in Fairbanks, Alaska), is also the agency’s lead plan of care coordinator for the waiver program. The PRTF waiver offered trainings that prepared her with specific interventions for kids with FASD. Brenda built a mentoring system within PHH to provide these interventions to youth with SED and an FASD. It is now the largest program in the state.

Initially, one mentor was hired to assist Joel, the first young man selected for the waiver. Brenda says his was a “test case” to determine whether mentoring would really be effective. Despite concerns about the possibility of an increased staff workload and family concerns about having extra people in the home it has all worked out. Joel’s mentor worked with him one-on-one every day, and eventually Joel started doing better in school and at home. As Joel improved, Brenda and her colleagues had something of an ah-ha moment: they were impressed by the results, realized that the extra person in the home wasn’t a problem, and they subsequently decided to expand the mentoring program.

Mentors enhance and reinforce the day-to-day efforts of parents and family members. Because some children with FASD have memory issues, they have difficulty following lists of instructions. Mentors assist the youth in breaking down instructions into smaller steps that can be repeated over and over until the child completes it with little intervention. For example, rather than tell a child to get ready for school, the mentor breaks down the directive into steps like: go to your room, find your school clothes, put them on, brush your hair, get your backpack. Then, they provide prompts along the way when the child forgets, recognizing that the forgetfulness is not deliberate but characteristic of the FASD. In addition, mentors use what’s happening in the moment to teach or make a point, not waiting until the next day when the child has likely forgotten about the incident. Mentors also serve as role models for positive social skills.

Mentoring in the Moment

Brenda Dow, Presbyterian Hospitality House

Back to Sapphire…. She came home to Alaska in May, had a full-time mentor for the summer, and started school in the fall. During the summer, she worked as a volunteer on a farm and also had a paid short-term job which helped her feel successful and productive. Her mentor helped create the structure she needed to keep her going. For example, when she would go for therapy, it was important for the mentor to tell her that after therapy they would go to the library and then to the park. When the mentor wasn’t with her on Saturdays, the normal chaos of family life during weekends was too much for Sapphire, so the mentor returned to re-establish some structure. The really good news is that with the extra attention Sapphire has received, she has been successful and able to stay at home.

Brenda is pleased that the waiver’s mentor program has overcome the initial reservations...
she and her agency had about it. There are still some challenges: Brenda personally struggles to find enough time for both parts of her job, plus, finding qualified mentors who are a good fit and have the right skills has been difficult. Despite these challenges, the waiver program and mentors have helped children who experience SED and FASD, to be successful at school, at home and in their communities.

Charting a Brighter Future
Ellen, Waiver Participant and Young Mother

With assistance from the PRTF waiver program at Presbyterian Hospitality House (PHH), Ellen is living in her own apartment with her infant son. Ellen, who has Fetal Alcohol Spectrum Disorder (FASD), is 19 years old and has lived for extended periods of time in foster homes and residential treatment facilities.

Ellen has known about her FASD since she was eight years old. One night while watching television she saw something about FASD. When she asked, her mother said, “That’s what you have.” Ever since, Ellen has wanted to learn as much as she can so she understands better how it affects her and what she can do to overcome it. She gets emotional when she talks about it, but is proud of having the determination and will to fight it.

To help her adjust to independent living, Ellen has had a mentor provided by the PRTF waiver. At first she was uncomfortable having a mentor around, mostly because she didn’t know her mentor well. Ellen thinks she might like a mentor who is closer to her own age and able to understand her better. However, Ellen sees that her mentor has helped her learn to be a good mother to her son.

One of the activities Ellen has been able to participate in is an important cultural activity—a fish camp—that helps her learn about her own Inupiat Eskimo traditions. Fishing is not the only activity that takes place at the camp; Youth also learn how to make foods like fry-bread and Eskimo ice cream. Ellen describes two different kinds of Eskimo ice cream: the one coming out of her own tradition is made with caribou fat or seal oil, berries and fish, while the other uses Crisco, sugar and berries. While she was at fish camp, Ellen also went swimming and learned to kayak, despite her fear of tipping over. She enjoys making the connections with her culture, and feels it is important for her son to grow up knowing about important aspects of their culture, like hunting, fishing and drumming.

With the knowledge she has about FASD and how it affects her, coupled with her own persistence, Ellen is succeeding as a parent. Having a support system helps, too, as she works to raise her son in a healthy, loving and safe environment.
Shelia Kirksey was aware of Tammy long before she came to her current position as a waiver coordinator with Georgia’s Department of Behavioral Health and Developmental Disabilities. Tammy was one of those youth everyone in Georgia’s child-serving system knew about. Diagnosed with schizoaffective disorder, Tammy had a rocky relationship with her birth family and spent most of her adolescence in a residential treatment facility.

Shelia became familiar with Tammy’s case soon after she began her employment with the state of Georgia in 2006. A social worker by training, her work with the state has focused primarily on kids like Tammy with high-level needs, serving as a liaison between state and community providers. Now as one of three waiver coordinators, she follows 90 of the 240 active cases enrolled in Community-Based Alternatives for Youth (CBAY), the name of Georgia’s PRTF Waiver Program. The waiver coordinators work with four contracted case management entities (CMEs)—community-based provider agencies that are directly responsible for coordinating the care of the children enrolled in the waiver program. Shelia reviews and approves the plans for wraparound services that the CMEs submit from their child and family team meetings. She also provides technical assistance to the CMEs, including information about the waiver program and training in wraparound.

According to Shelia, at the beginning of CBAY, Georgia’s six residential treatment facilities wondered about the purpose of the program, what outcomes were desired, and whether it might put them out of business if the goal was to move kids out of placement into community-based programs. She and other state officials worked with the PRTFs to help them learn about the program and develop good collaborative relationships that focused on creating opportunities for the best possible outcomes for kids. For the most part, Shelia says, the waiver program has been well-received.

In Tammy’s case, a fair amount of skepticism greeted the decision to include her in the waiver program. Why would it work if nothing else had? Would she just end up back in the PRTF, like she had so many times before? To help ensure Tammy’s success when she was discharged from the PRTF to a foster family, a wraparound plan for community supports was developed—and approved by Shelia—that included everyone involved in her life. Even though Tammy is still in foster care, she has begun to mend her relationship with her birth family. When she graduated from the waiver program, she wrote a letter explaining how the program had changed her life. She may even be looking forward to living independently sometime in the future, and with the right supports she will likely be able to be successful.

From Skepticism to Belief

Shelia Kirksey, Georgia Department of Behavioral Health and Developmental Disabilities
Watching Tammy’s success is encouraging to Shelia. Her biggest challenge as a state person involved in overseeing the waiver program has been making sure there are quality services available in the community to provide the kind of supports these youth need. Sometimes she finds herself needing to weed out providers and services that don’t meet the quality standards, and often it is difficult to recruit providers in more rural areas of the state. On the other hand, seeing youth like Tammy be successful and thrive in the community, despite doubts that they could, has been one of the pleasant surprises of the waiver program. The program is clearly having a significant impact in reducing the length of stays in PRTFs and has provided a great option for families who want to keep their children in the community even when there are significant mental health issues. Shelia has been gratified by feedback from family members who are pleased with their children’s success, and pleased that some initial skepticism and fear of failure is being replaced with optimism and proofs of success.

Miraculous Progress

\textit{Ursula Davis, Georgia Family and Children’s Services Division}

Ursula Davis is familiar with Georgia’s child-serving system, and has worked with children with high-end needs for a long time, whether in the Department of Human Services’ Division of Family and Children’s Services or the Department of Behavioral Health and Developmental Disabilities. When she first started working for Georgia CBAY, she was a regional field specialist—the person who tracked high-end children, monitored their placement (medications, psychological evaluations, discharge planning), and helped staff follow the treatment plan. She also participated in interagency planning teams as the required representative from the Family and Children’s Services Division. Now she supervises people who are doing the work she used to do. She works directly with the lead person for Georgia’s psychiatric residential treatment facilities and debriefs all cases with her. She also continues to chair one interagency planning team which gives her direct service experience.

For children to be accepted into Georgia’s PRTF waiver project, known as Community-Based Alternatives for Youth (CBAY), they aren’t required to be placed in a PRTF first although they do need to be eligible for PRTF placement. Usually, however, a child has already gone through several placements by the time he or she joins CBAY. While CBAY has not necessarily decreased the number of children who end up in Georgia’s seven PRTFs, it does change the length of time they spend there.

