INTERAGENCY AUTISM COORDINATING COMMITTEE
HEALTH OUTCOMES WORKING GROUP
WORKSHOP: ADDRESSING THE HOUSING NEEDS OF PEOPLE ON THE AUTISM SPECTRUM

TUESDAY, July 23, 2019

The Interagency Autism Coordinating Committee (IACC) Health Outcomes Working Group convened in Rockville, Maryland at the Hilton Washington DC/Rockville Hotel & Executive Meeting Ctr, 1750 Rockville Pike, at 9:30 a.m. Susan Daniels, Ph.D., presiding.

PRESENT:

JOSHUA GORDON, M.D., Ph.D. *Director*, National Institute of Mental Health (NIMH) and *Chair*, IACC

SUSAN DANIELS, Ph.D., *Executive Secretary,* IACC, Office of Autism Research Coordination (OARC), National Institute of Mental Health (NIMH)

ALISON TEPPER SINGER, M.B.A., *Chair*, Housing Outcomes Working Group, Autism Science Foundation

MAX BARROWS, Green Mountain Self-Advocates

JUDITH COOPER, Ph.D., National Institute on Deafness and other Communication Disorders (NIDCD)

SAMANTHA CRANE, J.D., Autistic Self-Advocacy Network

DANIEL DAVIS, Administration for Community Living (ACL)

PRESENT: (continued)

GERALDINE DAWSON, Ph.D., Duke University

JILL ESCHER, J.D., M.A., Autism Society
San Francisco Bay Area

MELISSA HARRIS, Centers for Medicare and
Medicaid Services, (CMS) (attended by phone)

LORI IRELAND, M.B.A., Ireland Family
Foundation

JENNIFER JOHNSON, Ed.D., Administration
For Community Living

DESIREE KAMEKA, Madison House Autism
Foundation

ARUN KARPUR, M.D., M.P.H., Autism Speaks,
(attended by phone)

AMY LUTZ, M.A., M.F.A., EASI Foundation

KIM MUSHENO, Autism Society

DENISE RESNIK, DRA Collective

RYLIN RODGERS (representing Ben Kaufman),
Association of University Centers on
Disabilities

SCOTT MICHAEL ROBERTSON, Ph.D., U.S.
Department of Labor (DOL)

JAY SHUKERT, Parent, Advocate, San Francisco,
California

IVANOVA SMITH, AtWork!

PRESENT: (continued)

STEPHEN WHITLOW, J.D., Merakey Gateway Transition Services

TABLE OF CONTENTS

PROCEEDINGS

DR. JOSHUA GORDON: Welcome. My name is Joshua Gordon. I am the director of the National Institute of Mental Health and in that capacity, the chair of the Interagency Autism Coordinating Committee. I want to welcome members of the IACC as well as the chairs and members of the Working Group on addressing the housing needs of people on the autism spectrum. The speakers who are here today, quite a great list of people who are going to talk about this topic, public attendees both here and those listening on the web. This is the final one at least for this iteration of a series of workshop that the IACC has conducted to do in-depth dives into particular topics of relevance for those on the autism spectrum and their families. Addressing the housing needs of people with autism and on the autism spectrum is incredibly crucial, incredibly important and a growing issue as we recognize the need to consider individuals on autism as they progress throughout the lifespan.

I am going to open with an apology, which is that my schedule prohibits me from staying here the whole day. I am going to be in and out this morning and then I am going to have to leave you around midday. But I am going to stay for as much of it as I can and Susan and the rest of my staff will fill me in on any particular issues of importance.

With that, I am going to turn it over to Susan and the chairs.

DR. SUSAN DANIELS: Good morning. I am Susan Daniels, Director of the Office of Autism Research Coordination at the National Institute of Mental Health. Welcome to everyone in our viewing audience, people in the room, our Working Group members, members of the IACC and our speakers today. We really appreciate you being here to talk about this really important topic and look forward to getting into our material.

I have a few announcements. One is that there is a live feedback link available on the webcast for anyone who might want to put in a last minute public comment and that will be open until 11:30. I was told it would be until 11:30. Yes? 11:30. Feel free to put in a comment there if you have not put in a comment already.

Also, we do have disability accommodations available, a quiet room. As always, the webcast is closed captioned and there is CART available in the room.

We are going to take some time for introductions in a minute, but first I would like to give you just a little background on why we are having this workshop.

As you see, the title of our workshop is addressing the housing needs of people on the autism spectrum. In 2019, the IACC convened this Working Group on housing issues for individuals with ASD [Autism Spectrum Disorder]. And the Working Group mission statement is in the autism community, we face a mounting housing crisis with growing population of autistic adults with diverse needs, lacking appropriate living situations. The goal of this Working Group is to examine a wide variety of housing options and service models for people with autism and to develop strategies to achieve a broad array of supported housing options throughout all of our communities that enable autistic individuals to achieve person-centered outcomes.

This Working Group is going to be looking at research and best practices on housing, implementation of federal regulations, and housing issues faced by autistic individuals with more severe disabilities.

The Working Group members are listed on the slide. They are also on our website. We just wanted to provide this for people who might be looking at this on the web. We do have our slides posted as well.

There are external members who have been invited to provide their expertise to the Working Group as well as members of the IACC in the Working Group.

The activities the Working Group has undertaken so far include a conference call that took place on June 20. We are having this workshop. And tomorrow the Interagency Autism Coordinating Committee is meeting in full committee and will have a brief discussion of the outcomes of this workshop.

We will be publishing a workshop summary in the fall. And the IACC may pick up this topic again when it reconvenes. The IACC is set to sunset on September 30, 2019, but there is pending legislation to reauthorize it, but the committee would go on hiatus until there is a new committee formed.

Because of the short timeline, we are not going to be able to dive deeper into activities around this topic. This discussion will be a key starting point for the committee's deliberations of this topic. We look forward to a great discussion today.

We would ask you to please be mindful of - we have several times for discussion throughout the day and we want everyone to have a chance to speak. If you have already spoken a little bit in the day, please give a chance to someone else to make comments before volunteering to comment at every comment period. But we do welcome everyone to participate and hope that there will be a robust discussion.

With that, I would like to give an opportunity to our chair, Alison Singer, who is a member of the IACC, a long-time member of the IACC, to give a brief introduction, and we also will be hearing from another IACC member, Samantha Crane.

MS. ALISON SINGER: Thank you. I want to add my thanks to everyone who is here to participate in today's important workgroup activities, including those of you who are watching and participating via webcast.

In addition to the agencies that are represented at the table that we will hear from during the introductions, I also want to welcome everyone who is here in the audience today, including representatives from the

Department of Justice and the Social Security Administration.

As we all know, the issue of housing is critically important. We have a dearth of appropriate living options for people with autism and a growing number of adults who are seeking solutions. Our goal for this work group will be to explore some best practices for housing for people with autism at all functional levels and to develop strategies to achieve a variety of options to support person-centered outcomes for a population of diverse persons.

One of the most promising aspects of today's meeting is the opportunity to hear about a wide range of residential options. During today's meeting, each one of us is likely to hear opinions and ideas with which we disagree. We may hear people discussing housing models that failed our children or ourselves miserably. And it may be challenging to listen to ideas that violate our own sense of what is needed and what is appropriate. It is important that we approach today's presentations with open-mindedness and respect.

We are not going to solve the housing crisis here today. But I do hope that each one of us leaves this workshop knowing that we share the same goal to build housing models that enable all individuals with autism to thrive in their communities.

On a practical note, as Susan said, we are facing some time constraints with this iteration of the IACC set to sunset at the end of September. I truly appreciate that the IACC recognized how important it is to focus on this issue and decided to make time for this workshop.

Our goal today is to leave the new IACC with a blueprint with which it could begin work on developing housing policy recommendations for the HHS Secretary. We will work toward this end in two ways. First, by reporting out on today's activities at tomorrow's full IACC meeting. And second, by providing the written summary that new IACC members can receive when they are appointed under the reauthorized Autism CARES Act.

Again, my thanks to all of the IACC and workgroup members and everyone who is here today to participate and listen. Thank you also to Susan and her hardworking team at the Office of Autism Research and Coordination for their hard work in setting up today's event.

It is now my pleasure to introduce IACC member Samantha Crane from the Autistic Self Advocacy Network to give her opening remarks.

MS. SAMANTHA CRANE: I’m Samantha Crane. I'm the Director of Public Policy at the Autistic Self Advocacy Network. ASAN is the nation's leading advocacy organization both by and for autism people ourselves. All of our leadership and our board are autistic and that includes people across a range of support needs and kinds of disabilities. We include people on our board who have been institutionalized who use augmentative communication to communicate and people with pretty significant support needs.

We have been really focused on housing concerns because of course all of us do need housing. We are facing a crisis of affordable housing. In particular, we have a lot of difficulty accessing both affordable and accessible housing in part because Medicaid waivers do not pay for the actual housing part of a placement unless someone is in a group home or other kinds of congregate facility.

We're really focused on maximizing autonomy across a range of support needs. We believe that autonomy is not just for some people. It's for everyone. And we're focused on community integration, which we recognize as a safety issue, because when we are isolated from the community and there are not people we love and care about constantly in our lives and our social life is dominated by staff, that actually sets the stage for neglect and abuse.

We recently hosted a self-advocate summit to discuss the true meaning of community integration. Our summit was attended by a variety of autistic people, including people who had been institutionalized and people with significant support needs, as well as people with intellectual disability.

The takeaways from our summit were again that community integration is not only something that makes our lives better, but it's also a safety concern. We feel safer when we are around the broader community.

When congregated, we end up having to sacrifice autonomy because our service providers want to engage in activities for the entire group of people, and we end up having to do not what we want to do, but what our providers want to do and what other people want to do.

We have also – one of the major takeaways was that tying services to housing is going to set us up for housing instability because when our services fall through or our services end up not being the ones that we need, we end up not being able - we end up not being able to stay in our housing.

Finally, we focus on the fact that everyone's housing needs are going to be different. When we build large housing projects that have - that are based on what it is imagined that we might need, we end up not having access to the housing that we really do need. Some of us might want to live right next to a family member. Some of us might need pet-friendly housing. Some of us might need housing that it's right next to an activity that we particularly prefer. And the consensus was that we would like to be able to build more affordable housing dispersed through the community in a variety of sizes, so some single unit apartments, some single-family housing if we develop a family or want to live with - that we choose.

We have written up a report on that summit on our website at AutisticAdvocacy.org. I really encourage you all to read this. And I'm really excited to hear more from some of our community members today, including some that were at this summit who came all the way to attend this meeting, and thank you.

DR. DANIELS: Thank you, Samantha. We will have some time now to go around and make introductions. After we go around the table, we'll go to the phone to see who is on the phone. Why don't I start and then we'll go around to my left?

I'm Susan Daniels, Director of the Office of Autism Research Coordination and I manage the Interagency Autism Coordinating Committee.

MS. SINGER: I'm Alison Singer. I'm the Co-Founder and President of the Autism

Science Foundation and a public member of the IACC. I am the mother of a beautiful and thriving 22-year-old daughter with autism who lives at the Center for Discovery, which we will hear about later. And I also serve as the legal guardian for my older brother, who was diagnosed with autism back in the 1960s when things were dramatically different.

DR. ANN WAGNER: Hi. I'm Ann Wagner. I'm in the Office of the NIMH Director and I hold the role of the Health and Human Services National Autism Coordinator, coordinating to federal agencies and departments that have activities related to ASD.

DR. JENNIFER JOHNSON: Hi. I'm Jennifer Johnson. I'm the Deputy Director of the Administration on Intellectual and Developmental Disabilities, which is the Administration for Community Living, the U.S.

Department of Health and Human Services. I am also a member of IACC.

MS. KIM MUSHENO: Hi, I'm Kim Musheno, Vice President of Public Policy for the Autism Society of America, Immediate Past President for the Consortium for Citizens with Disabilities, the nation's largest coalition of over 100 national disability organizations. And I helped advocate for housing services for my brother in law, Bill, who has autism and intellectual disabilities.

MR. DANIEL DAVIS: Good morning. I'm Daniel Davis. I am a Policy Analyst with the Center for Policy and Evaluation, Office of Policy Analysis and Development within the Administration for Community Living. I focus in particular on a number of the wraparound services and supports for populations with disabilities including housing. And I'm looking forward to today's discussion.

MS. AMY LUTZ: Good morning. My name is Amy Lutz. I'm here representing the National Council on Severe Autism. I also write about issues relating to severe autism, including housing, quite extensively. I am the mother of a 20-year-old son, Jonah, who suffers from severe autism and intellectual disability.

MR. MAX BARROWS: I'm Max Barrows, Outreach Director for Green Mountain Self-Advocates, which is a disability rights organization Vermont, peer-run. I am a self-advocate here. Glad to attend this meeting. I am a person on the autism spectrum and I'm looking forward to this discussion. I'm from Vermont.

MS. JILL ESCHER: My name is Jill Escher. Hi everyone. I'm a housing provider in the San Francisco Bay Area. I do scatter site community-based generic forms of housing. I currently have 12 adults with developmental disabilities as tenants, the vast majority of whom have autism. I've had up to 15 in the past. And I'm also president of Autism Society San Francisco Bay Area and president of National Council on Severe Autism. I'm the mother of two children with severe and non-verbal forms of autism.

MS. IVANOVA SMITH: My name is Ivanova Smith. I’m with AtWork! in the University of Washington LEND Program. I have mild intellectual disabilities and autism and I was institutionalized in my first five years of life and I was nonverbal, but I was able to be adopted here in America. And I want to talk to you about my passion for community living.

DR. TERRY HAMLIN: Hi. Good morning. I'm Terry Hamlin. I'm the Associate Executive Director at The Center for Discovery. I'm thrilled to be here. We are a very large

Center of Excellence in New York State and we care for children who really have pretty severe and complex forms of autism. I'm happy to share my story later. Thank you.

MR. JIM WHITTAKER: Good morning. I'm Jim Whittaker and I'm from The Arc Jacksonville and I'm the CEO there. Recently about three years ago, we built The Arc Jacksonville Village, which I'm going to present on a little bit later. And I'm also a board member of Together for Choice.

MS. GAIL GODWIN: Good morning. My name is Gail Godwin. I'm the Executive Director for Shared Support Maryland. I'm a presenter today. Thank you.

MR. MATTHEW OSBORNE: Good morning. My name is Matthew Osborne. I'm the Director of Adult and Residential Services at the Faison Center in Richmond, Virginia. I'm happy to be here and I'm also presenting today.

MS. KRISTA MASON: Good morning. I'm Krista Mason from Holland, Michigan. I'm the Executive Director of Benjamin's Hope, an intentional community, serving mostly individuals with profound impact of autism and also I'm the mother of two children. My youngest, Ben, has autism. Glad to be here.

DR. HEIDI ESCHENBACHER: Good morning. My name is Heidi Eschenbacher. I'm from the Residential Information System Project at the University of Minnesota. I'll be talking shortly. Thank you.

MS. RYLIN RODGERS: Good morning. I'm Rylin Rodgers. I'm the Policy Director of the Association of University Centers on Disabilities (AUCD). And I'm representing Ben Kaufman, who has been participating in this workgroup for AUCD.

MS. VERNONICA HELMS: Good morning. My name is Veronica Helms. I'm with the U.S.

Department of Housing and Urban Development (HUD), Office of Healthy Homes, and Office of the Director. I'm a social scientist and researcher that works on health and housing issues. I'm really excited to hear more about what you all have to say and to figure out ways that we can connect with folks at HUD. Thanks.

MS. LORI IRELAND: Hi. I'm Lori Ireland and I'm here from the Ireland Family Foundation. I am also the Vice Chair of the Autism Society of America. I will predicate any comments or questions that I make as whether they are coming from me personally or the Autism Society of America. I would like to preclude any of my personal comments for being attributed to the Autism Society of America. I have an adult son with autism, 29 years old. He is verbal in a very minor way. He has high needs and I speak to that. I also sit on the Admissions Committee for our statewide units in the State of North Dakota at our Developmental Disability Center. And this would be involved with those most severely impacted by mental health and developmental disabilities. Thank you.

MS. MARY ANDERSON: Hi. My name is Mary Anderson. I'm the Executive Director with ABLE, Incorporated, out of Dickinson, North Dakota. We support 100 men and women in Southwest North Dakota. And the company is 35 years old. I've been with the company for 34 years. I have a lot to say about housing and all supports. Thank you.

MR. JAY SHUKERT: Jay Shukert. I'm the parent of a 35-year-old son with autism on the road to independence. I work primarily in trying to find funding for complex projects.

DR. SCOTT ROBERTSON: I'm Scott Michael Robertson. I'm an autistic adult and I'm also a Policy Advisor in the U.S. Department of Labor's Office of Disability Employment Policy, ODEP.

MS. DESIREE KAMEKA: My name is Desiree Kameka. I'm the Director of the Autism Housing Network and the National Coordinator of the Coalition for Community Choice, both projects of the Madison House Autism Foundation.

MS. MAEDI TANHAM CARNEY: My name is Maedi Tanham Carney. I'm the Founder and Executive Director of Integrated Living Opportunities where we help families create inclusive communities for individuals with developmental disabilities. Today we have 28 families and 17 of them are living independently. I would say about 50 percent of them have the main diagnosis of autism. I'm also the parent of Ellie. She's 26 years old and she is intellectually disabled and she is now living independently.

MR. STEPHEN WHITLOW: Good morning. My name is Steve Whitlow. My wife and I are proud parents of three kids and the middle son is 19 and he is on the autism spectrum. About five years ago, we started a nonprofit in Baton Rouge, Louisiana to transition young adults with autism into the real world. And we are starting a transition house in the area, which will be an onsite delivery of that service. We joined forces with a company called Merakey in Pennsylvania, who has other housing projects, including one in Pennsylvania. It's an apartment complex that is mixed use for individuals with autism and neurotypical adults. We're pleased to be a part of this and thank you everybody for attending and we look forward to learning from everybody.

MS. DENISE RESNIK: (inaudible comments)

DR. ARUN KARPUR: Can folks on the phone introduce themselves now?

DR. DANIELS: Please wait until we are finished around the table.

MS. RESNIK: (inaudible comments)

DR. GORDON: Again, Joshua Gordon, director of the National Institute of Mental Health. I chair the IACC.

DR. DANIELS: Now, we can go to the phone. I know that it is hard because you cannot see each other. Go ahead. Is there someone on the phone that would like to introduce themselves?

DR. KARPUR: Hi. This is Arun Karpur from Autism Speaks. I am the Director for Data Science and Evaluation Research here at Autism Speaks. My apologies. I could not get into Washington, DC last night because of flight cancellations, but I'm happy to be able to join via phone. I'm here to learn from our community regarding housing and housing-related needs as we work on several of related topics along with our adult – communities to support improved access to housing supports and services. Thank you for having me and look forward to working with everyone on this committee.

DR. DANIELS: Thank you. Anyone else on the phone?

Is there anyone around the table now who might have walked in a little bit after we did the introductions? Anyone we missed? Is Lindsay Johnson here?

MS. LINDSAY JOHNSON: (inaudible comments) Sorry that took a moment. My name is Lindsay Johnson. I'm the Director of Policy and Partnerships for an organization in the San Francisco Bay Area called the The Kelsey. And we develop mixed income, mixed ability communities, and partner with other organizations and entities that do the same. I'll be presenting at one. I look forward to sharing more then. Thank you.

DR. DANIELS: Thank you, Lindsay. You can stay at the table if there wasn't another spot for you. Take Melissa Harris' spot.

Is Emily Rosenoff here?

MR. DAVIS: I think Emily was unfortunately going to have to miss.

DR. DANIELS: Thank you. Now, we are able to transition into the next part of our program. We're going to start with an overview of housing issues. This is going to be presented in two parts by Dr. Heidi Eschenbacher, researcher from the Institute on Community Integration at the University of Minnesota, and Desiree Kameka, Director of Community Education and Advocacy at the Madison House Autism Foundation.

Welcome Heidi. If you would like to go up to the podium to begin your presentation that would be great.

MS. IRELAND: I’m sorry. Madam Chair, can I ask one question? May we please define exactly what we mean when we use the term congregate living so that we're all in agreement on that? I'm confused.

DR. DANIELS: We didn't come up with a specific definition. I think that different people around the table do have many different perspectives. I did not say this earlier, but we're really pleased that we have so many different perspectives at the table to talk about these issues and also for the great geographic diversity we have around the table. I think this is the first IACC meeting that has this breadth of diversity from across the nation. We really look forward to that.

As people are talking, if you want to give more clear definitions of some of your terminology that would be terrific. Thank you.

MS. IRELAND: Thank you.

DR. ESCHENBACHER: Great. I'll try to give a definition when that comes up. Please nudge me if I didn't quite get there.

I'm Heidi Eschenbacher. I'm from the Residential Information Systems Project (RISP). We're a project that began in the early 1980s and we have data that dates back to 1977 about where people with intellectual or developmental disabilities (IDs or DDs) live and the types of supports and services they get while they are living in those particular locations.

One point of clarification about RISP that sometimes people misunderstand is that when we're talking about residential services, we're not just talking about people receiving services to live in a home, but they are receiving any type of services and it just happens to be wherever they are living at the time.

RISP does include people with autism. We know that there are people with autism that are in our data set that are served by state IDD or DD agencies, but we don't always know the exact proportions that are people with autism. But I will give you that information when we do know the autism breakout.

We're part of three longitudinal data projects of national significance that are funded by the Administration on Community Living. I'm from RISP. There is also the State of the States out of the University of Colorado and they focus on funding a little bit more. We have some funding data in ours as well. And then the employment side is out of UMass Boston and that's the StateData.info. These are all longitudinal studies that look at the types of supports and services people with intellectual or developmental disabilities get.

One of the questions we ask and try to answer is how many people have IDD or intellectual or developmental disability in the United States. Our estimates are not perfect, but they are an estimate. We estimate about 7.37 million people with IDD. When we are looking at that, that's including - our estimates are based on this. Zablotsky, which is a National Health Interview Survey data, which does include people on the autism spectrum, estimates 6.99 percent children, 0 to 17, with autism and IDD and DD. And there is 1994-95 disability supplement that was a part of the American Community Survey so it's old data. But our adult data estimates .79 percent of people have ID or DD.

Now one thing to consider with these two numbers is that the 6.99 percent children are based on categorical definition. That means they are either diagnosed or they themselves identify as having those conditions, IDD, DD, and autism whereas the .79 percent of adults are for the functional limitation definitions that is in the DD Act and it is also dated. It needs to be updated. ACL is actually working to update the ability to have reliable prevalence numbers.

But when you consider that there are 7.37 million people in the United States – when you look at how many – what percentage of people are served by DD agencies, there's about 17 percent of the total number, that's 1.23 million people receive supports and services for their intellectual or developmental disability through DD agencies whereas 20 percent are known to the DD agency. That usually means they are served. That's the 17 percent. The additional 3 percent are people who might be receiving services that aren't funding, but might be in-kind services or waiting for services.

I mentioned the developmental disability functional limitations. I pulled the information on functional limitations just to help frame what we're looking at. To be considered a developmental disability, the onset has to be before the age of 21. I assume most people probably know these, but I just thought it would be a good reminder. But you need to have three or more of the following major life activity needs in order to be considered to have a functional limitation. That's also what helps to frame who gets services.

Capacity for independent living and self-direction, mobility, learning, expressive language, self-care. I'm reading them out of order. Sorry. And self-care is all functional limitations.

When we look at this and we think about how many people - there's about 1.23 million people who are receiving supports and services. This graph shows the distribution of how many people per capita per 100,000 people in the United States and in each of the states are receiving services from their state DD agency. And the key thing I want you to see here is that there's about - it says 380 for the US estimate. That means that 380 people per 100,000 of the US population are receiving DD services. That's .38 percent of the US population. We do per 100,000 in the population because it is a little bit easier to digest.

But when you look at the range that there are in different states and I took off the state names. We sometimes take them off because it kind of muddles things a little bit. But the highest number of people served per 100,000 is 908 in Ohio. That means that a lot of people are receiving services in Ohio relative to the 87 per 100,000 people who are receiving services in Georgia.

Now, you can also note here is that there's a lot of numbers or a lot of lines below the 380 line. That shows that there are a lot of states that are serving fewer than 180 per 100,000 of the population. There are a lot of - fewer states who are serving a large number of people in the United States. I hear from time to time from various people who call our offices, but also friends and colleagues who I know of who have moved from one state to the next because they can find better services in another state. And that's one of the things to consider with this type of information is that sometimes people do shift to another state to find services.

You can also see in the colors - the full chart is in our report. It's available online for free download. But you can also note that the light blue, the family home is quite common for people to be served in their family home. But I'll talk more about that.

Where did long-term supports and service recipients or LTSS recipients with IDD live in 2016? Like I said, there was about 58 - a lot of them live in the family home in our data, 58 percent of people who receive supports and services from DD agencies live in the family home, 12 percent in own home and own home is one of those categories we often have people ask the definition for so I'm just going to give it. In own home, you either own or rent your home. You have control over your home. If you want to move, you can freely move.

