Lunch & Learn Webinar:  
Provider Experiences with Supported Living  

Presenter:  
Greta Byrd, Executive Director, Liberty Corner Enterprises  

This webinar is being sponsored by the NCCDD and North Carolina Money Follows the Person Project (NC MFP), a Medicaid project that assists Medicaid-eligible North Carolinians who live in inpatient facilities to move into their own homes and communities with supports.
The mission of Liberty Corner is to support people to live, work, and play in the homes and communities they choose. People are supported to live their lives interdependently, make informed choices, and achieve their dreams. People are Supported to HAVE A LIFE!
Jennifer’s story – Jennifer lives in an apartment with a roommate. They both use wheelchairs for mobility. They live just outside the city limits where there is no bus service so they have an accessible van. Jennifer requires support for all her personal care needs. Her health can deteriorate quickly and sometimes has to go to the emergency room. She has support to take her medications. She has support to help her with her meals. She has staff available 24 hours a day. Jennifer loves to go to concerts! She hasn’t worked in several years but would like to find a job.
What does Community mean? We strive to help support individuals to a part of their community. Not our community, not just the community of people we support but a community that is chosen. People have a voice and an opportunity to grow as individuals to be valued, contributing members of their communities. People have access to modern technology and community resources to achieve greater independence.

Paul lives by himself in his own apartment. He has a job doing a paper route where with the support of staff he delivers real estate papers to business drop boxes in the area. He also has a small vending machine business. Paul sings in perfect pitch. He loves music and books about music. He likes to spend time at Barnes and Noble looking at books about musical instruments. Paul likes the orchestra as well. This is a picture of Paul at the Y. Paul also lived in an AFL during his high school years. He lived in a small 3 person group home. Paul prefers living by himself. He doesn’t like it when there are too many people in his apartment. When a new staff is “shadowing” staff and Paul to learn his routine and his paper route. He prefers that they not do this in his apartment. Paul is a gentle, kind, soft spoken soul.
Barbara is a woman who has received waiver services for almost two decades. She has lived in institutional settings, congregate living arrangements, and an AFL setting in the past. She then moved into an apartment with another person receiving services in 2012. Three years ago, she asked her team to assist her to find her own home.

Barbara has been employed with the Town of Black Mountain for 8 years. Barbara is a people person and enjoys going to the YMCA throughout the week. Barbara moved into her own apartment in West Asheville, through the Key Program/NCHFA in July 2016. Barbara received 12 hours of support each day and had an alarm system on her doors to keep her from being vulnerable to others when staff was not with her. As she was settling into her apartment, her team connected her to Simply Home to seek out assistive technology to help insure she is safe when staff is not present. Barbara is now receiving an average of 6-7 hours of 1:1 staff supports each day with the addition of the assistive technology, and is very satisfied with her free time in her home. She has met neighbors who act as natural supports for her and lives in close proximity to her guardian, who also assists with Barb’s success in living the life that she chooses, on her terms. Barbara has more control over her money, how she spends it, where she shops, and is able to live comfortably. She is living a healthy lifestyle, and for the first time in more than 20 years, her diabetes is controlled with her diet and exercise. She has lost more than 80 and says she feels “great.”
Lisa moved into her own apartment this past year. Her guardian was very concerned that she might not be successful. Lisa was a little nervous too. After all, she had never lived on her own. Do you remember the first time you moved out on your own? Your first house or apartment that was really your own. I bet it was a little scary for you too. Lisa’s co-workers at Ingles which is a local grocery store helped her furnish her apartment. They even stopped by at Christmas time to bring her gifts and pizza. Lisa has Autism. And she lived in a small home with two other roommates who also had Autism. It wasn’t a bad place. She just had to share it with two guys. It just wasn’t her place. Everybody want to live how they wanna live.
Tammy and her husband, Kevin live in an apartment in Woodfin, NC with their three cats. Tammy has been receiving services for about 14 years with LCE. Over the years Tammy lived in groups homes, alternative family living, and in an apartment attached to a group home. Just about every model the service system could come up with except having a home of her own. Tammy received supports from a multi-faceted team to maintain her mental and physical health, as well as navigating social interactions and relationships.

Tammy and her husband moved into their apartment in October of 2015 through the Key/NCHFA subsidy rental assistance program. Beginning March 2017, Tammy transitioned from 11 hours per day of Community Living and Supports to receiving Supported Living Level 2 services. Prior to beginning Supported Living, Tammy received periodic waiver services throughout the week to support her with a variety of needs and outcome-based supports. Finding good staff matches and retaining staff with Tammy has been a challenge for many reasons, specifically because, like most of us, Tammy would like to have choice and control over her schedule each day. Supported Living has afforded Tammy the flexibility to have staff for the amount of time that fits best for her needs and desires each week. She has had much better success with staff matching and accessing her community on her terms since using Support Living. Tammy and her husband dream of owning a home of their own in the future, and the team is currently supporting them to look for property to buy and ways to finance a modular home to put on the property.
While we have 10, soon to be 13 people living in their own homes and apartments. We support others who live in some small and some larger group homes. It is our hope to transition all of those individuals into their own homes and apartments where they are the leaseholder not our agency.