Sam is one child from Ursula’s region whose progress has been called “miraculous” since he joined CBAY. Sam is 11 years old, and had been in two different PRTFs for one and a half years. His mother’s boyfriend physically abused him and he was put in the custody of child welfare and diagnosed with attention deficit disorder, bipolar disorder and conduct disorder. In the first facility, he struggled a lot, acted very aggressively, and didn’t make any progress. He was eventually moved to a second facility closer to his mother who was willing to participate in his therapy. The court approved him for the waiver program and he went home with his mother who regained custody after several months. When there continued to be challenges, and Sam’s mother was sometimes frustrated because the things she was doing to help Sam with his behavior issues weren’t
successful, their case manager was able to work with Ursula to assign another family team that gave Sam’s mother new tools to use.

To create the kind of positive outcomes Sam and his mother have experienced requires dealing with some systemic issues. Ursula notes that the care management entities (CMEs) Georgia assigns to coordinate the care of the children enrolled in the waiver program are not the same as the actual service providers. The CMEs coordinate the plan but don’t provide the services, and the provider agencies don’t always implement the specific treatment that has been recommended for a child. When things go well, the CMEs are able to step back, but they are always available to help with additional services or when there are problems. According to Ursula, working through the systemic issues is part of the process of learning what supports and services, and from which providers, are most effective and most likely to achieve the desired results for kids like Sam who might otherwise spend their lives bouncing around from one residential facility to another.

Something About Elijah

Written by Michele Bagby, Parent (Edited by Harriet S. Bicksler, MA)

My son Elijah faced many challenges as he was growing up. Many times I didn’t know what was really going on with him. I just knew there was something I couldn’t quite put my finger on. One thing I knew for sure is that there was something special about Elijah.

From the time he was a small child, some people thought Elijah was different or strange, but as his mother I saw him as unique. Honestly, I thought he was set apart for greater things. He was very withdrawn and somewhat depressed, and had a difficult time making his way from day care to high school. Many times I didn’t know if I was going to mentally and emotionally make it through the challenges he faced. I didn’t think I could care for him because I didn’t understand him. Elijah would cry for hours and hours. I didn’t know if he could hear me or comprehend anything I was saying to him.

When Elijah was nine years old, he started exhibiting severe behaviors. He self-mutilated and had violent spells when he destroyed anything that was in his way. He began receiving mental health treatment and was in and out of various placements. Even though I knew he needed treatment, I thought he belonged at home with his family. Sometimes he was discharged because the facility said he was too severe for them to handle, and sometimes I would take him out because I knew he was better off at home with his family. I thought that his being out of the home was causing even more emotional damage. I wanted him at home because it was where he belonged.

I loved my son. My heart ached for him and what he was going through. We dealt with many years of therapy, different providers and services but nothing seemed to work. Then something finally came along that offered hope, but at first Elijah refused to cooperate. Community-Based Alternatives for Youth (CBAY) develops plans for children and families to work on their issues together, with lots of support. As CBAY began working with us, at first it seemed like Elijah wasn’t listening, but eventually, he started really thinking about his life and what he wanted and needed to be successful. As his mother, I didn’t just want him to survive; I wanted him to thrive.

Elijah’s main goal was to be free from mental health services, independent and able to cope on his own. CBAY helped him to
achieve this goal. While CBAY was still working with us, Elijah had to return to residential placement in June 2010. When he was discharged, he was committed to leave all the negative influences behind and pursue his education at Youth Challenge Academy in Hinesville, Georgia. He chose Youth Challenge even though it was farther away from home because his aunt and uncle worked there and he knew he had a built-in natural support system there. On January 16, 2011, he left for Youth Challenge.

That day, as I waited for him to get on the bus to go Youth Challenge, I couldn’t help replaying the struggles we had over the previous years. Elijah was often severely depressed, sad and angry. He had no enthusiasm for anything and was totally unmotivated. Every day when I came home from work, he would either be asleep or sitting on the edge of his bed just staring at the television. I kept on reaching out to him, pouring out my love, and letting him know all the potential I knew he had. I refused to give up on him and settle for less than I knew he was able to do. No, I knew what was in Elijah; I could see the real Elijah deep down inside that depressed and unmotivated body screaming to be free.

So, on January 16, when we went to check in at Youth Challenge, I told him, “You have about 20 minutes to decide if you’re gonna get on that bus.” The sergeant in the final call said, “Okay, cadets, you go this way and parents, you go that way.” I ran downstairs to meet my son before he got on the bus. As the cadets came out to the bus, Elijah walked with an upright posture I had never seen before, being careful to do what he was told by the sergeant. He walked quickly to his bag to put on his sneakers, and reached out and grabbed me with one arm. For the first time ever in his life he hugged me and kissed me and said, “I love you,” then pushed away as if to say, “I gotta go now, Ma.”

My son manned up that day. I saw the man in my son that I had been waiting to see for so many years. There he was, just as lovely as I imagined. I saw years of prayers and standing firm on what I believed come true right before my eyes. He was absolutely beautiful to me as I had never seen him before. No longer was he crouched down but he stood there erect, silent and trembling inside, but as bold and strong as he knew how with his whole demeanor making a loud statement that said, “I can, I will, I must!” This was the young man I had been waiting to meet for 17 years. This was my son. I finally saw him stand up proud and strong, taking his rightful position as a man who could say with confidence, “I can, I will, I must!”
Life-changing. That’s the word Amanda uses to describe the PRTF waiver program. Placing her young son in a residential treatment facility was the last thing she wanted to do. She didn’t want to separate the family, but was almost to the point of needing to make that decision. Thanks to the waiver program, however, Cole has never been in residential placement and is doing very well, proving again that with the proper supports in place, even children with significant problems can stay at home in their own communities.

Cole is eight years old and lives with his mother, stepfather and an older brother and younger sister. When he was in day care and then in kindergarten, he was suspended because of violent outbursts. An evaluation identified a mood disorder. Amanda worried about her other children, who were often the victims of Cole’s outbursts, but she didn’t know what her options were besides residential placement or treatment foster care.

A psychotic break sent Cole to the hospital by ambulance from his pediatrician’s office. He was in the hospital for two weeks. After his discharge, he was still fairly unstable and so Amanda began searching online for help. On the state’s website, she found out about the waiver program and contacted someone who was able to schedule an evaluation for Cole. Following the evaluation, Cole was placed on a waiting list for about two months, but in the meantime staff helped get him into an alternative school.

When Cole began to receive services through the waiver program, Amanda finally had the support she needed. Perhaps the most important piece of the plan for Cole and the family is respite care. Cole spends every other weekend with a therapeutic foster family, which gives everyone a break. It took awhile to find the right fit, but now Cole enjoys the time he spends in the therapeutic foster home with children his own age.

The respite care and other supports have enabled Cole to be more independent. In addition to respite, a habilitation therapist and wraparound technician work with him. They have been helping him with his social skills, and finally he is learning to play with others and now has a friend who has some of the same issues. The habilitation therapist takes him out into the community, to the library and stores, to help him learn how to behave in public. The alternative school he has been attending gives him tools for managing his behavior, and he is now starting to transition back to regular school. He is doing well and has only had “little meltdowns” instead of the violent outbursts that happened regularly before.

When Amanda compares the before and after, she says, “Cole is like a different child.” Besides the mood disorder, further evaluations determined that he also has an autism
spectrum disorder and a form of epilepsy. He is now on a good combination of medications that don’t have negative side effects. But the differences are not just because of the right medications. The supports he receives from the waiver program staff have given him the confidence that he can grow up to be anything he wants to be—even an astronaut.

Before the waiver program intervened, Amanda felt very stressed, sad and hopeless. She and the rest of her family suffered a lot of physical abuse from Cole during his violent outbursts, she felt isolated and afraid to go anywhere with him, and eventually she had to quit her job. She didn’t know what to do. She says, reflecting on her thinking at the time, “Residential placement for such a young child was the last thing we wanted. We didn’t want to separate the family, but we didn’t see that we had any other choice.”

Since Cole has been part of the program, Amanda has been able to go back to work. She is also attending the local community college where she is preparing for a future career in social work. Whereas before Cole was miserable, now he’s a much happier child. He gives hugs to family members, and he’s excited about going back to regular school. The family is able to go out more; they’re looking forward to more things they can all do together in the future. Amanda has reason to hope that Cole will eventually be able to get a job and live normally in society either on his own or with assistance. It’s easy to understand why Amanda says the waiver program changed their lives!

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**Paying It Forward**
*Kathy and RD, Parent and Youth*

Kathy has seen it all—the good, the bad, and the ugly side of the children’s mental health system. From the very difficult task of raising a son with Asperger’s and other mental health disorders to learning how and teaching other families to advocate for their children’s needs, Kathy has experienced the whole range of emotions.

