### **IACC** Workshop



**TUESDAY, JULY 23, 2019** 

IACC WORKSHOP:
Addressing the Housing
Needs of People
on the Autism Spectrum







# Interagency Autism Coordinating Committee Workshop: Addressing the Housing Needs of People on the Autism Spectrum

Tuesday, July 29, 2019

Hilton Washington DC/Rockville Hotel & Executive Meeting Center

1750 Rockville Pike Rockville, MD, 20852

#### **Conference Call Access:**

Phone: 888-946-9416 Participant Passcode: 1391703

### Meeting of the IACC



#### **Morning Agenda**

9:30 AM

Welcome, Introductions, Roll Call, and Approval of Minutes

#### Joshua Gordon, M.D., Ph.D.

Director, National Institute of mental Health and Chair, IACC

#### Susan Daniels, Ph.D.

Director, Office of Autism Research Coordination, National Institute of Mental Health, and Executive Secretary, IACC

#### Alison Singer, M.B.A.

IACC Member Chair, IACC Housing Working Group President, Autism Science Foundation

#### Samantha Crane, J.D.

IACC Member, Housing Working Group Legal Director and Director of Public Policy, Autistic Self Advocacy Network (ASAN)

### **Meeting of the IACC**



#### **Morning Agenda**

10:00 Overview of Housing Issues

Status and Trends in Supports and Services from the Residential Information Systems Project

Heidi Eschenbacher, Ph.D.

Researcher, Institute on Community Integration

University of Minnesota

10:15 Trends & Insights from the Autism Housing Network

Desiree Kameka, M.T.S.

Director of Community Education & Advocacy

Madison House Autism Foundation

10:45 Morning Break

### Meeting of the IACC



#### **Morning Agenda**

11:00 Public Comments

Susan Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH and Executive Secretary, IACC

Oni Celestin, Ph.D.

Science Policy Analyst

Office of Autism Research Coordination, NIMH

12:00 PM Lunch

## Welcome Introductions Roll Call



Joshua Gordon, M.D., Ph.D. Susan A. Daniels, Ph.D. Alison Singer, M.B.A. Samantha Crane, J.D.

### IACC Workshop: Addressing the Housing Needs of People on the Autism Spectrum

**July 23, 2019** 



#### Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination Executive Secretary, IACC National Institute of Mental Health

# Improving Health Outcomes for Individuals on the Autism Spectrum WG



- In 2019 the IACC convened a working group on housing issues for individuals with ASD.
- Working Group Mission Statement:

In the autism community we face a mounting housing crisis, with a growing population of autistic adults with diverse needs lacking appropriate living situations. The goal of this subcommittee 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.

### **Working Group Mission Scope**



- Research and best practices on housing
- Implementation of current federal regulations
- Housing issues faced by autistic individuals with more severe disabilities



### **Working Group Members**



#### **Chair**

 Alison Tepper Singer, M.B.A., Autism Science Foundation(Parent/Family member)

#### **IACC and Federal Members**

- Samantha Crane, J.D., Autistic Self Advocacy Network (self-advocate)
- Daniel Davis, Administration for Community Living (ACL)
- Melissa Harris, Centers for Medicare and Medicaid Services (CMS)
- Veronica Helms, M.P.H., U.S.
   Department of Housing and Urban
   Development (HUD)

- Kevin Pelphrey, Ph.D., University of Virginia (Parent/Family member)
- Scott Robertson, Ph.D., U.S. Department of Labor (DOL) (self-advocate)
- Emily Rosenoff, Office of the Assistant Secretary for Planning and Evaluation (ASPE)

Self-advocate

Parent/Family member

#### **Working Group Members**

#### **External Members**

- Max Barrows, Green Mountain Self-Advocates (Self-advocate)
- Jill Escher, J.D., M.A., Autism Society San Francisco Bay Area (Parent/Family member)
- Lori Ireland, M.B.A., Ireland Family Foundation (Parent/Family member)
- Ben Kaufman, M.S.W., Association of University Centers on Disabilities
- Desiree Kameka, Madison House Autism Foundation
- Arun Karpur, M.D., M.P.H., Autism Speaks
  - Self-advocate Parent/Family member

