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UNH-Disability RAPP NH Webinar: Disability and Housing

June 1, 2022: 1:00 PM – 2:30 PM  
  
ISADORA RODRIGUEZ-LEGENDRE:   
Hi everyone, thank you for joining us today. We will give it a couple minutes as people join. Thanks for joining us today. We will give it one more minute.   
  
Alright, I think in the interest of time, we will go ahead and begin. Hi everyone, thank you for joining us today for this important panel presentation. My name is Isadora Rodriguez-Legendre, I served as the executive director as the New Hampshire Council on developmental disabilities.   
  
I will be your moderator here for today's webinar. We are very fortunate to have many of the people authors in the Disability RAPP. The Disability RAPP is in the New Hampshire… Institute on disability and the New Hampshire Council on developmental disabilities.   
  
The latest issue focuses on Disability and Housing and is available at drcnh.org.   
  
Thank you. This webinar will focus on key issues impacting people with disabilities and we will have authors from the latest issue of the disability RAPP sharing their experiences and information related to the articles they wrote.   
  
During this webinar, are a moderated panel will explore important housing topics. Like universal design. Institutional qualities. And where people with intellectual developmental disabilities currently live.   
  
Finally, we will have a brief wrap up touching on how the disability is ensuring that people with disabilities have access to appropriate community-based housing. Please use the Q and A feature if you would like to ask any questions. To any of our presenters.   
  
We have left time at the end to answer questions. So, if they are not addressed as we go on, hopefully we will get to it at the end.   
  
To better frame this presentation, I wanted to share with everyone attending today, the overarching question for this panel. Which is, how do we ensure that we have a system that is flexible, responsive, and respectful to those they serve?   
  
As we begin, I am going to ask that each presenter start by introducing themselves. And telling us a little bit about the focus of their article. So, with that, I am going to go ahead and to begin. Our first presenter is going to be Kelly. Kelly, would you please introduce yourself?   
  
KELLY NYE-LENGERMAN:   
Hi, good afternoon everyone. My name is Doctor Kelly Knight Linderman. I serve as the director of the Institute on disability here at the University of New Hampshire. It is a pleasure to join you today. My article focused on the term institutional qualities, which I will spend a little bit of time talking about when Isadora asked my first question.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thank you, Kelly. With that, we often hear that New Hampshire was the first state in the nation to close its institution for people with developmental disabilities. And yet, we see congregant living situations throughout our state.   
  
Where institutional qualities are live and well. We question for you! My question for you are, what are some constitutional qualities that remain in our system of housing and why are they problematic?   
  
KELLY NYE-LENGERMAN:   
It is a really important question, Isadora. The first part of that question is, I will talk about and define a little bit deinstitutionalization. You will hear that term throughout our panelists today.   
  
Deinstitutionalization is really a policy process that has occurred in the United States over the last 16 to - 15 to 16 years of until today. It is a process of moving our transition of individuals with intellectual and developmental disabilities from large institutional settings. So, think big buildings, 20, 30, 50, a thousand people living together under one roof.   
  
Two smaller community-based settings. Those smaller community-based settings can be big, but generally, what we see and talk about incongruent housing are smaller and larger group homes. Some of these community-based settings are either run by the state, in this case, the state of New Hampshire.   
  
Happening today. Or they could be run by private provider organizations, so we see across the country, this a movement of moving from these really large facilities to smaller community-based settings. One of the things that is really important to talk about, consider, and name, when we have this conversation about deinstitutionalization in community living are, even when we meet some of these definitions of smaller community-based settings, there are some inherent institutionalized qualities when we support people with intellectual and developmental disabilities.   
  
Even though we can say the settings are much smaller, there are things in settings -- things that are happening in the settings and places that really result in it still feeling like an institution. That is when we get the institutional quality. What are some of the things are happening in these smaller settings and still feel really institutional that are not necessarily honoring, individualization, or control over your living and home environment?   
  
When we think about, what are those institutional qualities that might exist in some of these different settings? We want to think about, what are the choices that any of us who are here today have in our daily life? And whether that is things about choosing when we get up, choosing what we want our food, or our lunch, or our menu to look like for the day, choosing who we live with.   
  
Even where we live. Do we want to live in this neighborhood? Do we want to live in this town? Do we want to live close to a family member or friend? Or do we want to live someplace different? Many times, some of these congregants and group settings still have qualities that do not give people choices about the roommates that they might be living in.   
  
The towns they might be living in. How big the house, apartment, the setting might be. Many times, we also see that when people are living in groups, both big groups and small groups, when we require some staffing or some supports those housing settings, a lot of that time some choice or control is removed or not deeply considered. So, some people might have to adhere to schedules of other roommates or other house guests.   
  
They might have to incorporate the direct support worker schedule into their own life schedule. They may not be able to participate in some of the things regarded in daily living, going to the grocery store, meal planning, homemade. Those might be things that are taken care of or done by a provider or an organization.   
  
In some settings too, restrictions in certain parts of your home. Restrictions to access to food. More specific mealtimes. We also might see or hear about restrictions of personal privacy or visitors. Again, if you are living in a setting or a home where there are some of these rules, these kind of qualities and parameters can still really make it feel like an institution.   
  
I want to be really careful to say is that, sometimes we do these things very unintentionally. In the sense that if we think about our history, these really large organizations and facilities, small spaces, we have not necessarily transformed our policies and practices to align with that.   
  
So what we see are, these qualities get carried over into a variety of settings. And you know, Isadora, getting back to the core question of, "what can we really sort of do about it?" First and foremost, one of the things we can do is name that.   
  
To say, "please do feel institutional. These do look institutional. And people who are living in these settings are saying I do not want these kinds of restrictions." I need to have choice and control. I should be able to come and go as I please or select the roommates or people that are living and working with me.   
  
Those are the kinds of things that we were talking about. Institutional qualities. We cannot forget to say, just because we have moved from institutions, does not mean that those things cannot and do not exist. In some of our very current settings today in nature.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thank you. So, just to follow that up, what do you think are some of the housing models that we could use more of here in New Hampshire?   
  
KELLY NYE-LENGERMAN:   
I want to ground that in this idea that choice and control really need to be at the center of all housing and decisions around community living. Again, our service system is not necessarily always set up to prioritize that. That is one of the things that we need to continually work together about. How do we build a better system that puts choice and control of individuals at the forefront?   
  
That said, when we think about that area, are we really digging down with individuals to say, "what is it that you want? What type of support do you need?" Not everyone needs 24/7 support. Some people do, some people do not. When we think about models that can work well both in our state and have worked well in other states, it is really being able to provide that continuum of support to say, "yes, even people with significant support need and can live dependently in the community. They can do so with flexible funding models, with potentially environments that have the community care option or we call it an enhanced family care in New Hampshire."   
  