By the time Kathy was finally introduced to the wraparound services that are part of Indiana’s PRTF waiver program, she was more than ready for something that would actually work for her son, RD, now 20 years old. She and her husband adopted RD when he was very young and knew by the time he was 18 months old that he had some disabilities. When he was three, they took him to his first psychiatrist who chalked up his problems to being “just a boy—he’ll grow out of them.”

Over the next years, RD was expelled from every day care in the area. When he was seven, a therapist told his parents to have him arrested so he could get help, and so they watched him being brought into a courthouse in shackles and sent away for residential treatment. RD spent time in various residential facilities. When he was home in between placements, he was repeatedly kicked out of school and would be stared at in public “like he had horns growing out of him” because of his disabilities and difficult behaviors. RD describes himself as being very aggressive in those days: “I was always trying to hurt my parents. I had learned to be a very good manipulator.” So when the director for the Systems of Care project first talked to Kathy about wraparound services several years ago, she was understandably skeptical. She was sure it was just another lie on top of all the lies she felt she had already been told.

Kathy and her husband (who has since passed away from cancer) and RD ended up
being the first family enrolled in the Systems of Care project. Unbelievably for Kathy, a miracle happened—she received amazing support, including the kind of support she had hunted for years. Even more significantly, they actually asked her what she wanted. She learned about Individual Education Plans (IEPs) and her rights as a parent, and for the first time felt like RD was able to get what he really needed from school. Since being part of Systems of Care and receiving wraparound services, RD has made significant progress. He’s done well in school and is finally recognized as being extremely intelligent—something that is often true of people with Asperger’s but gets lost in the frustration with behaviors. He hasn’t been hospitalized in several years, and despite Kathy’s being told it was a waste of time to put him in school and he would never graduate, he has a high school diploma and has gone on to college, thanks to help from tutors and the availability of online classes. He graduated near the top of his class. Kathy acknowledges that RD still has ups and downs, but he is learning coping skills. RD says he has learned social skills and understands better who he is and that it’s okay to be the way he is. He says, “Everyone always said I’d never pass school, I’d never succeed at anything, but I proved them wrong. I have my life going the right way now.” Even now that he has transitioned out of wraparound services and into the adult system, his wraparound team continues to stay in touch with him and support him. RD says with conviction, “I couldn’t have done anything or gone this far without their help—they cared about me more than any other group I’ve been in.”

Both Kathy and RD are paying it forward. One of the issues Kathy identified early on was the stigma attached to mental illness, and so she has worked hard to reduce it. “Most of our kids thrive when they hear positive things instead of all the negative things. People are starting to understand mental health a lot better. You can’t catch mental illness from someone. You can actually help a kid have more self-esteem.” She now works as a lead family contact person for United Families, a parent-run organization that supports families of children with emotional and/or behavioral challenges through education, support and advocacy. Kathy talks about her passion for her work: “I don’t want anybody to walk in my footsteps. I want to make things better for kids with mental health challenges. I want people to see how youth can succeed. I want there to be hope for kids and families.” For his part, RD is involved with FIRE (Finding Improvement by Reaching Empowerment), a branch of United for Families that empowers youth and young adults to have a voice in their own care and treatment. “It’s awesome,” he says. “I see so much potential in the people around here.”

Kathy firmly believes that Systems of Care and wraparound services are money well spent. “I’m seeing stuff I’ve never seen before,” she says. The stigma of mental illness is starting to go away. There are results: parents are getting involved and they are seeing successes every day.
Developing Self-Pride

*Emily Fohl, Caseworker*

When Emily Fohl first met Krystal, she had just moved to a new foster care placement. Krystal had been removed from the care of her biological parents at age 7. She was placed in many homes throughout the next few years, including her grandparents’, until she repeatedly threatened to run away. From there she was moved to the YES home, to a pre-adoptive foster home, and then to the foster home where Emily Fohl began working with her. As a child, Krystal experienced sexual and emotional abuse by her extended family members. She lacked social skills, didn’t know how to interact with her peers, and was often in trouble at school for inappropriate and disrespectful behavior. She disrupted class, yelled at teachers, and got into physical altercations in the foster home.

Emily started working with Krystal in Systems of Care in March 2009. Krystal’s foster parents were an older couple who had seven other foster children. Krystal was involved with the Department of Children’s Services, a Guardian ad Litem, George Jr., Foster Care Select, and Intensive Youth Services with a Community Mental Health Center. Initially, each of these providers attended the family team meetings, including Krystal’s foster parents. During these meetings, Krystal would completely shut down. After Emily discussed the meetings with Krystal, she decided to invite only a couple of the providers to the team meetings so she would feel more comfortable and willing to participate. She also invited a friend to her meeting. These meetings were much more productive and Krystal felt as though her voice was truly being heard.

Since she started the Systems of Care program, Krystal has come a long way. Her teachers report significant improvements with her social skills and confidence and she has passing grades. A few months ago, Krystal came out as lesbian and reports that she is proud of who she is. She was experiencing difficulties with her foster parents, however, because their religious beliefs conflicted with Krystal’s sexual identity. Her case manager starting looking into alternative foster placements and found two women who were foster parents in a nearby town. With them as her foster parents, Krystal would be able to finish school, continue her therapy appointments, and live without hiding who she really is. Unfortunately, the older couple who were her foster parents, the foster care agency, and the Guardian ad Litem fought to keep Krystal in her original placement, suggesting she was “confused about her sexuality” and a constant problem. Krystal made her wishes known and confidently told the team and, most importantly, her case manager and legal guardian that she wanted to be moved to the new placement. Krystal moved in with her new foster parents in January 2011 and transitioned out of the Systems of Care program. She graduated from high school in May, and planned to attend a technical school to pursue a career as a veterinary technician.
Kevin is a case manager in a mental health center and works with youth who receive services through Kansas’ PRTF Community-Based Alternatives grant. He helps youth transition from psychiatric residential treatment facilities by coordinating services with the wraparound team to improve the youth’s likelihood of success. He encourages youth to engage actively in home and community-based services and to work toward their goals.

Kevin believes that the PRTF CBA grant “uniquely addresses a core need within the community where I work by providing services to youth who are struggling and challenged.” Their needs are met through services tailored to the youth’s home and community settings. Kevin continues, “The program helps youth and their families rebound from tragic and unfortunate events more effectively and successfully than other programs.”

As an example, Kevin shared the story of Adam who had low self-esteem, experienced some bullying and couldn’t live down the memories of some of the unusual and attention-getting behaviors he had engaged in, such as setting fires and getting into fights. Consequently, Adam turned to self-harming behaviors that led to his hospitalization. When he was discharged from the hospital, he received community-based services including case management, therapy and parent support through the mental health center. By the time he was ready to be discharged from the mental health center’s services, Adam had learned to control his behavior. He subsequently graduated from high school and is planning to pursue further studies.

Kansas has been providing home and community-based services to youth with serious emotional disturbance (SED) for more than 20 years. Since implementing the PRTF CBA grant in 2008, approximately 450 youth have received various home and community-based services: wraparound facilitation, attendant care, independent living skills building, parent support and training, short-term respite care, professional resource family care, employment preparation and support, and community transition supports.

Because Kansas has both an SED Waiver and the PRTF CBA grant, community mental health centers often compare the programs. Kevin has worked in both programs, and believes the PRTF program differs from the SED waiver program because it is specifically designed to meet the needs of youth who have more intensive, exhaustive and demanding needs. Since working with the PRTF program, he has seen more youth reach their goals and graduate from the program because they have ample supports in place to help maintain their improved level of functioning.

Kevin describes the PRTF program as very beneficial for youth who transition out of a
structured residential treatment setting to a more open and least-restrictive environment. Home and community-based services have a positive impact on families. Matt is another youth who was in a PRTF for more than two years. His situation was aggravated by a speech impediment that frustrated him. When Matt was discharged from the PRTF, the mental health center’s Rapid Response Team with a wraparound facilitator made sure supports were in place to help him succeed. Matt received short-term therapy and achieved stability.

In the PRTF, Matt had been used to a one-room school environment, attentive teachers and a rewards system. Kevin intervened with the local high school, and the school made accommodations and modifications with teachers, technology and the environment to carry out his Individualized Education Plan (IEP). During his recovery, Adam didn’t need respite or crisis services; he maintained stability and his anger and self-harming behaviors decreased. Kevin plans to incorporate his recent training in Positive Behavior Supports (PBS) into his continuing interactions with Matt.