Host or foster family is 5 percent. That means you're living in someone else's home. If you had control - and then DD or IDD group home of one to three is 7 percent, four to six people who have IDD, DD or autism is 11 percent, 7 to 15 is 4 percent and 16 or more is 3 percent.

Now, someone had asked prior to looking at this what various people consider congregate settings. In our data, we used to consider congregate settings 16 or more and then it shifted to seven or more. Now, we are looking at congregate settings as four or more. And part of the reason for that is because the Medicaid settings rule is looking - emphasized a little bit more on four or more, but also from our advisory council of

DD agencies, they had suggested that four or more is an appropriate congregate setting number though you will find different definitions for sure.

But one of the things that RISP started off from the very beginning was looking at the number of people who live in large state-operated institutions. These are the large state institutions that are state-operated, that are run by state employees and housed 16 or more people.

Here, you can see that in 2016, there were 19,502 people housed in large state institutions. That, by the way, is the first time since 1910 that large state institutions have fallen below 20,000 people. 1910 is obviously off of this chart, but I thought I would mention that little piece of information.

But if the peak was in 1967 with 194,650 people living in large state institutions, the ICFs– I added some – of the key policies in place, ICFs came about around 1971. Intermediate care facilities for individuals with intellectual disabilities, and those are oftentimes considered institutions that provide 24-hour care for people with IDD along with some health benefits. But they are much more structured than the home and community-based services that came about in 1981.

Then we also added some – 1990 was the ADA, 1999 was the Olmstead Case and then the Medicaid Settings Rule is 2014. That will be implemented in 2022.

One of the key reasons to look at some of these policy issues is that when you look at the light blue area, those are the children in institutions. And one thing you notice is that de-institutionalization first started with children. The number of children went down dramatically over time and then as there was more home and community-based services, and services that were for a smaller group home, smaller than 16 or more people with ICFs and, the number of adults also started to go down in these large institutions.

Then when considering these large institutions, we do have data on diagnosis of autism and large state-operated institutions. And in 2016, there were about 19 percent of people who lived in these large state-operated institutions who had a diagnosis of autism. About 14 percent had no ID or mild DD. And 48 percent had 2 or more conditions.

We do have some other statistics on what types of conditions people have in the large state-operated facilities because we do a separate, more detailed survey on these facilities. But you can see that these are the types of facilities where people with high needs would generally live.

Next, we're going to look at funding. When you compare the Medicaid ICF or intermediate care facilities for individuals with intellectual disabilities, or we waiver recipients and waivers are a home and community-based service, you can see that there is - these are the two prevalent types of government funding for people with IDD.

And here you can see that waivers have risen dramatically over time. The number of people served has also increased dramatically through IDD agencies over time. We have those charts in our report. There are more people served, but there are also more people served on the waiver.

ICFs are on the decline, but there are still quite a number of them. 74,614 people who were living in intermediate care facilities for individuals with intellectual disabilities (IIDs) and that is of any size. That is the number of people living in the United States in ICFs and IIDs.

In ICF/IIDs, they have 24-hour care, shift staff and health care. It is a fairly extensive amount of care for all recipients where waiver recipients receive a range of services depending on their needs.

Here is the average cost per person of ICF and waivers. The striped line at the bottom is the average for all ages. And then we also look at people who are 21 and under and people who are 22 and older.

For the 22 and under, you will note that it is often - it is always less expensive. As adults age, we become more expensive to provide treatment and care for. That's one thing you'll note is that another thing to note about the age differences with the cost per person is that a lot of times people who are 21 and under do receive some services through educational channels and those wouldn't necessarily appear here.

In 2013 - actually, it was in 2016, a study came out. But in 2013, I pulled some data that was more autism-specific. In California, there was a study that looked at the range of services, supports and services through the DD agency in California. And this was the average cost per person in California.

One of the things you'll note is if you look at the RISP report, there's a wide range on the average cost per person across each state in the United States depending on their service model. But what this helps you see is what type - how much each type of support and service tends to cost relative to each other.

By the way, RISPs' average in 2013 for the waiver was $23,000 or so. That's close to probably some of the average - people receive various types of supports and services.

I thought it was interesting to note to recognize both the types of supports and services that people will receive, but also the relative costs.

The other thing that a study that my colleagues had implemented, was led by Amy Hewitt at the University of Minnesota, found that people with ASD are more likely to live in their family home. There are 29 percent higher odds to live with a family member and 42 percent lower odds to live in their home compared to other people in the DD system.

Lastly, I'm going to focus on some data that's not - that I work with sometimes, but it's not RISP data. It comes from the National Core Indicators. And the National Core Indicators look at service system outcomes. It can also look at people with autism diagnoses. You can pull data depending on whatever their diagnosis is, not for all diagnosis, but autism is one of them. This includes 36 states. One key thing about comparison between National Core Indicators data and our RISP data, our RISP data comes from all 50 states plus the District of Columbia whereas National Core Indicators' states opt to go into the National Core Indicators' data set. They opt to participate. This is 2015-16 data and it includes 36 states.

But it's interesting to note that when looking at the data overall, there's about 18 percent of people with ASD who receive LTSS [Long-Term Services and Supports] that are named on their lease. One percent owns their own home. And 53 percent have a provider agency-controlled or own their residence.

You can see though that the provider agency-controlled residence is lower for ASD than for all of the DD system of the data that's included in NCI, but also that there are 43 percent living in the home of a parent or a relative for people with ASD compared to 35 percent of the entire DD system. When I say entire DD system, I should clarify that that is of the 36 states that participated.

Rights and choice. Lastly, this is my last slide of data. Again, this is NCI data so it's 36 states. But something to note here is that people with ASD appear to be making more decisions about their budget or services, or changes to their budget or services, at 91 percent compared to 81 percent in the entire DD system.

But there are a little bit smaller percentages that are quite close and marginal. But one thing to also look at is not just the comparison between ASD and NCI, but there are only about 40 percent can lock their bedroom if they want to. Although if you are living in your family home, you might not be able to lock your bedroom in most homes. But have a key to your home. That's a pretty foundational thing. And only 40 percent of people have a key to their own home.

They have rules about friends or visitors in their own home. That ranges around 34 to 38 percent between NCI and ASD.

And about a quarter of the people who are involved in this survey - these are adults, by the way. I should've mentioned that as well - would like to live somewhere else.

I just thought I'd highlight those few things. I have some references that are available. The references about the prevalence are available in the Larson publication. That's the RISP report.

And we do have some other resources. We do have a study that's in progress. It's a scoping study about institutions, new institutions and residential options for people with autism, ID, and DD. We're working to look at what are the other range of options that we should be considering as we're looking forward and what is out there available for people. The RISP 2017 report is in process and we are analyzing that. It will be out probably early next year.

And then the other thing - this is more related to the University of Minnesota, but a colleague of mine, Jerry Smith, has done some cross-cultural films in autism that were looking at African American, Hmong, Latino, Native American and Somali community access to services in Minnesota. DHS in Minnesota had asked him to create this set of videos. And a lot of people are finding them helpful in other states as well. We're also a part of the ADDM project. That's it.

DR. DANIELS: Thank you, Dr. Eschenbacher. We're going to take both of these presentations one after the other and then we'll have time for discussion.

Next, I'd like to invite Desiree Kameka to the podium.

MS. KAMEKA: Good morning. My name is Desiree Kameka and I run the Autism Housing Network. I am so fortunate to be able to travel all around the country and see what is happening in the residential world in different local communities.

The young woman that's in that picture is an individual on the autism spectrum. She's currently living independently. But her home and support options are not meeting her needs and she has a vision for something better in her local community. My job is to help her save time, money, and not reinvent the wheel.

We're going to take a quick look at what the Autism Housing Network as a website can offer. The Autism Housing Network was actually a recommendation from the Opening Doors study that was done by SARRC and ASU and the Urban Land Institute about ten years ago. We have a reach of about a quarter of a million people at this point in time. I'm going to show you some data from a very limited market analysis that we've done in Colorado. And then I have a couple of interest points for potential research in the future that I think would be key in order to move policy and funding in a direction that's going to increase options and decrease barriers.

(Video shown)

Housing is so important. It is the place of our rest, our refuge, the place where we are able to recharge to face the world again. We know that it's also a strong social determinant of health. This issue of housing is really the core of stability for a lot of people. If one does not have stable housing where they can be empowered and invigorated, how is that going to trickle out to all other aspects of their life? This is a key thing.

What I know from running the Autism Housing Network for the past ten years is people do not understand their options. They do not understand different service delivery options. They do not understand the pros and cons of different property types. They do not understand how to navigate the system. It is extremely complicated. And once you figure it out in one state, if you go to a different state, you have to start all over again. I am getting weekly calls from people who are losing their primary caregiver, individuals on the autism spectrum, siblings, cousins, nephews. Hey mom is going into the nursing home. I don't know what to do. What do we do? What are our options? This is happening more and more.

Autism adults are experiencing homelessness. I believe they are experiencing homelessness at a higher prevalence rate, but we do not know that they are experiencing homelessness. Too many autistic people contact me because they are trying to find support.

A lot of individuals on the Autism Housing Network or who are looking for housing options are not identified by the Medicaid system. They are ineligible. In some states, eligibility is based on IQ. If you don't have an IQ or an intellectual disability of under 70 then you are not even on the books. You are not even in the system, falling through the cracks.

And then the other element of autism that is also falling through cracks are individuals with high support needs so individuals who have a history of self-injury or aggression and not just self-injury that's intermittent, but self-injury in which you're detaching your retinas. You are giving yourself bloody noses. You are causing yourself to hit your head so hard that it's rendering you unconscious. Providers don't want to serve that population. They are saying no, sorry, we can't help you. And then individuals are isolated in their family home and the family is also isolated.

The reality is people are forced to stay in their family home. There isn't a choice unless you are experiencing homelessness or your primary caregiver is about to die, most people are unable to access residential supports. Scattered-site market-rate housing is unaffordable. It's not accessible and people are evicting because the reality is sometimes behaviors that are associated with one's experience of autism is disrupting of neighbors and property destruction. A landlord is only going to replace the knob on the toilet five times before they decide I'm not renewing this person's lease.

Medicaid authorities and the local housing industry - they don't talk to each other. The communication is just - there is a wall. They don't understand each other's language. They don't understand the population. We don't have data on what this population wants.

Mate crime and abuse happens often. The study that I know of was done in 2012 and 67 percent of autistic individuals will be the victims of abuse. A study in the U.K. said that 80 percent of people experience mate crime, which means somebody becomes your friend in order to abuse, neglect or exploit you.

I want to make a special note. Institutional abuse and attitudes can happen in any building because abuse is done by people. Four walls do not dehumanize and abuse people. People dehumanize and abuse people. It's a cultural thing.

We created a five-part video series to talk about the benefits and considerations of different property types and service delivery models. I review about 18 different models in this five-part video series. It's not all bad news. I want you to know that autistic adults – they thrive when they are given the opportunity to live their own life. Just like neurotypical people experience huge autonomous growth when we leave the nest, it's the same thing with the neurodivergent population. We should make sure they have the opportunity to continually grow. There are groups organizing all around the country to create local solutions. There would not be so much time and effort into it if what was already available was actually working. But what we're finding out is the status quo is not meeting the needs of everyone.

NIMBY [not in my backyard] is not as prevalent. Also, there are a lot of people who are doing community development that are self-advocates. We are finally giving self-advocates a greater platform for them to be able to express what it is that they want for the future, and we need to be listening to the broad range of perspectives. And for those who can't advocate for themselves, whose family members or friends have to advocate for them, everyone has to be at the table and we have to have these very uncomfortable conversations. I am so glad that we have such a diverse representation here because we need to be talking and moving forward in the same direction.

And then a lot of local communities want to be neuro-inclusive. They get it. We are shifting. This is not the '60s anymore. People recognize equality in people who have neurodivergent or are different cognitively.

We started a program called the Empowering Communities Initiative where we are educating the neurodiverse community. We are educating people in what their options are and then we're serving them. And we are taking that data and we are bringing it to local leadership in the housing industry with the hope that it's going to increase the housing stock to meet the local need.

This example and the data in the next couple of slides is specifically from Colorado from three counties, Douglas County, Arapahoe County and the City of Aurora. Approximately 126 people took the survey. Forty-four percent of them were representing autism or Asperger's and then 10 percent of that were self-advocates.

In order to get their attention, I like to show a little bit of numbers. In Colorado, there are over 12,000 people living with a caregiver over the age of 60. Right now, someone getting residential support somewhere outside of their family home - it's only 10,000. There are more people living with a caregiver over the age of 60 than they currently have being served with residential supports in any setting.

The growth rate is not substantial. There are fewer than 3500 individuals that have been given supports to move out of their family home in the last 15 years. What is going to happen to those 12,000 that are living with a caregiver over the age of 60?

I like to frame this for local communities through three lenses. There is 100 percent. Someone does not have any additional support and they are going to have to rely 100 percent on government funding. That means they are going to be placed in an institutional setting, an ICF/ID [Intermediate Care Facility for Individuals with Intellectual Disability], a host home, a group home, or they have to find affordable housing and use the Medicare waiver.

And then there is the second option where local communities, families, individuals can invest in housing. The housing creates a core of stability and then they can decide which service delivery model or service provider that they would like.

And then for a very few amount of people in the U.S., some people can private pay. We see a lot of transitional options that are coming up. And I feel as of right now, they are all private pay, but they should - people who want to transition into independent living and can, should have some sort of funding stream to be able to do so.

I think even for our conversation today, having a quick review of terminology that was decided upon first through the development of the Autism Housing Network and then in 2018 at the Global Leadership Institute and Autism Housing Network Think Tank, we decided upon some terminology that we've been using. I would love your feedback. There is a piece of paper in your folder that lists a little bit more in detail some of the descriptions that we've put together. I would really appreciate anyone's feedback who wants to write on that and then give it back to me.

But relationship between housing and services. Provider-controlled means one's housing and their services are inextricably connected. Consumer-controlled, which means when housing and their services are completely disconnected. Different service delivery models can occur in both of those settings. For example, agency-based rotational staffing. An agency is responsible for recruiting, hiring, firing, scheduling, all of the stuff that can be done in a consumer-controlled setting, meaning in one's own apartment. It can also be done in a group home type of setting where the agency is providing the care in one's home.

Consumer-directed supports. The individual with a disability and their support teams, identifies, hires, fires, and schedules their own stuff.

Host family home. When an individual without a disability invites someone with a disability to live in their home, collect rent, and provide services.

Shared living. I don't like it when these two terms, host family home and shared lived, are used interchangeably. These are two different mechanisms. One is provider-controlled, which is the host home. Shared living should be respective just to consumer-controlled. When an individual with a disability invites someone without a disability to live in their home and when that relationship doesn't work anymore, they can ask them to leave.

And then paid neighbors. Someone in your apartment building or maybe the neighbor down the street is paid to be on call and be able to support you. They don't live in your home, but they definitely live within proximity.

Property types. Accessory dwelling units. Helping families realize that they can put a tiny home or a mother-in-law suite, which would give their loved one their own privacy and their own space. And in the future, once that family unit moves, it can be either an income stream because of rent or a core of natural supports.

Bequeathed family home. Maybe it's the parents that need to move out of the nest.

Scattered-site, single-family home, apartments, single apartment buildings, townhouses.

Co-housing communities or intentionally neurodiverse neighborhoods. This is when a group of people come together to either buy homes that are within walking distance or develop a neighborhood. Each of the homes might be owned by different families. They could have different service delivery models. Essentially, you're creating a neighborhood in which people want to live in neurodiverse relationships.

And then a planned community is just like in the housing industry when a developer is going to identify a property, build a building and they are going to think about a target audience to be able to build. They are going to build a concierge service or amenities and things like that. This can be done with the neurodiverse population too where the housing is intentionally designed and has built-in amenities and supports for the neurodiverse population, for the autistic population. I can be 25 percent of the residents are autistic, 50 percent, 75, 100. It doesn't matter. What should matter is what the local community wants.

In Colorado, we educated them. They had to sit through a three-hour training session before we surveyed them because we wanted meaningful results from people who were meaningfully informed.

Talking about support needs, we found that at least – there was a total of about 50 respondents who are on the autism spectrum or were representing someone on the autism spectrum. We see a lot of people who need one-to-one 24-hour support.

When we talk about the average cost of a waiver versus ICF, the reality is if someone needs 24-hour support and there is one person being $10 an hour to be able to provide support for that individual, it's going to cost about – what was the math -- $88,000. We could talk about the averages of things. But really we have to know who it is we're supporting, what are the supports they need and can we provide them with just enough supports so that they are successful without overly restricting them and making sure that they have enough supports so that they are not going to fall through the cracks.

Service delivery models. After being informed, it was really surprising that most people would want to live in a shared living arrangement and a lot of people were interested in consumer-directed staffing. There are still individuals who are still interested though in provider-controlled settings, host homes, group homes, ICF/IDs. These are still desired options even after being educated. It's important that we have a variety of choices.

Barriers to one's access in the community. Thirty-three people said that one's lack of social skills to be able to maintain relationships was their biggest barrier to friendship. Having to meet someone, get their number, schedule, decide where you are going to go, get transportation to go there and then go hang out and do that all over again takes a lot of effort and energy and social skills.

People feeling overwhelmed by crowds or the unexpected was the second highest. Lack of transportation. These were all the elements that were really above the rest so lack of transportation, not enough money, not enough support whether that's paid support or natural supports, all major barriers. And then a lot of people were declining to go do things in the community because they didn't want their parents to go with them. Surprise. Surprise.

What is important for people's future? We asked them a lot of different options. These were the top options. The purple is extremely important. The green is important. It's really, really extremely important for people, over 75 percent, to be as independent as possible. A high respect for privacy. Having one's own stable home and life. Feeling accepted for who I am. Living with or close to my friends. Emphasizing personal safety. Neighbors who know and can support me. And then a setting that supports a fit and healthy lifestyle. These were the top things that people were interested in, in whatever future residence that they were going to choose.

Rent, buy, or bequeath. Provider-controlled. Six people were interested in that. Thirteen of the people needed to have some sort of assistance to be able to afford rent. Five were interested in renting. Nine want to buy. We have to talk about asset development in this community. It shouldn't just be thinking about rental, but what about asset building in this community so individuals have an asset if they want to move to some other location?

Property types. Now this is a big one. Twenty-three are interested in staying in their current family home, which means their family will leave and they can either rent rooms to other people or have an accessory dwelling unit.

And the two that I think are really important because there is a lot of talk about this. There is a strong demand to live in an intentionally neurodiverse neighborhood or a planned community. We are seeing this in the data. These types of settings must be considered and understood because it is certainly a demand in the population.

And then another thing to note. Seventeen were unsure, which means we have to be able to tell more stories so that people understand what their options are.

These are some of the things that rated really high, important, or extremely important. Over 60 percent was having a grocery store nearby, a gathering space with free activities, access to public transportation, huge, a theater room to watch movies with others, a walking or bike path, a sensory room to relax and de-stress, or having restaurants or a food court nearby so I don't have to prepare and eat home by myself all the time.

What type of built-in features? These were the top built-in features. Single-level optimized for aging in place, easy clean features, smart home equipped. People were most desiring to pay extra for a smart home equipped home. And then sensory-friendly design and features. More than 60 percent wanted all of those things.

And then built-in services that don't necessarily need to be Medicaid funded, but that can become part of rent, having a house cleaning service, having a shared dining area or a meal plan, a ride share, other transportation options, employment, community navigator, 24/7 help desk or on-call in-person support and then emergency help intercom. These were all things that people would want. Kind of like built-in supports in their housing options.

Going into the research needed, we have to have foundational nomenclature. We have to be talking the same language in order to research and measure the outcomes. Right now, we are not. Number of people in a home is not good enough. Any data that is being collected must be person-centered. It doesn't matter if we are looking at how many times do people go out to restaurants per week. Well, it has to be measured in relation to how many times do people want to go out to that restaurant. What are the barriers to them being able to go to a restaurant? Are they going to their preferred restaurant? It has to be person-centered. It can't just be are people going to their faith community every week. What does that mean? If they're atheist, it doesn't matter if they are going to a faith community. They don't care, so the data is going to be skewed. Everything has to be person-centered.

How are the states going to meet the demand? What is the strategy? Are the states talking about how are we going to prevent forced institutionalization? Are people just being placed in the next empty bed? Too many people are being displaced because they do not have access to housing.

And then what is the impact of being forced to stay in your family home? That learned dependency over decades. What is the cost variable of that? And also what about the quality of life? So many people say when I talk to parents, my child, I had no idea they could X, Y, and Z. Once they moved out, they grew so much.

Disability impairments associated with disability can sometimes be supported through the environment. Sometimes it is the environment that can most disable someone. What changes in the environment can be used to decrease disability of one's impairment, especially talking about abuse mitigation. Too many people are being abused. This is ridiculous. We have to be able to look at that very hard. How can we prevent people from being abused?

How are home designs and physical accommodations going to increase access for individuals with cognitive disabilities? What about smart home and assistive technology? How is it going to impact the direct support workforce, which we are in a crisis for? And how is it going to help individuals be able to better self-direct their lives? We have to be able to talk about individuals with high support needs. How can we make the housing environment better for them?

And then there are a lot of private pay options around the country. Why are we not comparing these? Are private pay options doing a better job than the publicly-funded ones in the same area both in quality and financial analysis?

What is the percentage of autistic adults and their families that are homeless? Is it a higher percent? What if they are able to access autism-specific intake? Are they going to be able to get better supports if the individual who is doing the intake can actually understand the autistic person's needs and support them in an autism-specific way instead of assuming that they have a drug addiction or just a mental health challenge?

Does autism optimize housing, improve retention outcomes? And most importantly, what type of set-asides, incentives, can funnel funding for the neurodiverse population, not just people with disabilities as a set-aside? There are set-asides for people with HIV and AIDS and chronic homelessness. There has to be a set-aside for the neurodiverse population. There are too many people who are ending up in more expensive and more restricted environments because they don't have access to affordable, accessible housing.

There is a direct service professional crisis. We need to stabilize it. People who have the most impact in people with autism’s lives are often the ones that are providing the direct support every single day. How are we going to decrease repeat offenders of abuse? When somebody is accused of abuse, if there isn't evidence for a conviction, there's nothing on a record. They can go to a different agency and continue the pattern of abuse because it's not showing up in a background check.

What's the impact of autism-specific training for direct service providers? Does it increase outcomes for the autistic individual? How are we using technology more efficiently?

Let's talk about discrimination. At what points should states be held liable for not providing enough affordable, accessible housing, which is causing the forced institutionalization of people with disabilities? At what point are the states liable to the Olmstead Decision? Can Medicaid legally restrict one's LTSS' money, waiver money in a setting that is their own, that is their own home?

How many people - how many first responders and ER visits are being performed because people don't have an appropriate support system? How are we using other systems that are not supporting this population in crisis, when really we should be providing the supports in the first place so that people don't have to go to the ER when they are in crisis?

And then, how are nuisance laws preventing people from wanting to access help? In some parts of our country, when you call 911 more than a couple of times, they start fining you. People who are in abusive relationships or abusive situations might not want to call for help because they are afraid they are going to be fined and they are on a fixed income.

These are some really big issues, but I do - I believe with everything in me that if we are able to work together, solutions are possible. There is a better future out there for autistic adults. I want to be part of that. I want to invite all of us to really try to work together and get on the same page so that we can have a better future for the neurodiverse population. Thank you.

DR. DANIELS: Thank you. We are a little over time. What we are going to do to try to make up the time is we will not have a break so people will have to just excuse themselves to use the facilities if they need to. We'll have time for one to two questions. Please keep your questions and answers short. If we have time for a third time, we'll take that too. And then we are going to move right into the public comment. Thank you.

Any questions for our two speakers? Liz?

MS. ESCHER: Thank you. Just a quick comment on one of the slides presented by Dr. Eschenbacher. It's not really a question, but just a clarification. It was a little misleading -- the 2016 study from California

DDS showed some average costs for a variety of services. You have to understand that the DDS in California is the payer of last resort. That slide omitted actually the bulk of costs involved in supporting adults with autism in the community. It omitted, for example, Social Security, in-home support services, what is called IHSS. It omitted HUD payments for housing. It omitted other forms like the transportation subsidies, other subsidies that go into supporting day services. And also the vast majority of adults with autism in California probably 90 percent are still living in the family home with their parents or their family caregivers. It omits actually the end paid caregiver force. It's really important when you look at a slide like that to take it with a grain of salt.

DR. DANIELS: Scott.

DR. ROBERTSON: Thank you for the data that was shared and the information. It's really helpful for the background here. I think particularly the most striking to me is that we need to have a strong emphasis for what supports can help folks who are facing adversity because of homelessness. We haven't really studied that really much at all in the United States. A lot of the research focused on homeless autistic people has been out of the United Kingdom so Great Britain. We have several studies in that area. It would be nice to start seeing more data on homelessness and autistic people's experience with that and related barriers and factors that lead to it from here in the states.

I hope that maybe in the next couple of years, we can see more folks taking interest on exploring qualitative and quantitative research studies on the homelessness experiences of autistic youth and adults.