It can or may or may not be having options to have roommates with or without disabilities. In your environment. It can be living in your own home and using a pay-as-you-go or pay as you need to build support model to say, "hey, I need support going to the grocery store. I need support during this aspect of personal care." Buying or using services for what you need rather than say, "I need to live in a home that has 24 seven support."   
  
The other thing I will say, Isadora, that I think is really important, two things to keep in mind. One, how do we continually use technology to enhance independence and how does technology can be used in a variety of different models to basically be able to support people to live more independently and have some more control over the types of things they might need, day-to-day, or week to week.   
  
The other thing to think about all of these models is, the role of the direct support workforce. I mentioned that even people with really significant support needs can live independently in the community. But as we know, and we'll talk about today, the role of the direct support worker is still very critical to high-quality, authentic community living.   
  
Because we continually find ourselves across the nation in both a direct support workforce crisis and shortage, we as a state in the community need to say, "if we care about housing options and we care about individualized services, we have to be attentive to our direct support workforces as well."   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thank you so much, Kelly. Before I move on to the next panelist, does anyone have anything else they would like to say or add? OK, our next panelist is winter… Winter, please introduce yourself.   
  
WINTER TRABEX:   
I am Winter Trabex. I work with the (unknown name). I am a freelance supporter for (unknown name) which is a local disowned newspaper.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thinking. So, my question for you, Winter is, what role has your housing played in your ability to live the life that you want? How has that changed over time?   
  
WINTER TRABEX:   
It has been night and day. When I was homeless, it is like being in prison or worse. You do not have a choice on hardly anything. You do not choose when you wake up, when you go to sleep, when you use the bathroom. You have to be in (indiscernible) at certain times. Everything is chosen for you.   
  
Having my own place has been so liberating! I have a lot more choices now. I am enjoying my life! I can actually enjoy my life. When you are homeless, you do not enjoy life. Anyone who says they are homeless and are enjoying their lives, that is just on a good day, I guarantee you.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Yeah. I ask you also the same question I asked Kelly. What systems of support or housing options would you like to see made more available for New Hampshire residents with disabilities?   
  
WINTER TRABEX:   
I guess I would say that, I would really like to see court appointment public defenders for eviction cases. In regards to disabled people. I just went to court today. But I noticed -- what I noticed is, these big housing property companies, they have all kinds of lawyers.   
  
They have all kinds of evidence. And then there is this Senate representing themselves. It is unbalanced. I think that would go a long way to helping attendance stay where they are rather than having a disabled person thrown out and then going… Which is even worse.   
  
The shelters we have are insufficient for the needs of our disabled community. They - there is one in Manchester. There is two in Vermont. The one here in Manchester has a set of lung stars. It is an old building, used to be in the YMCA building.   
  
It has a set of long stars. And an elevator. So imagine if you got kicked out of your house, you are disabled, you go to the shelter, you're in a wheelchair, you cannot get upstairs to your bed. What do you do? It does not work!   
  
For people like me, I need extra sleep. More than usual. I need like 10 to 12 hours of sleep every day. They don't let you sleep how long you want. You are out of bed at 6 o'clock morning. And if you don't like it you can leave. That's what they offer you. They don't make exceptions for doctors notices or medical conditions.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Really appreciated your perspective in your article about how little person centered services are, that should be universally accessible for people.   
  
WINTER TRABEX:   
Yeah, I mean I can see that they want to keep costs down. And they want to pull out as many services as possible. But at some point they have obligations to meet. They have things they need to do. You cannot just treat it like a business. It is a service. You are going to lose money. If you are not willing to lose money, why are you doing it?   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Right. Even though there has been some progress, why do you think so many people with disabilities struggle to find housing they can afford?   
  
WINTER TRABEX:   
Of all of the time, let's say someone moves out of the shelter, into an apartment, well, the mail would go to the shelter from the Social Security Administration. It gets returns, the Social Security will credit their benefits until someone can verify their address. Or let's say the rent goes up. It has been happening lately. A lot of property owners have been renovating their places, and evicting their tenants whether they are in good standing or not.   
  
The next thing you know, you have got to find, you're making $600 per month from Social Security like I am. If you are with a private landlord you have to meet $1500 of rent every month, and how do you do it? Your only option is to apply for HUD housing here in the city. You cannot do that, what are you going to do?   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Yeah, so there should be more options available that really help address people's needs is what I hear.   
  
WINTER TRABEX:   
The shelter should be absolutely fully accessible according to the federal standards. And it is not even close.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thank you so much for that perspective. Also here to provide parents perspective on housing, access and accessibility, we have Jody. Jody please introduce yourself and share a little bit about your perspective.   
  
JODY VAN NESS:   
...   
  
ISADORA RODRIGUEZ-LEGENDRE:   
You are on mute.   
  
JODY VAN NESS:   
Alright. Better. My name is Jody Van Ness, and I am mom to a son named Andy who lives his life with autism and cognitive disability. He is 33 now. So we have been at this for quite some time. Our dual journey to find him, or help him find a life he chooses to live. And I have had some wonderful people along the way that have helped us, and ended up in my last position of the University of Minnesota's Institute on community integration while Kelly was there, and retired just last summer. So I have been able to proverbially sit on both sides of the desk so to speak. To see how things come about, how things are done, what are the policy and decision-making happens.   
  
But also, being an advocate alongside Andy as he looks to find his place in this world. Most times it is kind of a nice weave, and other times it can be really difficult. But we know, back in transition days where we started thinking about what would be next, and he has siblings who are older than he, so he of course expected he would go to college, get married and buy a house because that was what his siblings had done. We knew that we didn't necessarily say that those things weren't going to happen, but it was likelier they were going to look a little different.   
  
So we started talking about options. Because with autism the one thing that has an impact on and he is he doesn't quite understand things that he hasn't actually experienced. He is a very kind of experiential learner. So we started talking early about housing. And from my seat in those days, I kind of looked at that as the pinnacle. Finding the right place to live would lead to everything else. I had this full security that this was kind of a linear situation and we were going to cross things off as we went. First of the housing circumstance, then the employment, making sure his social circle is well in his community is developed.   
  
But what we found really quickly was this was not at all a linear process, but it was kind of a dance. Where you would have an impact on impact on where you live, where your work had an impact where you lived, where your friends were in the access to transportation and so on. So all of a sudden, the housing wasn't just about housing. It was about a piece of Andy's life we had to figure out. And in the last 10/15 years, and he has journeyed from living in a group home, recently he had been living with a live-in caregiver who is his age. But we found really quickly, and that lasted three years actually. Whereas it went really well, and he developed some amazing skills. He was extremely lonely. This young man he was living with was very, really had his nose to the grind, he wanted to buy himself a home, he wanted some very specific things, he was a musician, so he was gone all of the time other than that 9 PM to 7 AM which was his consider his time he had to be there. So no real friendship was gained by that. Which there are a lot of roommates who don't necessarily achieve that, their roommates, they are not necessarily the best of friends.   
  