Kevin concludes, “The PRTF CBA grant program helps youth transition from a residential setting into an environment where they can thrive—all because they have professional supports, the necessary services, and proven-team practices.”

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**Defying Expectations**

*Tylan, Youth*

Sixteen-year-old Tylan is defying expectations. Many people thought he would never make it through high school. However, after many years of being in and out of psychiatric hospitals and residential treatment facilities, and receiving a variety of other services, Tylan is finally attending regular school and will graduate next year. He is self-confident, has social skills, and has made friends.

Tylan has been in Kansas’ children’s mental health system, receiving some home and community-based services as well as inpatient and residential, since he was in first grade. As a child, he was socially awkward and had a difficult time making friends. Tylan’s mother describes the “snowball effect” of his behavior being teased by his peers, then Tylan acting out aggressively, resulting in him becoming more and more of an outcast. He was suspended from school 16 times in second grade. He was kicked off the basketball team for punching a youth who pushed him. He has been hospitalized four times mostly because of his violent behavior.

For almost a year, Tylan and his family have been receiving services through Kansas’ PRTF Community-Based Alternatives waiver program. His mother reports that the most helpful part of the program has been the parent support and training. When Tylan was hospitalized, a parent support person drove with her to the hospital. Since the five months he stayed at a psychiatric residential treatment facility was the longest he had ever been away from home, his mother appreciated the support that helped her through that “really, really hard” time. She has also learned not to react to his behavior and how to consider different perspectives when dealing with him.

For his part, Tylan reports that the program has helped him deal with his anger. The staff at the community mental health center usually cheer him when he’s having problems with others. He says he never feels forced into changing his behavior, but admits that the staff are “really persuasive.” His family relationships have improved, and he and his mother are very
close. The services and supports he has received have helped his self-esteem, and taught him about his mental health needs and how to express his feelings. His mother says, “He handles himself better than other kids who don’t have mental health disorders!”

Tylan has worked hard and deserves much of the credit for his improvement, but he and his mother both also credit the waiver program for providing so much support. “Without that support,” she says, “life wouldn’t have been livable.”

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**Mature and Independent**

*Ashley, Youth*

Since she entered the PRTF waiver program the second time in February 2010, Ashley, 16, has matured and developed independent living skills, and her relationship with her family has improved. After being in residential treatment multiple times mostly for aggressive behavior, she first entered the waiver program in 2009 but soon had to return to psychiatric residential treatment. Now well into her second stint with the program, she has been receiving home and community-based services, including wraparound facilitation, training and support for her parents, skill-building for independent living and short-term respite care.

Ashley’s mother has definitely noticed the difference in her behavior. She says, “The services and supports he has received have helped his self-esteem, and taught him about his mental health needs and how to express his feelings. His mother says, “He handles himself better than other kids who don’t have mental health disorders!”

‘Ashley is more mature and notices when she does something immature. She also communicates better with the staff.” She has built rapport with staff members, and as the trust and rapport have grown, she is more comfortable talking about her feelings. Another provider notes that Ashley’s newly-developed “independent living skills are showing her how to be more responsible for herself and teaching her to take care of herself as she approaches adulthood.” The respite care she receives gives her a break from home and space to relax and feel the support of other adults.

Ashley herself recognizes the improvement—she says she is much less aggressive with her mother and she is beginning to establish a relationship with her father. With all the support she has received, she has been successful and has been able to stay at home in her own community.
When Donna thinks about what it was like before her son Danny, now 19, was part of the waiver program and what it is like now, she names three things that made the difference: the emphasis on the positive, the creativity, and the respect the team has for Danny. The team always focuses on Danny’s successes, even while they are honest about the challenges he faces. When it is difficult to come up with a solution to a challenge, they ask, “What are some other ways we can look at this?” They make sure Danny knows he is a major player on the team, challenge him to take responsibility for himself, and ask him how they can help him.

Donna and Danny Sr. adopted Danny at birth and had no knowledge of his medical history. By the time he was 6, they knew there were a variety of issues, including attention-deficit hyperactivity disorder, anxiety, depression, a cognitive disorder, and possible bipolar disorder. They also learned that he might have fetal alcohol spectrum disorder. He was in regular school until age 9, and has had an Individualized Education Plan since third grade. Starting at age 8, he was in and out of psychiatric hospitals. He was suicidal in sixth grade and spent more than a year in a residential treatment facility during middle school and then another 18 months in a different facility when he was in ninth and 10th grades. During his last hospitalization several years ago, he started receiving wraparound services. Denise, a member of his wraparound community facilitation team, has been working with him ever since.

Denise meets with Danny at home. This works better, given Danny’s fear of change and issues with separation anxiety. At first he was very shy and hid in his bedroom and didn’t like talking about his problems. After the third or fourth session, however, he was actively participating. Donna credits the team with helping Danny get through his teenage years and graduate from high school without having any legal problems. While he hasn’t been able to live on his own yet or hold a job, he has started to think about taking some courses at the local community college and volunteers at an animal rescue shelter and a therapeutic horseback riding program.

“Whoever thought this up is pretty smart,” Donna says about the waiver program. The structure the program provides seemed artificial at the beginning—“lame” was Danny’s word—but it’s worked for him. He goes back to his goals chart all the time to help keep him on track.

Donna says that without the support from the waiver program, she would not have had the emotional energy to continue dealing with all Danny’s issues on her own. She confesses that she was burned out from raising him. There are still questions about how independent he can be because of his cognitive deficits. He
Vivian knows children. She’s taught kindergarten and first grade for more than 20 years, so she’s seen lots of children with a variety of personalities and issues pass through her classrooms. But it’s different when your own child is dealing with significant challenges. Vivian is also a single mom with two sons, ages 12 and 14. José, her 14-year-old, was about the age of her kindergartners when he was first diagnosed with attention-deficit hyperactivity disorder (ADHD). That diagnosis started the family down a bumpy road of hospitalizations, medications, alternative classrooms, residential programs, and various forms of therapy until José was finally accepted into the PRTF waiver program.

José’s initial ADHD diagnosis and treatment triggered manic episodes that changed his diagnosis to bipolar disorder. Even with a more accurate diagnosis, however, it was difficult to find the right combination of medication and therapy that would work for him. He was hospitalized at age 8 with hallucinations and scary dreams. In second grade, he was placed in an emotional disability classroom, where he slept all day and fell behind academically. In third grade, he went to a therapeutic school with fewer kids; he did reasonably well there until sixth grade. Over the years, he was hospitalized eight times. He would respond to medication adjustments and do well, come home, and eventually cycle downward again and he’d be back in the hospital.

Finally, when José was in seventh grade, he was placed in a residential program one and a half hours away from home. His home visits always started out well, but then after two weeks, his behavior would escalate. During this time he was referred to the Maryland RTC waiver program.

Since becoming part of the waiver program, José is doing much better. He has a young adult male mentor, Sam, who sees him several times a week. Sam and José interact with each other very well. Sam is a good role model for José, especially since José’s father is not around. Sam spends time with him, walking, talking, going to lunch, etc. Crisis intervention services anticipate issues and help José work through things ahead of time. Vivian has not had to make any actual crisis calls. A caseworker provides support with monthly visits. José also participates in music therapy and is taking guitar lessons. His music and guitar are an integral part of his coping skills. He would like to be in a band, and is very creative and musical. He is still in the day school program at the residential facility and is now in ninth grade and achieving As and Bs.
Vivian admits there are ongoing challenges with José. He blames his mother for various things and doesn’t like her to tell him anything. He often ignores her and doesn’t follow through with what he is supposed to do. While he doesn’t have as many temper tantrums as he used to have, he is still impulsive.

On the other hand, Vivian describes the difference between before the waiver program and now as “night and day.” Whereas previously he was often out of control and would always find a way to negate any positive comments, he has learned through his therapy group to start with the positive. Vivian says their home is “almost peaceful” and her goal is not to have a house of conflict. Before, José had to be in a different room from his brother because they always fought; in fact, his brother was actually afraid of him. Now they can play together and they have a normal sibling relationship.

José also now believes he has a future. He dreams of becoming a scientist—perhaps a paleontologist to learn more about the animal bones he keeps finding—and is talking about going to college. He also made the basketball team, something made possible by his change of attitude. For her part, Vivian wants him to be able to be independent and function on his own, and she would love it if he could achieve his dream of becoming a paleontologist. She credits the waiver program with helping the family believe they will be able to be successful on their own after it ends. At the beginning, when things weren’t going so well, she worried that this intervention wasn’t going to work either, but once all the supports were in place, the cycle she had become accustomed to ended and she and José can look to the future with hope and confidence.