DR. DANIELS: Thank you. Ivanova.

MS. SMITH: I really like the statement about the right of people to move out of the family home. I think that that's a big important part of the right for all of us to grow up. There are a lot of misperceptions about people with intellectual disabilities that we are mentally children and that's not true. And we need to help parents understand that their child has the right to grow up and move out of the home and move out of the nest just like their non-disabled sibling. Thank you.

DR. DANIELS: Amy.

MS. LUTZ: Thanks and I wanted to thank Desiree and Heidi for all the great data. But one thing I wanted to point out is that some data that we didn't get is any data at all comparing different residential models that we'll be hearing about later in terms of rates of abuse and neglect, for example, or quality of life measurements and that's because there really is no good data to compare all these models.

The studies that have been done have been so profoundly flawed that in an editorial published in 2017, David Mandell at Penn, who I believe is part of the IACC, said that our decision-making is based on – and residential settings is based on values and not data. I really believe this research is needed. But as we go forward and compare these different models, there is no data that says living in an apartment is better than living in a 16-person intentional community.

DR. DANIELS: Daniel.

MR. DAVIS: Thank you. One thing – thanks for both presentations. One thing that I was looking at with regard – Desiree, to your presentation is when I looked at the map, I found that I think it was 43 of the planned communities on there indicated they accepted Medicaid HCBS waivers. But outside of the whole issue of whether – the settings rule, I noticed that only a quarter or a third of these communities met particular needs such as daily medical support, one-to-one supports, or high behavioral supports.

The concern that I have there is that seems quite troubling that because Medicaid state eligibility requirements for waivers are usually not that rigid and usually discourage cherry-picking clients, totally excluding even consideration of the HCBS setting. There is that challenge that I see. Thanks.

MS. KAMEKA: I want to note that the listings that are on the housing directory are crowd-sourced. They are not like an automatic list so people need to submit it. It’s certainly not comprehensive. Some of the settings that you might be taking a look at might not exist yet.

On the Autism Housing Network, we provide a space for people who want to develop opportunities to put that so the filters. They might be saying who they are interested in potentially serving in the future. It's important to know whether the setting is existing or not.

And then in terms of the HCBS settings criteria, there is not a number in the final rule in which limits the amount of people that can live in an apartment building. It's all based on outcomes. And so to just say that just because there are 40 people living in an apartment building that this must not be an HCBS-compliant setting is erroneous because we have to be looking at the outcomes.

The new guidance out of CMS in March 2019 focused on outcomes. How are the services being delivered? How are individuals able to manage their day? Do they have a key? Do they have access to food at all times? Can they have friends come over? I think that that is really important that we don't just focus on the number of living together. That we are focused on outcomes and service delivery models.

MR. DAVIS: I think what you said about the recent CMS guidelines. We, at ACL, would absolutely agree that those qualities and characteristics are primary. Thank you.

DR. DANIELS: Lori.

MS. IRELAND: Thank you very much. Those were wonderful presentations and very useful when I go back to my state. My question is in terms of the survey-oriented statistics that were given, how were non-verbal people included? I probably missed your explanation of that. But how are the non-verbal people included in those statistical findings?

MS. KAMEKA: This was an informal market analysis, using Google Forms. An individual who cannot - just because one is non-verbal, I think many of us agree that it doesn't mean that you don't have a mode of communication. I do not know who filled out those surveys because it was not done in a clinical setting. It was done in someone's home or on their phone. I'm unsure.

I'm assuming if an individual could not read and understand and fill out the survey independently that they had either support staff or their family member be able to help them fill that out. I don't think that answered your question, but in a way it does because I don't know.

MS. IRELAND: As you can tell, it is a particular concern of mine that many of the statistics and opinions are given by people who can speak for themselves and therefore in many of the instances, we're looking at things that represent a part of our population, not the total population.

DR. DANIELS: Thank you very much for keeping this discussion very concise. We are going to need to move on because it is time for the public comment so we are going to move into that session. If we have time to pick up more discussion before lunch, we will.

At this time, we would like to move to the oral public comments. We have three oral public commenters who are on the list for today. First is Dr. Eileen Nicole Simon.

DR. EILEEN NICOLE SIMON: I am here today to present the same plan I submitted for consideration at the IACC workshop meeting in May. I do appreciate the comments on what I proposed, especially those from Joseph Joyce of the Autism Society of America.

I hope for more discussion at this meeting of a possible way to both house and find employment for developmentally disabled autistic adults.

Marriott has a chain of Residence Inn hotels with a full kitchen, dining space, and living-room area in each unit. I asked for discussion of developing a possible plan for housing autistic adults in a few units of each Residence Inn hotel, and employing them to also work in the hotel.

I recently took a grant-writing course at UMass Boston. Looking for private foundations that seek to provide grants for worthy causes, I noticed that Marriott has several philanthropic organizations, including the Marriot Hotel Philanthropy. The online link to the Marriott Foundation is marriottfoundation.org.

I want to contact Marriot with my plan. I will have to find collaborators for this effort. I hope I can have more interactive involvement in this workshop, beyond making this brief presentation.

Providing for the lifelong needs of developmentally disabled autistic people is a more serious issue than many people realize. Best will be when autism can be prevented. But in light of the epidemic that began in the 1990s, solutions must be found and immediately for providing appropriate lifelong care.

I do hope for discussion of this idea by members of this IACC workshop on the urgent need for housing. The employment component would also provide meaningfully daily activities. Thank you.

DR. DANIELS: Thank you, Dr. Simon and thank you to the other oral public commenters also for being with us. We'll hold discussion until the discussion period.

Jillian Copeland, are you here? Thank you.

MS. JILLIAN COPELAND: Good morning. Sorry. I am a teacher so I expect a good morning back. Do we need to get everybody out for a little movement break?

A little about me. My name is Jillian Copeland. I have four sons. My third has developmental challenges. I'm the founder of a school, the Diener School, located four miles from here in Potomac, Maryland. We have 50 students with varying disabilities, about 30 percent with autism.

And my current project that I'm working on now with my husband is called Main Street Connect. Main Street is two miles down the road. If you make a right on Rockville Pike, you bump right into it. It's a 70-unit apartment building. Twenty-five percent of the units are set aside for adults with disabilities. Seventy-five percent of the total building units are affordable. We are not a service provider. We are a housing model. We are located in Rockville Town Center so there is walkability for pretty much everything. We're 500 feet from transit, both Metro and bus.

And the best part of Main Street, to me anyway, is our membership. We currently have 1300 members. We are a member-based model with many professionals that can help create circles of support for our adults with disabilities.

Our greatest part to serve our membership because obviously there will only be 40 to 50 adults with disabilities out of 150 people living in our building, but residents and members can join Main Street and be a part and join in our community, which was our ground floor and half of our second floor, which is 10,000 square feet of community space. It has a wellness center, a teaching kitchen, a multi-media room, a classroom, a coffee shop, a cyber lounge, and a peace and movement meditation mindfulness space, outdoor patio, gardens, you name it. Opportunities for social, educational, recreational activities, a place for all people to belong.

One of the things that I love about Main Street, and one of our members thought of this acronym is we're a BYOI model. That means bring your own independence. As I said before, we are not a service provider. We are a housing model. Anyone can choose to live in Main Street with the supports that they need. We will be offering a scaffolding of supports available for not just our members, but residents of the building and that will be a fee-based service. But if you need one-to-one support in your apartment, you bring that with you through your service provider. If you need access or physical help for a yoga class or to attend a cooking class or just to be a part of an event, you bring that caregiver, that person with you if you need help to access that.

We created Main Street for several reasons. One, we couldn't find a model like this that we needed for our son. We went out to our community, our local community here in DC, Maryland, and Virginia, and we said what are you guys looking for? Adults with disabilities and your families and caregivers. What are your needs? And basically, as Desiree said, every need that we found on there was in Desiree's presentation. They wanted to walk somewhere. They said that even living independently in an apartment was fabulous, but it wasn't enough. It didn't give them the quality of life that they wanted because they didn't have a community support wrap around them.

Many of their family members talked about what's the difference if they live in my basement or they live in an apartment, but they are still playing on their video games after work every day. There still isn't that community support or opportunities for friendship and social engagement. That's part of the reason and why we created the model that we did.

How are we able to do it? I've been in the non-profit world for a long time. We have the financial support to do. My husband is in real estate so we applied for HUD's LIHTC [Low Income Housing Tax Credits] credits, which is a big source of our financial stack, and we know a lot of the local and state politicians. We happened to have all the resources to be able to do this, which we also understand most people don't.

Our barriers. Contradictory regulations. Financing. How do you keep a building like this sustainable? Our tenets are inclusivity, affordability, and sustainability. And the sustainability even with a big financial stack that we have a lot funded already is still a problem over time. We're working that through now.

Fair housing, compliance issues, public hearings, lots of barriers to creating these kinds of opportunities, living opportunities for folks with disabilities.

Lastly, I think what's really important for us is what's next. We continue to work on task forces. We continue to put out information like webinars to help others around the country create their own spaces and memberships. We're working with our local government to increase our - we have in Montgomery County what's called a Housing Initiative, the HIP fund. We want to not only increase that fund, but we want to designate some of that money just for adults with disabilities so that they have places to live. We want to incentivize local developers. We're already meeting with them to ask for their help and that they can create set asides for adults with disabilities.

We are working with the University of Maryland to collect data on quality of life issues, pre-Main Street, post-Main Street, hoping that will help.

We are also part of George Washington University's new study that will be hopefully starting in the next few months so we can be a part of that too and maybe that can help shape and inform policy later on as well.

I invite any of you. If you are interested in seeing Main Street, I live a mile down the road. I'd be happy to take anybody there later this afternoon or tomorrow. Just let me know. Thank you for your time.

DR. DANIELS: Thank you, Ms. Copeland. Next we have Susan Jennings.

MS. SUSAN JENNINGS: Hi. My name is Susan Jennings and I am founding member of Keeping Individuals with Intellectual Disabilities

Safe. I'm also the mother of a severely autistic young man with dual diagnosis, IDD and comorbid psychiatric disorders. It has been a long, hard journey, a journey still continuing.

He's the autistic individual who tears off doors, kicks in walls, kicks out van windows, elopes into traffic and so forth. He was placed right away out of high school into a group home, several group homes, and was discharged. In the space of four short years, he was discharged from six different group homes by three different providers who could not manage his challenging behaviors in their particular residential models. They are told they can manage everyone, but they can't. There are systemic shortcomings to the community group home system that no amount of money can remediate. I will discuss that in a minute.

But while he was there, his eye socket was broken. He was covered in mysterious bruises. He was exposed to pornography. He slept on a bare mattress in his street clothes. They used psychotropic drugs to sedate him. It didn't work. It backfired. His behaviors became worse, but it leaves him with a host of, a Parkinsonian tremor in his hands, female breasts, intractable insomnia, and psychotic breaks with reality.

I hear a lot about forced institutionalization, but you can't force your way into an institution at least not in Pennsylvania. They've been closed to admissions for at least 30 years.

We were able to get an attorney. We were able to force our way in to a state IDD or what I call intermediate care facility in Pennsylvania called White Haven Center and that became his salvation. That became his sanctuary.

My son is not an anomaly. He's not alone. He's not unique. There are 500,000 - the DDS case load, 40 percent represent autism. Eighty percent of those are children, but they are coming of age. There will be 500,000 autistic adults entering adulthood in the next ten years and they will need housing.

Now my son was in six different psychiatric wards because the group home would put him there and then discharge him. He stayed in one psychiatric ward for six months. This is a phenomenon known as psychiatric boarding. It is unfortunately becoming more and more common. The Washington Post did a story on it, Nowhere to Go. Young people with severe autism languish weeks or longer in hospitals.

When you eliminate the institution, two more institutions rise in its place, jails and psychiatric wards. Both expensive. Both inappropriate.

There are systemic shortcomings to community group homes. They cannot serve everyone. One size does not fit all. Olmstead recognized this when they said in their ruling. As already observed by the majority, the ADA is not reasonably read to impel states to phase out institutions, placing patients in need of close care at risk. Some individuals may need institutional care from time to time to stabilize acute psychiatric symptoms. For other individuals, no placement outside the institutional settings may ever be appropriate. For these persons, institutional settings are needed and must remain available.

For someone like my son, the intermediary care facility offered a superior form of care for him. What seemed to be the least restrictive settings, a group home, was actually the most restrictive because it could not meet his severe behavioral challenges.

In most instances, large institutions are less expensive than scattered dispersed community settings. At this point, when the centers are closed to admissions, there are fixed costs at the centers. There are fewer patients to share the cost. That's why they seem more costly. But in fact, in a congregate care setting, there are fewer professionals to serve more patients and they know this in hospitals. They know this in private. This is a financial efficiency that the rest of the world uses.

All the trauma and abuse that my son suffered in the community group home was not cheap. It cost $369,000 to pay to the provider. That did not include room and board because $345,000 to the taxpayer to throw him in and out of the six different psychiatric wards. And I'm not counting the thousands of dollars for 911 calls to the police, emergency rides to the ER, the court costs to Section 302 him into psych wards.

When you put someone in an appropriate setting with too little assistance and supervision, it costs you more. The state center is a bargain, the all-inclusive. And why does it work? It works because ICFs must meet the most rigorous standards in order to be certified by CMS, Appendix J, which is 254 pages long.

Community settings do not have to meet this standard and they seldom do. ICFs must engage in active treatment, which is a rigorous implementation of treatment, training, and health services. Waiver homes do not and they seldom do.

I want to talk a little bit about the DSP [Direct Service Professionals] shortage. You're basically asking frontline caregivers to handle life and death emergencies at fast-food wages. There's no opportunity for advancement. They seldom have benefits. It's a thankless job and I don't blame people. Two out of five DSP workers will leave in a year and there are 20 percent of vacancies that will never be filled. What you have are long, ever-growing waiting lists for whatever inadequate services are left.

There's a cruel movement afoot to get rid of all out-of-home services for the disabled individuals, in particular, autism. If aging parents do not have the strength or the facilities or the resources to keep their big, strong, tantruming sons from running into traffic, detaching their own retinas, breaking their windows, who does? Certainly not adult foster care. They wouldn't fare any better.

What are you left with? You are left with jails. You are left with psych wards and you are left with the streets. We are a big enough and a great enough country that we can offer a full range of services including ICFs. I hate to call it the lower end of the spectrum because they are not any lower in humanity than any of us. Thank you.

DR. DANIELS: Thank you, Ms. Jennings, and thank you again to all of our oral public commenters.

We are going to take a few minutes to listen to what we received in written comments. I'd like to call Dr. Oni Celestin from my office up to give us a summary of those comments.

DR. ONI CELESTIN: Good morning. The IACC Housing Working Group has received written public comments from five commenters. The Working Group has been provided the comments in full, but they will be briefly summarized here.

Ms. Marjorie Madfis called attention to housing policies in her home state of New York that are potentially problematic for individuals with developmental disabilities such as her adult daughter.

Specifically, she noted that landlords can choose to not accept checks from two different sources as rent payment. This would exclude individuals who receive a subsidy to pay their rent.

Another policy allows landlords to decline to rent units to participants in programs such as those that assist individuals with disabilities.

Ms. Lori Kay wrote to ask the Working Group to prioritize housing options for individuals with challenging behaviors, who are unable to live with their parents or in group homes.

Dr. Eileen Nicole Simon described the experiences of her two adult autistic sons. She believes that long-term health insurance should be available to everyone at birth. She feels that PTSD care should be available to parents of autistic children. She asked the IACC to investigate the role of perinatal complications in the development of autism.

She also believes that there should be federal oversight of state mental health services and that the federal government should establish an autism care fund to cover the lifetime cost of services for autistic individuals.

Ms. Meghan Dawson is concerned about the long waiting list for housing in her home state of California and across the country. She urges lawmakers to pass legislation that will address the service needs of autistic people across the lifespan, including insurance reform, housing services, and adult services.

Mr. Gene Bensinger commends the Working Group for addressing this issue and advises them to focus on policies that will help to attract public and private investment in housing infrastructure for individuals with disabilities.

He notes that given the heterogeneity of the autism community, it is important that individuals and their families are able to make the housing decisions that are best for them at any given time. He also notes that the housing needs may change over the course of an individual's lifetime.

This concludes the summary of the written comments. Thank you again to everyone who submitted comments.

DR. DANIELS: Thank you. Next, I would like to share the one comment that we received through the live feedback link. And because we only have one and it is short, I will read it out to you.

This is from Kathy Dolan from the State of Wisconsin. Our social services lack understanding of autism which in itself creates a barrier to solutions. Autism has created the same as if someone has had a stroke or is cognitively impaired. Inappropriate placements are harmful to individuals, create public safety issues, are costly in hospitalizations, police interactions, and inappropriate courtroom appearances. Many end up in our prisons for lack of appropriate housing and supports. Thank you to our live feedback commenter.

We have a little time for discussion. And because we're doing well, we may have some time to get back to the other discussion if we have time. First, let's take any comments on the public comment. Does anyone have comments on public comment that has been raised today?

MS. SMITH: My concern with ISC institutions is that they do not respect people's right to grow up and do not allow people to experience adult activities. There is restriction of movement in institutional settings that makes it so that people are not truly free.

If these campuses were like college campuses where people can leave and go into the community and not fall away from the community and had access to public transit and had access to adult activities like being able to have romantic relationships, be able to make friends without disabilities and have their friends visit and have personal choices in their life. I believe every single person with IDD should have the right to grow up and have these adult freedoms just like anyone else without disabilities. We should not be in prison. And those institutions – a lot of times they imprison people and they don't allow people to leave and they don't allow people to have relationships that other adults are able to have. Thank you.

DR. DANIELS: Anything else on public comment? Daniel.

MR. DAVIS: Yes. Just responding to the commenter who was speaking before to ICF/IIDs. I would first of all say that I think that what happened to her son is extremely troubling. We do need to improve oversight in all settings.

I would just add that the oversight issues are also well documented in some ICF/IID settings. There was the case in Arizona recently of a sexual assault that went undetected until the woman had a baby.

The other point I would make on that is that from the data that we heard before from Heidi Eschenbacher. While there definitely can be exceptions, my understanding is that on average the cost of ICD/IIDs per individual is greater than the cost of living in community settings.

MS. SINGER: I think it is important that we keep in mind that for every category of housing, there will be examples of success and examples of failure. There are opportunities for people to have adult activities at all ranges of settings.

My daughter lives in an intermediate care facility. Let me tell you. It is the opposite of a prison. It is the only opportunity she has had to participate in adult activities. She has a full-time job that she would never be able to have outside of that setting. She is active in the community in the town where she lives. She has an opportunity to go to fitness classes in the community and go to stores in the community. I think those opportunities would not necessarily be available to her just because she was in a group home.

There are instances of individuals who are in group homes whose lives are far more restricted and who spend far less time engaged in the community. They may physically be located in the community, but that doesn't mean that they are being invited over by their neighbors to watch the Super Bowl or have a barbeque. It just means that they are physically located closer to non-disabled people.

But I just think it is important for us to realize that abuse can happen in any setting. Abuse happens on college campuses. It happens unfortunately in a variety of settings. I think we just need to keep in mind that good and bad can happen in a variety of settings.

DR. DANIELS: Thank you. I did receive one other live feedback comment just at the last moment. I'm going to read that one for you before we continue discussion. This is from Rayshiang Lin. New Jersey.

Many families are paying for the needs of their adult autistic members. Those families really need support from community and government where they can get help and guidance to transition their loved ones to live outside their family homes or where can they get this help. It appears that the resources are only available for people receiving Medicaid benefits. Would you address resources outside of Medicaid? That was that comment.

Did you have a question, Samantha?

MS. CRANE: I just want to make a clarifying point because I think that there is a lot of discussion about whether ICFs are better or worse than group homes. Those of us who are advocating for community integration, I think I can also speak for Daniel and Ivanova that we are not advocating for group homes. We agree that group homes are often institutional in nature and highly restrictive in nature. They tend to be provider-controlled settings where people can't, as the presenter earlier on mentioned - people often can't - don't have keys to their house, have policies restricting their visitors, have policies that will restrict whether or not they can lock their door. We would argue pretty strenuously that that is not the community and is in fact quite restrictive.

I am very concerned that when people are talking about ICF placements, there is this assumption that no one in the room has been in an ICF and that all of the people that were advocating for being in the community are completely different from the population of people who have been in ICFs. That's simply not true.

As I mentioned earlier in my opening remarks, when ASAN hosted a summit on the meeting of community living, we included people who had lived in group homes and who had lived in ICFs in the past. The history of the Disability Rights Movement, broader than the autism world, includes quite a few people who have lived in ICFs or nursing homes and have moved out into the community and have shared their experiences firsthand of feeling isolated, of feeling that they had to obey a lot of rules that weren't their rules. There were a lot of restrictions on autonomy that were based on the fact that they were in a congregate setting and had to rely on the rules set by the institutions.

DR. DANIELS: Thank you. Heidi.

DR. ESCHENBACHER: I just wanted to make a point of clarification on the presentation about the average cost per person. Those average costs per person for both RISP data and the California data were all average costs per person of funding from the DD agency and they are not the full cost of providing services to someone with DD of any type.

Because we already do know that people do receive other types of services from oftentimes from government sources, but we don't actually know the full cost. I just wanted to make that point of clarification that our data really is a reflection of what individuals are receiving on the basis of having DD.

The other piece on this is that The Arc and the University of Minnesota collaborated on a study called the FINDS study, which was - I can't remember the acronym right now. I'm sorry. It's F-I-N-D-S. It's looking at what supports and services, families feel as though they get and what they need. And part of that study looked at the opportunity costs that families are often facing, not having a job, for caretaking roles and things like that are being disrupted from their work because of caretaking emergencies. That might be another piece of the puzzle, but we don't have the full picture.

DR. DANIELS: Thanks. Terry Hamlin.

DR. HAMLIN: Thank you. I just wanted to just say to Susan just thank you for your presentation. Your son is exactly who we care for at the Center for Discovery. I think what is so often missing in these conversations, and I sit at a lot of the state-level conversations in New York, is that we really don't have very good acuity measures on this population. We use IDD as an acuity measure. And the children that we care for and why they are in restricted placements at least initially have tremendous comorbidities in terms of their physical health. They don't sleep during the night. They have severe gastrointestinal problems that cause tremendous pain. They have severe seizure disorders and a whole host of mental health conditions that if you are not treating them, these children can't advance to the next level. I don't think that a lot of people bring this into the equation when they talk about this population of kids with autism.

My recommendation would be that we start to really think about an acuity measure if we are ever going to help these kids and adults. We have to understand what these comorbidities are and what treatments are most effective if we want to get them to the next level. Thank you.

DR. DANIELS: Thank you. And we did work on comorbidities in the last couple of workshops of the IACC and had some great discussions on that topic. Did I see one other hand on this side? Was it Jill?

MS. ESCHER: Thank you. Just two quick comments. As I said before, I am a provider of scatter-site community kind of generic type housing and apartments, fourplexes, et cetera.

I just did a really quick handout. I just wanted to point it out - 12 years providing autism housing, 10 lessons learned. It's in everyone's packet. It summarizes some of the hard knock lessons that I've learned along the way. I just wanted to emphasize and really to follow up on what Desiree and other speakers spoke about is there's absolutely no one size fits all. As much as I strike to provide community-based generic housing, it obviously is not the right thing for a lot of people. I champion this model very strongly, but it cannot be seen as the be all and end all. It has not worked for some of my tenants as hard we try. And other people I hear from have been evicted. That was mentioned. The high risk for eviction - from similar models. I did want to just want to bring that up.

And the other thing I wanted to talk about is what we've seen today in terms of theme are really two things. One is quantity and one is quality. The quantity issue that we are facing in the autism community is absolutely catastrophic. I use that term really with a great deal of care. It is catastrophic. What we are seeing based on California data just in the developmental services system is that the number of adults of autism will quintuple over the next 20 years and we have no reason to believe that it is very different in other states. We are already exceeding capacity in terms of what our communities can offer. This group and others really need to come up with formidable, powerful policy shifts that can account for this.

I just want to show you a quick graph. This is from the California Department of Public Health. I know it's hard for you to see. But it shows the birth year prevalence of autism from 1990 birth year to 2013 birth year where it peaks. We are now seeing at least with boys more than 2 percent of all boys born in the state end up in the DDS system as autism cases. That is from a very low number. It barely showed up on the radar. This is just developmental disability type autism. The red is males. The blue is females. It's about more than a four-to-one ratio in California.

The number issue, we have to deal with and we have to deal with it in a realistic manner. We also have to talk about quality of services. But you can't talk about one without the other.

DR. DANIELS: I'm going in an order that tries to get people in who have not been able to speak yet. Max, I think you had a comment earlier. Do you still have a comment?

MR. BARROWS: I do. It is about the first presentation. Thank you so much. About going back to the housing. Going back to the housing thing, I just want to mention a few things about physical structure and size. I found that when it comes to physical structure and size, gated communities, farmsteads, cluster of group homes, even if they may include people without disabilities, they are not community. When we live in those settings, we are just left out of society in general, just segregated from the general scope of community life. I think that people should have the opportunity or just the freedom to choose wherever they live whether or not it's in a rural, suburban, or even heavily urban community and with access to just reasonable places for them to belong like recreation aspects of community life, even just places of commerce.