This is Richard. He lives in a six bed facility. Richard is in his 60’s. He has a Traumatic Brain Injury. When he was in college just days before his 22nd birthday he had a motorcycle accident. Richard has a seizure disorder and short term memory loss. Due to his brain injury, Richard doesn’t have a sense of taste or smell. At times in his life, he has become very thin due to not having an appetite. Richard shares stories about the remembers the time before his accident. He talks about being in college. You know that Richard is a man of incredible intellect. And shares great stories about those times. If you ask Richard how he is doing, he will say with great enthusiasm "Fantastic”. I have known Richard for more than 20 years. I reintroduce myself every time I meet him. I don’t doubt that Richard’s needs are met at the group home. But it is not his home. He didn’t decide who lives with him. Can you imagine not deciding who lives with you?

Everyone, no matter the medical or behavioral needs should have the right to be supported in their own home.
I love this photo because it represents two things to me: taking a risk and getting support to take that risk. In this photo, Tracey is reaching out to Mary Sue to reassure her that she is going to be ok in the water.” I get a lot of questions from families, guardians, other providers about risk.

They ask what I have started call the three “F” questions, “What if there is a fire, what about friends – aren’t people lonely, and on and on. - and what these questions are really about are about is the dignity of risk and when coming from providers about liability. The questions are – “What about a fire – its about safety. Every parent, every provider wants a person to be safe. No argument there. What about Friends – on this one I challenge our belief that loneliness and community connection is not cured by living in a group home with five other people. It is about being a part of your community, living where you choose and being with the people you like and want to be with when you want to be with them.

The last F – let’s just call romance. People want intimate relationships, people, fall in love, the get married. Just like Kevin and Tammy.

There is right risk in providing supported living. This picture reminds me without dignity of risk – we wouldn’t learn to swim, learn to drive a car, we wouldn’t fall in
love without dignity of risk. Right risk is about providing the support that is needed no more/no less to insure that individuals have the life they want.
I like to end with some of our Challenges and Barriers: Our challenges have nothing to do with the support of individuals. We know we can support individuals with diverse and complex needs whether those are medical needs or needs for behavioral or mental health support or all of the above.

There is a shortage of Direct Support Professionals. This impacts the individuals we support. This impacts our staff who work overtime and our QP’s who work to fill in. Because we consider Supported Living as a full time support not a periodic support.

There is a shortage of affordable housing. Asheville is an expensive place to live. A recent article came out putting Asheville up there with San Francisco and Miami as having the largest disparity between wages that people earn and the cost of living. We know we can support people to live in their own homes or apartments, we just can’t find places that are affordable for them to live. Our HUD Section 8 or Housing Choice Vouchers have a waiting list to get on a waiting list. And the Targeting Program with Key housing subsidy has long waiting lists as well.

What we have learned:

The individuals we support need us less than we thought they would. The other thing that we have learned is that our model of team support works. We have a QP supervisor who does service coordination, planning and supervision of staff. We
have an Assistant Service Coordinator who is the team leader and works both with and as a direct support professional to insure the continuity of staff and scheduling. They also insure that individuals have continuity in the service and supports by providing coaching to the staff on the needs of the individual.

The QP team also provides 24/7 on call support as well as serve as back up staff when needed. There is a weekly consultation team meeting of all the QP’s and Assistant Service Coordinators to support one another in problem solving regarding the needs of individuals or staff.

As an agency we have to be creative and flexible. We have to do a lot of service coordination and crisis support. While we do work with mental health agencies and NC Start, we often find that there are gaps in those services. We have to advocate on behalf of the individual and their families to get the support that is needed. This takes time and staff resources. We have co-opted Nike’s famous slogan instead of “Just Do It” – ours is “We Just Do It” – no grumbling, no pointing fingers, no we shouldn’t have too, no “whose on first” – we’ve all been in those meetings where the systems gaps were identified. I’ve been asked – how do you afford to do that? You can’t bill for that. As an agency, we look at it this way. We can’t afford not to.
Music is the universal language and in song we find some universal truths. There is a song by the Bodean’s called Closer to Free. Jesse Smathers came up with that connection to this project. Jesse and I have worked together off and on for the past twenty years in different capacities. We both worked for Blue Ridge Area Program, and then for a short time at Western Highlands and Smoky LME/MCO’s. I have been drawn to work on the Provider side of the fence and he has remained a constant force on the public management side of the fence. I returned to LCE as the Executive Director last fall. When I was here from 2003-2011 as Residential Director, Jesse and I had a conversation about Paul around 2008. Paul had CAP services which at the time had about an $85,000 annual limit and an additional state funded contract of about $300 per day. Jesse called me up to tell me that the LME wouldn’t be able to continue the state funded contract. Funds were being cut. As you might recall, 2008 was the beginning of the recession. I confidently told Jesse that I didn’t think we would need that amount of funding. I was confident that Paul with careful person centered planning and the opportunity to live in his own apartment would lessen the need for the level of staff support he had historically had. Over the course of my career, I have seen this happen time and again. As providers, we pick services that are more expensive because we are providing services to the highest level of need when we have individuals in congregate settings. And some of those needs are created by the environment not inherent to the person needing support.

I am constantly reminded by Paul and others we support that we expect individuals
with I/DD to have coping skills that we don’t expect of ourselves – that we would never expect of ourselves. How would we react to living with people that we didn’t choose to live with or whom we do not like. How would we react to having little choice or control over our lives? How would we react to having someone show up on our doorstep who we have never met and then have them provide personal care? Or tell us to calm down when they know very little about us.

I want to close by saying – what we have learned is:

People with intellectual disabilities want an opportunity to live a life like you and me. Everyone wants to be closer to free.
Thank you for attending our webinar!

Please take a minute to complete our survey that will be sent out via e-mail today

A copy of this archived webinar and PowerPoint presentation will be available at the NCCDD website at
https://nccdd.org/supported-living-making-the-difference.html