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**Imagining the Future**

*Adrian, Parent*

Adrian credits the Maryland Coalition of Families for Children’s Mental Health (MCF) with providing her with the support she needs to keep her son Donte at home since he was accepted into the RTC waiver program. MCF is an organization that provides caregiver peer-to-peer support, a service available to guardians in the waiver program. In 2008, Donte, who is now 14, was hit by a van and sustained a traumatic brain injury that affected his left side and continues to cause problems for him. The brain injury compounded the difficulties he was already having as a result of his attention-deficit hyperactivity disorder that had landed him in a group home the year before.

Through the RTC waiver, Donte receives wraparound services, physical and occupational therapy, talk therapy and he has a crisis plan. He is steadily making progress, despite the disabilities caused by his brain injury. His mother notes that he used to say “I can’t” a lot more than he does now; his self-esteem has improved, and he is doing well (mostly As and Bs) in the alternative school he attends. He has goals for himself—some of them the typical teenage dreams of becoming a famous rapper or professional football player, but he also has more realistic desires to become a counselor to help others with problems. His mother admits to being afraid that he will reinjure himself; she wants to be able to relax and not worry about him when he plays football. She hopes he’s able to finish school and go to college.

Getting to the point of being able to imagine a future filled with possibilities has not been easy for Adrian and Donte, however.
Adrian is a single mother with four children living at home, and she was laid off from her job awhile back. She often felt like she was all alone fighting a system she didn’t understand and was stacked against her. Without the waiver program and advocacy support from the Maryland Coalition, Adrian is convinced she wouldn’t have been able to get any help and she wouldn’t even have known what was available and possible. Advocates from the coalition have helped her find the right school for Donte, set up appointments for his Individualized Education Plan and accompanied her to IEP meetings. They also accompanied her to court when her older son was charged with a crime. They have provided material support as well, such as a bedroom set for her son, and are trying to help get a computer for Donte to help him with his reading. The family participates periodically in the coalition’s once-a-month games nights and occasionally in their drum circle. The range of supports offered by the waiver program through the coalition have been key to the success that Donte and his family are finally experiencing.
Mississippi’s PRIF waiver program is known as MYPAC, for Mississippi Youth Programs Around the Clock. MYPAC makes it possible for youth who would otherwise end up in residential placements as a result of their serious emotional disorders to receive the services they need to be successful in their home communities. Services are family-driven and strengths-based, and include intensive case management, wraparound, respite, group therapy, tutoring and transitional living assistance. In addition, each family is connected with a family support specialist who has had personal experience as the parent or guardian of a child with SED and who helps answer questions families have about MYPAC.

Following are stories illustrating the effectiveness of MYPAC from the perspective of a youth, a parent and a clinician, respectively, plus a fourth showing how MYPAC’s Flex Fund feature helps youth learn to live independently.

**“They Don’t Let Me Quit”**

*Kayla, Youth*

“They don’t let me quit when I want to quit. They make my day better when I’m having a bad day.” That’s how Kayla talks about the wraparound staff who have helped her achieve independence.

Since Kayla has been receiving services from MYPAC, she has finished high school, earning her general equivalency diploma (GED). MYPAC staff supported and encouraged her when she was preparing to take the ACT and when she applied for junior college. She also had a baby and started the process of becoming an emancipated minor. As part of that process, MYPAC staff helped her move out of her mother’s home into independent living and handle the emotion of making that significant transition.

Kayla also credits MYPAC staff with helping her change her attitude. “I don’t have any more outbursts. I’m not so angry,” she says. She appreciates their persistence with her as well. They remind her of things she needs to do, and they encourage her to ask for help when she needs it.

**“They’re My Family”**

*Angela, Parent*

When she’s asked what she enjoyed most about the treatment team providing services for her son Jayden, Angela says, “They’re not a treatment team. They’re my family.”

If it hadn’t been for MYPAC, Angela is convinced she would have given up. Jayden spent time in numerous residential facilities. Angela had been through a lot, and wonders what would have happened to Jayden if she had given up: “Would he be somewhere I couldn’t see him? Would my family be broken up?”

The most helpful services Angela and Jayden received from MYPAC were wraparound services, home visits by a counselor and a therapist for Jayden. Angela
believes that more positive change happened because MYPAC staff worked not just with Jayden but with the whole family. They talk more with each other, and try to discuss their problems instead of yelling and calling each other names. “We smile,” she says, “and it’s just a beautiful sight. It really is.”

To express her feelings about the services her family received from MYPAC, Angela wrote a poem called “Saving the Best for Last.” In the poem, she writes:

I know a family that did not laugh, talk, or be around each other
Until MYPAC was discovered and the impact was a relief.
God brings people, better yet angels, into our lives and three of you opened our eyes
To a very beautiful, peaceful and relaxed environment where the anger evaporated into God’s hands....
I will be saving the best for last because I know what’s left in my past.
I salute and give you all your props for the three angels in my life. Who would I fall on or who shall I call? Can I take a picture and hang my angels on my wall?”

“One of the Best Programs”
Joshua Everett, Clinician

Joshua Everett is a clinician for MYPAC. He has worked with other programs where he would see clients an average of once every couple weeks. With MYPAC, however, he goes out more frequently to see clients at school and in their homes where he can sit with the family and talk with them about the progress they’re making and what still needs to improve. He also finds that there is more ownership of the process with clients in the MYPAC program than with any other programs he’s worked with.

Joshua believes real change happens more quickly than with many individuals he has treated for years but only sees sporadically. He also believes MYPAC is more effective because the services are more intensive. When he’s able to check in with families regularly and have a more holistic view of what’s going on in their homes, communities and at school, plus get information from the whole wraparound team, he thinks he can be far more effective as a therapist. He is able to use the goals the family and child have set for themselves in the treatment plan. In addition, he can use the strategies the wraparound process has developed to help the family meet their goals. He also appreciates that intensive case management services are available for his clients through MYPAC. “MYPAC is one of the best programs I’ve had the opportunity to work with,” he says.
Taking Responsibility as an Adult

*Ivan, Youth*

Now 19, Ivan has struggled with abuse and neglect his whole life. He frequently had angry outbursts and engaged in threatening behavior, which put him at risk for out-of-school placement. He faced criminal charges, and spent a short time in jail. To cope, he created an imaginary world of Asian characters similar to a video game, and his creativity and artistic talent are helping him learn how to use that world as a safe place.

Ivan’s family is very poor, which has affected their ability to take care of their personal hygiene. This was embarrassing for Ivan, but he didn’t have enough money to buy what he needed to improve his appearance. MYPAC staff used Flex Funds to provide him with personal hygiene items like soap, detergent and shampoo.

While in the MYPAC program, Ivan has earned his occupational diploma and is following the recommendations of his probation officer. He plans to attend an art institute. He has also worked on being responsible to manage and pay for his own medications. The staff has helped him learn how to create and follow a monthly budget. He devised a system where he enlisted his brother’s services as a “bank”—his brother would hold his money until it was time to pay for his medications. Eventually, he was also able to include his hygiene products in his monthly budget.

Ivan is now proud of his appearance and enjoys “dressing for the ladies.” He recognizes that he is a loyal and compassionate person. While he still struggles with anger issues, he is working with a therapist to develop healthy ways of expressing his anger. He has been able to complete all his treatment and independent living goals and has a stable housing arrangement. He is taking responsibility as an adult and is proud of his achievements and the decisions he makes.
Kelly is a social worker who has worked with youth at risk for almost 20 years and as a child protection specialist in Montana for the last four years, met Aneisha when she assisted with her placement in a foster home after her discharge from residential care. Kelly connected with 17-year-old Aneisha in a way that was different from how she usually connected with children and adolescents in her care. She also knew there was a very small likelihood that Aneisha would find a permanent placement, given her age and the severity of the issues she was dealing with. So, when no one came forward offering to take Aneisha, Kelly applied for custody and on January 31, 2010, Aneisha came to live with Kelly and her biological child, also age 17. Kelly requested assistance from Montana’s PRTF waiver program which she knew to be very creative in the way it works with families, and on November 13, 2010, she officially adopted Aneisha.

Kelly talks about how many other child-serving programs are very formal in the way they do things and often require families to fit the program’s mold. Or to be more blunt and use another metaphor, many programs function as though they are “processing cattle.” The PRTF waiver program, on the other hand, is individualized and doesn’t separate formal from informal or natural supports. Her church and family have provided a lot of support; for example, the youth pastor who Aneisha respects became part of Aneisha’s team. As a result of these and other natural supports in the community, Kelly hasn’t had to access a lot of services beyond the respite help she requested in the beginning because of Aneisha’s behavior issues.