Unfortunately for Andy however, he is a really social guy. And all of a sudden this became clear that this was going to be a very lonely existence. He could do his laundry and he could cook some of his meals and he emptied the dishwasher and clean his home, but he was always sad at the end, and it made us realize we needed to move on to whatever was next. About that same time, my mother who is 93 and had been living in Florida for 25 years decided she was going to move home because she no longer wanted to drive. So they moved in together. In what has been extremely interesting about this, is that I watched him, who had always that she had always relied on DSP support, turn and instead very empathetically, for someone who lives with autism, help her. The joy and the skills that he developed in terms of relationships living with mom this last nine months has been awesome.   
  
But with most living situations there is a downside. My mom is 93, something could happen at any minute. We know how fickle the housing support system is, and we know it can take many months to find something different. We have kind of started looking around again. And what we have come up with, at least in the state of Minnesota, who I think is very progressive in their support systems and very family and person centered, what we're looking for really is a group home setting with friends. But with support. And he has a rare genetic disorder, and the medication that keeps him on the even keel with us causes weight gain if he isn't very careful about what he eats. And we have come to realize that someone is always going to have to be there to help supervise that for him.   
  
So now we are looking at, OK we need supervision. We want a social circle of people he chooses to be part of his life. We need a location that he can afford, and that it's close to work. He has a very good job and a bio technical company working in their buyer has supplies, it sounds awful but it is really not. They recycle pacemakers and so on, he works for (unknown name). Don't want to give that up. So how will the stance that we have started out with continues? And when I really sit back and think about this, it continues for my other children as well. This isn't just about disability. It is about living one's life according to what resources we have, and what our dreams are. And for none of us does that always align easily or conveniently.   
  
But again, we are sitting now looking at OK, well we just bought a new home so that my mother could live with us. That means what can we do now when their lease is done this winter that would move him in the direction where he could still be with his friends, he could still participate in all of the communities that make his life whole for him, and still live within the supports as they are defined by the state of Minnesota and our federal government. So I know I am going to go ahead because I know your next question will be, is what does that look like? What needs to be available? We see a growing year. And we are really excited. It has to be flexible. It just cannot be check this box and this is what you get. We have a DSP crisis. Even if we wanted to find people to pay to hang out with Andy and to provide some of the transportations, some of the supervision with his eating, they simply don't exist anymore here. So when we look at this we know we need support. We know we need to grow natural supports. We know we need help breaking into the community to help people who don't have disabilities to understand what a natural support means. Those are the things I think that are going to continue to grow our options rather than limit them.   
  
And I think when we talk about struggling to find places to live, I think there are probably a lot of families that are told there is a waiting list for that and awaiting links to for this and so on. I am kind of a tenacious person that was never going to happen for us. But I totally understand how it does for a lot of people. Where they kind of give up and think OK, we're going to take the option that has the path of least resistance. And often times that doesn't change much. So we know that everyone is struggling right now. We are all dealing with inflation, we are all dealing with rising residential costs that no social program will ever be able to keep up with. And we have a lack of good, natural supports, people in the community to understand what it means to be helpful.   
  
I was sharing with the group yesterday, and I will kind of wrap up with this, that my son grew up in a faith community that he very much valued, and that is a very important community in his world to him now. And he takes the bus, the lift actually to downtown Minneapolis to go to this big old church because he loved the tradition and the robes and the choir and all of these things. And we went to church with him on Easter, and he has been going there now for a year and 1/2. And not one person other than the pastor said good morning to Andy when we came in. And I just wanted to cry. Because he is a great man. He is fun and he has gifts to share and of course he does need some support, but I thought, that is what we want to change. Not so much the formal supports, is how do we help you become a member of the community in a way that is really authentic and have the flexibility to make choices in where he lives, where he works, who he spends time with, of course and what his dreams are. I hope I answered your questions.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Yes, you did a wonderful job. Before we move on I just wondered if anyone else wanted to add anything or say anything. I really appreciated your perspective about really educating communities about the value of embracing citizens of different abilities. And having that system be away that people can really live the life that they want to lead.   
  
KELLY NYE-LENGERMAN:   
Isadora, this is Kelly… Isadora pointed out this point of how Social Security benefits and other types of benefits affect where you live, how you get your mail, and all of that. Jody also talked about how… One of the other things, and maybe we have not explicitly names this is that, inherently, the way that our services are structured for people with disabilities and their families in this country is in a place of deficit and poverty.   
  
To say, we are creating and perpetuating independence. Again, I do not necessarily think that that was always the intent. If you look at the design of the way that we do business in all of these areas of community living, sometimes what we end up with. Often, I think again, unintentionally, get in this cycle and trap where you can only live in these places. Or where this type of housing assistance is available.   
  
To Jody's point at the end about so much of this is also about our connections to the community. As a system, we cannot do it all alone. Part of many of these solutions come back to enhancing natural supports and relationships that we all have.   
  
And how do we make sure that those get extended in the same way to people with disabilities, too? To me, I saw that loose connection of interconnectedness and importance of natural supports and community fellowship, as well.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thank you for that. I see Winter also added in the chat that disability is evaluated based on your ability to work and make money. That is problematic. That is how a hearing before an Administrative Law Judge usually goes. When you apply for Social Security.   
  
That perspective is kind of a very limiting. In what someone can contribute to their community. So moving on, our next presenter, our next panelist is Sherry. Who wrote about important ways that data can help identify and support housing needs for people with disabilities.   
  
Please go ahead and introduce yourself, Sherri.   
  
SHERRI LARSON:   
Hi, I am Sherri Larson. I worked at the University of Minnesota… Community integration. It is our University Center of excellence and developmental disability. I have worked most of my career on a project that keeps track of what is happening in terms of where people with intellectual and developmental disabilities live. In 1967, when there were hundred and 94,000 people living in state run institutions, the situation was very different than it is today.   
  
Today, we are under 20,000 people living in those places. We have tracked that journey. I have information both at the national and the state level about residential and in-home supports look like for people with intellectual and developmental disabilities.  
  
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thank you so much. We talked about how proud New Hampshire is to be one of the states who have closed their large state operated institution.   
  
Although some state run institutions for people who have intellectual and developmental disabilities still operate, 17 states including us no longer have that state operated, large institutional setting.   
  
My question for you is, what can we learn from the state who have moved away from large institutions? Show --   
  
SHERRI LARSON:   
One of the big questions may not already talked about… Five states do not have any large institutions at all. Private or state. So, the message from that is, there is not anyone who cannot successfully live without being in an institution. We can serve people with a whole wide range of needs and community settings. There are states who have proven that that is possible.   
  
And that it is doable. However, the state that are still operating those services need supports. Technical assistance and Medicaids available to provide not just the poorest people, but they provide a lot of supports to states.   
  