I just want to point out quickly too that a home should not be considered at all in the community if more than four unrelated people live in it. We believe that people should live in houses, condominiums, trailers, whatever they choose. We should have the right to privacy. We must be able to have time to ourselves in a private space where we can lock the doors. We should also live with people that we want to live with and that we feel comfortable with instead of being forced to live with someone who maybe unknown or dissatisfying. We should have access to houses of worship, places to work, stuff like that and also just with choice. I could go on and on here. But for the sake of time, we should have the choice about where and who we live with and how to spend our time and where we go, what to wear, who to chill with, and the list goes on and on.

DR. DANIELS: Thank you. Josh.

DR. GORDON: It's been really instructive for me to listen to this and also to hear the voices from really across the spectrum, as we say.

I'm hearing a lot about the desire from individuals with autism not to be segregated, to have autonomy in many aspects of their lives, freedom to choose where they live, privacy, and other requests.

I'm also hearing though that there is an urgent need, growing more urgent by the moment, for pure and simple in number of housing slots.

And then finally, we've heard from many advocates for the more severely disabled who may not be able to at times represent themselves that there are individuals who cannot function and live in places that might offer the kinds of autonomy that many of the self-advocates around the table are advocating for.

But I think those who have remarked that in every care level there are good and bad examples. There are working solutions, and solutions which aren't working so well is really crucial. And it also sets the stage for this afternoon where you are going to hear from a lot of people who operate, run, and live in these facilities and homes and in the community.

I think as you listen to those stories, what we seek to do really is learn from the examples at each level of care for what is done well. Is there facility-based care that despite their size manages to respect to the degree that is possible the autonomy and privacy of their residents? Are there organizations that work really hard to keep people in the housing situations that they desire and support them to the level that they need support? How can we scale it?

Finally, just as a representative of our federal government, it would be wonderful if we could provide everyone with all of the freedom, choice, privacy, lack of segregation that they desire, but the other thing we need is scalable solutions that we can afford. If we are going to be making recommendations to the branches of federal government that will have to set standards and that will have to help figure out ways to pay for all this, we do need to think about the fact that we can't offer everybody everything that they absolutely want and still achieve the numbers that we absolutely need.

I would ask those of you who are advocating for freedom, segregation, autonomy, and privacy to think hard about what's most important for you when you listen to those presentations and recognize what you think will work for different people, for you, and for others.

I would also asked those of you who are advocating for people on the more severe end of the spectrum, to think about and recognize situations that will work for the people that you are advocating for that are scalable, so that we can come up with some ideas that we can actually take forth and not just be asking for pie in the sky stuff, but actually for thinking about what could we say this is what we need. What could we bring to our legislative bodies? What could we bring to federal agencies that works and is scalable?

DR. DANIELS: Thank you. Kim.

MS. MUSHENO: Thank you. I really appreciated the presentations this morning and thought they were very helpful. Thank you for that.

I really feel strongly that if the HCBS rule is implemented with fidelity and obviously we need a lot more resources that it should not depend on the setting. It should depend on the individual's desires and needs. I have been in a situation where my family member has been a three-person setting and still felt institutional-like and a lot of that.

I keep thinking that a big part of quality is in the direct support workers. I agree with those that were saying that we are not paying direct support staff enough to be caring for humans. That is really important.

And then another thing that just has not been brought up yet that I think is really important for our federal government to work on is that we don't have a national long-term care policy. Some of us in this room have worked on with Senator Kennedy who is now rolling over in his grave I'm sure because on the CLASS Act, the Community Living Assistance Services and Supports Act. This was passed as part of the Patient Protection and Affordable Care Act in 2010. And then a year later, it was repealed. We were so disappointed for that because that was long-term services and supports based on functional need, not diagnosis. I think that's really important as well.

I think that besides needing a lot more resources, we also need to talk about having a national long-term services and supports policy. Thank you.

DR. DANIELS: Thanks. Denise.

MS. RESNIK: Thanks. And what we are talking about here is very complex. Housing is complex. Support of housing is not only very complex, but also very expensive. Josh, you're correct. We cannot look to the federal government to think that they can do it alone. We have to recognize the economic sensibilities of what we can and what we can't do. It does require private sector getting involved, along with philanthropic sector, along with our public sector and certainly our non-profits. But we can't expect to create a new wave of housing by looking just to the federal government.

But what we can do through the federal government is look to those guardrails, those things that can better protect us and recognize that what we are creating is an emerging marketplace.

We have been through this before. For those of you who are old like me, you can remember that over 50 years ago, we introduced senior housing. I worked for that senior housing developer who introduced Sun City in Arizona. It was going to be the haven for retirees. Fast forward 50 years, now you look at all the different price points, locations, amenity services for a senior housing population. Those who can re-career, those who have medical and health issues, those who need higher levels of supports.

And what we have also heard repeatedly this morning is this definition and requirement for community, because no matter what you need whether you're a person with autism or you're a senior, it is the community. It could be a community within a community, but it's the spaces in between, spaces for health care, employment, lifelong education, and more. Where we can agree repeatedly is that need to build the community, the recognition of what autism is, what it isn't, and the universal concern, Kim, as you recognized and as our presenters did also of those direct support providers, because that's what will help fuel this new wave of residential options.

DR. DANIELS: Thank you.

MS. MELISSA HARRIS: This is Melissa Harris with CMS in Baltimore. I apologize for being quiet earlier this morning. I had to step away from 10 to 11. I did want you to know that I was on the line. I will be on the line for this afternoon's sessions.

The Medicaid Home and Community-Based Services regulation that is at the crux of a lot of this conversation although not all of it is implemented in the portion of CMS that I sit in. I'm happy to answer any questions about it or provide some additional context for it.

I've been struck as I've been listening to the public comments both oral and written that there's quite a lot of - despite the fact that people can bring very strong opinions to the table about the role of the federal government and whether the settings regulation was a good idea or not, there's a lot of consensus among people that this is not a one size fits all conversation, that every person is going to bring a different mindset to the table about what they want to do with their lives. They are going to bring a different set of needs to the table about the kind of supports they need to fully integrate in their community and they are going to bring a different idea of what community looks like and what kind of role they want to have in their community. We knew that going in to the development of the regulation.

We are also very cognizant that the population of people across the country receiving Medicaid-funded home and community-based services is so divergent. We have people all across the age spectrum with very different health conditions and needs. We really worked very hard to find the right array of regulatory criteria that would provide some standardization around expectations for providers and states, but would not look to inject a standardized way of living for people because that's really the antithesis of what the regulation is trying to do.

We always go back to the person-centered plan as the crux of the regulation even though there are some now standardized criteria for what a home and community-based setting in the Medicaid program looks like. Those criteria still find their way back to recognizing what each individual wants and needs from Medicaid-funded supports and underlying the implementation of the regulation is a recognition that each individual's person-centered planning should really be leading the way to be that person's expression of what they want and what they need.

As we are several years into the implementation of work and progress at the state level, at the provider level, at the stakeholder level associated with using this transition period that runs through March of 2022 to achieve compliance with the settings criteria. We are aware that any number of different looks of housing can and should be compliant with the regulatory criteria.

We've issued some revised guidance within the last several months that we hope solidifies the idea that different types of settings that are on various points of a spectrum of independence or co-location can meet the settings criteria. That's really the point of where all of our energy should be focused on this implementation is making sure that the setting complies with the settings criteria and that can be done either in a fully integrated independent housing unit all the way to an assisted living facility all the way to a farmstead or other type of intentional community. All various shades of residential settings can be compliant with the settings criteria because we know that people are wanting different things in where they live. Our job as the federal government and CMS is to make sure we are providing the right kind of technical assistance, infrastructure to states and providers, on the various ways to comply with the regulations.

But I hope people take seriously that this is not - this regulation is not meant to rid the country of a particular look of housing models. It is not designed to infringe on anyone's choice. It's designed to say that among all your options for where you are going to be living, whether we are talking to an individual beneficiary himself or herself or whether we are talking to a family member about looking for the most appropriate setting for a loved one, that the individualness of the person you love is going to be taken into account and respected by the provider and the infrastructure that the state and federal governments have put into place.

I'll stop there. I did want you to know that I was on the phone and then I'll be around to react from the CMS perspective this afternoon. I really always appreciate so much hearing the perspective of people who are living the receipt of Medicaid-funded services on a day-to-day basis. Your perspective is premier in making sure that we are doing this right.

But I also did want to provide some background to how we are looking at the settings regulations since I know it is – whether or not it's explicitly involved in these conversations, it's always in the background. I appreciate you letting me inject a little bit.

DR. DANIELS: Thank you so much, Melissa. We have five minutes left. I have four people on this list. I'm going to go in the order of Steve Whitlow, then Lori, then Scott, then Ivanova and then I think we will end there.

MR. WHITLOW: I'll be very brief, but I just wanted to make two comments. First of all, I'm relatively new to this game. I thought I couldn't find the data, but now I know there is no data. I would say that one of the key elements of what we produce out of this meeting should be a call for some sort of collection and standardization of the data so we can make comparisons as to what the models really do; otherwise, we are really relying on anecdotal evidence that is unreliable.

And the second part of it is I'm fortunate enough to work for a fairly large organization that is willing to listen to creative housing ideas. But the end question always is how are we going to pay for it and sustain it. If we don't ever understand, as Ms. Resnick said and Dr. Gordon says. If we don't understand the marketplace, we can never really understand the models. The first thing that we are going to have to do is understand the marketplace, where those funds are going to come from, where the options are for the various levels of care. And once we understand the marketplace then we will be able to better understand which housing models fit in which place.

DR. DANIELS: Thank you. Lori.

MS. IRELAND: I'm going to display my ignorance again. Are there other sub-groups in the United States population citizens who receive government funding, which would include Social Security and Medicare? Are there other sub-groups other than the IDD-MH population who are restricted in this way as to who they choose to live with or how many they choose to live with? Are there other groups or is this the only group?

MS. CRANE: The HCBS settings rule applies to absolutely every person with a disability who gets an HCBS waiver.

MS. IRELAND: I understand, but is it only disabled people who are restricted?

MS. CRANE: I believe also that there are HUD regulations on segregated housing for other groups as well. You couldn't get a HUD voucher for an all African American housing project. That would violate the Constitution of the United States.

MS. IRELAND: But you could get a HUD waiver and then all African Americans chose to live in that community?

MS. CRANE: My understanding is that that is not how the settings rule works. We are talking about settings that are designed for - there is an apartment building and one person with a disability moves into one unit. And then another person with a disability happens to move into another unit. That is outside the scope of the settings.

What we are talking about are settings that are designed and restricted for the use of people with disabilities. We are not talking about two of the three adults that live in my single family house that are disabled. I am one of them. That has nothing to do with the settings rule because we are not a specifically disability setting.

DR. DANIELS: We do have someone from HUD here who may have some comments.

MS. HELMS: I do just want to emphasize of the housing choice voucher program. You can choose to live in any unit you want as long as the landlord chooses to participate in the program. There isn't any sort of specification on that.

DR. DANIELS: Thank you. Next, Scott.

DR. ROBERTSON: I will try to keep my comments brief. I agree with the emphasis on self-determination, self-advocacy with individuals. You can see a lot of that in the settings rule in terms of the philosophy there that is shaping in terms of the implementation for the settings rule and what it means for home and community-based services, which cross connect not only to community live, but to employment and other aspects of folks' lives including hopefully more in the future transportation so you can access work and community living.

I was particularly struck by the comment that was made in that live comment from New Jersey where it mentioned Medicaid. That a lot of folks may not be eligible for Medicaid. When I lived in Pennsylvania and helped develop the adult autism waiver there, one of their two adult-focused Medicaid service systems there that they now have in Pennsylvania, which was one of the constraints that they had. You don't need an intellectual co-occurring intellectual disability diagnosis alongside your autism there. But you do need to meet the level of care standard, the ICF level of care standard and that's pretty much across the board. For Medicaid and a lot of folks don't meet that eligibility and may be ending up homeless or just have other major vast adversity in life experiences and can't access employment, et cetera, because of the fact of not being able to qualify for Medicaid, but may need a small amount of services, a small amount of residential services and other services to access employment, integrated community living. I think we should keep that in mind.

I concur with what Kim had also mentioned that we need longer-term plans and focuses on what long-term supports mean in the United States. I think hopefully we can see some innovation in that space from us in government and at the federal level, and our collaborators at the state and local level in government, and also the nonprofit and for-profit world, and maybe see some different ways on approaching that and having better policies and practices to address a lot of these barriers and gaps that have been around for a long time.

A lot of voices are not heard of autistic people who are struggling and not able to access integrated community living that they want to and, again, sometimes may not even need as – some other folks, but not be able to access anything because we often have a one size fits all model in many cases.

I hope we can have some change in innovation in this space and maybe some of that will come arise in terms of the discussion in the afternoon presentations that we have here today. I'm encouraged that we are having the conversations that we are having today.

DR. DANIELS: Thank you. I will give the last comment to Ivanova before we break for lunch.

MS. SMITH: I just want to clarify my comment earlier that institutional settings are not a building. It's a way things are administered - settings where there is a lot of control of the individual and where they go, what they do. That's what I mean when I say institutional settings. A person is being institutionalized. They are discouraged from making their own decisions and having their communication - the institutional settings are about - it's a mindset of control and having power over another individual. The institutional settings and group homes. There can be an institutional mindset and an individual unit or an apartment if you have a caregiver who tells you that you have to get up at this time. You have to do so. Or you can't go out at this time or you can only go out – it is a mindset. It is an idea of control that is institutionalization.

When we talk about supports, I think we need to separate the idea of long-term supports from control. You can support a person, but I think there are ways to support people with IDD without controlling them. There are ways of giving people support in cooking and in helping people not self-injure without controlling them and without taking away their rights to privacy and their rights to personal freedoms. Thank you.

DR. DANIELS: Thank you. With that we are going to be breaking for lunch. There is a restaurant here in the hotel as well as Starbucks. There are some restaurants in the area, but they might be a little challenging to get across Rockville Pike and next door only has a few options. The hotel restaurant may be the best bet.

I'd like to ask the Working Group to meet over on this side for a photograph before we go to lunch. And then we will be coming back at 1 o'clock to start talking about our next session, which will be intentional community models. We look forward to that and thanks for a great discussion and letting a number of you participate. We look forward to hearing from more of you next time. Thanks.

(Whereupon, the Working Group recessed for lunch at 12:05 p.m. and reconvened at 1:05 p.m.)

DR. DANIELS: We are going to be going into our session on intentional community models. Our next speaker is Denise Resnik, CEO and co-founder of the DRA Collective in Phoenix, Arizona. We welcome you, Denise. You can go ahead.

MS. RESNIK: Thank you. I am going to start with a brief film to give you an idea and a little bit more about First Place AZ, which opened one year ago this month.

(Video shown)

We have a very big vision at First Place, which is to ensure that housing and community options are as bountiful for people with autism and other neurodiversities as they are for everyone else. And what's required in order to do that is to create a marketplace. I've personally been at it for 22 years.

It's important that you understand what First Place is and what it isn't. One of the biggest challenges in developing First Place is that we wanted to create something for everyone. We know there is not a one size fits all.

What we have adopted is this vision of what is attainable. What can we do now and then what can we do next? Importantly, this is a little bit about who we are. Most importantly at the bottom - I love this vision of what is community. Community represents the people in your life you don't pay to care about you. And the only way they can care about you is if they get to know you within your community, within the broader community. Importantly, this is individually focused. This is about consumer-controlled choice. It is most importantly about home and how each of us defines what is home.

At this time, what we are not. We are not licensed. We are not a medical home. We are not assisted care. We are not for those who have serious and violent behaviors. We do not have the staff for that. We cannot support our residents and their peaceful, quiet enjoyment in this particular setting.

Through the years, again, 22 years of them, we've conducted a lot of research. This represents a piece from our National Family Roundtable. And it was hosted with individuals on the spectrum and their family members. We gave each family member two large pieces of poster paper and a marker. On one, we asked them to draw their greatest hopes and dreams. On the other, their fears. Because of the limitations of this screen, we didn't include all the fears, but you know them and you've lived them.

At the very center of it, what do we want? We want our loved ones to be happy. We want to be happy. And then right after that, we want them to be healthy, which is why we have a thousand square foot health spot within First Place.

We are also very concerned about finance. Think about what we are doing, almost in reverse of the senior housing reference I mentioned earlier, that we are not creating assisted living. We are not a licensed property, but we are creating more supports and over time trying to increase the level of independence and reduce the cost while increasing the quality of life and choices over their lifetime.

We have had technology planners from Intel working with us on our technology platform, being very mindful of the economic sensibilities associated with technology and also as its name implies, we may be the first place you live after your family home. We may not be the only place. We didn't want to load this with so much technology that it would preclude people from learning some of those skills themselves.

We have a 24/7 concierge. You can see that families really wanted individuals to have a room. Everyone drew the home, but they wanted them to connect to the broader community. What do you do all day? Where are you working? Where are you worshipping? Because once again if you look at that corner on the right that is what answers that looming question of who is going to care for them when we are no longer able to do and that's going to be community.

This property is also based on the Opening Doors report, which we published now ten years ago and which was presented at the IACC meeting in 2010. It includes ten specific design goals and guidelines, several of which have been adopted in the property known as First Place Phoenix.

We also conducted a focus group of over 100 family members, hosted two national design charrettes. There has been a lot of work that has gone into First Place.

In walking through the property, you would experience no fluorescent lights. They are all low voltage LED lighting. You would experience technology applications, security, safety, and importantly our location within light rail and public transit walking distance.

We have three uses within First Place. Our first opened almost five years ago in an affordable housing property that co-located seniors without autism with our students with autism. That's a beautiful program known as our Transition Academy. When I talk about it, I'll talk about participants and students. It is a residential program also now housed at First Place.

I'll also talk about the apartments and that's supportive housing, fair housing rules the day. We have individuals in their 20s, 30s, and 40s. And a diagnosis does not determine what you need in your housing. We are neurodiverse, neuroinclusive.

And finally, the third use is our Global Leadership Institute. That is where we are promoting training and data collection and advancing policy. You heard in Desiree's comments earlier today the work that we are doing with the Autism Housing Network and

Madison House on a sister study to the Opening Doors report.

This concept that was introduced in the film, this kintsugi art is a defining concept for First Place. Our architects after understanding the three specific uses and programming needs, they asked us not to start there, but to start in that gold resin space, that space that brings us together, that space that brings people out of their rooms and connecting to their neighbors, that space that connects our apartment residents with our transition academy students and also informs the work of the Global Leadership Institute.

That gold resin is also used outside of First Place, which you see right in the center of it all, as you see those gold spaces in the community. Now these are the spaces that we have been developing through the Southwest Autism Research and Resource Center for 22 years, places for work and places for education and health care. This is why PBS NewsHour in their two-part series a few years ago acknowledged Phoenix as the most autism-friendly city in the world. It is allowing not only First Place to be developed, but other properties to be developed too so that we have more choices, more choices at different points in life and at different ages.

Within the First Place property, I mentioned the three different uses. I'm going to focus first on our Transition Academy, but I also want to acknowledge that in October, we will be hosting our sixth Global Leadership Institute Symposium where we have brought together pioneers from across the country and around the world that are also working on innovative properties. There are some amazing things that are happening in the community. We're going to hear about them I know today, but also this place where we recognize – we're not going to be advancing policy just from Phoenix, Arizona. It's going to take us all and it's going to take the data collection that we are also doing at First Place and hopefully many of your properties will be doing it too.

Together with the Autism Housing Network, we have been advancing a quality of life survey. We're administering that to all of our residents now. We are using that at four other properties.

Within the Transition Academy, it is a two-year tuition-based program. It has started as a private paid tuition program and we are excited that we have been making some advancements in that space too. It is like post-secondary education. You have to enroll.

You have to be accepted to the program. The number one criterion is you have to be committed to wanting to live independently and your parents have to commit to the same, because natural consequences we understand are very important.

We not only have the didactic learning taking place through 32 semester length courses. This is a collection of those courses called Learn4Independence and that happens in the classroom two hours every day at a community college campus within the community. It is our instructors at SARRC and at First Place that are leading that Learn4Independence curriculum, and the rest of the day, they are applying what they learn, how to ride the light rail, how to make change, how to stay safe, how to make your meal, how to invite a friend over, how to clean up, how to learn how to live as an adult.

This curriculum is also being licensed to other groups across the country. We just completed our sixth license.

In terms of outcomes over the past four and a half years, 50 percent of the graduates had never been employed. Upon graduation, 94 percent were employed.

You can also recognize that 28 percent of the graduates had experienced living outside the home prior to the enrollment. And upon graduation, 89 percent were living outside the family home.

Fifty-five percent of the graduates are now living at First Place properties. That includes both First Place Phoenix and the affordable housing property that I mentioned. We are getting ready to break ground on a second affordable housing property. That, again, co-locates seniors with individuals with different abilities.

This recognizes that we have finally after four and a half years earned public support. This means that students in the Transition Academy, if they are qualified through our Division of Developmental Disabilities and Arizona Long-Term Care, have been able to braid together about half the cost of the tuition. That's over $30,000. We have intentionally been working on this, but we couldn't start within government. It didn't support the model. But once we had outcomes and once we stayed close certainly to our leaders within our state, we were able to start bringing together that public and private support. Where we start is not necessarily where we end, but we have to start someplace. And once again, we started with what was attainable.

Within the First Place apartments, we have many features and amenities. You saw a picture of the Lego lounge. We have a cardinal's electronic game room, a fitness room, a culinary teaching kitchen. We do not have group dining. We are teaching people through the culinary kitchen how to make those meals on the very same appliances that they have in their apartments. And the technology space also all those kitchens are equipped with motion sensors, which will automatically turn off the stove or oven over a prescribed period of time if it doesn't sense motion.

We have focused also on making sure that the property is supported. We support that property and also have people bringing in additional services. Again, consumer-controlled. We, through the Opening Doors report, recognize that we needed to separate the real estate ownership from the supports and that is why in 2012 we created a sister nonprofit to SARRC called First Place AZ. There is a much different risk tolerance that real estate requires than what SARRC is as a services and research organization.

This represents some of the areas of skill building where we are helping individuals promote independence and also recognizing how they can enjoy this very supportive community that we have in Phoenix.

We learn by doing and unlike the senior housing model, if you would, these support providers are there to help teach people how to do more things for themselves, recognizing that people have different limitations and different abilities.

Community life is a key feature of things that are happening at First Place and it is robust. There is Meditation Monday and

Taco Tuesday and Wellness Wednesday and Thirsty Thursday. By the way last week when we were making Thirsty Thursday, we had virgin daiquiris. But sure enough, a group wanted to jump upstairs in their apartments and I'm sure spiked their daiquiris and that's their choice in terms of what they do in their home.

When we ask ourselves those tough questions, somebody from an opposite sex or the same sex said what can they do in their homes. These are private leases. And any time we get those really big questions. How long can they live there? Can they live there forever? We look up at the private market, the market place to answer those questions. Yes. People live there now in their 20s, 30s, and 40s. Several will be there as their first place for a few years, developing their skills and for some it will be a forever place. That is their choice.

Within the First Place Global Leadership Institute, we have five centers. Unfortunately, those names aren't popping up, but we have our Center for Education Training and Employment, one for community and real estate development. A third is our Center for Applied Research. Our fourth is the Center for Expression, think arts and different ways to express and communication, and also a fifth, which is our Daniel Jordan Fiddle Foundation Center for Public Policy.

That Global Leadership Institute predates the opening of First Place. We've been at it for several years. We have a logic model that has identified ten priority issues, ten issues that affect all of us no matter the housing model, speaking to quality of life, the issues of isolation, the housing crisis, business models. We can talk a lot about what we want and what we desire. But let me tell you. This is not easy and creating a financial model, a sustainable financial model is critically important.

Support providers. Also critically important. And a universal concern for us all and recognizing the heterogeneity. This is not a one size fits all, but we have to better define who we are, what we want so we can talk to a market place, a public, private, nonprofit, philanthropic interests to deliver what we want and what we need. The nomenclature and the segmentation are huge issues in order to advance this new wave of housing, this new wave of real estate.

Earlier this year with our governor, we announced through our Center for Education Training and Employment that we were creating 500 jobs thanks to recruiting a back office

IT firm from Delaware called the Precisionists. And over the next five years, we will create 500 jobs for people with autism and other neurodiversities.

Now, if you think about this for just a moment, we have the capacity of 79 people living at First Place. It's important for you to recognize First Place not only as a real estate developer, but as a community developer. We are creating opportunities for jobs, actually 1000 by 2025. We are creating opportunities for health care, for lifelong learning, critically important in terms of developing community.