With regular Medicaid services, counseling services are limited in scope and time, but with the waiver program, there is no limit. Aneisha has been seeing a therapist twice a week (six hours), something she has very much needed. Her therapist, Tara, had an accident and was not able to see Aneisha for about two months, which was a difficult time for Kelly and Aneisha. While Tara was on medical leave, Kelly was able to access counseling for herself, not only to help her process her own feelings of inadequacies as a parent but also to maintain some stability until Tara came back.

“I don’t know what we would have done without Tara,” Kelly says. Tara’s availability for frequent and intense therapy with Aneisha is a crucial ingredient in what Kelly says is the best thing about how the waiver program has worked for them. Before Aneisha came to live with Kelly, she attempted suicide three times, cut herself repeatedly, suffered from severe post-traumatic stress flashbacks and was hospitalized five times in two years—all stemming from years of physical abuse by members of her birth family, including a rape at age 7. Since becoming part of Kelly’s family...
and having regular intensive therapy sessions with Tara, Aneisha has not been hospitalized nor has she attempted suicide, and there has only been one minor cutting incident. She continues to have flashbacks but she’s been able to handle them well, and while she almost needed to be hospitalized a couple times, a good safety plan helped to avert the crisis.

Kelly’s personal experience with Aneisha and the waiver program has changed the way she works and given her much more empathy and patience for what families go through. When she tells families she understands what’s going on in their lives, it rings true because she’s actually been there trying to cope with the same situations. She also understands better than most how important it is for families to be in agreement with what the waiver program is trying to do and for case managers and social services personnel to provide a lot of support and guidance. Kelly is a strong advocate and she knows how to negotiate and maneuver in the system to get what she wants for Aneisha and herself, but she knows that most families don’t have her background and don’t know the system or what they want and how to get it.

Participation in the waiver program is for a year at a time, with renewal possible. During that year, Kelly provided a stable environment and lots of support for Aneisha as she continued to deal with the effects of the trauma she experienced. Kelly applied for re-certification to allow them to stay in the program for another year and hopes that whatever hesitancy there might be will be overcome by an ongoing need for extra support, especially as Aneisha also begins to work on all the issues related to her family of origin. She has had no contact with her birth parents and very limited contact with her siblings; any move to develop those relationships will require the kind of careful preparation and significant support that the waiver program can provide.

They Have Your Back

Nicky and Jason, Parents

“It’s an amazing program,” says Nicky, referring to the program that has been supporting her and her family. Nicky and Jason, divorced parents of JR, age 9, became involved in the PRTF waiver program and its wraparound services when JR was discharged from a residential facility. He was admitted to residential placement because of his oppositional and defiant behavior, issues with authority, and inability to put his feelings into words. He had also threatened to hurt or kill himself, even though his dad doesn’t think he really knew what he was saying and was just trying to find a way to get the help he knew he needed. His parents were engaged in a “very bad kind of power struggle” and weren’t consistent in the way they handled their son. They also didn’t fully understand what should be acceptable behavior for children and weren’t able to set appropriate rules.

JR is what his mother calls “a normal nine-year-old rambunctious little boy who has a mind that doesn’t stop.” He and his brother and Nicky live with her mother, sister and brother-in-law and nephew, plus pets. So JR heard a lot of different messages about what he was allowed or not allowed to do. Now that JR is in the waiver program, the family—including his dad Jason—works together much better to support him and set limits for his behavior. Nicky and Jason establish consistent rules that apply in both their homes. Whenever there is an incident with JR, Nicky reports, “we’re on the phone to each other,
saying ‘this is what happened.’ We’re pretty good at following through at both our houses.”

JR’s wraparound team has helped develop a variety of community services to support him and his parents. He is receiving therapy, and he’s been able to attend programs like summer camps that give him an opportunity to experience success. Nicky has also received counseling for herself, realizing that she can’t help her son if she doesn’t help herself. She also appreciates having choices and a voice in what happens to her family. She can talk at team meetings without being interrupted, and she feels free to say whatever she wants without being penalized or criticized. The team listens and agrees to work on whatever issues Nicky raises. For his part, Jason has learned how to choose his battles with JR and Nicky, and to put his own feelings aside and find a way to work with his ex-wife on behalf of JR. He also appreciates all the extra people who are part of JR’s life, partly because they provide another perspective on what’s going on with JR and help him and Nicky talk about what’s best for him. Both Nicky and Jason also credit the parenting program, Circle of Security, for giving them specific help with their parenting skills and how to work with each other.

Nicky and Jason are enthusiastic in their praise for the program. Nicky says, “The people that work there are absolutely amazing. They have your back 100 percent for just about everything.” She loves their team and believes they’ve become like a family. Jason would definitely recommend the program to anyone with a child who is struggling. In fact, he is so enthusiastic about the program that he’s thinking about volunteering as a mentor to other children. Having been through a lot in his own life, he believes he would be able to connect with children who have problems, as well as with their dads because he could share out of his own experience. “If I can help even just one, it will be worth it,” he says.

More Time and Flexibility

_Darcie Kelly, Clinician_

After having worked in several residential treatment facilities as a therapist, Darcie Kelly understands how the PRTF waiver program has made a positive difference for children and families. Her background in equine therapy and social work, combined with a strong sense of social justice and desire to make things better for children with emotional and behavioral problems, made the waiver program a good fit for her. With its emphasis on family choice and community integration, the model meshed well with all the other work she was already doing.

Darcie emphasizes several elements of the waiver program that she finds particularly valuable. She often feels pressure as a therapist to help families achieve their goals and make things better, but this is difficult to accomplish alone. The team approach allows her to step back and not have all the responsibility herself, and instead be able to watch others help families succeed. “I’m able to kind of fall into the background, into the woodwork,” she says. “I really enjoy that.” She has the opportunity to work with a team that can really support the family.

Another aspect of the program that Darcie values is the time she’s able to spend with families. She notes that there really isn’t much you can do in the traditional 50 minutes a week of therapy, more than simply checking in with someone. When a family is struggling, more time is needed—maybe a whole evening with the family to help keep them together. In
addition, before, she often felt like she was a passive participant in case management meetings. She might be able to report on progress being made, but so much of the focus was on what was going wrong with the treatment plan. Now, she says, everyone is on the same page, including the family and other natural support people. The family is invested in the plan because they helped create it and they understand it. Darcie enjoys participating in meetings where the team is able to remind the family how well they’re doing, point to specific successes they’ve had, and reinforce the fact that they are in charge of their own future.

Darcie also really appreciates how well the waiver program works to ensure that the child and family are integrated into their home community. In her previous work, despite having a discharge process in place, it was often very difficult for residential programs to make connections in the community. There were family support people, peer groups and other strengths in place, but the programs weren’t able to expand beyond their own walls. The waiver program encourages them to make the efforts and now they’re being successful.

With the funding that is available to do creative and fun things, Darcie has helped youth to get memberships in a health club or participate in events like a local horse show. Healthy extra-curricular activities are extremely valuable for children who have either not had the opportunity or are not living a healthy lifestyle. For example, one youth requested to participate in a horse show after being a spectator and discovering a trigger to her previous trauma when she saw how the horses were being treated. The youth made it her goal to show the other children the deeper relationship and communication that can occur between a human and their horse partner. This was a very healing experience for her, and would not have been possible in an office setting, let alone without the support and planning available through the wraparound process used by the waiver program.

The ability to be creative is part of one more aspect of the program that Darcie appreciates—its flexibility. She can tailor services to fit the individual needs and interests of the child and family—the word “individualized” isn’t just a buzz word. Since she and other support people are not confined to the office, they can be with the family in their home, go out for a cup of coffee or a Coke, go to the library, or spend time with the horses. Unlike regular Medicaid services that are based on the medical model, the waiver program allows for flexibility regarding what, when, where and how the family believes natural and professional supports can be helpful. Issues are resolved much more quickly, saving money and helping the family graduate successfully from the program and go on to support other children and families.
Several years ago, when the South Carolina Department of Health and Human Services convened a committee to evaluate their children’s mental health services, the Federation of Families for Children’s Mental Health was the only family organization represented. Diane Flashnick, director of South Carolina’s Federation chapter, was persistent in arguing that home-based services that support the family are very important. When the PRTF grant opportunity came along, the Federation of Families wanted to make sure that families be able to choose the provider they wanted. Their insistence paid off, and after the grant was awarded to South Carolina, the Federation was chosen as the neutral entity to help ensure that parents have meaningful choices for their children’s treatment and explain the services that are available.