- Amy Lutz, M.A., M.F.A, EASI Foundation (Parent/Family member)
- Kim Musheno, Autism Society
- Denise Resnik, DRA Collective
- Jay Shukert (Parent Family/member)
- Ivanova Smith, AtWork! (Selfadvocate)
- Stephen Whitlow, J.D., Merakey Gateway Transition Services (Parent/Family member)

#### **Working Group Activities**



- Conference Call June 20, 2019
- Workshop Addressing the Housing Needs of People on the Autism Spectrum – July 23, 2019
- Full Committee Discussion July 24, 2019
- Workshop Summary Fall 2019
- Future activities may be planned by the next IACC

# Status and Trends in Supports and Services from the Residential Information Systems Project (RISP) risp@umn.edu



Heidi Eschenbacher <u>hje@umn.edu</u> Principal Investigator: Sheryl Larson <u>larso072@umn.edu</u>

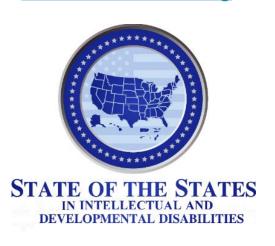
Preparation of this presentation was supported, in part, by cooperative agreement (90DNPA0001-01) from the US Health and Human Services, Administration on Community Living. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore necessarily represent official AIDD policy.



# Longitudinal Data Projects of National Significance

# Developmental Disability and Bill of Rights Act of 2000

State of the States University of Colorado stateofthestates.org



Residential Information Systems Project University of Minnesota risp.umn.edu

Employment
State Data
UMass Boston
statedata.info

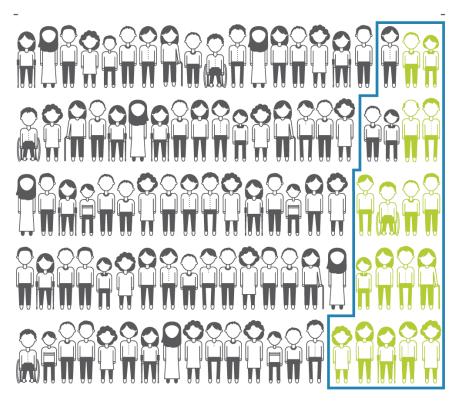




# How many people have IDD in 2016?

**7.37 million** people in the United States had Intellectual or Developmental Disabilities in 2016

- 6.99% children (0-17 years) had ID,
   DD, & ASD (Zablotsky et al, 2017)
- 0.79% adults (18+ years) had ID/DD according to DD Act Functional Limitations (Larson et al., 2001)



20% 1.49 million people with IDD were known to or served by state IDD agencies

17%

**1.23 million** people with IDD received long-term supports or services through state IDD agencies



### "Developmental Disability" Functional Limitations

substantial functional limitations in 3 or more of the following areas of major life activity:

- (I) Self-care.
- (II) Receptive and expressive language.
- (III) Learning.
- (IV) Mobility.
- (V) Self-direction.
- (VI) Capacity for independent living.
- (VII) Economic self-sufficiency

DD Act (2000) 42 USC 15001 Sec. 102 (8).