If you think also about this idea of public-private, nonprofit and philanthropic collaboration, think about it like a super highway. If we think about the government holding their lane for supports and think about private sector, advancing real estate and getting out of the lane of the government so that the government doesn't hold onto a lot of real estate, think about the nonprofit bringing together and enticing if you would the philanthropic sector so that we can innovate. We can experiment. We can make mistakes and that we can learn from that. And that's what we are proceeding with as a concept in terms of the super highway. It's going to take us all to advance this next wave of real estate and all the models that all the people need.

We have, after one year at First Place Arizona, we are celebrating a lot of firsts. People's first home, their first bus ride, their first key, their first date. We've been enjoying quite a bit. Many of the firsts happening at First Place.

DR. DANIELS: Can we try to wrap up so that we can move on to the next speaker.

MS. RESNIK: No problem. We are using the Quality of Life Survey. There is more on our website in terms of lessons that we've learned through the years and in terms of what home is, home, as you define it.

Our son, Matthew, pictured in the middle, has been making his transition and I'm sharing some of those lessons learned as well. Thank you very much.

DR. DANIELS: Thank you. Sorry about the schedule. We started about seven minutes late because the microphones weren't on yet. But we'll try to make up the time with the discussion.

Next, we are going to be hearing from Krista Mason, executive director of Benjamin's Hope in Holland, Michigan.

MS. MASON: Thank you. It's a pleasure to be with you. It's Holland, Michigan, not

Holland, the country. A few people asked me. Less exotic.

I'd love to share just a little bit about the inspiration and background for Benjamin's Hope. I am the Executive Director and Founder of Ben's Hope and the mom of Ben. My son, Ben, today is 23 years old, 6 feet tall, 240 pounds and quite profoundly impacted by his autism.

His story is much like many families. He was typically developing for the first year and a half of life and impy and mischievous and gaining language. And over a matter of four months, it was as though he just enfolded into himself. His days became rage kind of morning to night. We were 1997 in Columbus, Ohio. Autism was not a household word. We were going to specialists and found ourselves in front of a doctor at Ohio State on Ben's second birthday. He said to us that day - Ben is playing with this trains. He said your son, Ben, has autism. He is still the same Ben you love and you don't have time to sit around feeling sorry for yourself.

Three months later, Ben is doing a 40-hour a week ABA program, auditory integration training, and fancy glasses. We had every hope based on the research that by first grade, Ben would be indistinguishable from his peers. Does anybody remember that language? Some parents in the audience.

At that point, I still could not envision for Ben a life that would involve his autism and that that would even become a beautiful part of his life.

Fast forward, I'm going to show you a two-minute picture of where we are today some 20 years later.

(Video shown)

Benjamin's Hope. Live, learn, play, worship model. Today, when I'm in this conversation, I want to focus mostly on our residential services. But in early days as we were dreaming about this, our vision for this is the same vision that I have for my child who isn't affected by autism of a life of community and belonging, engagement, and purpose.

It was interesting that it took us to the idea of a farm. Sometimes people say why did you do a farm. I did not grow up farming. I know nothing. I keep plants alive. The farming piece of this came from observing Ben. Ben is not a person who is traditionally verbal. He can't say to me, hey mom, this is my dream for my life. But in studying Ben, I can see his communication in a nonverbal way about where he thrives and what's important to him.

This led us to the idea of a farm community that will both integrate our broader community into everything we do, and also that we would go outward. Ben's Hope. Live, learn, play, worship.

There are models similar to ours around the country. We have often people that visit us as they are starting to envision something in their community. And one of the things that I often hear is this feels different. Why does it feel different? I believe the reason that it perhaps feels different isn't about the physical structures that exist there or even the activity that people are engaging in, but about our values.

I'll give you an example. There is a gentleman. He gives me permission to share his name, Peter, who lives at Ben's Hope. Peter has an uncanny ability to see when a lightbulb is out. Right now, if he was here, he would tell us exactly which lightbulbs are out. He wanted to be part of the team of replacing light bulbs. We looked at this and considered the fact that Peter does have a very significant tremor. Going up on a ladder and replacing a lightbulb will be something that he wouldn't feel safe doing.

My facilities guy and Pete went to the hardware store, bought a PVC pipe the size of a light bulb, and Peter identifies the light bulb that is out, puts it in and my facilities guy goes up and together they replace this. It's a culture and a value about doing with, not for. It's about dignity-based communications, speaking with men and women as adults in a way that respects them as adults and it's about presuming intelligence.

So often I look at this and I think the real difference I think in what is happening at Benjamin's Hope has to do with our values.

This talks a little bit about some of the things that go on at Benjamin's Hope and the idea that we believe that having purposeful engagement is central to being human. And about half of the men and women, the 33 men and women who live at Ben's Hope, are not traditionally verbal. Creating opportunities for purposeful engagement is a wonderful thing.

We take a whole-person approach. We talk a lot about honoring people in their unique giftedness. If you were to say to me I want to come work in Holland, Michigan and be part of Ben's Hope, you might join our staff. We have a staff of about 100. And years ago when I was thinking about what do you call a staff. A residential aide doesn't sound dignified. Direct care worker. We landed on the idea of a sidekick. I Googled it. And a sidekick is a friend, a companion, and an adventurer. We loved the mutuality of sometimes I need your help, sometimes you need my help. This is the foundation of our culture. So that the men and women who live at Ben's Hope are growing in skills and feeling respected as they do so.

This gives you a quick glance at the number of folks that are onsite at Ben's Hope in a given week. Different things that go on. As well, we are volunteering at the local museum. I have an individual who works at a local theater. We volunteer at the hospital. We are out and the community is in. It's richly integrated.

Lastly, this is a little snapshot of what our funding looks like. As I mentioned, we are serving men and women who are in many cases quite profoundly impacted by autism. Their behavior supports are significant to help them be safe. This is an expensive model of care. We are relying on Medicaid funding to do this, which presently covers about 75 percent of the cost of care. This is much a community-supported model because it's necessary to be able to provide this quality of care.

In closing, I thought it would be nice to share with you a statement written by Lucas. Lucas is a man who lives at Ben's Hope. Ben's Hope is a place where everyone is welcome, not only the residents, but the community also. I don't have to be scared of not fitting in because everyone is welcome.

I never thought there would be such a place like Benjamin's Hope. I don't have to hide anything ever. I don't have to worry about not fitting in.

I'll tell you. Lucas has a job at our hospital. He actually has a job as well at a local camp. He's richly involved in our community. He probably could choose to live in a lot of different places, but he has chosen to live here because there is something about this community that helps him feel valued as a person.

In closing, I'd like to say we all need a place to belong where we are known, where we are loved, and where the person who we are is celebrated. I'm thrilled to be able to share about Ben's Hope with you as one option among many needed options in our country. Thank you.

DR. DANIELS: Thank you. Next, we are going to be hearing from Terry Hamlin, the Associate Executive Director of the Center for Discovery in Harris, New York.

DR. HAMLIN: Thank you very much, Dr. Daniels and Alison. Thank you so much for inviting me. It's a real pleasure to be here. The discussion was just remarkable this morning.

I just want to clarify. We're under the intentional community section here. I don't really consider the Center for Discovery necessarily an intentional community, but we are a continuous learning community. I would probably describe us as being more like an agricultural college. We have classes for the individuals who live with us. They are learning every single day along with our 1700 staff how to advance their lives. We happen to be in a very rural setting on about 1500 acres of land spread throughout Sullivan County and really many of our adults are now living on Main Street in Hurleyville or around Main Street. They've advanced their skills.

And what's really unique about this center is that we, in New York State, are a Center of Excellence and we actually care for the most challenging individuals in New York State. These are children and adults who come to us who have severe, aggressive or maladaptive behaviors, self-injurious behaviors. That's the entry criteria to come to the Center for Discovery.

We've really developed a program where we are really thinking about what are the drivers of those behaviors. I talked a little bit about acuity before because I do think that acuity in this population is not well understood at all. But the drivers are in three dimensions, the biology of the individual. What are the health problems in the population and what are the mental health problems?

The behavior. What are the lifestyles of the individuals? Are they individuals who just prefer to stay in their room? Are they individuals who just like to eat two foods? Are they individuals who have really poor sleeping patterns and are up for days on end? What is the biology? What is the behavior?

And then what are the environments that are best for these individuals? Naturally where the housing conversations come in because there are certain environments and we do a lot of research. We have a major research institute at the center as well. We do a lot of research around environments. I'm going to show you some of that research.

But when we talk about medical comorbidities in this population, we cannot ignore the research. This is Lisa Cohen's research. Many of you have probably seen this before. The individuals who come to us, at least the more severe individuals, have gastrointestinal problems. They have the hypertension, diabetes, obesity, sleep disorders, seizure disorders and almost every one of them, at least 99 percent of them who are with us have a diagnosis of anxiety and many times depression.

What are interesting though are the suicide attempts. The individuals who come to us are more severe in terms of IDD. We are not seeing the suicide attempts. But when I speak to my colleagues who are working with individuals who are considered much higher functioning, who are advocating for themselves, that suicide rate is significantly high. In addition to that, they also have a lot of the medical comorbidities.

We can't neglect the medical problems in this population.

There was also another large study in Sweden that confirmed that heart disease, suicide again, and seizures were the major causes of premature death in the population.

A lot of these diseases actually influence each other such that you have new disease states that are more prevalent in autism as well. And that would be cancer, Parkinson's disease, and stroke. Stroke victims are seen in individuals with autism at much higher rates than in the normal population. I think this highlights the complexity in the individuals that we are dealing with. Again, this is just another study. There are studies after studies that confirm that individuals with autism have a whole host of other comorbid conditions.

The environment can really be designed to reduce some of those life-threatening conditions that are both physical and mental health. And a lot of these conditions that we are seeing are inflammatory conditions and stress-related conditions. You can design environments that reduce those problems in the population.

This is some of our research. As I said, we have a major research center. But I think one of the things that is often not thought about is stress of the caregivers in the environment. We talked a lot this morning about abuse and neglect. And indeed, when you are working with individuals who have significantly challenging behaviors or even individuals who need a lot of care, there's tremendous stress.

I'll just talk you through what you are seeing here. We have a psychophysiology lab where we are measuring stress through advanced technology. Somebody would wear a stress monitor on their wrist. It's called electrodermal activity is what it's picking up. It's a measure of sweat. It comes from the sympathetic nervous system.

But you'll see here is a person with ASD, one of our individuals. And here, this is his measure of stress. He's pretty calm right here. And then right here there is a spike and that is a significant maladaptive behavior. He actually tipped a table over here and became extremely stressed by sound in his environment. You can see. He's stayed stressed for a while and then started to calm down.

What's interesting about this is that the caregiver - it could be a parent. In this case, it was a staff member - was also stressed and actually has - what we are seeing is chronic stress, which can happen over time in individuals. But as soon as this child had a behavior, if you see right here, there is a mirroring that happens. There is this social contagion. The stress is actually contagious. The next person in the room or in proximity to the child has a stress response. And then in this case, their caretaker stayed stress throughout the entire time.

This third one. This was the other caretaker who came in who was relatively calm until they relieved this person, this person left the room right here. This person came into the room and look what happened. Just the anticipation that this individual could have a behavior caused a stress response in the other person. This is replicated time and time and time again such that you have high rates of chronic stress, hypertension in the population, and all the other things that happen when individuals are chronically stressed. The way that you design an environment is extremely important for individuals who have complex forms of autism, or any autism actually.

It brings me to Billy. I'm just going to show you an example of one of our kids who came to us in his very late teens. He was an individual who was excluded from school because he had such extreme aggressive behaviors. He spent two years in his bedroom, literally not leaving the bedroom, only eating pizza and mozzarella cheese for two years. You can see he's morbidly obese. He has every one of those conditions that I outlined before for you in that one study.

(Video shown)

You can imagine him trying to live on Main Street. Not so good. You're going down is what the police used to say to him when they used to come to the house because the parents couldn't control him. You're going down was what he used to say.

I'm going to show you what he's like now after coming to live for the Center for Discovery where we understand the biological underpinnings in autism and we treat those biological and lifestyle problems. Here he is now.

(Video shown)

Totally transformed. If you understand biology, if you understand lifestyle, if you understand environment, you can change somebody's life. And the cost associated with this child now in living on Main Street is greatly reduced than what the cost for him living at home, using an emergency room department, being placed in a psychiatric center for periods of time and even living in an ICF situation. We have to get smarter. We need more science and we need to become much more aware of all of the other problems that affect how these individuals can function and not function.

Built environments can either support or hinder the well-being of an individual. We are extremely intentional about how we design environments for folks. We worked extensively with Temple Grandin to design some of our homes for individuals. Some of the things that we know make a huge difference are single bedrooms. The individual – if they have their own bathroom, there is a sense of privacy. As I said, gastrointestinal problems are very prevalent in the population. It takes a while for individuals to calm down, to have bowel movements on a regular basis. Having your own bathroom and not having somebody knock on the door really does matter for this population.

Having calm and naturalistic and local artwork on the walls makes a huge difference. The muted southwestern color palette and Temple Grandin talks a lot about this. Those pale oranges, grays, things that you see that reduce stress in the individual are really instrumental in creating an environment.

Having plants, having acoustic ceiling tiles. Noise is especially problematic for individuals with autism. Having those acoustic tiles or even carpets hanging on the walls makes a huge difference.

Having a window. There is tremendous amount of research about being able to see nature outside your window that helps reduce stress, promotes healing for the individual, and just creates overall general better well-being.

Having an east-facing window. Circadian rhythms are a problem for individuals. They don't sleep well at night. But having an east-facing window where the sun is rising in the morning actually sets the tone for your melatonin to be produced. It helps the circadian rhythm throughout the day.

A place to retreat to is extremely important. There are things that happen every day in an individual's environment. Whether they are in the workplace or whether they in the home place, having that place where someone can just retreat and go and be comfortable by themselves is also important.

And then a place to meet others. I often go into homes and in other programs. We're fortunate to be able to travel a lot. You see these giant living rooms or giant kitchens and places. You think that individuals with autism are all going to congregate there and have fun. Not so much in this population. They like smaller spaces. They like more intimate places, places that are designated for things to happen. We create those meeting places where individuals know that that's where I go and that's where my friends are and that's a happy place for me.

This is what a place may look like. This is in one of our homes so all the east-facing windows. There is plenty of nature. We are in a rural setting. If you are not in a rural setting, as I've said to many of my colleagues in Manhattan, put a tree or something in the house. Just do a planted one. If an individual is going to eat the tree, because some will, maybe just some things outside of the window, some window boxes just so that you are seeing some greenery, or go to a park. Make sure that there is absolute opportunity to experience a park and places of nature. You see the acoustic carpets here. On this particular one, you see the wood flooring as much as possible so there is natural and building supplies inside the house.

Here is a bedroom. This bedroom has – almost every one of our bedrooms – they are single bedrooms. There is a place for the individual to retreat to if they want to use their bedroom for that. East-facing windows. This individual has their own bathroom as well. Really calm photos so exactly what I was describing before.

This is the Main Street that we're working on. We're working collaboratively with the local town to build the Main Street. We've invested millions of dollars through philanthropy to build out the Main Street.

The town and the individuals who are shop keepers in the town are taking classes from us. They want to know how to support individuals with autism. They want to be able to provide feedback to us to say these are the types of things that are important for an individual. Again, we're talking about people who are the most severe on the spectrum.

What my point is here is that it doesn't just have to be higher functioning individuals who have that opportunity on a Main Street. If you understand how to treat individuals that are more severe, you understand what their needs are and you can give them the supports that they need, they too can function and have a wonderful life. This is the town of Hurleyville.

Some of the other additional supports. We grow all of our own food at the Center for Discovery. We have a gut microbiome study that will be released in December, so pay attention to that. I think it will change protocols for how individuals are prescribed food. It's the largest study of its kind. It was done in conjunction with Baylor Medical Center and Columbia University. We are going to show that the gut microbiome of the children and the adults living at the Center for Discovery is significantly, stunningly better, different, healthier than all other individuals around the country who also participated in this study.

We also have lots of regular exercise opportunities, social connectedness, all the sleep hygiene, and that everything that we build has all non-toxic building products and cleaners so that we don't constantly expose individuals to toxins in the environment.

This is one other individual. I'll just show you his video here.

(Video shown)

He developed a significant anxiety disorder. What I think his family found out is that he was being severely bullied in school, which is pretty typical in our population. Here he is now.

(Video shown)

He made his own video for this. He's very excited about advancing his life and now he can, because of the awareness of all of his other problems that he had and addressing those issues.

Just a little bit about the center. We have 1200 individuals that we support on an annual basis. We have about 1700 staff right now. We have 23 pediatric homes that we support and 23 adult homes. Again, most of the adult homes are in and around the Main Street.

We have a total of 336 individuals who live with us. Again, they all start out on that very, very severe range. We work in school districts. We have 12 major university partners and we are located about 90 miles northwest of New York City.

That's it in the Center for Discovery. If you would like to know about the center, you can visit us at the CenterforDiscovery.org. If you are interested, we just did a piece for Good Morning America on the Center, which features our food program, but also how the children through the use of art and music are able to advance their skills as well. Thank you so much.

DR. DANIELS: Thank you. Next, we will be hearing from Lindsay Johnson, Director of Policy and Partnerships at The Kelsey.

MS. JOHNSON: Hi. Good afternoon, everyone. Like was just said, I am the Director of Policy and Partnerships at The Kelsey. We are a San Francisco-based nonprofit organization that creates mixed income, mixed ability, inclusive community. And the word inclusion is kind of thrown around a lot in this space. I thought this video --

(Video shown)

Those are some of our partners. We thought better to hear from them than me telling you. Some of our partners that we work with locally. But a little background on us. The Kelsey is the result of the lifelong work and passion of our founder and CEO Micaela Connery. Micaela had a cousin named Kelsey who had multiple significant disabilities.

When Kelsey wanted to move out of the family home around the same time Micaela was looking at colleges, her family really struggled to find accessible, supportive, and most crucially affordable, housing for their daughter. She watched her aunt and uncle struggle with finding Kelsey a place, which she eventually did in Newport, Rhode Island.

But then Micaela who had worked in disability services her whole life up until that point decided to pivot to disability housing and actually attended the Harvard Kennedy School, participated in their housing program and incubated the model for The Kelsey mixed income, mixed ability, and they were the initial seed funder.

When we say mixed income, mixed ability, what we mean by that is that all of our projects, all of our residential communities have a range of incomes. This means we have market rate units. We have 80 percent of area median income units 60 percent, 20 percent. And then we also reserve extremely low-income units, recognizing that many, not all, but many individuals with disabilities rely solely on SSI as their source of income and will be paying their rent out of that SSI paycheck.

With that background and then we also – our mixed ability. Specific to this conference, we actually are not focused specifically on autism. We take a cross-disability approach and take a broader approach to intellectual and developmental disability.

But in our projects, we actually have a mix of people with and without disability. To us, that's really what inclusion means when we talk about inclusion at The Kelsey.

In just under 18 months, we have received seed funding from the Chan Zuckerberg Initiative. $11 million from the City of San Jose for our first pilot inclusive project and have secured over $7 million in land value. We've been able to make a pretty quick traction in the Bay Area, which is exciting because our goal is by 2021 to actually have three pilot sites in the Bay Area, a rental model, an ownership model, and a co-living model. And the idea is that with these three pilots under our belt so people continue to operate and oversee is that when other folks in the industry in their communities approach us as they do daily, asking how we've done it even though we actually haven't formally done anything yet, but that shows you how great the need is, that we can look to our three existing models and say what's the best fit for your community, for your budget, for your children.

My work at The Kelsey is really centered on partnerships and relationship building, community building. And for the last year, that has taken the form of our Together We Can Do More Initiative. This initiative was funded by the Chan Zuckerberg Initiative and brought together over 300 cross-sector stakeholders from around the Bay Area to participate in a three-part workshop series.

I think most notable about the cross-sector aspect – so these individuals included market-rate developers, affordable developers, parents, advocates, siblings, city and county officials, architects. Some people who had been at the table for decades, some people who had never been invited to the table. I think that was a bit of a takeaway here was the value of non-traditional partners. It's easy to assume malice and say people don't care. But actually, what we found in our process was it really came down to basic education. Once people had the information, they had the skills that could be leveraged to promote more inclusive housing in the Bay Area.

We also recognize that passionate, informed people were having quality conversations about the issue of disability housing, but yet they were happening in silos. Parents were speaking exclusively to other parents, advocates to other advocates, affordable housing to affordable housing. How can we harness the energy in all these different groups and get them in the same room and working towards tangible solutions?

I think that's also something that really - if you look at our project goals. Identify the problem, align the resources, design the solutions, and plan for next steps. We really did put a focus on tangible solutions and actionable commitments because we heard in focus groups when we were planning this project, people were so tired of going to these types of meetings, sharing very personal stories, taking off work to go to these meetings, these roundtables, these convenings, and we all sit there and we listen to each other. We say yes, it's hard. Yes, it's sad. Yes, it's a big problem. And then everyone packs up their bag and goes home for the day and there isn't really a set of steps they can take to feel like they are taking action. We wanted to change that.

We asked our stakeholders throughout this eight-month process to come up with ten tangible actionable interventions that either The Kelsey or our partners could work on in the Bay Area. You can read the full report online at this link here. This report covers the whole organizing process as well as highlights other inclusive models, including Main Street, Jillian's organization that she spoke of earlier.

Also, we developed three frameworks for inclusive communities with our partners that we think have application across the country. Please check out that report.

But in regards to the ten interventions, the top three identified were, one, a public, permanent funding source from the State of California for IDD housing; two, an inclusive coalition of partners and policymakers; and three, to pilot inclusive communities in the Bay Area. We were fortunate to be piloting two at this time.

And what I will say is, in contrast to the woman who spoke before me, we are very much still in the development phrase of this process. These buildings are not in operations yet so we don't have any operational takeaways.

But what I can tell you is that we do have very strong takeaways from the development process. The first is that cities crave these projects and they really crave them when you can weave the issue of inclusion and housing diversity and getting people who have been traditionally excluded from housing markets into units when you put it under the larger umbrella of the affordable housing crisis. Every city in the United States is struggling with affordable housing.

For a city to look at a project that solves affordability issues and creates an opportunity for more inclusion and more diversity, they are going to be all over it. We've been very fortunate to have the City of San Jose as an incredible partner in our first project.

Our second takeaway from the development process is that developers are there and waiting to be approached. They want to help and they have a ton of experience that they can use to get these projects done.

For our San Jose project, for example, we are working with a market-rate developer, Sares Regis, which has thousands of multi-family homes in California. For our San Francisco project, we're working with a nonprofit housing, Mercy. You can see that there's not really for-profit, non-profit. None of that really matters. What does matter is that the developers are there. They have the skills. But they need inclusion-minded organizations and individuals to guide them. Housing is housing. You pour the concrete. You plant the plants. You do the thing. But what is different about disability housing? What is different about inclusive housing? Where we can guide them to make sure that these products are as accessible and inclusive as possible?

Our model aims to address what we see as the three primary barriers to housing for adults with IDD, which are affordability, accessibility, and inclusivity.

On the affordability piece, most people with disabilities are excluded from market-rate products. Especially those who rely on SSI are even excluded from affordable products. Even if there are products out there that exist for people with disabilities, many people with disabilities still cannot access them because of the price plan, which is why at The Kelsey, we use a unique blended capital stack of public, private, and philanthropy dollars to ensure that we have a minimum of roughly 20 units per project that are set aside for extremely low income adults with disabilities who rely on SSI. This is very important to us that these individuals are always available to access our projects.

We also include units at other levels of affordability, some market-rate units, so we encourage folks with disabilities. They can live in those units as well. We really acknowledge the income diversity across disability.

In terms of accessibility, we like to take it a step further and of course comply with ADA and people can move safely and freely and comfortable in their housing. But we also want to be – we are thoughtful about how we design for accessible community, whether designing warm and inviting community spaces that people actually want to hang out in, or working with our universal design specialist to create hallways where you actually have a higher chance of bumping into somebody to say hi, rather than a snaking path in the back, where there are many opportunities for connection within our building, facilitated actually by the design. We do that by involving universal design architects as well as service providers in every step of our design process, and of course most importantly the voice of self-advocates has been instrumental in our design process and our work from the start.

Finally, this issue of inclusivity. Micaela's research led her to believe that in a building's operations, it actually wasn't enough just to have a property manager or a service provider overseeing things, but that you really needed to build in someone to facilitate that inclusive community for residents to connect residents to each other, to connect residents to the building, and connect residents to the community at large.

The Kelsey has put into all of our operating expenses for our buildings funding for two full-time live-in what we term inclusion concierges, and these individuals are available to our residents with and without disabilities.

The example we often use is let's say you just moved from Philadelphia and you hear people go to San Jose Sharks' game. What bar do we all meet at before? What's the most popular bar? They can answer that question for you. Or if you are a resident who has staff come and get you ready in the morning and they don't show up, the inclusion concierge can jump in and do that for you. We really see this as amenitizing inclusion.

I wanted to wrap up by saying that Kelsey's favorite sign was more. We really thread this idea of more through all of our work today and our mission and really everything we do. Our takeaways that I'd like to leave you with are that more and new partners and resources can and must be leveraged to address the housing shortage for adults with disabilities. We know this is a complex problem. We know this is a problem at a very wide scale and that is going to require cross-sector action. No one organization and no one sector can nor should be responsible for solving this alone.