Diane learned what it was like for a parent to try to navigate the children’s mental health system when her son was eight years old and first diagnosed with ADHD. He had been a difficult infant and toddler and she was a first-time mom and, by her own admission, an inconsistent disciplinarian. When he was eight, he had what Diane called a “big eruption.” He was convinced he was “dumb and stupid” and was suicidal. She had him evaluated and diagnosed and thought she would get the magic plan that would fix everything. When that didn’t happen and he continued to struggle in school, despite his high IQ, she despaired of his ever graduating from high school. Eventually he went to technical school, earned his degree, and is now a successful young adult. But Diane has never forgotten how hard it was for her as a parent.

She first connected with the family advocacy network through a parent support group. She worked for the National Alliance on Mental Illness for several years, and later served as the state education trainer for the Parent Training Information Center for seven years. She has been director of the South Carolina Federation of Families for Children’s Mental Health in South Carolina for the past 10 years, helping to position the organization to assume a leadership role with the PRTF waiver program.

South Carolina’s PRTF Alternative waiver program, CHANCE, is not statewide and started out in only three counties. Now the program is in six counties and the state would like to expand but was unable to do so in the past due to the economic environment. However, the state has recently been approved to expand, and they are in the process of preparing for that expansion. Slots for the waiver are currently limited to 50, but will soon be increased with expansion.

The Federation believes it is always preferable to keep a child at home, even when the child has significant mental health issues. But the reality is that many families have not had that choice, and services have tended to be costly and disjointed. Sometimes a limited
amount of respite care has been available, but often once parents have reached the end of their ability to cope with their child’s issues, there is no other choice but residential placement—unless, of course, they give up custody to the child welfare system. Another option available for families is offered through the Continuum of Care, a Division of the SC Governor’s Office that provides intensive case management for children with serious emotional disturbance. There is almost always a waiting list for the Continuum of Care, and sometimes children need more support than the agency can offer. The waiver program is an option for these children and their families. More providers are inquiring about enrolling to be CHANCE service providers and there is currently a waiting list of children eligible for the program.

Diane says that families that have participated in the waiver program have been happy with the services they’ve been able to access. Many of the children were in residential treatment, while others needed significant support to prevent them from ending up in a residential placement. There are still challenges, however. Providers are not always willing to accept that families should be able to choose the provider they want; they’re used to simply waiting for referrals to come to them rather than aggressively developing the kind of services families would want. Also, because there has been a lot of staff turnover within the waiver program and many people have been doing more than one job, there has not been as much training for providers in the PRTF waiver program as would have been helpful. At the same time, thanks in part to people and organizations like the Federation and its leadership, South Carolina is beginning to move away from thinking that psychiatric residential treatment facilities are the solution for children with significant mental health needs. In partnership with the Federation, they are doing what it takes to create opportunities for families to have meaningful choices in services that will help them keep their children at home.

**The Personal Satisfaction of Seeing Families Succeed**

*Belinda Pearson, South Carolina Federation of Families for Children’s Mental Health*

When she received her master’s degree in social work, Belinda Pearson could have pursued a career working as a therapist with children and families, but she didn’t think she wanted to do front-line work. Her job as a family advocate with the South Carolina Federation of Families for Children’s Mental Health meets her need for direct contact with families and gives her the personal satisfaction of watching families make progress.

The South Carolina Federation of Families chapter is an integral part of the waiver program. They are responsible for making sure that families accepted into the PRTF waiver program (called CHANCE in South Carolina) understand the options for their children’s treatment. Belinda’s first contact with families is after they have been referred to the waiver program. She records the child’s history of treatment and services for the past year and submits the information to the Department of Health and Human Services, where the project director reviews the case and starts the Medicaid eligibility process. If the child is eligible for Medicaid, the project director then notifies the Federation and they ask the family who they would like to complete the level of care assessment. If the child has met the level
of care requirements and there is space he or she is approved for the waiver program.

Family choice is a critical component of the CHANCE waiver program in South Carolina. Belinda helps the families navigate the system and choose a case manager from a list that Belinda maintains. The case manager in turn helps the family choose the services needed and which provider they would like to work with. Many of the providers offer mostly traditional core services such as individual and family therapies rather than some of the more intensive services these families often need. Belinda makes sure that families know that if they are not satisfied with the provider they have chosen or something isn’t working for them, they have the option to find someone else without jeopardizing their participation in the waiver program.

While some case managers and providers have resisted when families have chosen other providers, some have recognized that it is good business to work harder to please families. Belinda tells about one provider that has tried to diversify the kind of therapists they have available, so that they have both male and female therapists, different ages, etc. As a result, this agency has begun receiving more referrals from the waiver program.

The present caseload for Belinda is 50, spread out over six counties. Belinda sees families face-to-face every 90 days to review their cases. She also stays in touch by phone, and families can call her any time if they have concerns or questions. Even though the goal of the PRTF waiver program is to prevent residential placement (or make it possible for children to come home from residential placement), Belinda notes that some children have not been able to make it at home.

Belinda tells the story of Will and Nancy, who are raising three of their grandchildren, boys ages 9, 12 and 16. The boys’ mother and sister were both murdered after the family had already applied to be part of the waiver program for one of the boys who had significant behavioral issues stemming from having previously been abused. The boys were in foster care and suffering from post-traumatic stress disorder (two of the boys had found their mother and sister after their murder) before their grandparents took them in. Two of them have been in and out of residential treatment. The waiver program provides a lot of the support to the family, including individual and family therapy, not only because of the issues the boys are dealing with but also because Will and Nancy are elderly, sick and in wheelchairs and need the support. An uncle also lives with them and helps out; he has become something of a father figure for the boys. Belinda maintains contact with the family and knows that without the services provided by the waiver, all three boys would most likely now be in residential placement.

Belinda derives a great deal of satisfaction from being able to track the progress that families make in the waiver program. She sees them at the beginning when they are often in crisis, and then six months later, she can often see that families are doing much better and she has helped to make that happen.

The Staff Aren’t There for the Paycheck

Cheryl, Parent

Cheryl is so pleased with the help she and her son Jeff have received from the CHANCE waiver program that she wants to help get the word out about it to other parents. She believes many parents don’t know what services are available when their kids are having emotional and behavioral problems. If a friend hadn’t told her about the program, she wouldn’t have known.
Jeff, now almost 17, was born more than two months prematurely. Cheryl and her husband, who passed away in 2008, always suspected that something was wrong. Jeff had problems as early as day care and pre-kindergarten and his teachers said they thought he probably had attention-deficit hyperactivity disorder. Their family doctor, however, didn’t want to talk about any problems and said he was too young for a diagnosis. Cheryl received some support from a group run by the Federation of Families; a trained counselor would talk about different issues children and families deal with. This is where she was first introduced to the waiver program.

Over the years, Jeff has struggled at school. There have been safety issues—like running out into the road. He disrupted the class, acted out as a way to get attention, and couldn’t seem to keep his hands off other kids. Cheryl insists he never did anything really bad, but school was difficult for him and he didn’t want to be there. He was also the victim of bullying at school.

When he was in sixth grade, Jeff’s father died. They had been very close and the loss was devastating. Jeff’s behavior problems continued, and finally in eighth grade he was accepted into the waiver program. A behavior interventionist went to school with him, in a self-contained classroom for children with emotional and learning disabilities. The behavior interventionist was like a mentor for Jeff and helped keep him out of trouble. Cheryl is convinced Jeff would have ended up in an alternative school or the juvenile justice system, but instead he improved significantly and was able to stay in school.

After the summer when the behavior interventionist was not with him, Jeff went to high school in a regular classroom. With no support and still angry about his father’s death, he got into a fight at school and was assigned to homebound instruction. This was when the waiver program really stepped up. Cheryl says, “Staff were able to enroll Jeff in a charter school where he takes classes online and will be able to finish high school and graduate. He has a learning coach 4–6 hours a day who helps him with his school work. This home-based support is providing the structure Jeff needs.”

A therapist comes once a week to talk with Jeff about whatever is going on in his life. He’s finally beginning to open up and deal with the “heavy stuff.” All along there have been challenges with finding the right medications. As he was growing up, it seemed that he was becoming even more angry, and Cheryl was concerned that the antidepressant in combination with his ADHD medication was making him violent. So he stopped taking the antidepressant. With his therapist’s help, Jeff is learning anger management skills and how to deal with it more positively. At the same time, because his depression was increasing and he seemed to be withdrawing again, he started taking another medication for anxiety and depression.