# How many people with IDD receive LTSS from IDD Agencies?

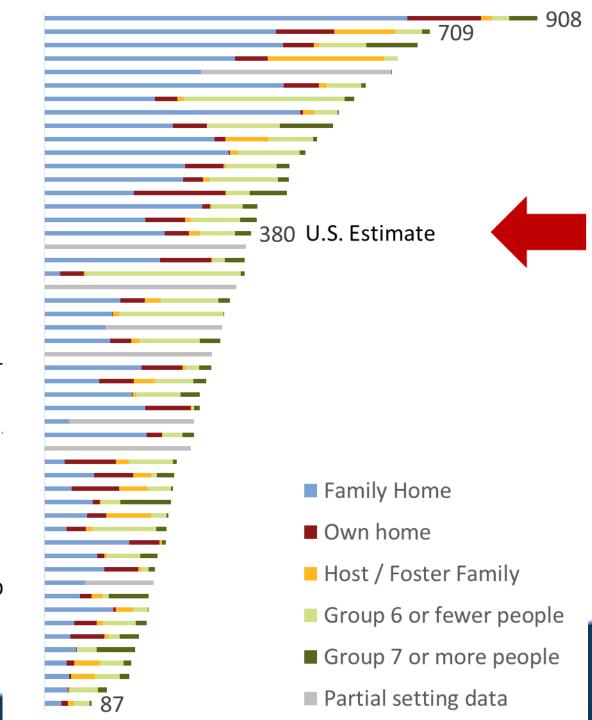
1,228,700 people with IDD receive LTSS from IDD Agencies

380 per 100,000 (0.38%) is the number of people with IDD who have LTSS across the U.

States vary in how many people with IDD get LTSS from DD agencies from:

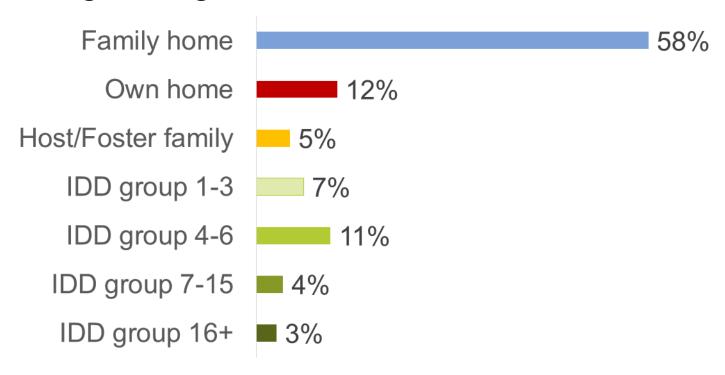
87 per 100,000 (0.087%) to
908 per 100,000 (0.908%)





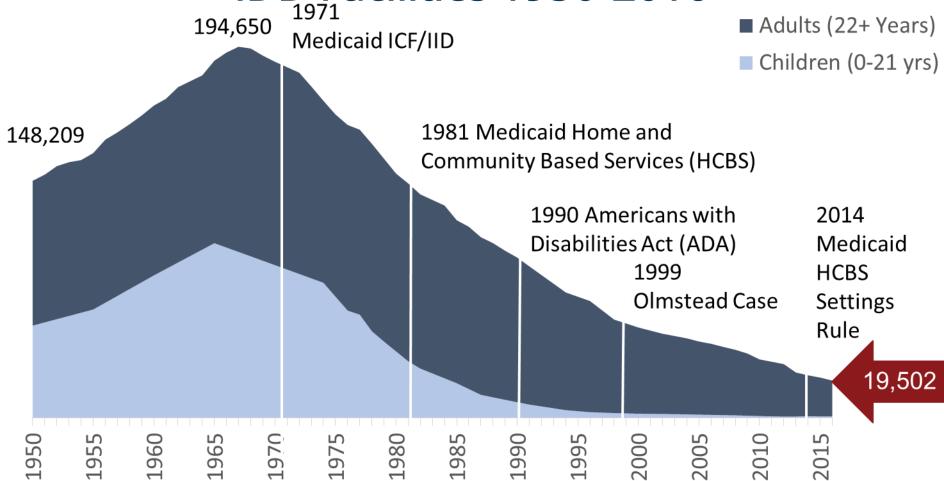
# Where did LTSS Recipients with IDD live in 2016?