In terms of money and fellow programs… Supporting people in individualized settings. So, what else have we learned? One of the things that we have learned early on, when Medicaid came into try to address the horrible conditions and institutions, one of the things they did is they said, "hey, we will pay for half the cost of institution services but you have to approve the conditions. This is crazy! This is really not OK."   
  
So, they require those institutions to downsize. To reduce the number of people living there. And so, early on, when institutions began to downsize and close, the answer that we knew to do was to create nonstate settings for people with intellectual and developmental disabilities and a lot of times those were in large institutional settings.   
  
Over time, we move to smaller and smaller settings. The states that still have a lot of people living institutions have an opportunity that these states did not! They can learn from the experience that building big institutional settings for state operating settings is not helpful.   
  
And so they are actually able to skip that step and move right to sue providing supports an individual's settings. It is a great opportunity for those states. The last thing we learned is that, there are - states continue to struggle with a very small subset of people. Those who have milder and moderate intellectual disabilities, are a danger to others, or in the criminal justice system full so that is an ongoing challenge and states are continuing to wrestle with the best way to serve those individuals.   
  
I can tell you with confidence that the best choice is not to house them in an institution with other people with intellectual and developmental disabilities. So, those are some of the lessons.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thank you. Relatedly, where are people who used to reside in institutions going from? And I would say, have some states transition to community-based services better than others?   
  
SHERRI LARSON:   
I already started to talk a little bit about the factors that impacted institution downsizing and closure. One of the factors I did not talk about is, in 1974, or 1975, there was a federal law that was passed that mandated that states provide a public education to all children, including children with disabilities, no matter how severe those disabilities were.   
  
That change in policy made a huge difference. Because, prior to that change, the only way parents can help their children to get an education was to send them away to an institution. Now, in 75, beginning in 75, we have this option for parents to keep their children at home with educational supports. That made a lot of difference and families stopped asking for institutional services.   
  
In a lot of cases. In 1981, Medicaid figured out that it was probably bad policy to pay for support an institution, then to deny subversive people who want to live with her family members in their own homes.   
  
They created what is called the home and community based waiver program. That offered support allowed people to continue to live with family members. That had a huge impact.   
  
Today, most people with intellectual and developmental disabilities live with family members throughout their lives. For people who do not live with her family members, as I mentioned before, initially those who left institutions went to private or large group homes. Now, most people are moving to small group homes. Four people or fewer. Her individualized head setting. So their own home, or foster family homes…   
  
We have changed the system. We have changed how the system looks and operates. There are some states that are far behind and other states that are far ahead. And you asked how -- what the differences are between states.   
  
The states are incredibly different. Where you live really makes a difference in terms of what your access to support is. In fact, in the most recent report that we put together, we were able to show that people with intellectual and developmental disabilities were 10 times more likely to get locked from supports and services in some states than they were in other states.   
  
It is a dramatic difference. New Hampshire is in the top five in terms of providing supports to people who have intellectual and developmental disabilities. But, it is wildly different from state to state.   
  
Another big difference between states is, some states focus their supports really exclusively are very much on people living with family members. And other states do not provide very much support to families.   
  
Some states provide a lot of support to people living in their own homes and other states do not. And so, one of the biggest issues today is, in equity.   
  
States have a lot of discretion about how they run their programs. And it really does make a difference where you live. People who live in New Hampshire have a lot more opportunity than people who live in other states.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
That is great. I also wanted to - your article is heavy on data. And the rest specifically. Which Kelly put in the chat for everyone as a resource. Why is it important to track, analyze… Were people with developmental disabilities live and how can we learn from that information?   
  
SHERRI LARSON:   
I am convinced that without national data showing the problem, hundred and 94,000 people living in institutional settings. And tracking what is happening, we would not be where we are today. The data that was provided at the University of Minnesota, at the time, the University of Colorado and the University of Massachusetts in Boston has been woven into both policy and into court briefs.   
  
The have been used to spur action on improving the places where people receive supports. And so, those data are necessary. We need to identify where we have been successful and we need to be able to find where there are issues and to monitor whether what we are doing is helping to fix the problems or whether the problems are getting worse.   
  
So, some of the things that I run into, I collected annually from state IDD agencies. And some of the agencies do a really good job. They have really good data systems and can provide all of the information you asked for. Others have really difficult times with that.   
  
One of the issues that some of the states wrestle with this, they cannot report the difference between how many people live with their family members versus how many live in their own homes.   
  
They only know that people are getting in-home supports from someone. And that - in terms of monitoring people having the life that they choose and having individualized supports, there is a big difference between people who live in their own home and people who live with family members.   
  
We know from research that the outcomes are quite different. And often times, people who live in their own homes will have more choices over things. On the other hand, people who live with their family members often have expanded natural supports available to them.   
  
That are more difficult to maintain for people within their own homes. So, that is one of the challenges that we have. The other challenge is, continuing to provide accurate, up-to-date information about people whose needs are not being met.   
  
So, about waiting lists. And some states have good information about that, other states do not. There are a few states that report no waiting list, including New Hampshire…   
  
The differences there. The good news for New Hampshire, is that, they have been able to provide for the last three years. Complete information to the risk project to monitor where you are.   
  
New Hampshire, as I mentioned before, ranks the top five states in terms of access to services overall for people with intellectual and developmental disabilities. And they did not report anyone waiting. So, one or another one of the programs are available to provide supports. Whether it is a Medicaid Waiver or whether it is the Medicaid State plan service. Or whether it is some other service.   
  
Those services, at least in terms of what they have reported to us, are typically available. Also we know 97% of the people in New Hampshire live in -- who do not live with her family members, live with six or fewer people. And 94% do not live with her family members live in shared homes shared by three or fewer people. About 37% live in homes shared by a family member.   
  
There are still people in nursing homes in New Hampshire. There was not one nonstate IDD facility with 36 -- 26 people… 1715 people. So, those are some of the key highlights that I can tell you. Because states are providing the data. It is incredibly important. As you can see, valuable to state policymakers, to advocates, to researchers, and to others who care about the lives of people with intellectual and developmental disabilities.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thank you, that is really helpful. Stephanie, did you want to add something?   
  
STEPHANIE PATRICK:   
I just wanted to follow up on Sherry's data and point of that data is really critical because you do not know where you need to go unless you have a sense of where you are. But, I think the end of your data presentation actually pointed out to me some questions about, you know, thinking about -- think critically about the data and what the picture painted for people with disabilities in New Hampshire.   
  
So, I am Stephanie from disabilities rights… I will introduce myself. But, I know that the state regularly reports that no one is waiting on a waiting list for services. However, that is not actually accurate.   
  
There are a number of people who are waiting for services. They may have been approved for waiver services. They have gone through the process and they are in the process of getting a budget approved. They are not actually adding services.   
  
I mean, I talked to families every week who were like, "I have not had a DSP to help my family in the last two years." So, you might not be on an official waiting with this. New Hampshire's DD waiver, the waiver that serves the results, and the incoming supports waiver, the waiver that supports children says clearly, "we do not have a waiting list."   
  