As we discussed earlier with the Together More process, oftentimes untraditional allies, untraditional partners are the most effective ones so just thinking creatively and bringing new people to the table.

More individuals can be served when we collaborate within our disability sector. We get questions a lot from both advocates and family members and even service providers themselves who say you guys are a housing organization. You don't really have the service background to which we say you're absolutely right. We don't have the service background. But we do know we're smart enough to bring on to fill the gaps. And we're going to find the best service providers and build the best team of partners and partnerships so that all of us are leveraging our respective excellences, ours on the inclusion front and the housing front and working with the developers, the service providers with the staff and the planning and the schedules. If we all bring our collective strength to the table, we're going to get a lot more done than forcing one person or one organization to do it all.

More inclusion is desired by all people. The takeaway here is that in so many of our focus groups, we had men and women who would say I had friends with disabilities in grade school. I had them in high school and then kind of disappeared when I went to college. I didn't even think about that. That's so weird. What happened?

We know that this is a missing gap. People across the board, not just advocates, not just loved ones with a disability, family members and things like that. This is a universal desire to build more inclusive communities. We know that people - this is a missing gap in current apartment buildings and city living.

Finally, more is possible when communities include people with disabilities. Often in this work, we hear the very real and tragic fear from parents. What happens to my child after I die? We hear that at The Kelsey and we acknowledge that.

But what we are seeking to do is turn the challenge of disability housing into an opportunity to build better, more connected, more inclusive communities so that question changes from what community has to take on my child after I die to what community gets to have my child. Thank you.

DR. DANIELS: Thank you. Let's take a few minutes for questions. Samantha.

MS. CRANE: I want to talk about something that happened during the presentations, which was that an autistic adult was shown being restrained on video that a presenter was giving. And I had said earlier on that many - some of the people that had been part of our housing work group are here today. Many autistic people have had very traumatic experiences with being restrained and with being portrayed as a problem and someone who deserves to be restrained, based on the things that we say that we want. The person who was being restrained on the video had expressed a desire to have pizza, which any of us want pizza, we can usually have pizza if we want and we don't get restrained because we really, really want pizza.

That video was very traumatizing for more than one autistic person in the audience today. I think we just really need to be very sensitive that there are autistic people in the room watching these videos. We have a variety of experiences and we need to really take that into account and not think of our presence in the room as being the problem, but maybe the things that are being said about us is a problem.

DR. DANIELS: Thanks Samantha. I would say that I'd ask any other presenter who may have sensitive videos to use your discretion and perhaps not show the video if you think it is going to be a sensitive issue. Terry.

DR. HAMLIN: I would just like to respond to that. I really do appreciate that. I just want to clarify a couple of things. One, the individual was definitely not being restrained for pizza. He did get pizza because that's what he wanted and it was a Whole Foods pizza, much healthier pizza for him, which he really did appreciate and certainly appreciates now. That was his second day. He was constantly being restrained in the other environment.

My point was that when he came to the center, we were well aware of what was happening. He was actually heading to jail before he came to us. We really examined from a biological perspective what the underlying problems were and he had some pretty significant medical problems that hadn't been treated. Immediately our team, our physicians, and our clinicians worked with him. And then you saw just six months later the video of him on his treadmill celebrating life and now he lives on Main Street.

But that's the reality of some of these children when they are in programs that really don't understand - I'm sorry - in adults. Yes. I am sorry. It's difficult for them. But I think that more programs are understanding all the biomedical problems and they are starting to treat these children and these adults, but we need more. We need more science. We need more education. And we need more sensitivity across the board. I do apologize if that video was upsetting.

But when we think about housing, if he were to live next door to somebody, it wouldn't be very successful in a community setting. We have to address these issues and help these individuals and these adults become healthier and become happier with more vitality with the ability to really live on a

Main Street. There's a lot of work to be done. There's a very large population of individuals like that boy who are not in the population right now, not in society.

MS. CRANE: He was a man. I’m sorry. This correction has been made multiple times at this point and it's getting upsetting to Ivanova and to me. I think that we should probably table this conversation. I think the fact remains that there was a sensitive video being portrayed. Many of us have very traumatic experiences being restrained.

DR. DANIELS: Let's just try to be sensitive here. I would like to table this conversation as we have other things to talk about in the session and we are really limited on time. Are there other comments that need to be made before we go to a break?

MS. CRANE: I also had a comment about a different issue if that's okay. I was interested in some of these presentations, but I'm also sensitive to what I believe Steve was pointing out, which is cost issue. According to its website, for example, First Place Arizona cost $3800 a month. Many other housing options - intentional communities that are listed in the Autism Housing Network cost upwards of $3000 a month. Some of the places, including First Place Phoenix, exclude people with significant behavioral challenges. It's harder to explain that the $3800 is because you're serving people who simply would otherwise need a very intensive institutional level of care.

This is an issue that we really have been concerned with for a while that when you're basically building your own amenities that are just for the planned housing community that cost is going to be built into the cost of the development whereas if you have a model where you are relying on amenities that are already existing in the community, you aren't going to have to pay those costs. That's a point that I wanted to make.

DR. DANIELS: Thank you. One more question before we break. Max.

MR. BARROWS: I have a few and I will make them short. One comes from the presentation - two come from the presentation previous of this one, and then the third comes from this presentation. The first I have is how would - about the jobs, how would you create 500 jobs over the next five years because it was stated that - and I'm just curious to know how that would be accomplished.

And then my second question - actually, I'll just make it short. And then the one for this presentation is how has the voice of self-advocates helped in you designing the work that was designed?

MS. RESNIK: If I could respond to that question. The company that is expanding to Arizona is called the Precisionists. They are a back office IT firm. They work with people across the spectrum, including those that have the ability for data entry and scanning all the way to programming. They are working with a diverse group of abilities. It is on our website in terms of their model and over the next five years, that is what they are projecting in terms of 500 jobs over the next five years. As of today, they have hired 35 people on the spectrum.

If I could respond to Samantha and your question and concerns about costs, supportive housing is expensive. And at $3800 a month that does include their supports, community life, amenities, and the home. That rate should also be compared to what Medicaid in our state is paying on average before the real estate for people to live in those homes or in homes and that's at $3600. I think we need to all recognize that we are offering and what we are doing is expensive. When we put our hand in the pocket of the government, people don't feel it as much as when they put it in the hand of their own pocket and the private funds. We need to recognize that.

And, again, as I mentioned, we are starting with what is attainable and as you also heard, I hope, how we are working with our policymakers in Arizona to create that crosswalk so we can begin to braid together both the public and private funds based on proof points. It's where we are starting. It's not where we are stopping.

DR. DANIELS: Thank you. Now let's go to our break. We have the next session starting at 2:25 so we'll be a little short on the break and we'll welcome you back at that time. Thanks.

(Whereupon, the Working Group took a brief break starting at 2:18 p.m., and reconvened at 2:32 p.m.)

MR. WHITTAKER: Good afternoon, everybody. I'm Jim Whittaker. I'm the CEO of The Arc Jacksonville. It's my pleasure to share the story about The Arc Jacksonville Village, which we actually just celebrated our third anniversary in April. I'm going to start it off with a video and you can hear from the residents there and some of the families.

(Video shown)

MR. WHITTAKER: As I mentioned, The Arc Jacksonville Village has been open for three years. It was a ten-year project. It was actually the idea of family members and folks that we serve. We had several focus groups in the early days and actually the design of the village had a lot of input from those family members and we, today, have 121 residents that live there. You can kind of see the layout here. It's like a big circle as you come in. And it happens to be in one of the better zip codes in Jacksonville. It's very walkable to grocery stores, entertainment, medical facilities. The bus line is right at the end of the street. The location is absolutely incredible.

What we did is we try to create a really vibrant community and a lifestyle. As I mentioned, the concept was by families and people served. It is independent living, semi-independent living, if you will. A few people have 24-hour around-the-clock supports, but most do not. The average person probably has a supported live-in coach, maybe five hours a week, eight hours a week or so. Folks here pretty much can live independently.

One of the reasons for the village is families wanted to make sure their sons or daughters had the opportunity for social engagement. Many of them actually lived in apartments in the broader community at one time and even though successful and they may have had a job, they would go to an empty house, with neighbors that just did not include them. They sat there until the bus came the next day for them to go to work. This gives them the opportunity to really be engaged.

These are just some photos. That's our lobby there and our great room behind it. The community center is about 12,000 square feet and it's sort of the heart, if you will, where everything happens.

We offer dining in the evening. It's totally voluntary. Everybody's apartment is equipped with a kitchen. If they choose to eat in the dining room that is their choice. We actually contract out for the dining services with another company.

We have activity space within the community center for small classroom sorts of things. We do not offer any day services at the village, but there is a fitness room, which is very popular. We have a game room and we also have a movie theater.

The village was actually a partnership of many folks to include government. It is an affordable housing tax credit community. If you can access affordable housing tax credits, it's a wonderful way to at least partially fund the development.

We also launched a capital campaign and The Arc Jacksonville raised about $7 million towards the project. The total project cost was about $22 million. Again, that was three years ago Florida prices. Some of you are from more expensive states would probably find that price tag at maybe $30 million or $40 million.

Just to kind of give you an idea, again, of the funding sources and all, the nice thing about the tax credit project is you have no debt; therefore, we are able to offer very low rents.

We also part of that $22 million that we raised, we also had to have startup expenses, cost of buying vehicles, training staff, buying furniture, et cetera.

I will give you an idea of the staffing. We don't have a heavy staffing pattern. Again, most of the folks there are receiving only the supports they need. We have a village director, a director of services. We have supported live-in coaches. We do have two coaches that live onsite in apartments so they are accessible 24/7.

We have an activities team. We have a personal enrichment counselor, which is probably one of the most important positions we have. We also have a nursing student training project manager. We have lots of nurses that are attending nursing school that actually spend time at the village.

We are an AmeriCorps and VISTA site. We actually have AmeriCorps members and VISTA assisting. And our Xplore Offsite Team. If someone wants to go to a day service, they can, but it is offered offsite.

We actually contract out for all the housing management services such as the leases, their fair housing part of it, the maintenance, et cetera. So anything bricks and mortar the housing management company handles.

Rental rates. You can see our rates are very low. About 30 units are extremely low rents. They are approximately, I believe, now $326 a month. That same unit, which is not as low, is $606 a month. The rents are very low. A typical apartment of this quality in this neighborhood, a one-bedroom unit, would go for about $1500 on the regular market. These are very low rents.

We also have some units that are two bedrooms. I always suggest to anybody who is considered building, build all one-bedroom units. If we had to do it over, we would do that. You are just looking for a lot less complications once you become operational. Putting two strangers even though they have their own bedrooms and own bathrooms sharing a unit can just get complicated. One bedroom seems to work best and people can hang out with whoever they want to hang out when they want to.

The fees for The Arc Jacksonville Village. There is a service side and then there is a rent side and a personal expense sort of side. If you're private pay, which are about 50 percent of the people are, it's only $900 a month for all the staffing, which includes all the activities, shuttle service, et cetera. Rent depending on where you fall with rents if it's $300 a month or $600 a month then an individual would also have their personal expenses, food, clothing, cell phone, cable TV, et cetera. Approximately the private pay people are paying in total of about $2000 a month. Fifty percent of the people are on Medicaid Waiver. If they are on Medicaid Waiver, we are not the provider. The Arc Jacksonville does not provide the services. Basically, those folks – their cost would be $2000 minus the $900 because they are getting waiver services funded.

Just some shots. These are actually duplex, triplexes. Under each roof, there are either two apartments or three. This is a typical apartment. Again, we got input from families and persons served. And some of the things we added to the units, which were good ideas. We, for instance, put drains in all the bathroom floors, right in the middle of the floors because we have a lot overflows happening if it's from showers, tubs, or commodes.

All the units have emergency on-call intercom systems so at any time somebody can summon help.

These are just little facts here. We're always 100 percent occupied. We have about 6 percent a year for the past three years. We always have people lined up waiting. Right now, I just checked the other day. We have 300 people on the waitlist. Again, the project – the success of it has actually amazed me. I had no idea. But when people see it especially when they visit, they want one. From your states too, we've had visitors throughout the country coming to look and many of them want to go back and do something very similar in their community.

Also, too, an interesting thing is that this is totally inclusive as far as people accessing community. There are no restrictions. We do not monitor who is coming and going. We are a gated community, but everybody has access to the gate with their key cards, their family does, their providers. The gates are open during the day. They only close at dark and open at dawn. We do have night security that patrols the grounds, if you will, in a golf cart to make sure everybody is safe. In three years, we have not had the first incident where we've had to call law enforcement, et cetera.

I think right now about 80 of the 121 are employed in the community and they are employed in many different capacities from maybe working 15 hours a week all the way up to full-time employment.

We have lots of amenities. I'm sure most of you have been to Florida. Everybody has a pool and palm trees. We have them too. We have gardening. We have exercise trails. We have lots and lots of things to do outside. There's our basketball court and the gardening. That's it on the village.

I want to mention this. In Jacksonville, all the other IDD organizations – we've all sort of band together. We belong to Connectable Jax, which is a campaign to connect typical people to our people in a volunteer capacity, also to promote employing individuals with IDD. One of the big things the campaign has done and we have all adopted it is instead of using the word disability, we now use the word difference.

Anybody who would like information on the Connectable Jax campaign, they can just Google it and all the information that's posted there can be used. There are no restrictions whatsoever. I appreciate it.

DR. DANIELS: Thank you. Our next speaker is Matthew Osborne, Director of Adult and Residential Services at the Faison Center in Richmond, Virginia.

MR. OSBORNE: Can everybody hear me? Thanks everyone. My name is Matthew Osborne. I'm with the Faison Center. The Faison Center is a nonprofit organization in Richmond, Virginia. We provide services across the spectrum and across the lifespan. We're celebrating our 20th anniversary this year. Our adult program, which is made up of two different residential programs and one adult day program. We are celebrating our fifth year this year so we are really excited about that. We've made a lot of mistakes and learned a lot over the last five years. I'm going to present some of those highlights and some of the lessons learned.

(Video shown)

MR. OSBORNE: The Faison Residence, as you saw in that video, we're a 45-unit apartment complex where a majority of the units are for community members. It's affordable housing. It provides access to first responders to live there also, college students, young professionals and then also those who are in their later years getting support that way.

We do have three staff who live in the building. It can provide access to 24/7 supports if needed. One thing that sets us apart as well is our integration of smart home technology. The idea behind that is for it to help ensure safety, but also to respect privacy. There's a thin line there. We try to build a bridge between those two.

The whole idea is to not have them rely on that smart home technology. It's to teach them the skills to be independent and hopefully fade that out. You saw some of that in that video.

As you can see, there are some of our funding sources. And on the next slide I have some data here as far as funding sources.

The average age is 28. The youngest is 22. The oldest is 39. When I arrived two years ago, we had about - less than 10 percent of our adults were employed. Now, we have 72 percent and they are employed at least 20 hours a week. Out of the 72 percent, 80 percent of them have worked in the same job that they chose for over a year now.

As you can see here, a lot of our individuals are receiving SSI/SSDI. Eighty percent are on those social benefits. And then 83 percent receive the Medicaid Waiver for supports. That does not pay for rent.

Since 2014, two individuals graduated. And when I say graduated, it just means that we help them learn skills. We help them to become more independent. We faded out services. And now these are individuals who are looking to move out, looking to find another apartment to rent and move on. And three again are ready to graduate. There are just some barriers there as far as portability of their voucher.

Eighteen individuals are currently in our program. I talk a lot about transportation here because it's a huge barrier. Two of them earned their learner's permit through our driving simulator. Ninety percent of them have mastered public transportation and 100 percent ride sharing. This is important. We talk a lot about outcomes. We're swimming in data. I think that's what sets us apart too. Faison is – we're experts in both the behavior of our individuals and of our staff and we collect a lot of data.

One of the outcomes here with transportation is helping people just become more mobile and access their community. There are unmeasurables. A parent contacted me the other day, letting me know how important it was for her and her family to know that her son rode a rapid bus transit to their house to celebrate the mom's birthday, all independently, all on their own after receiving that support from our staff. That's an unmeasurable. I know that parent now – they are feeling a little bit better about that question as to what's going to happen to my son when I'm no longer here.

Some lessons learned real quick. I just want to make sure I'm staying within my timeframe here. I think the biggest thing is just with our practice and behavior, we're creating a lot of systems. I use a hardware/software analogy. What we provide is high tech with a human touch. We're able to dial in and learn about why people do what they do and try to develop environments and programs that ensure success. Again, it's a lot of learning. We definitely take a lot of time to listen.

Some of the mistakes we made early on was just our communication wasn't that great. A lot of parents were wondering why does my adult child not go into the community. It's because they weren't receiving a lot of feedback. Now we started a monthly newsletter that provides them a lot of information. I'll show some pictures in a second here about some of the activities we're providing.

Consultation. Knowing where our limits. Knowing that with a high-verbal adult population, you're going to see a lot of mental health, or that has the potential to exist.

A lot of our measures too are outcome measures. Include things like accessing adequate mental health care, reducing their dependence on psychotropic medications, but knowing when to refer out, knowing when to access experts to help with some of those mental health symptoms.

Preference assessments. We run preference assessments daily, not just for our individuals, but for our staff. And not surprisingly, a lot of overlap there. What we do, as an organization, is we try to reinforce and set up and provide resources to help individuals and staff go out into the community and do the things they enjoy and become part of their community.

This is just an example here. It's from our newsletter, but it's a fishing trip. I can honestly say that in that photo there are individuals, but the rest of the adults in that photo are community members. Again, it started off with an interest of a resident fishing and a staff person fishing and we worked with this company called Beyond Boundaries, another nonprofit, to establish opportunities for fishing, development of new relationships. That's another outcome, another piece of data that we collect a lot of data on.

This is our first out-of-state visit to the National Aquarium. We did that just last month. It's a two-hour van ride, but everyone had a good time. There, again, started with a staff person and an individual sharing their interests.

Another thing about health and wellness. A lot of our staff are active and our residents benefit from that. If you look at your lower left, that's a resident running a 5K with one of our staff members. And then in the potluck to your bottom right, we have a staff member that's interested in healthy eating. We invite both our individuals and also community members to come and create a healthy meal along with a recipe card and share that meal together.

Nature. Getting out in nature and also environmentalism. Lots of individuals with that interest as well so getting out into nature and cleaning up our parks. Those types of activities develop those interactions with community members.

That is just a snapshot. I wish I had more time to share more about the Faison Center. I welcome you all to come to Richmond to really get a glimpse and speak to our residents and see things from their perspective. Thank you.

DR. DANIELS: Thank you. Next, we're going to hear from Maedi Tanham Carney about the Integrated Living Opportunities program.

MS. CARNEY: Hi. First of all, I want to say thank you for still being here. I know that there are only two speakers after me. It's a really long day.

My name is Maedi Tanham Carney. I am the Founder and Executive Director of a nonprofit called Integrated Living Opportunities (ILO). We are a completely different model than with every model you’ve seen or heard about today. We are not real estate. We are about community building.

Basically, the two things that we are not are real estate and we are pooling our resources. This is a more affordable model than if just going into a building of sorts.

Our mission is we help families create inclusive communities to facilitate networks of support for adults with disabilities to enable them to live independently and to live as integrated contributing members of their communities.

(Video shown)

MS. CARNEY: (inaudible comments)

But through this process, I found an organization in Illinois called Center for Independent Futures. They were creating communities without using any state funding. In Illinois, the most you can get for waiver services is $25,000 a year.

I interviewed them. We wrote a blog about them and then I asked them to come to Maryland to talk to my families, my followers from my other business to talk about how they created communities using little state funding. Sixty families came in 2013. From that process, they have a training called the New Futures Initiative Training about how to create communities. Five families from Maryland went with me and we did this training.

Typically, when people go through this training, it’s four to eight families that have known each other for life and want their children to move out into some type of community setting whether it’s an apartment or a condo or a house or whatever the case may be. The families that went with me were all – the only normalcy about them was they from Montgomery County. They all lived in different places. Their children, young adults, were of different abilities. Some had autism. Some had intellectual disabilities.

From this process, we decided to create integrated living opportunities because we knew we wanted to be a sustainable model. We realize that people have choices of where they want to live, and we don’t want just to say here is a building and here is what’s available. I applaud everything that's out there and I wish that in every single state that we had every single model that we've heard about today so everybody had a choice of what they needed and obviously for different abilities of our loved ones.

With ILO, because these five families were very different, we created what we call pods of community. Just for simplicity, we're calling them communities. Today, in Montgomery County, we have a pod in Gaithersburg, a pod in Germantown, soon to have one in a community in Rockville and we have one in Bethesda. These families get together twice a month. It's like a support group. We talk about what type of needs that they need, how to move out into the community.

We are also in Washington, DC and in Northern Virginia. In DC, there is no affordable housing at all. And if there is affordable housing, it goes to the homeless first and then low income. There is nothing in DC about disabilities whether it's physical or developmental. It's a huge problem.

I'm basically working with a couple of developers in Washington, DC that are building very nice, big villages, if you will, or have lots of units and trying to work with them to have them carve out some of their units for ILO.

As I shared, we are not about the real estate here. We are about families coming together and deciding where they want to live together to create a community.

In Gaithersburg, we have seven men with autism that live in one building. An affordable housing developer came to us and said we'd love for your - we believe in your model and we'd like your self-advocates to come be in our building.

Four families got together and it wasn't until last year that I'm now a paid Executive

Director. We've been a volunteer organization the whole time and the parents have really rolled up their sleeves to really make this work because they believe in this model of choice of where they wanted their loved ones to live.

These four family members got together and we created all the memorandums, understanding, all the agreements between the parents and the supports and things of this nature.

Today, we have seven men living there, ages from 26 to 51. Outside there is an article that was written about the Crossings and it's called *On Their Own But Not Alone: How a Group of Men with Autism Found an Independence Their Families Weren't Sure They Would Ever Have*. It really is about how we established building the community.

As I shared, we are a community-based, independent living, nonprofit. It really is – what's making us successful is we have a staff member called the community builder who in every single pod of community we have a staffed person that gets all these individuals to get to know who is in their community. For example, in Bethesda, we have five self-advocates, two of them are living independently in apartments right next to each other and the other three are still in their parents' houses. She gets together with them, does activities with them twice a week, and then she also works with them one-on-one.

In the Crossings, because they are all in the same building, they get together. The community builder meets with them once a day for about 15 minutes and gathers them for an activity on Wednesday nights and then does activities with them on the weekends.

We have another community builder up in Germantown and Rockville that gets those guys together too. It really is about building peer-to-peer relationships.

Our first community builder in Gaithersburg – it took her six months for these guys with autism to recognize that they weren't going away, that they were all going to be in the same building. Today, with the seven of them, there's about six of them that really – it depends on the evening, but three to five – they are all hanging out in the same apartment watching videos. They go across the way to 7-Eleven and things like this.

When somebody moves into a pod whether they are still in the parent's house or we help them move out, we make sure that they know what their organic supports are in their particular area. For example, up in

Gaithersburg, the community builder takes them to the police station, which is just across the street, so the police know who our gentlemen are. They actually have helped. They helped a few of them in some scary situations.

My daughter, who lives in Washington, DC, lives in the Cathedral Commons area. When I went to the Starbucks with her after she had been there for four months, the barista was saying you must be Ellie's mom. And that's what we're building is the organic supports.

The population that we are serving is basically individuals that can live independently, but definitely need the supports. Some of them are 24/7. We ask that they do bring their own supports. But we are what we call - I would say the umbrella of supports over everybody, that if you have waiver services and you bring your own supports, that our community builders are the glue that creates the peer-to-peer relationships between the individuals in each of these communities and takes them out and does activities with them.

We are all about inclusiveness. The self-advocates choose where they want to live and with whom. We, too, have seen that it works best when they live individually; however, there are three girls in the DC area that are thinking of – the parents are thinking of purchasing a house for them to live together. We could potentially have a live-in community builder with them.

When families come to us, they do go through a training to understand what we mean by community and how to build the housing and the support and matrixes to make it a successful model for the self-advocates that work with us.

ILO does foster the full inclusion of the self-advocates and provide the supports to ensure their success.

We are a vendor and Montgomery County – they want to have self-directed funds with DDA and this is huge because I would say half our families do have waiver services in Northern Virginia, DC, and Montgomery County. In Montgomery County if they are self-directed, they can use those funds to pay for ILO services. This is big, as you know, because it's all about affordability.

We do help families find affordable housing. We work with them and we educate about MPDUs in Montgomery County and where to look for low income tax credit buildings and also, as I shared before, we work with developers to try to help them create niches for ILO.

As I shared, the one in DC, they have some inclusionary zoning apartments, which are affordable, but they are not going to deal with the District anymore. They don't want to. They absolutely love our model and they are considering possibly carving out 10 to 15 units just for ILO, which would be an incredible thing.