**1,228,700 LTSS Recipients** who receive services and supports through IDD Agencies





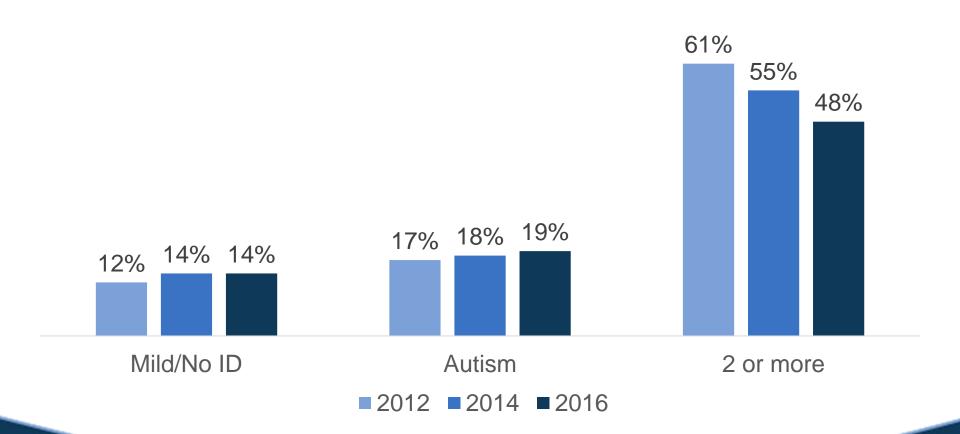
# Number of Children and Adults in Large State IDD Facilities 1950-2016