What they will also say if you push them on this is, "we do not control the money. The legislator controls the money. Sometimes, there is not enough money for everyone to get the services that they need. Or sometimes the services say we will pay $12 an hour for you to have a DSP, there is actually no one willing to work for $12 an hour in your community and that is all we will pay you."   
  
So, you are waiting, somehow. You're just not on the list.   
  
SHERRI LARSON:   
People have an mate -- unmet needs for services... We did an evaluation for Minnesota's waiver 20 years ago, and following that many family said that they were not able to use the money that they were allocated because they could not find anybody to provide the supports. Addressing direct support is critical. Medicaid has taken some pretty dramatic steps in the American rescue plan, and offering a lot of resources to states to improve their systems. To help increase rages, to help provide recruitment efforts and training. But those policy changes will take a long time to actually make a difference. And we have a crisis right now.   
  
So there aren't simple and fast answers to that. It is not simply throwing more money at the system. This is a system that is broken and has been broken for quite some time. In terms of advocacy and in terms of policy, we have got a lot of work to do to try to resolve this issue. Workforce is a very big factor.   
  
Then the other factor honestly is the lack of affordable housing. Accessible, affordable housing. It is great if you have your Social Security dollars that provide $600 a month. You have a waiver that provide supports. But a lot of people who have those two things cannot find a place to live because there isn't a place. That is another huge, big critical issue. It is going to take a lot of support to figure out – I don't know how to fix that, it is systemic and getting worse, the pandemic has created the inflation and that is raising the cost, the housing costs are skyrocketing, there is all kinds of issues that surround that. So the work is not done. That is the other message. The work is not done.   
  
We have accomplished one mission, which is to stop treating people as nonhumans in nonhuman conditions in big institutions. But we haven't addressed the human needs that are existing for people with intellectual and of elemental disabilities.   
  
KELLY NYE-LENGERMAN:   
Sherry, that was really well said there at the end. We move from one thing, but in our pursuit of that other things and other problems, and our work isn't done. One of the things I wanted to highlight, I am not sure people have picked up on this message throughout the panel, is that we need both data and advocacy working together in collaboration. Because as we have talked about. Our legislators and many policymakers want data and costs and things like that. That is the part of good and effective government. At the same time, to Stephanie's point into winter's point, is that Dana only tells part of the story of that. That is why we need to be working so closely and collaboratively together through all of our organizations, through individuals and families, for messages for policymakers, state agencies, and messages for each other.   
  
Because again, we might be working over here on the data, things at the University, but miss some of the new ones that really comes through those individual family experiences and vice versa. So I hope that again, other folks take away that we all have a role in this, and whether you are working in advocacy, research, policy, direct service. That we all have a valuable voice and a contribution to bring to the table as we try to build better solutions in the short term and in the long term.   
  
SHERRI LARSON:   
Kelly, just want to applaud you and your partners in New Hampshire. Do you have the DD Council and the University Center of excellence and the protection advocacy cosponsor copublished policy relevant publications, and then to follow those by joint webinars, is a great model. We haven't done that in Minnesota. I think it is something that we should take a closer look at. We talk to each other, but we don't necessarily put that talking to joint action. So that is great. The other thing we struggle with at the University of Minnesota, and I am sure you think about it a lot, is translating the information we have into formats that people can understand and use. One of the things our funding agency, the organization or community living, asked us to do in this current funding cycle is to create a publication that was written by all... I have data, and targeted to people with disabilities and their families. So we created a document called 30 years of community living that summarizes the story. And we worked very hard to make sure the language we used was understandable, not just to families but also to people who have intellectual disabilities.   
  
But we have got way more to do in terms of what our responsibility is as researchers to make sure that the information we have gets translated and is used by people who need the information.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thank you. I just want to piggyback off of both the direct support crisis but also the housing crisis. We hear about low vacancy rates and we have talked about the competition for these scarce resources. There are a lot of low income workers who are competing for the same apartments as people with disabilities. And unfortunately, in New Hampshire, landlords can discriminate against and that is something that needs to be addressed.   
  
One question that I would also pose to everybody, is how can we work together to really advocate, to developers and New Hampshire that there is this need to create more inclusive and universally designed housing for people with disabilities. And similarly, how can we change the message to landlords? That is not OK to discriminate on someone based on someone's income or whether they have a voucher, that housing is a basic human need and that we need to really work as a community to be able to support all of our members to have that need met.   
  
SHERRI LARSON:   
Let me just quickly comment and then I would love to hear what your partners have do say. The Administration for Community Living is very aware of this issue. They have created what they call a housing and services resource Center four states. They have done webinars, they offer resource materials. They are doing what they can from their perspective with their parameters. To try to help states to do, to improve things. CMS is also really through the American recovery act funds, they have, those funds specifically can be used by states to build or acquire affordable, accessible housing, as long as the housing is not disability specific. So as long as there can be people with disabilities living there, there can be people in multiple apartments in a building that have disabilities, but there also has to be other people who are part of the general community. Maybe they are low income and they need low-income housing, maybe they are on housed, they are homeless, they need a place to live. The home and community-based waiver is restricted to only home and community-based settings. You cannot use that money to pay for services in a big intentional community, unless the communities integrated and there are people with disabilities. Those are federal resources that are hard to address this. But I would love to hear what the rest of your partners are doing.   
  
SPEAKER:   
I do think this a great opportunity to take advantage of this now. Like you said earlier, New Hampshire has significant American rescue plan funds that the state is using, or talking about using, to address a number of these issues that we brought about today. Abel New Hampshire which is another one of our partners, advocates building Senior quality, one of there is to address senior housing issues and they have been working a lot in the grassroots level to try to engage people. We can definitely share some information about their advocacy with the new housing, New Hampshire housing finance agency and others who are really thinking about how to prioritize the resources that we have right now. Which are limited. This is a unique situation to have this much federal money come into New Hampshire. Partners from other states may not know New Hampshire does not have an income tax. We don't have sales tax. So typically even though we are a wealthy state on paper, if you look at the average income of people that live here, our state resources to devote to this are more limited than you would think. So I think it is a really critical time to speak up now and use this money in that way.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Winter.   
  
WINTER TRABEX:   
One of the things that happens, it is pretty common with someone with a disability is trying to afford an apartment, they use their Social Security money, they supplement it with a job. Something happens, their condition worsens, they need to stop the job, then all of a sudden they cannot pay rent, they are taken to court for nonpayment. Landlords don't want that. They want consistent, steady payment. There needs to be away, I would suggest, raising Social Security according to the living wage, which I would say is about $4000 a month. So that anyone can afford an apartment without having a landlord worry about are they going to pay or are they not going to pay? I'm just going to take the person who has actual proof of income that is higher than this other person. That is how disabled people get left out. The Social Security just isn't enough.   
  