As Cheryl thinks about Jeff’s future, she knows that his intelligence will help him succeed. His father was very mechanically gifted, and Jeff is following in his footsteps. He can take almost anything apart and put it back together. He’d like to work with his hands and have his own business. Cheryl just hopes he can be successful at something he is passionate about. When he was in sixth grade, she never could have imagined such a thing even being possible.

Without the waiver program Cheryl doesn’t know what she would have done. She says she almost panics when she thinks about the program being lost, perhaps because of lack of funding. “Lots of families could benefit, and there are so many issues with kids,” she says, so the government should continue to fund the program. Her family’s experience is that the staff are not just there for the paycheck: they give her son a lot of love, want him to succeed, and genuinely care about him.
As a licensed clinical social worker and co-director of a relatively new agency in Richmond, Virginia that provides intensive in-home and crisis intervention services for children who are at risk for out-of-home placement, Kathy Levenston applied to participate in Virginia’s PRTF Waiver Program. Home for Good is a small agency, but unlike many agencies in Richmond, they were actually interested in becoming involved with the waiver program. Because there are many home based counseling programs in the Richmond area, they needed to do something different to distinguish themselves from the rest. When few other agencies were willing to work with the PRTF waiver program, Home for Good found people who had the necessary expertise to help them be able to offer the waiver services, and thus they have been able to distinguish themselves from the myriad of other agencies.

Home for Good’s waiver program case load is small—only a few cases at any given time. Services include therapeutic consultation, mostly related to behavior issues; training for family caregivers in being strengths-based, managing behavior and learning to communicate better; and in-home support for families. Their caregiver training includes anyone who is working with the child and offers networking and support so caregivers don’t feel so alone. While caregivers are being trained and enjoying each other’s company, their children enjoy snacks and games.

Kathy describes the success of the waiver program and Home for Good’s experience with it as “seeing that kids can make improvements and stay in the community if they have the right supports.” To illustrate that, she tells the story of Liza, age 9, who would go in and out of the state hospital—the only option available—at least once or twice a month. She was out of control and urinating in the hallways. She had severe temper tantrums and was very violent, and on at least one occasion threatened to cut her single mother with broken glass. A private psychiatric hospital wouldn’t admit her and sent her home to her mother who had her own mental health issues.

With the support of the waiver program and its case management and therapeutic services, Liza is living at home with her mother and younger brother. Although she has had a few episodes of behavioral escalation, they are not nearly as violent as before and she has not had to go back to the hospital. Her counselor is a petite woman with a bad back who told Liza that if she jumped on her she would hurt her. Fortunately, Liza has been able to control her behavior and has not hurt her counselor. She has been attending an alternative school, but may soon be able to attend a special education class in a regular school. She is no longer at

The Challenges Are Worth the Effort
Kathy Levenston, Home for Good
Nancy Toscano is a licensed clinical social worker and Central Region Community-Based Services Director for United Methodist Family Services (UMFS) in Richmond, Virginia. UMFS is one of the providers offering referrals and assessments for children and families enrolled in the PRTF waiver program. With experience working in a variety of settings with children who are at risk and their families, including children on the autism spectrum, UMFS was drawn to the waiver program because of its promise of support for youth as they transitioned out of a residential facility and into the community. UMFS had firsthand experience with youth entering foster care after discharge from a residential treatment facility with no real or effective plan for supportive services in the community.

UMFS has a wide network of services that include treatment foster care, intensive treatment services in our Child and Family Healing Center and in Leland House, as well as school-based services and adoption services. The use of PRTF waivers to provide support services to the children and teens entering treatment foster care either from an outside residential treatment center or their own intensive treatment center was appealing.

Nancy points to various ways the program has helped children make successful transitions to the community. Families have had access to respite care, and youth have been paired with companions in the community who have supported and mentored them. A great example of the success of the waiver program was the adoption of a 17-year-old girl. Mary had been in treatment foster care and struggled with coming to terms with her childhood history of abuse and neglect. She acted out with defiance, fighting, property destruction, and promiscuity. She was removed from the treatment foster home and placed into a PRTF at UMFS. The foster family stayed involved throughout her year-long stay at the treatment center. Mary worked extremely hard on her treatment and was ready to transition back into a home. She hoped it would be with a relative, but was disappointed when this fell through several times because of the family’s wish to end contact. Her goal was eventually changed to adoption. Her current foster parents were not able to adopt her, but used transition paperwork that is not reimbursed for intensive in-home providers who provide case management for the program. However, she and Home for Good are working with kids who have severe issues—post-traumatic stress disorder, depression, substance abuse, oppositional defiant disorder, bipolar disorder, and so on. Most have had severe trauma at some point—abuse and neglect, or witnessing domestic violence. Some also have cognitive issues. If the waiver program can help these kids and families thrive in their communities, then Kathy says the challenges are worth the effort.

Successful Transitions to the Community

Nancy Toscano, United Methodist Family Services

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coordinated to help her move back into their home successfully. The family also hired their adult daughter as a companion through the waiver program. A bond formed quickly and deeply with this person, which ultimately resulted in Mary’s being adopted by her companion. Mary graduated from high school and is currently hoping to serve in the Navy.

UMFS functions primarily as a referral and assessment agency and therefore relies on other mental health agencies to provide the direct services recommended by the waiver. One of the challenges Nancy has encountered is finding providers who offer the array of services available through the PRTF. Despite these challenges, UMFS has been able to successfully use the waiver program to provide crucial transition coordination for children leaving residential treatment. Many of these children had completed their healing work in residential treatment but were not yet ready to enter into a family and the community. The PRTF waiver allowed UMFS to work with these children to prepare them for the transition from a structured residential setting to more fluid family life in the community. Without the PRTF waiver, this would not have been possible.

All Children Deserve a Chance

Bonnie, Family Member

Bonnie’s 18-year-old niece Tyra has been an honor roll student and is on target to graduate from high school and go to college. She’s been successful as a student, but she’s had serious challenges in other parts of her life. As a result of her significant emotional and behavioral problems, Tyra has spent time in various out-of-home placements. When it came time for her to transition her back to the community, Bonnie helped Tyra get accepted into the waiver program so the family would have the support they needed for her to live at home.

When Tyra was five months old, Bonnie, who is her great aunt, took her into her home because her birth mother struggled with drug addiction and was unable to care for her. For the first few years, Bonnie’s mother helped out a lot, and she has depended on other family members and friends and outside services for additional help. Tyra has a history of aggression toward people and is often very impulsive. She has been treated for bipolar disorder, attention-deficit hyperactivity disorder, anxiety disorder and disruptive behavior disorder. A neuropsychological evaluation a couple years ago indicated that she also has a cognitive processing deficit. Over the years, she has been on multiple medications, many of which may not have been helpful. Anger issues, defiance and temper tantrums when she doesn’t get her way cause problems for her as well. She has been in and out of hospitals and residential facilities, and spent time in treatment foster care and a group home. She has also had issues with law enforcement.

Respite care was the key service that enabled Bonnie and Tyra to be a family again. Bonnie notes that when family members work full-time, like she does, it’s very difficult to care for a child with behavioral health issues. Respite care helped Tyra go to school and be in a safe environment, and Bonnie knew she was being cared for while she worked. The waiver program bridged the gap and gave Bonnie’s family the support they needed to manage their daily routine. Bonnie emphasizes how difficult the transition from residential placement is for a child and family. If there is no support, or no way to connect to community resources, the transition isn’t likely to be
successful. She speaks especially about how crucial it is for family members to have respite care in order to continue to stay involved and about the importance of having other individuals with specific expertise to assist families. In addition to respite care, Tyra has also received companion care, and family members have received family caregiver training.

Bonnie believes something like the waiver program needs to be broadened to meet the needs of more children. Many families don’t know about the program, plus it’s limited in that children have to be in a residential facility or at risk of placement to be eligible. It would be helpful if the same supports available through the waiver could help prevent the behavioral crises that lead to eventual placement. If Bonnie had her way, all children with mental health disabilities in Virginia would be able to stay at home and be connected with resources in the community, services could be accessed easily, and there would be places where children could go during the day and be safe while their parents work.

Tyra would like to be “grown up,” live in her own apartment and have friends over, and be free to do what she wants. Bonnie also hopes she will eventually be able to have a normal life, but she’s not there yet. She still needs support; she’s very naïve and impulsive, and lacks the skills to live independently in part because of her cognitive deficits. Tyra is a great example of why Bonnie advocates for continued and expanded services and supports in the community for all youth with mental health needs. Just like Tyra, “they are individuals,” she says. Despite their challenges, “they deserve a chance to be somebody.”