ILO is a resource to families for public and private funding. There is a lot of staff and board members and people - part of ILO, that come with a wealth of information. The families don't just have a place for a future for their loved ones to move out into a community with others that they won't be alone. They get educated in financial planning, estate planning, government benefits, and affordable housing.

We are working on being sustainable. We're still young, but we have been successful in some grant and foundation money. We do provide the guidance to families for their own funding resources.

One thing that is happening with ILO is that we are in our fifth year. Some of the family members have seen their loved ones be out and on their own for about three years now and the parents are in their 70s. They are concerned about what happens when they pass.

ILO - we're not there yet, but we are partnering with organizations with what we call long-term facilitation, which means that we are creating a plan that somebody will step into the shoes of the parents and understand what type of services and needs and wants that their loved one has and where does the money come from.

The parents can - first, they understand what we are all about when the child or young adult is in the parent's home and then we help them move out into a community. We get them the supports over and above if they have waiver supports, to be included in the community and work together and know who is in their particular pod. Then the parents - we try to keep the parents slowly stepping back, and then we're going to incorporate this long-term facilitation, so the parents really could go on a trip for three to six months and ILO would basically be the one that would take over until the passing of their parents.

Right now, as I shared, we're not there, but we're working on it and we are partnering with other organizations that do this type of long-term facilitation.

As I shared, when parents come through – when families come through ILO, we have a training. It's a two-day training of about, what do we mean about community, and we share about housing matrices, support matrices, what we mean about our staffing structure, and all the different types of pods that are out there. And then families choose which pod that they want to be part of, and the parents get together every two months to share what's going on and to help each other to move their loved ones out into the community.

All families' self-advocates go through our full life process skills inventory – our inventory assessment, which is an assessment on their abilities in the home and in the community. We can work with them. We have life coaches on staff that work with them to get them to a place where they feel comfortable. We love to have this happen when they are still in their parents' home and then they move these skills with them when they are moving out into the community.

Our support and staffing model. We have a community life coordinator who is basically a case manager and she is the boss of all the community builders. Right now, we have about five community builders. We have two life coaches on staff. As I shared earlier, we are working on the long-term planning and facilitation.

This is the Full Life Model. This is our assessment. We go through all these different areas. We ask questions about their abilities. Then we write up a final report. This is an online assessment. It's very powerful. At the final report, the staff does come to these meetings. They understand the self-advocates as well.

The parents can take this report if they want and have their one-on-ones work with the self-advocates themselves or as I shared, we have the life coaches that they could use to help them gain the support, the independent living skills that they need.

That's basically us. I just want to share again that we aren't real estate. We are about choice. We help families create areas of community where they want to live. It's a very progressive model.

And the article – it's outside on the table outside and it really shows what we mean by building community and how the community builder is the support that helps these guys build peer-to-peer relationships and know that they are not alone out in the world. Thank you.

DR. DANIELS: Thank you. Our next presentation will be from Mary Anderson of ABLE Inc. in Dickinson, North Dakota.

MS. ANDERSON: Hello everybody. I have been practicing. I'm going to stay within ten minutes. What do you think?

I started our journey with ABLE Incorporated in 1985. As I've said before, I've been a long time. We had the opportunity of moving people from the state institution into at the time eight group homes. What surprises me is that since 1985, not a lot has changed in the housing world. I'm going to talk to you about how we've tried to mold and fit into that world as we go. It is a journey. I welcome you to take that journey with me.

I'm going to be exposing you to my naivety as we go. Number one, I wanted to point out our values and beliefs. I just enjoy - if you were to come and read our values and beliefs because we really do truly live these and we think they are very unique. I did highlight we value communication, we value and appreciate and embrace change.

On the community, we did not have to spend a lot of time asking people about our housing. We had three group homes called transitional care living facilities. That's TCLF for those of you who know lingo in the housing world. And we had people who were very unhappy in those three homes. Communication. We didn't have to use much. They were screaming at us. Get us out of here. We had to then use one of our values of let's get creative with housing.

I want to just reiterate. We all believe in this room. Everyone should have a choice of where to live. The reality for all people is that choice is limited to affordability.

For most people with intellectual disabilities, and in our case 100 percent of the people that we support, are going to be fitting under the umbrella of affordable housing, low-income programs. Let's look at those programs. They are kind of exciting.

Number one, 55 and over. This is not a good option for people who are 20 years old. 62 and disabled. This is also not a good option although we've exercised this. Affordable single-family housing. I will say to people this is typically for us the least stability, the places where people are not wanting to go and our families were loudly saying we do not want to be in this. Affordable multifamily, Section 8 housing vouchers, home ownership programs. By the way, we have had people that have home ownership in our company and that has worked out well for a period of time, but a lot of people have then since sold their homes.

I want to talk to you more about affordable family multifamily. When we were talking about – oh my gosh, people do not like these group homes. What are we going to do? We looked at the affordable multifamily housing. What we ended up doing for those of you who want to do what we did is we went to our city planners and said what's going on. Where we can buy land because we thought we needed to build? They said why don't you just get into this affordable housing development that's being built already.

In this unit, I believe there were something like 20 some units. We said that sounds good. If we don't have to build, let's do this. The trick to this was being first on the list. I want to tell you that for a year I had all the applications filled out. I was calling them every day saying we have to get first on the list. They finally said to me stop calling us. We're not opening this up for another year. But surely, we were calling them daily when it got closer to be able to get first on the list into these units.

What we knew is that we were going to move people from the large group of eight people and because this unit had two and three-bedroom apartments, we were just really going to move people from having eight people combined together to people that are going to live together with two and three people.

I appreciate what Jim is saying when he talks about this is not the best model for people. People have intense and complicated communication needs. When you put two people in with intense and complicated communication needs, it's oftentimes a recipe for disaster.

We knew it, but we didn't have any other better remedy at the time.

This is what happened to us between 2006 and 2015 in Dickinson, North Dakota. These are the units, as I described for you, that were available through this regular development project. We made 21 moves in that period of time, mostly to address roommate incompatibility. We would move this person into this apartment and then this person into the other apartment, hoping that things would get along well.

The incompatibility also extends to the fourth roommate. They call him Foxy. We called him Killer. Killer was an animal that was a little disgruntled. This caused the roommates to not be happy.

The other incompatibility issues that we ran into and I'm sure you face this as well is environment itself. Look at these steps.

Those are treacherous for any of us. We had three people who were getting along, but one person just could not get over her fear of steps.

The other thing was – we had a person that had a seizure disorder and she had no place to live, but she did have a place to live with steps. I finally had to pull the plug when I found out that our staff were walking in front of this 170-pound woman to prevent her fall down the steps. We said enough. We have to get moving.

What's interesting to me – if you look at this slide, I pointed out this bedroom scenario. What's going on here is if you look at the bedroom sizes in this multifamily, it was large bedroom, small bedroom. Now, when you're moving people together, there's always going to be a challenge of who's going to get the small bedroom and who's going to get the large bedroom and who make those decisions. Those were always very complicated things.

What that brought us to is we learned and understood better in this multifamily housing that these are really designed for family units - have usually one wage earner and the others are children; therefore, there is the larger bedroom and a smaller bedroom.

Now, in this case also what we didn't understand is that when you are looking at these kinds of things, these are combined households. Most of your programs, a lot of your programs besides I think Section 811s under HUD are combined incomes. We had three people living together. Look at the difference in income: $20,000, $11,000, $16,000. Their combined income was $47,000. And then when you look at the income limits, it's $45,000. I have no idea how all three people made it in and then the dog, but they did make it in together.

But that's something you have to be aware of because we found that providers in North Dakota right now are trying to help roommate situations being based on incomes. Not only do you have incomes that you want to get in, you've got to be eligible to get in, which means if you're over this amount, you're typically not going to get in and then once you're in, look at the difference of ranges of how you're going to split 50/50 income.

Actually, these three people did pretty well. They liked each other. They were growing tremendously. But when the fourth roommate came in, this person said I can't live here. She moved out. That left two people who got along very well. Now, look at the rent splits. 24 percent of annual income and 43 percent of annual income. One person couldn't spend enough and one person is starving. Not only combined incomes look at this, combined incomes look at heating assistance. This person could not get heating assistance because she's in a combined income scenario. Some things to consider in housing just the inherent issues and difficulties along the way.

What we did is we looked at this and we said Housing 101. Know thy people. Then build for them. And build it within proximity. And the reason for proximity was we could not by the State of North Dakota spend more money on staffing supports. If we were going to move people out of those environments, we had to keep within those staffing ratios.

That was a complex that was built in 2014. We moved in July 2014. Twenty-six units. It's built by Lutheran Social

Services, which is a great partner by the way. They built these units with our design in mind. If you look at this bathroom, we have a track ceiling lift that goes from the bedroom into the bathroom for people who are using adaptive equipment and physical disabilities. They are able to go right into the bathtub. One of our people says beam me up Scotty every time he uses this because he can actually use his own remote to help himself into the bathroom. On this side, there's a large shower area so a person has choice in this environment.

This is truly aging in place. People aren't going to have to move from here because their needs are really going to be met well.

This is another unit. This gentleman was living at home with his parents. He's 25 years old and thinking I want something different in my life. Try to find a housing project that has physical accessibility for this particular individual. We could not find it.

We took those same programs in Bowman that we used to build that project and we built with a private person again, a developer. We built this with this in mind. Now, you can get into your closet. It's barrier free. You need another closet because you need to have adaptive equipment stored somewhere else. The kitchen is fully accessible. The bathtub is elevated with a platform and you can put your lift right under and a person can get into the bath tub there.

What's really nice about this is having washers and dryers in your spaces. If people are having continence issues, there is a dignified way to do laundry without running through your whole home. This has been a phenomenal project for him.

These are people -- look at the smiles. We hit the mother load here. People are very happy.

But then I'm going to show you what the data looks like about moving people from roommate situations into places where they had their own space.

In this case, person one, two roommates, lives alone. In 2017, look how well she has done.

I want to just preface this. I'm going to show you four people. We moved 24 people. We just don't have the data. Frankly, we just didn't have time to pull data. But we did find for four people what this looked like for them. These are going to be very good for everybody, but this is the only four we took data on right now.

This person lived in a group home. We had to convince the parent to say we think she could do better. We think that she could live in her own apartment and that's the provider telling the parent that. Again, look how well she has done. But she is with a roommate. She is doing exceptionally well.

This person, again, having one roommate, lives alone, doing very well.

This person we put up here is a specialty conversation because this person actually wasn't on our radar. She was doing well. Her roommates were doing well. We thought everybody was happy. Look how well she has done. Two roommates to one roommate. She's living alone now and really excelling.

We see that CMS believes scattered housing is optimal. We have some thoughts on that because if you looked at the first original slide, people were scattered in that environment. We would not have hit a concern - not a concern of CMS on those levels, but it was a huge concern when you're grouping people together.

But I want to show you what the fiscal note looks like and what concerns we would have. This is about people talking about how to maximize dollars and get those dollars spread throughout for other people. In this particular place at Metro, we have nine people. We're serving people at about a little under 200 hours a week. We would have to go up to 600 hours a week if people were scattered. In Sullivan apartments, we staff right now at a little over 400 hours a week. We'd have to go up to 800 - over 800 hours a week if people were scattered.

What people don't also realize is that if you are going to not have people in proximity where you can get to those supports intermittently and you have to go to scattered housing, you're going to increase the restrictive level because that's going to take 24-hour staff to partner with people.

I just wanted to pretty much end my presentation there. We do have a staffing crisis. Even when you talk about cost, it's about how do you find the human resource potential. Dickinson, just to explain, this is not a bad company. We are not a bad company just saying. We have 20 DSP positions out of 63 in Dickinson, North Dakota. This has been our case since 2012. If you guys understand the dynamics in North Dakota, we are in the middle of oil impact in our community. This has been tragic. I used to panic before 2012 when we have five openings in the company. I thought that was awful. Now, we're at 20. This is just a huge crisis. Even if we could afford to have all the 24-

hour supports and what not, we just cannot find the staffing potential.

That's pretty much what I wanted to tell you. I thank you so much for allowing me to speak today. We have many things to say about housing. I know that not everybody is in favor of ICF/IID homes, but we just recently in 2017, rebuilt our ICFs. We opened four state-of-the-art ICFs in our homes. We have six people living there. They have access to a main floor of 5000 square feet and then there is a lower floor of 5000 square feet. We put that lower level in so that our families could enjoy the opportunity to be with their one family member. They are phenomenal. If anybody wants to come see us, we'd love you to come to Dickinson, North Dakota and enjoy our hospitality. Thank you so much.

DR. DANIELS: Thank you. If it's okay, I’d like to have us hear from Gail Godwin before we go to discussion because then we can just have a longer discussion with no interruptions.

Gail, would you please step to the podium? Thank you.

MS. GODWIN: I was hoping for a much longer break. I get all day to get more nervous and collect a ton of notes and have too much to say.

It is an honor to be here. Like Maedi said, thank you for still being here at this hour. I know it is late, long, and the information has been incredible.

My name is Gail Godwin. I started Shared Support Maryland almost 13 years ago, early August of 2006. My background in general is working for people who are labeled with the most significant and severe disabilities and

I only say that so that going forward, knowing that our examples are about all people without exception.

Shared Support Maryland is driven by their customers. We use person-centered planning as our job description, if you will. And we do not own any homes. We have a budget of $500,000. No mistakes can be made. And all of those are important as we go through and talk about the model of support that we use.

We support about 110 people and for purposes of this meeting, about 45 of those people identify as autistic.

We have no assets. We have nothing to fall back on for anyone. That means we have no real estate. We don't even have a car to sell if we need a couple of thousand dollars. We have a very small line of credit, only for the eight employees that we employ to work for each person.

We don't have space. It's actually exciting that we have these things because we don't have the responsibility of them either.

Our time and resource are our most important assets. It is best being spent to help people gain their own assets. I've heard that a couple of times over the course of the day. Having a job is an asset. Having your own home is an asset. Being able to sign a lease and having things that help you live a life are the things that we spend most of our time doing.

Our relationships and resources are there for the taking. We believe very strongly that providers and people really hold the bag when it comes to resources and people. We want to get out of that and a direct line of gaining that resource or using it is to the person, not through me, not through the company. We'll talk more about that as we go along.

Just one of the three times we co-signed a lease. We were in control and that goes against everything that we believe in, why we started. The co-sign resulted in a couple of things. One was us owing $20,000 to a rental company, which if you just heard about our budget, it doesn't work real well. We believe it is because of the culture that people came from. And what I mean by that is that things are taken care of. I do not believe that because you have housing that your life is taken care of. But if housing is paid for you, there is not something that says in the next home that you live in, you're responsible for it. That is something that we learned really hard.

Ultimately, we asked everyone to - we had to leave off the lease and two of those people left our company and one remains. We've all learned to work together and learned how to help people be a renter and be a tenant. That is just some examples.

We believe that natural, everyday tactics are the way to go. Treating people with the same level of respect that everyone else has, we're on the same playing field. When we have a referral for someone new, we ask what your name is and where you live in the state so that we know that we can reach you. We assume that everybody wants the same things. We all define them differently and that's where we start.

We want to support people as much as we can to become employed. We know that not everybody wants to and again cultural - where people come from is that has not been an expectation. It is not expected; therefore, you can get support from shared support. But we hope that at some point, you believe that's something that you want to. It helps people gain resources and access to a lot of things that if you were not employed, obviously, you cannot get.

Knowing and connecting people to experts that are in housing. Unlike many other people, we are not the housing expert. We would like to be in our field. I think we like to be generalists. We want to do it all. We know that is not us. We help people connect straight to landlords and real estate agents that are not in human service.

We focus on the planning and above all the execution of the plan. We have all been in pilot projects where we help people an amazing future. And that plan ends up in a file cabinet, which we don't have anymore. It will be on the cloud and implemented.

I just talked a bit about the anchor, allies, associates, agenda, and assistants. We look at those as the resources. We look at that for every person and look at what might be missing and help people to fill those gaps.

People need to know about housing stock and neighborhoods. We believe strongly that the housing stock is available. We believe that it is just as available to anyone in the world as it is to people with disabilities. There are vacant homes all over. There are places that need rehab. There are places that are being sold and rented and they are there for anyone's taking. People need to know the housing programs. We heard before about educating people. We think that is number one.

The other resources people need are landlords and realtors to find the homes.

Pulling people together to help do that increases the likelihood of people gaining the housing.

We look at our role in services, which I'm going to talk most about in these five areas. John O'Brien talks about them. If you're from the DD service world, this is our role in service accomplishments. It is community participation, encouraging valued roles, presence, capacities, and autonomy. Nowhere does it say that people live independently. We try not to use the words that don't really mean anything and that is one of them where we are encouraging people to do a lot of things before they get to do the next thing that is really about being an adult.

This is the person I'm probably going to speak the most about. Lou. I hope that he maybe hits a bell with most of us. Lou was the last person to leave one of the institutions in Maryland that closed over the last ten years. He is a person that has autism. We would consider it significant. The behavioral challenge is significant, et cetera.

Some of the things that we were able to do were, one, to engage a person who - he's from Baltimore City, right up the road, about 45 minutes. We engaged a landlord that was from Baltimore City who was also a real estate agent. This also happens to be my brother-in-law. People say that maybe I coerced into this and I continue to do so.

But the helpful part about that was that he was able to understand what we did as an organization and able to speak to other landlords about the possibilities of renting to people with disabilities in and of itself.

He was able to talk to a landlord about adapting a home that would support a person like Lou. He was able to talk to him also about accepting a voucher. This was not someone, a landlord that accepted vouchers, but he was able to discuss with him the benefits of that. That was a huge in for this person.

His exceptional sensitivities are what we call it and he called it were things like we looked at colors. These were some of the things that people were talking about in the facilities that can happen in the community. Very soft colors for him. We looked at allergens. We looked at all of everything that we knew that could upset him or be a real problem for him and made that work in his particular home.

Staff were not trained in aversives. They were not in restraint like they were for him in the institution, which everyone thought was a huge risk for us to take. As it turned out, no one has needed it. His life literally changed the moment he walked into his home.

There was Plexiglas discussion about putting that in the windows. It was never needed. It was totally delayed and ultimately never needed.

The other thing that was – we just talked about staffing crisis. We could never fill a position where he received two people serving at him a time. It worked. He didn't need the two. So really working on his entire environment was essential.

We used some of the services like Money Follows the Person. We have a live-in caregiver service like most waiver services do today.

Our landlord - we heard from someone from New York. I'm sorry. Not the landlord. But our state has a rule that your sources of income do not matter when you're renting. You are able to get 50 sources and it could be from disability service. It could be from HUD. They all have to be accepted if you are accepting a voucher.

The roommate model, as I mentioned, the live-in caregiver was what was used when Lou moved. Most people talk about using highly trained clinical staff. This would have been a person that a lot of people would have said that before. Instead we advertised on roommate.com. His family disclosed that he has autism. We went ahead and did that. And a regular person answered the ad. He was the newly found father of a son with autism. And what I mean by his son had just been diagnosed. He never knew that you could live with somebody with a disability in this kind of role. They still live together ten years ago.

These are some of – I think I could keep talking about Lou. Maybe we'll come back. Jacquie, we'll skip.

When someone has no voucher, which is the case for probably half of the people that we support who live in their own home versus their family home. Tony is one of them. He has a history of being controlled and punished. If anyone were to co-present with me, it would have been Tony today, but he was unable to do that. I got an email from his provider that said I was making the biggest mistake of my life in helping him move out of his group home. And most of you don't know me. That is very motivating for me. Off we went.

Again, another 10, 12 years later, Tony uses – does not have a voucher. He has moved from place to place to find the right place for him. He lives in a space that he shares common living space with another person. He lives in this county, Montgomery County, which is expensive; therefore, that is the arrangement that works for him.

He works three jobs in order to afford it. Work is very important to him and he talks to other people about it. When he needs something, he finds another way to bring in his resources.

His level of support when he moved from his group home and day support, not a program, was 24 hours 7 days a week. It's not something he wanted. Most people do not by the way and therefore shared that with people in a way through his behavior.

Currently, his budget. He does not use $32,000 to $40,000 a year that he did when he lived in the group home. His direct support has diminished. Most of the support he accesses is a coordinator type of person just to help him keep things on track. This is not something he believed about himself and not something that anyone else believed about himself, but I think is really important. This is not for everyone that they reduce their budgets.

But I think we need to look really hard at the kind of support that we are providing to people. We tend to over-support people. I think we can all agree. I think if you wrote down every single thing a person does all day long, 10 out of 15 people are getting more support than they probably need. Look at it minute-to-minute.

For Tony, that is important. I wish he was here to talk about it.

This person I believe still lives in one of our institutions, who landed there because she was transsexual and could not find a way out. This was another pilot project where we got to do person-centered planning and unfortunately left and was not able to carry this out.

What was really important about this is that a lot of conversation happens around people. It doesn't include the person. When she walked in, she took the markers from my hand and said I'm going to draw what I want. This is what she wanted. A row house in Baltimore. She lived two hours away from home. Baltimore was back home. And someone said - I don't know. It was a psychoanalyst in the audience at one point when I shared this and said there is a lot behind this picture. I don't know about that, but I do know that the sun meant that every day was great because she was living where she wanted to. Her partner is next to her. She's in the pink. Above is a disco ball. It is hard to leave that knowing that that person is still living there. These are the kinds of things that in our experience at Shared Support Maryland keep us accountable. When people say this is what I want, we make sure we can help get it done.

Safety, behavior, risks, and concerns. One person that we plan with - Sean was a person that lived in a residential school in Delaware. I am not going to go through this entire plan, but to show you that people that have the most significant disabilities in autism and all of the things that we talked about all day, planning can happen so looking at a vision for Sean. As we go through this, there are the safety needs of the home. We list everything. We have thoughts on roommates. Everyone makes a choice about their roommate. There are no assigned roommates.

UNKNWON PARTICIPANT: (inaudible comments)

MS. GODWIN: Sure. The people around Sean are important. We plan about the people that are around each other and who those people are chosen to be.

There are six pages on supporting Sean in every moment of his day. This meeting was attended by 15 clinicians because they were worried about where he was heading. The clinicians actually gave us some of the most amazing feedback about him living in the community than anyone else did aside from his mother.

We talk a little bit about matching staff. People choose their staff. What I did not mention in the beginning and I meant to is that everyone we work for is a common-law employer. Through self-directed services, you are the employer of record; therefore, you make choices about their staff rate of pay, vacation time, whether you want to hire them or not, and all the rules that follow to be a common-law employer. With this model, we want to know what kind of staff you want. And typically, our role is to help people find those staff and help set up interviews. The person is involved from the very beginning through the hire and beyond.

The impact on long-term planning with this kind of support is that what you do now, as we know, impacts what happens later. When people are already in charge of their living situation, they are already paying some portion of it. It is removed from service and possibly the family home.

You have a set up that can be left with the person. It is not at the cost of an anchor in that person's life that if that person leaves or passes away that the home is disrupted as well. This is something that we believe in strongly. That experiences, belief, opportunities, and assistance obviously are 100 percent connected. If we don't support all of those areas that people lose out.

Being among and part of the community, the real community, is a civil right. It is a social responsibility that people have to make sure all of us are there. It is medically necessary. I would say that for Lou and for Tony that their cost of medical needs has decreased. It combats isolation.

As an organization, we do measure our customer service survey. We have no data unlike all of the other charts you saw all day long. But we can tell you that we do measure isolation because we found that helping people move into places of their own even with the roommate that they choose, people do experience isolation and that is important.

We also look at autonomy, choice, and authority as our main areas of data collection for people.

I do have recommendations, but my time is up. Thank you.

DR. DANIELS: Thank you and thank you for being flexible with the schedule so we could try to stay on time.

Now, we have some time for questions about the presentations and then we'll move into a general discussion. We will just go from there. Max.

MR. BARROWS: Yes. I have a question for the first presentation, The Arc Jacksonville. In your presentation, I'm just curious to know. Do you have any plans to integrate the community that you were referring to into a larger Jacksonville - he's gone. I was just curious if they were going to make what they are doing in the larger community of Jacksonville and other parts of Florida. That's what I wanted to know. But I guess he's not here to answer that.

DR. DANIELS: Sorry. I think he may have left. If he comes back, he can answer that. Jill is next. Anyone else, raise your hand so I can see you.

MS. ESCHER: I just wanted to make a comment - last question about costs. I know Samantha Crane brought up this question about how do you compare costs in one model compared to another model. As a housing provider myself, I spend a lot of time with a lot of spreadsheets talking to a lot of people in the community, housing agencies, regional centers, support agencies, families, even people at the state level about how do costs shake out across different models because I want to create new models in my area.

The lesson that I've learned and this should be unsurprising I think to all of us in this room is that the housing portion at least for the population I'm trying to address is really a very cheap portion. It's a small portion of the overall cost.

The housing portion shakes out at almost the same across different types of models. If you do my model, which is scattered-site, or if you have a kind of co-housing model or even if you have something that's "more congregate, more kind of farm oriented", the costs are roughly comparable across all the models.