SPEAKER:   
I think that is a great point. And it is not flexible enough so that if you have a job and suddenly you cannot work for a couple of months, it is not easy to get that Social Security benefit back if you can even get it back. And that is how people get behind. So that is really critical.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Does anyone have any other comments or anything they want to share on this topic before we move on?   
  
WINTER TRABEX:   
Developers making affordable housing, I know where I live in Manchester we are working on giving out-of-state developers. One from California who has proposed affordable housing units at an old police station. We are looking at building back old properties that have been burned down from fires. This has been a process that has been going on for a few years. It is going to be a process that has been going on for several years, we are working on it. Definitely not fast enough for me, but we are making progress.   
  
SHERRI LARSON:   
I think the biggest challenge in any of those developing projects is to make sure they are both affordable and accessible, fully accessible. So that people whose needs change over time who already have disabilities that require modifications, have a place, that is the bigger shortage area. It is not of interest affordable housing, it is affordable, safe, and accessible housing. So as we are building now, we have these resources, let's make sure that what we build is affordable, accessible, and safe.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Yes. And it is good to know that we have a system that is really coming together on working on these issues. And Sherry talked about the collaboration between the DEP network partners, and we collaborate with so many more groups and organizations here in New Hampshire, I feel very fortunate that we are able to present some of these very timely and very important issues with one voice. And be able to advocate for the needs of people, because we are all people and we all have the same needs.   
  
With that, I am going to go ahead and move to our kind of closing statements. I am going to invite Stephanie to introduce herself before we wrap up.   
  
STEPHANIE PATRICK:   
I am Stephanie Patrick… Including intellectual disabilities. On a variety of different disability related issues. We care very deeply about these issues and are glad to be a part of this conversation.   
  
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thanks, Stephanie. What is the law doing to help and the legacy of institutionalization for people with disabilities?   
  
STEPHANIE PATRICK:   
Yeah, well I think, there is a lot of work to be done. That is how I will started. Disability rights, one of the things I did want to mention earlier in our conversation about waiting list is that, we continue to litigate around issues related to New Hampshire's access to services for people with development disabilities.   
  
Including people who are under 21. We have an active case right now that is pending at the New Hampshire Supreme Court about access to services for people that are younger than 21 through the DD waiver. We are also very concerned about people who are told, "your situation has to change." New Hampshire has three categories of how they prioritize people. People that are new to the system, people that are turning 21, and people that have circumstances that change. We are very concerned about that piece of the factor weeding list that New Hampshire does not have, apparently according to their data.   
  
Sherry mentioned a few laws. Including the IDA which was passed in 1975 into the changes to New Hampshire's Medicaid Waiver back in 1981. You know, that was a long time ago.   
  
That was a lot of work to do. There was also in 1999, which was 23 years ago. The name Mac versus LC decision, this was United States Supreme Court case that said that unjustified segregation of persons with disabilities constitutes discrimination under the Americans with disabilities act.   
  
Another significant lot to protect the rights of people with disabilities. However, I think that there is still a lot of work to be done at how housing fits into this picture.   
  
Housing is, as you know, a critical component of independent living and we have to have these conversations. New Hampshire needs to be thinking even more about how housing fits in with its obligations to comply with Olmsted. And what it looks like to make housing a part of integrated living for people with disabilities.   
  
As often kind of, I would say, most of the litigation I am aware of focuses on services. Not so much on housing. Housing has to be a part of that picture. You've seen from the stories we have heard from (unknown name) and Winter, critical -- housing is critical for services… If you do not have anywhere to sleep at night. Work a place for someone to come into to help you get those supports need.   
  
We definitely need to continue to do this work. If you want to read more about the laws impacting housing for people with disabilities, I would encourage you to look at the (indiscernible). There are three articles in this issue that might be interesting to you. Their first article is an article that is an overview of housing rights. The next one is specifically around housing and emotional support… That is an issue we get a lot of calls about. There is a lot of confusion about emotional support animal and a service animal.   
  
And what that means in terms of your rights. In terms of housing and also public accommodations as you are out and about with your animal that is providing services or emotional support.   
  
There is also an article about an effort that was led by New Hampshire legal assistance, another one of our partners and a lot of this work. To protect venture holders against discriminations. Section 8 is the typical way that people who are low income are able to access housing that would otherwise not be affordable to them.   
  
As we mentioned earlier, discrimination against federal holders is still okay in New Hampshire. And so, there was an effort to pass a law that would protect people who were holding those vectors against determination that did not pass during this legislative session. I am sure that that advocacy will continue. I would encourage you to read those articles.   
  
In (indiscernible) to find out more about those things.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Thanks, Stephanie. That concludes our panel presentation. I want to thank all of our panelists for their contributions to the webinar and to the disability RAPP. Like Stephanie, I encourage everyone to check out the latest issue. There is a lot more information and additional resources about universal design, housing rights, and lived experience accessing housing.   
  
We do have time left to answer some questions. So, I think there are a couple that have come through. The first one is, related to someone's individual experience.   
  
Where they have moved to New Hampshire from another state. And their son lives in a community, I am assuming that have supports were he was happy.   
  
They moved into a 55 and older condo complex. When their son came to visit, did not want to return to their home.   
  
So, because they cannot stay in the 55 and older community, the question is really about, what can we do? There is no place in New Hampshire for him.   
  
To really Access supportive, affordable housing. How can his needs be addressed and their needs be addressed? This is a question that unfortunately, I do not have a hard answer to.   
  
I think we have heard from all of our panelists that we are working on this issue. This is an issue for many people.   
  
Both in and out of state. In that we need to really build resources in New Hampshire that help support people and get their needs met, close to their family. In their community. Where they want to live.   
  
SHERRI LARSON:   
Just from an (indiscernible) perspective, I will tell you that that is probably the most common information request I get from families. It is, sometimes it is in the form of where should I move if I need support for my son or daughter and my state does not provide them? Other times, it is in the form of, I live in this state, we have a waiver right now.   
  
We need to move to another state, will my waiver transfer? The answer is no. You go back to the beginning of the waitlist. The way the policy is set up right now, the waivers are not transportable across states. The waivers are set up by state. They are different from state to state.   
  
They do not transfer over. So, that is a huge gap!   
  
STEPHANIE PATRICK:   
I was going to say too, I think if you are not connected to any services and supports either through the agency or community mental health centers or through the brain injury Association, I do not know what kind of disability or child has. But, if any of those are relevant, if that individual is able to - would be eligible for nursing home services, they can access the CFI waiver.   
  
New Hampshire has a number of Medicaid waivers that your child might be eligible for that come with some sort of supports to help - that can help you. They come with his management or service management which is often a resource to help you find things. The other thing I will say is, New Hampshire is very local. So, a lot of things that you need to find resources, you have to really kind of connect really locally with your communities.   
  
I will tell you, I live in Epsom, New Hampshire full stop which is a small town, maybe 2000 people. I think the way people find housing, from what I can tell from the Facebook page, and through my conversation with neighbors is, by just talking to other people.   
  
Those apartment rents in a day or two by having those local conversations. I would encourage you to reach out locally near you to small towns and communities and try to kind of build a network and see if you can find people who know people.   
  
Might have access to some of that stuff. Especially if your child does not need an accessible unit. If you need a physically accessible unit, then they are so hard to find!   
  
I keep trying but I think those are really, really rare. If that is not a requirement, if steps are okay. If a pattern that does not have grab bars and other things would be OK, then you might be able to find that a little bit more easily through local connections.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Anyone else want to share on that question?   
  
SHERRI LARSON:   
Stephanie, can you repeat again, for someone who is new to the state. Is not connected to the Medicaid system, where is the first place to go for the Medicaid system?   
  
STEPHANIE PATRICK:   
It really depends on what kind of disability have. So, if you have an intellectual disability or developmental disability, you would go to your local area agency. We can follow up if you want to reach out to one of us and figure out which one that is. There is 10 different ones across the state. If you have a mental illness, you would go to your community mental health center. There is also 10 of those, I think, across the state. They are very locally based.   
  
If you have a brain injury, I would reach into the brain injury Association of New Hampshire. They are a statewide agency and they have a lot of good resources for individuals with brain injuries.   
  
And then if you have physical disabilities and you want to access Medicaid services, the way to do that is through the choices for independence waiver.   
  
I think you would - I would Google that are reach out to one of us and we can help you figure out. There is a number that you call. I cannot remember what it is off the top of my head to get access to those services. These are all Medicaid based services. It is for people that are Medicaid eligible.   
  
The other resource that might be helpful for someone with physical disabilities would be, Granite State Independent living.   
  
Which shows a lot of the independent living services and office or home based services for people with physical disabilities in particular.   
  
We can put those - if someone is taking notes, we can put those in the follow-up with the recording with the video, too (Laughs).   
  
ISADORA RODRIGUEZ-LEGENDRE:   
I think that would be helpful for a lot of people.   
  
SHERRI LARSON:   
If there have any questions, I have a question for Jody, would that be okay?   
  
ISADORA RODRIGUEZ-LEGENDRE:   
Sure. There is one other question.   
  
SHERRI LARSON:   
Let's do that and then if we have time.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
The other question I have is, whether we as professionals and advocates working, are we working with community officials and planners with regards to housing needs and choice for those with intellectual and developmental disabilities?   
  
The Reader's Digest is, yes we are working on the… They are also working with developers in different cities and like Stephanie said, a lot of this work is very locally based.   
  
And so, each city or town is going to have different building code requirements and specific laws about what you can and cannot do.   
  
Regarding accessory dwelling units for example. That has become problematic. We continue to chip away at it.   
  
You know? And I think education and information is key. For a very long time, people just did not understand that there was this other group that needed to be considered when building accessible, affordable, community-based housing.   
  
And that now that we are becoming part of that conversation, wherever we are, wherever we go through New Hampshire, that more people are having that aha moment. Where, you know, they recognize that we also need to address the needs of all of our community residents.   
  
And that that means finding ways to specifically support building and development of housing that is integrated and community-based and that can support someone with a development or intellectual disability in the neighborhood where they want to live, or the where they were, or were they have their social connections.   
  
Anyone else want to share on that?   
  
KELLY NYE-LENGERMAN:   
This is Kelly. From the perspective of the IOD, I would say the short answer is, no, not currently. One of the unique things about working with, as you said, in a university setting is, because we are soft money funded, a lot of our projects and services are based on money that we bring in through grants and contracts.   
  
It has probably been nine, at least eight or nine years since we have had staff that are specifically focused on projects, work, advocacy, and research related to housing.   
  
I will see that we have two current open positions for assistant research faculty that are recruiting for one in particular focus on aspects of community living around housing direct support workforce.   
  
And other areas. That is something that we, here at the IOD in New Hampshire, really do want to grow. There are other, as he said, similar to the work -- not similar to Sherry's work, but more options to do more housing focus work some of you think of the IOD and our role in this for our particular status, we can be a connector in terms of helping interpret, develop data.   
  
That helps answer some of these broader questions. As well as kind of thinking about how might we do some public education outreach. I certainly hope in the coming years, that is a footprint that we will grow. Because it is clearly a very significant need for state.   
  
That will be able to have more of a public role in that.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
I also want to add that we need your help. If housing is important to you or the individuals that you love, we need you and your voice and your story to really talk, bring this issue out into the light. Really talk to your councilmembers, your state reps, we do a lot of legislative advocacy during the session. There are always bills related to housing. We really need you to help us make changes in New Hampshire that can support the growth of housing stock essentially, for people with disabilities. So talk about it. Anyone else?   
  
WINTER TRABEX:   
Can we answer Alex's question? Alex (unknown name)? It is at the bottom of the answer page.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
OK. I just think it came in. Alex says I live with my mom and love living with her. But what happens when she is no longer around? She wants me to live on my own. That is a great question, Alex. I think that a lot of families are faced with the situation. New Hampshire is an aging state, and a lot of family members at some point will no longer be able to support individuals who need supports in order to live in the community. So what happens then?   
  
So this is part of the reason we are talking about this and bringing this issue to light and asking for people to help bring their stories and connect with people who have the ability to influence development of housing in New Hampshire for people with this availability – make disabilities, because of that issue exactly. Stephanie did you want to add something?   
  
SPEAKER:   
The way it should be working and expectation people with disabilities should have, if they are involved with every agency in particular, this should be a discussion that starts when people are in their 20s. What do you want now? Would you want your life to be now? And what you decide at age 20 is not maybe what you decide at age 30 or age 40 or age 50. That can shift. But those discussions should be happening as you think about what your life is going to look like, and how the system is going to evolve to meet your needs that may be different than what your needs are today. In thinking about what that looks like.   
  
I think that in a system that is designed the way I want it to be designed, in the way I know Isadore and Kelly and all of our panelists wanted to be designed, you are taking steps to really consider what that looks like at the beginning. And figuring out, to try it out. I will tell you, he moved here from Louisiana. I have a friend who has a son with significant disabilities. She has been thinking about this since he was 15. She is actually building that she has his own apartment that is part of her house that he lives in now, right next to her, with his direct supports. He is not in her house anymore. Because she knows that eventually she is not going to be in that house anymore, he is going to be in the house by himself and he is transitioning to learn the skills so that he is not living with her anymore. But she is close by. So this is a good kind of transition, he is in his 20s. She is hopeful he has another 20 years of living nearby her if that is what he wants. Or maybe he won't, maybe he will want to move somewhere else. They are really actively thinking and putting together a plan about what this can look like for him. And that is what the system should be doing for everyone with developmental disabilities and other disabilities here in New Hampshire. Jody touched on I think a lot of that as well, those same points about thinking about her son and what that looks like. Jody do you want to add anything? I know you are thinking about that as well.   
  