The change of course is in the supports and services. That's where you see sometimes two, three, four, five, six times the amount you're spending on bricks and mortar, you are spending on services and supports.

When we are talking about cost, we're really at least - again, this population. I am trying to address a more challenging population. That most of the costs are not in bricks and mortar.

I think it's really important to know that the adaptive level of your client is driving the costs. It's not the other way around.

The other thing I really wanted to - if any of the speakers had a comment on that, if your experience has been similar to mine. I live in my bubble in the Bay Area. I could be wrong about other places in the country.

And the second point I wanted to make and I really appreciate it, especially when – and Teresa really brought this up. De-stressing the environment. When you're trying to address the needs of people with greater challenges and unfortunately we saw that a lot of our models are not addressing the needs and can't address the needs of people with greater challenges. De-stressing the environment is very important. That often does entail greater cost. These are people who often need open spaces, who often need special materials, who often need special amenities.

I talked to some families and they are like there's no way I'm going to have my kid live anywhere without a pool, for example, because that's what makes him happy. Those can actually add additional costs.

I'm interested in your feedback about that observation as well.

DR. DANIELS: Thank you. Alison. Others? Ivanova.

MS. SMITH: My question is for the presenters. Have any of the residents been able to have romantic relationships in the facilities? If a couple wanted to get married and still live there, would that still be possible for a couple with IDD? Thank you.

DR. DANIELS: Do any of our speakers want to address that from your communities?

MS. MASON: I'll address that. We have some people who have dating relationships and they are very fond of each other. They haven't expressed an interest in marriage, but I think if it was a mutual and covenantal understanding that would be awesome.

MS. ANDERSON: Ivanova, we are the same. We have people who are dating and we have some people who are married. It is a non-issue for us.

DR. DANIELS: Denise.

MS. RESNIK: Through the First Place Transition Academy, we've had a number of people who also have been involved with romantic relationships as well as those who have moved in to the First Place Apartments.

Jill, getting back to your issue, I really appreciate the comment so that we understand when we're comparing apples and apples and oranges. You're absolutely right. The majority of the costs are the supports, in our case, both the amenities and community life. It does all add up. We're trying to do it with economic sensibilities in terms of building skills and also helping transition where they might go next. It's very important.

When we look at the different models, we begin segmenting them. And, again, going back to nomenclature and definitions of what we're talking about and what we're not so that we understand when we're looking at the different housing models how they are differently supported for different people and the associated costs.

And until somebody has developed a property as you have or I have and operated a property as many of our speakers have, people I think don't fully appreciate what's required in terms of scaffolding of financing, of legal documents, of community policies, of operations, and the scaffolding also of the associated costs associated with making sure that it can be sustained. It is complex.

DR. DANIES: Scott.

DR. ROBERTSON: Related to the last presentation from Gail, I was especially interested in how the mention of - that a lot of the service providers did not have the belief that individuals could be transitioning into these settings that they ultimately were successful. I wonder how widespread that is even beyond what you all have been accomplishing in Maryland because I think it's phenomenal what individuals have been able to gain and what fits for them what they wanted in terms of autonomy and their quality of life and to have the supports kind of fit around that.

I take into heart also what you had mentioned about it's more about enhancing what you're doing with staffing or optimizing it, not necessarily always increasing staffing because sometimes individuals may even thrive even more with less staffing or staffing done in a better way that fits what their needs are and what their goals and objectives and whether that's for work or for integrated community living activities. I very much value what you had to share.

I did have a couple of questions. When you were putting together the way you all have approached in the last several years, did you connect with similar organizations in other states across the U.S. or maybe internationally?

The other question I had was about - feel free if this is maybe a tougher one or if you don't want to answer the second one, is on funding models because you sounded like you were a relatively small organization, I think it was $500,000. You said the budget. What streams do you have that fund the financials in terms of the organizations? Is it relationships with the providers that do that? Do you have donations that support the organizations?

MS. GODWIN: Thank you. Thank you for your comments as well. The first question was about how do we research to do what we are doing. We did connect with – at the time, this was 13 years ago. A lot of the models were micro-boards that are closest to what we're doing now. We did absolutely meet with people that were running their own micro-boards and also often partner with another organization, Values Into Action, which is in Pennsylvania, who operates very similar to the way that we do. We're about the same age. There are not a lot of organizations a lot older. We're learning as we go, but we do find some people, the U.K. outside of our United States that have more experience doing it I guess this way in terms of self-direction. We are always looking to partner with others to see what's different.

And then our budget of $500,000 is made up of – we do provide the service of support brokering primarily to people in the consumer-directed services. We look at hours of support. It is completely variable. If you would like four hours this month, you might not want four hours next month. It is that self-directed. If you don't like what we're wearing, you may leave us tomorrow. It is difficult to keep that up.

We often do training for fee-for-service. We have a couple of grants. We do provide the support broker certification training in our state among other things. Our fundraising. Since we are small, we do a fundraiser every three years and hope that brings in something. We do try to diversify that so that we're not dependent on just the ebb and flow of what people would like.

DR. ROBERTSON: Thank you.

DR. DANIELS: Over here we have a suggestion that we move into a time where we can talk about some of the take-home messages of the day. I know that we still had a number of people who had questions. Are any of those questions really pressing before we move into talking about overall messages? I see three. We wanted to do some summarizing and getting ready for the IACC tomorrow.

MS. SINGER: I think our charge as a workgroup is to be advisory to the IACC, which is advisory to the secretary. I think we want to leave today with some very specific ideas that we can present to the IACC so that they can move this forward. Some of the I'd say cross-cutting themes that I think emerged today were ideas of how – we saw a lot about different models at different levels of care, but how can we scale these models to meet the growing demand for capacity. I think that's one area where we might want to try to be advisory.

And the second would be around this issue of funding that has come up so often. What suggestions can we make for how we might direct funding to be realistic and serve the needs of as many people as possible and enable as many people to have access to lots of options without being overly idealistic?

I think when you're looking at public funding, you're talking about meeting people's needs, not necessarily giving them everything that they want. Where can we start to draw some conclusions and specific ideas that we can present tomorrow to the IACC?

DR. DANIELS: Right. Lori.

MS. IRELAND: There is a group of people that none of the groups have really covered, which are those that have absolutely no funding and I don't meaning housing bricks and mortar. All of the things that we have been presented are predicated upon people having some level of funding. That is not true in all states.

I know we have thousands of people on a waitlist to get any funding at all for services in the State of North Carolina. In other words, an adult in the State of North Carolina with a developmental disability that is not already on the waiver and is out over age 22 gets no services, zero dollars, nothing. That is something we didn't cover at all in this group. I know it's hard to believe for people who live in other states, but this is the reality across the United

States and gets back to the question of state-to-state variability.

There is no plan to give any more people waiver slots in the State of North Carolina. What is this committee going to recommend for those people across the state who have absolutely no funding, not just bricks and mortar, but no funding whatsoever?

DR. DANIELS: Daniel.

MR. DAVIS: I want to start by saying I think that's a very important point and I do think we do need to take a look at state variability because there are clearly some states that have large, unattended waiting lists that are not getting addressed. That actually is to some degree part of what Olmstead enforcement frankly is supposed to partially be addressing that.

I know there was just recently a ruling in the DC Circuit that in fact said that that waiting list has to be progressing and not at a rate of a trickle that there actually has to be progress to providing people with services. Again, that's the only DC Circuit and other Circuits are in different places on that.

MS. IRELAND: And it is not enforced.

MR. DAVIS: That is another challenge as well.

I would also add that I think one place where I think I've heard a lot of agreement and I was even talking with Heidi about this earlier is that I think we all can agree that more data collection and more data instruments are needed in order to inform and drive evidence-based practice and to support the business case for providing more housing.

I think that it's very clear we've made some progress in terms of the data infrastructure, but we're nowhere near where we need to be. I think that to me strikes me as an overarching recommendation that I think people who come at it from a lot of different perspectives can agree on.

DR. DANIELS: I think I saw either Krista or Heidi down on the end.

DR. ESCHENBACHER: Thank you. This is Heidi. We do estimate that about 80 percent of people who have DD probably do not get services from their DD agency. Now, they may get services from elsewhere, but that's our approximate percentage of that.

But on the other thing about the funding piece that we hear a lot of and Melissa Harris would probably have to confirm this one. We hear a lot about bundled services versus unbundled. That is, when an agency has a package of services that they are going to offer the individuals who go to that agency have to take the full package or a few selected items from that package. And sometimes we hear that that is oftentimes limiting and that's where the funding and the service types come together.

It just seems like some clarification about how – to what extent are services unbundled? Are they possible for people to pick and choose what they need? That's part of the Settings Rule, but I believe that needs further clarification.

DR. DANIELS: Thank you. Earlier Matthew, did I see your hand up?

MR. OSBOURNE: I was going to speak to the question about relations and it led me to think of other things that came up with different comments. I think essentially – and I'm going to simplify this crudely. Two things as a provider that I think would help is to address some of the over burdensome regulations that interfere with choice and also access. As far as the relationship question is concerned, yes, we wholeheartedly support relationships in our program; however, we have regulations that prohibit people with two different support waivers to share the same apartment. It just doesn't make any sense. There are a lot of other ones that I could give you examples of.

The other thing would be funding. I think we have to look at this. The reality is it's a business. We're a nonprofit agency, but we have to be profitable and we have to recruit highly-qualified staff. I think that oftentimes - and we have a lot of data and we'd be happy to share it and be a part of any committee, but those are the two variables that I think if we can start to focus on those two, we can incentivize those providers to expand their services and expand their reach. But it's two-pronged. You have to remove those burdensome regulations.

DR. DANIELS: Thank. Rylin, did I see your hand up?

MS. RODGERS: Yes. I will start by disclosing that I'm late to this conversation and I'm filling in for a colleague. But I've been pondering something that feels missing to me as you look forward to tomorrow and the future recommendations. I think it builds off of Heidi's point that we know that the majority of people with developmental disabilities aren't receiving DD services. I think the lessons of some of those individuals who I'm fortunate enough to count as colleagues and friends and mentors and their experience with housing and the success and the variety of ways that housing and community living has looked really can inform the conversation.

We've heard a lot of models today that talk about significant needs. We've also heard some of the evidence that we've learned across the disabilities spectrum about supporting people to live their choices and individual self-determination may impact success. I feel like those lessons really are important because I'm challenged by not reinforcing a concept that the risk of community and those options aren't available to an individual based on their disability status. I want to think really broadly about all types of supports and options of community living that we access as part of the solution moving forward.

DR. DANIELS: Max.

MR. BARROWS: I just wanted to have a quick question for the presentation that did the Integrated Living Opportunities. I'm just curious to know if you could briefly explain

– can you explain long-term facilitation and do the Integrated Living Opportunities – will that take over roles of guardianship or any other roles?

MS. CARNEY: We are in the early stages of this. We would hope not to take over guardianship that we would work with the families if there is guardianship that they have successor guardianship. The same situation is being the rep payee. We wouldn't want to be the rep payee for the money.

But our goal is to have the self-advocates live independently with the supports of ILO and that the parents could step away and that we will be able to step in and know where their special needs trust are or where the funds would come from and that a staff person from ILO will be able to manage the waiver services or manage any of the things that the parents are doing for right now. As guardianship, we're not there. Probably won't go as the same situation with the money as rep payee.

DR. DANIELS: Geri.

DR. GERALDINE DAWSON: First of all, let me just say how much I learned today and how I much appreciate all of the speakers. I think it's just an amazing amount of work that is being done of many kinds. It's just really have been edifying for me.

I'm thinking about the take-home message for the IACC. Early on I think it was Desiree who talked about regardless of all the different models that outcomes is really key in defining those outcomes. It made me think about - I'm sure that there are already some existing definitions of outcomes.

But I think from a research perspective, it would be very interesting and helpful to know if we can decide on outcomes and how those outcomes are associated with important economic and other factors that legislators would be interested in. Eventually, it's around policy and trying to get changes made and often those decisions are driven partly by an economic analysis.

But also it made me question. What are the factors that actually contribute to those outcomes? If you can define what a good outcome is, what are the factors that are going to drive those outcomes? I feel like we just have so little data about some of these really fundamental concepts that would be needed to make good decisions.

The second thing I think is very much what Daniel was saying about a need for more basic information around what's available across all the states, but maybe more importantly is how do those individual differences affect and drive things like economic outcomes and other important outcomes that are more related to people and their quality of life. Again, going to a legislator and being able to provide data on here's a state that does X and here is the positive benefits from that and this is why we need maybe a uniform access to services.

And then the third thing that struck me was the fact that we've really been focusing a lot on adult housing as is appropriate. But I think there also needs to be a focus on the entire lifespan in preparing for that. If we could recommend and almost mandate for educational institutions to be preparing people from a very early age to be able to have the most independence when they are ready to leave high school and move into the next phase of life. A simple thing like how do you actually make choices.

If you are 6 years old and you're in a classroom and you're not being able to be given choices, you haven't really learned how to make choices in your life. Just even concepts about providing choice and certainly factors that lead to more independence.

I think they just need to be part of the educational curriculum from a very early age. I honestly don't think teachers are thinking about this very much at all. Those are my three points.

DR. DANIELS: Thank you. Amy.

MS. LUTZ: Thank you. There are two takeaways that I want to make sure are not overlooked in this conversation. First of all, I just wanted to thank Melissa Harris for providing some very important clarification that all of the amazing programs we've heard about today are compliant with CMS regulations and can inspire people to go out and build new types of communities. I totally respect that not everyone wants to live at First Place or at The Arc Village, but that's exactly why we need all of those different models because of the vast range of needs, preferences, and definitions of community.

But the other takeaway is more disheartening for me and that's how little of this conversation has focused on the population of those who require the most intensive and expensive supports. I think only the Center for Discovery and Benjamin's Hope welcome autistic adults with very severe and challenging behaviors, which is basically our constituency at the National Council on Severe Autism. And if there are any of our families who may be listening to the live stream and hoping to learn something that might alleviate their panic at what's going to happen to their loved ones when they can't take care of them anymore, I'm guessing they are still pretty panicked.

I think we need a more focused discussion about this particular population that really can't be served in most of these models that we've heard about today.

DR. DANIELS: Thank you. Gail.

MS. GODWIN: Thank you. Just to bump one comment ahead just to comment. That comment is that two of the three people that I described do fit that description. I would love to be a part of that conversation if that happens.

A recommendation that I have is to really think about the focus on generalization. We know that generalizing, learning in one environment in order to be successful in another is difficult for most people and by definition, federal and state for people with developmental intellectual disabilities. To look at models that support the real living in a home, there is nothing like real living in a home and it is impossible to replicate outside of actually doing it.

This is the second point. Looking at monitoring, looking at a way that is respectful to monitor for isolation and institutionalization. I say that as part of the struggle that we have in our model of support that isn't necessarily a model, but what people want and make a choice about is that it can happen in someone's home, as has been said many times. How is that monitored?

A third is to really recognize and make sure that the loopholes between serving people in their homes, the true difference and complete separation of housing and services is happening.

In my experience, there has been a lot of effort to make sure there are some things that really – that they are not truly different. They are not truly separate. Organizations are providing both in some potentially trickier ways, but I think it still is a problem with authority, who is in charge and where decision making happens. Thank you.

DR. DANIELS: We are almost at 4:30. I'm going to allow a couple more questions and then back to Alison to help us wrap up. Desiree.

MS. KAMEKA: We are at a time right now in our history in the disability rights movement that we've never been experiencing before where people have been supported. They are getting support. Most of it is in their family. home. But there's that large number of people that are living with a caregiver over the age of 60. There is not a plan.

I think it would absolutely essential for there to be some sort of prevalent study that talks about what are the support needs of the vast array of individuals on the autism spectrum, not just individuals that would be identified currently by the IDD system, but the broader spectrum. What is it that they need in terms of supports to be able to live and whether it is housing, property type service delivery models, all of those types of things, but really understanding what is going to be the demand when parents pass away and what's going to happen? We have very little data on that.

I think a lot of systems that are already in place, like identifying people who are at risk of homelessness, are not counting people who live in the family home who are about to lose their primary caregiver and their home.

I think we really need to talk about the DSP career path so when we are talking about research, how can we really make direct support professionals have a dignified career path where they are not also living in the cycle of poverty just like the people that they are serving? How is it when - if there is federal minimum wage hike, how is that going to affect the reimbursement rates of Medicaid for DSPs? How does immigration handle - how is that going to influence the DSP crisis?

There is a lot of interconnectedness and that's what I love about the Interagency Autism Coordinating Committee is that we do have the different federal agencies coming together to talk about issues. I really look forward to having more discussion about the

DSPs, how we are going to meet the demand because the reality is once parents - I get every week a contact of someone who has died and now they don't know what to do. This is happening more and more and more. We have to figure out solutions and we have to figure solutions fast that are scalable that are going to be cross disciplinary.

DR. DANIELS: Thank you. Denise.

MS. RESNIK: In addition to the universal concerns of the human resource crisis, the support. Desiree, you just acknowledge and Geri, the data points to ensure we are moving the needle on quality of life is this consistent reference to community. We need to create the community that's neurodiverse, neuroinclusive. And what we consistently heard were models about inclusion concierge, community builders, community life coordinators, life coaches, sidekicks all after this community integration piece. We can call it by a different name, but it is consistent no matter the property or the type of supported housing that is required.

And also, Amy, in response to what you acknowledged, I wanted to let you know that we started with what was attainable first with affordable housing property with seniors and students with autism. We went to First Place. And the next place we're going to go is for the more significantly impacted based on what we've learned. We're not there yet. We can't do it all at once, but we're aiming for that too. Thank you.

DR. DANIELS: The last two comments will be Scott and then Daniel.

DR. ROBERTSON: I just had a few quick comments, one, which was related to that. I do think a lot of these models actually do have pieces that are very applicable to folks with a variety of experiences as far as support needs. I guess I disagree with the earlier comment that I think there is a lot of pieces that have been shown here that it would be very applicable.

The second quick thing is related to looking at a needs assessment, if you will, related to prevalence. I have actually been encouraging that for many years. I do hope it's something that maybe IACC can consider in the future. When I previously served in IACC as a public member, we got some language into one of the plan updates. I think it was in '13 or '14 so several years ago, about potentially pursuing that area, because it has been done in England years ago in terms of a comprehensive needs assessment. It's been done in the states like Pennsylvania, but it has not been done nationally, especially around adults, around housing, around transportation, around employment, et cetera. I don't think it would be that costly, and be very beneficial for what it would bring.

And then the other quick comment was – and I think this has been a great day by the way. I think we've learned a lot and I think it's very helpful to be hearing what's working out there in terms of successful models is on the data. I wonder where we can think more creatively outside the box and trying to solve that data, which continuously comes up at meetings and conferences here on autism and on broader disability issues.

I wonder also specifically on this housing end and correct me if I'm wrong. Our federal partners over at Health and Human Services and ACL. Is there anything in terms of for instance that NIDILRR, National Institute on Disability, Independent Living and Rehab Research? Did they do housing as part of that? I know they are broader disability and not just autism-specific, but I know that – is there any way that they could focus on it or maybe for NIH [, et cetera?

One of the things that we're limited on and I don't know if this is the case also for HUD is we don't have a research entity. We look to the other agencies that do have research as part of their infrastructure in the government. That's one of the difficulties in the federal government is not all the departments have research agencies. We can't always grow the data pool as well as we would like. But I know that NIDILRR tends to do research in areas. I know that they've done, for instance, transportation and employment, et cetera. I don't know if folks from ACL could answer in terms of if them or maybe another research agency could be focused on that housing and to collect better data that can enhance this because data is definitely needed, qualitative and quantitative, in this area, even though we've seen more scholarship published on autism residential and related community-based services in the last several years. We still need more data.

MR. DAVIS: I can answer that and then go into my last statement. NIDILRR actually does fund a significant number of housing studies. NIDILRR specifically has been looking at issues around social isolation, rural health, and housing, also impact to barriers within the housing, and to communities. There definitely are a number of studies that have been done in that area. While NIDILRR does five-year plans, there are certainly opportunities for public input and for plugging in ideas coming from stakeholders such as the IACC here. If there are recommendations that come out that can certainly be factored in the next time that NIDILRR takes a request.

And HUD actually does have PD&R [Office of Policy Development and Research], which I believe, Veronica used to actually work there, which is their research arm. They have done evaluation on some of the 811 models as well other things.

One quick point is that I had a bit of a different understanding of what Melissa said. My understanding was that she said that all of the settings could reach that, not that they were there right now. I think that is two different things. I do just want to emphasize that point that I think she is saying that she believes everybody is capable of getting there with some assistance, but that's different from saying everybody is there right now.

I would just say from ACL's perspective, social isolation has been one of our administrator's big priorities. Some of the discussions particularly with some of the concerns about scattered sites are that we do - and about farmsteads is, we do have concerns about the health impacts of social isolation from the broader community.

I think that one thing going forward that I think would be fruitful for discussion is how some of these models - digging deeper on how they connect their residents with the broader community. Thank you very much.

DR. DANIELS: Thank you. Alison, do you have some comments that you'd like to make as we wrap up?

MS. SINGER: I think we heard a lot today that adults with autism want autonomy and they want to have the opportunity to make choices. But I think we also heard that we need more options for people who may not be able to operate in some of those places that offer that level of autonomy.

I think through the presentations today we saw lots of different examples of best practices at different care levels. But I think we still need to focus more on how we can scale these models to meet the growing capacity. When we hear about a waitlist of 300 people, I think that's an area we need to focus on.

I think we are still struggling with how to pay for these systems. I think we're also really wrestling with the fact that we don't have good data on outcomes, or as Geri said, the driver of outcomes. These discussions, as David Mandell likes to say and we like to quote – these discussions are very much based on values and individuals' values rather than on the data. I think that's an area where we can focus.

That's also an area where fortunately the IACC has some purview and can actually make some inroads. I think that's a very positive outcome.

I think we talked – when we looked at some of these models, we looked at very vibrant housing models where I think people were able to exercise a good degree of independence. But I think also today we were able to see or maybe just get a glimpse of what individuals with very severe autism are facing every day and that we, as Amy said, need more residential options for those individuals as well. We learn that in an evidence-based residential center even individuals who have the most severe types of autism with aggressive and violent behaviors can gain skills that enable them to be more integrated into the community, as Daniel was saying.

We cannot be afraid to talk about this population or to view videos of them. Every housing model practically that presented today showed a video. We have to make sure we are not excluding from our discussions people with the most severe autism because those videos are uncomfortable to watch. They are uncomfortable for me to watch. They are uncomfortable for everyone to watch, but they are also very real examples of what families are facing every day.

MS. CRANE: Sorry, can I butt in? Because the person who had gotten very upset about this had been institutionalized and had been restrained and related to the person in the video and that is why that person was very upset about the video. I don't think we're excluding people – I think if we show these videos without warning, we are excluding the very people that you were talking about from participating directly in this meeting.

MS. SINGER: I don’t know that anyone was excluded from participating. Those people who are participating at this meeting need to be able to discuss options for all members of the autism spectrum.

MS. IRELAND: Alison, can I make one suggestion of a study just really quickly is the cost of not providing housing? I know my brother is the Chief Medical Officer for a hospital chain in California, not the California you see on television, but the rest of the state, which is actually quite rural and agricultural. He has a child now in his emergency room, which is a very high-cost bed. And the reason is it's a 12-year-old with behaviors that rise to the level of where there is no placement for him in the State of California. It's currently sitting on the governor's desk, but that means that that hospital chain, which is not-for-profit, must eat the cost because the parents have said we're done. That is a huge cost to society, Geri, that we cover up or pretend doesn't exist. There is a 12-year-old sitting in an emergency hospital bed with no place to go and we don't factor that in when we are looking at the costs of not providing the housing.

I think that we need to be a little bit more honest about the total cost of individuals who are denied housing of any kind that's appropriate for them. I think that's really important because it is a hidden cost to society. Obviously, when you look at your medical bill and you're mad at how high it is, when you come out of the hospital, some of that is due to the fact that people like this child have to sit in an emergency room bed in a large hospital because there is no place else for them to go.

MS. SINGER: Just to finish up on the summary. Thank you, Lori. I think we also started to create a good list of next steps that we will present tomorrow to the IACC. As I mentioned, I think some of the items on that list are actually within the purview of the IACC to take action within the strategic plan for research and others can be presented in an advisory letter to the secretary if the new IACC decides to take those steps.

I just want to thank everyone who participated today. I want to thank all the presenters. I want to thank all the commenters. I think it was a very important step to take and I look forward to the discussion tomorrow at the full IACC. Thank you and thank you again to Susan and her team.

DR. DANIELS: Thank you to all of you, to the working group, to the speakers, who flew here from around the country or came by train or car, to members of the IACC who are here with us today, and I'd also like to recognize the OARC staff for the hard work they put in to making this meeting happen, especially preceding the meeting that we're going to have happen tomorrow. It was a marathon. We appreciate their effort.

Thank you. And you’re welcome to join us for the full IACC meeting. It’ll be back in the same room tomorrow and that will be the last one of this session of the IACC.(Whereupon, the Working Group adjourned at 4:45 p.m.)