JODY VAN NESS:   
Cheryl mentioned in the chat, asked about what we are doing now, looking toward the future. And I think I am probably the one in the family that has constantly got that, what does 10 years from now going to look like? Because I think I am probably the realist, I also know the system well enough to know that I cannot necessarily count on even what we have now been there then. It is very fluid. And I'm guessing that is true from state to state, we have only lived in this constant in Minnesota, so that is all I have to draw from. But I have done some looking as to where, I have kids living over the country, and what that would look like someday for Andy. And as Kelly pointed out, it is like comparing apples to oranges. Everything is so different.   
  
So when you are faced with uncertainty, I think what you do is look at what are the resources, what does Andy himself bring to the table that we need to look at here? When he was little and I was very protective and felt he was a vulnerable adult, we use that term so freely, I have really come to appreciate what he can do. And how that is really changed what we look for in the future. And it wasn't just about whether or not he could feed himself, whether or not he knew how to make a grocery list, those are kind of easy things. It is more about where is he socially safe in the community? How do we grow communities? And one of the things that I have really come to understand as I have gotten older, and this is true not just about Andy's life but my own as well, is that I cannot totally construct Andy's future for him. Even though I would really like to. Because he has changed so much in the last 10 years, I can only begin to fathom what the next 10 will look like.   
  
So what I am trying to do is look at options. So that he gets to pick from a set of options, or a menu of opportunity to build his life rather than be constructive for him. And that is really what has come out of person centered planning for me is getting rid of the need to control everything. But at the same time, not just let things "happen", because that never works out very well for people who have such a little or small voice in the greater community. He really does not have the voice he should simply because of the circumstances, just our culture and whether or not he is valued or not for who he is and what he is, not for what can he be as a resource or how much is he going to cost us.   
  
So Cheryl, in terms of your question, we know some things about Andy. We know he wants to live with other people. We know that he wants to be close to work because transportation, even though he luckily can use lift, it is extremely expensive. We know he likes a variety of communities and does enjoy inclusive communities as well as people that are similar to him in terms of both his strengths and his challenges. So I am constantly of their looking for new communities. So if I hire a DSP, my question is, and he needs peace things. He enjoys these things. What can you bring into his world that we don't already have going on now? And it is really the hard question for them to answer because they are being framed as caregivers. We don't need a caregiver. Andy does not need a caregiver. We don't call them DSPs, we call them coaches. Because that is really what they are. And for some of them it has evolved into friends. And that is a choice to make together and then I honor that.   
  
So it boils down to me trying to figure out, OK, how can we look at a setting that is a little bit like a group home because he is going to have supervision on site for his medical, his genetic needs. I don't expect a roommate to serve in that capacity. So that leaves out the idea that he would live with a roommate. He has a girlfriend of five years, they desperately want to get married and move in together, but her parents don't, that is not going to happen. So that took the roommate, wife scenario off the table recently. Which totally uprooted our whole conversation. So what does a group home that is not a group home look like? How do we maintain a level of supervision and support where the person who is supervising and supporting is just a member of the group, not an overseer of any of them, manager. That is not what we are looking for here.   
  
How can it be affordable? And how can it provide all of those things Kelly you talked about, what makes an institution and institution, those things, we fall into those things so easily when we start putting someone in charge of a group of people. So we are trying to find some way to bring together probably three or four people that want to live together, that have the supervision they need, have the choice of how they live their lives even though they are part of a group or a community of a house. And it all can still be paid for by our state waiver system.   
  
And we are in the early stages, we are talking to some different people that, there is a faith community that has living options. And we are working with them and they are in our area, working with them to see what something like that would look like. The church sees us as a part of their mission, and underwrites their facilities, so they have a little more support than perhaps having to rely on Social Security. But again, it is all about community. It is all about building natural supports in figuring how they fit together. And how we can use the resources available to support a natural process.   
  
I feel Andy, because of his age and autism, has written the outside bubble of change since he came into this world. And I have kind of taken a backseat behind him (Laughs) And I remember the day we were both sitting on a therapy ball reading of book and we popped into when separate directions on the floor and we laughed about how that is like our life is, we get going in one direction and that is not working anymore we have to take another one. But as long as we have options, I think most families, as long as they feel supported and they feel like they have options, they are willing to have these discussions, they're willing to also meet in the middle somewhere. I think it is when they are back to the corner and said this is what you have today, it is the only thing available, someday you are going to die and your kid is going to be left by themselves, that is the stuff I have nightmares about.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
I think a lot of people do. We only have a lot of -- a couple of minutes left. I want to ask if there is any final statement or take away that anyone would like to give to folks attending today's panel.   
  
KELLY NYE-LENGERMAN:   
I think for me, one of the other threads I have seen through all of this, and I think those of us who work in the field or the industry as well here, that all means all. That inclusive community based housing that is focused on individual choice isn't just for a select group of people. We are talking about everybody. And that includes people who have higher or different or unique support needs. So I think that would be something I would also want to leave in closing.   
  
WINTER TRABEX:   
It is not merely about what you can afford, it is about what you need. It is about what works best for you, not merely what you can buy. New Hampshire I think gets caught up in that too much and I don't like it.   
  
SPEAKER:   
I would just link people with the importance of speaking up and telling me stories about the housing crisis is impacting you and the other crises in New Hampshire support system are really impacting you. New Hampshire has a very large legislature with a lot of – that is making a lot of decisions. And the way to influence them is to talk to them, to call them and say "I am one of your constituents. This is my story. Can you help me?" You have no idea how many legislators brought legislation this year because that exact situation happened to them. So if we want them to be changing the laws and making them different and making them better for people with disabilities, we have got to make sure they know why this is important to you. And it makes each difference. You do not have to go in there with 1000 page research study on the importance of this type of housing or that type of housing. They don't expect that from you. And they probably don't want to hear that anyway, they get enough of that from advocacy organizations telling them why you you want them to help you. And keep speaking up on these issues. Not just the legislator, but the executive Council, the finance agency, all of the people who are making these decisions.   
  
ISADORA RODRIGUEZ-LEGENDRE:   
That is a great point Stephanie. I just want to add that we are a resource. There may not be answers or solutions to all of the concerns and issues presented here today yet, and I hope that is a yet. But we are working as a state and as a collaborative group to really see the changes that we want to happen in the system come to light, and we do need your help and your support to do that. But we are not going to stop trying to make the effort.   
  
Feel free to reach out if you want to share your story. If you want to be part of an article in the future for the disability RAPP, we can certainly use your experiences to bring that information to New Hampshire citizens working on these topics.   
  
And with that, I think that is a wrap.   
  
SPEAKER:   
Thank you everyone.   
  
Live captioning by Ai-Media

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