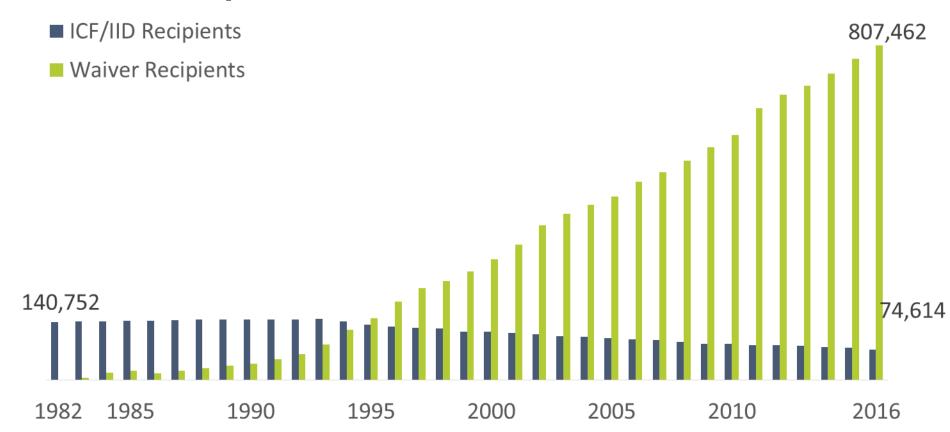
Source: RISP - Larson et al, 2018

#### People with an Autism Diagnosis Living in Large State-Operated Facilities with 16 or more people



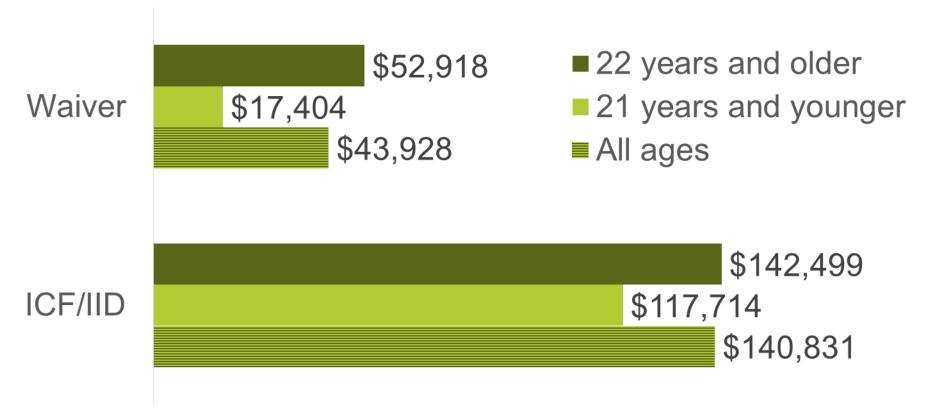


### How people are funded: Number of Medicaid ICF/IID and Waiver Recipients with IDD 1982 to 2016





# Average Cost Per Person Medicaid Waiver and ICF/IID by Age FY 2016

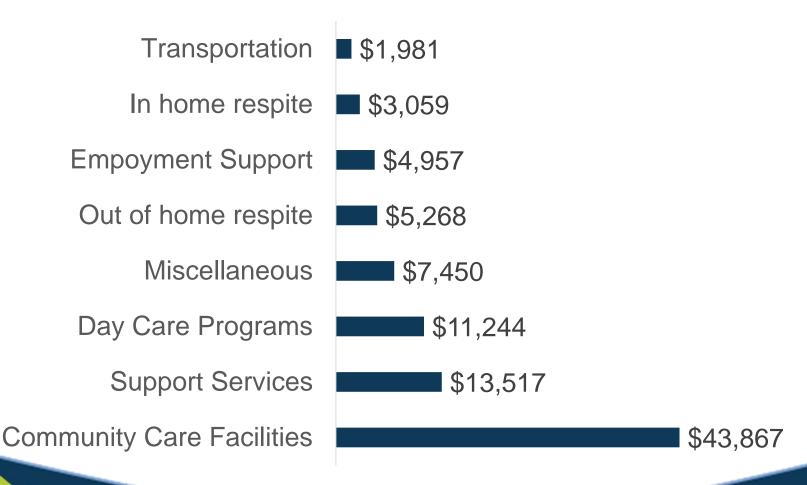


ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities



# Per Person Expenditures for Persons with Autism in California FY 2013

Leigh, Grosse, Cassady, Meinikow & Hertz-Picciotto (2016)





# People with ASD are more likely to live in their family home

"with age, gender, and level of ID and challenging behavior taken into account, people with ASD had

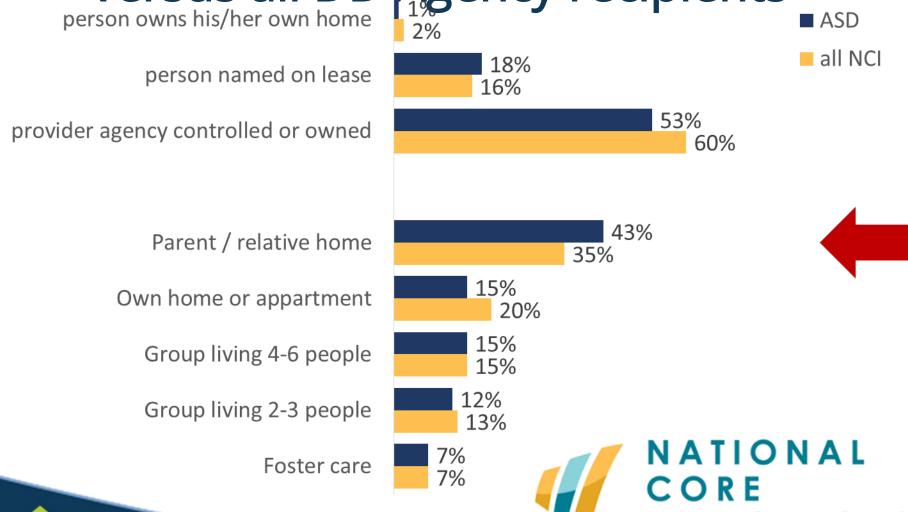
- 29% higher odds of living in a family member's home, but
- 42% lower odds of living in their own home

when compared to people with other developmental disabilities who received residential services through state IDD service systems"

(Hewitt, Stancliffe, Hall-Lande, Nord, Pettingell, Hamre, & Hallas-Muchow, 2017)



# Living arrangements of people with ASD versus all DD Agency recipients





ICATORS

# Rights & choice of people with ASD overall DD Agency recipients

can lock your bedroom if you want to

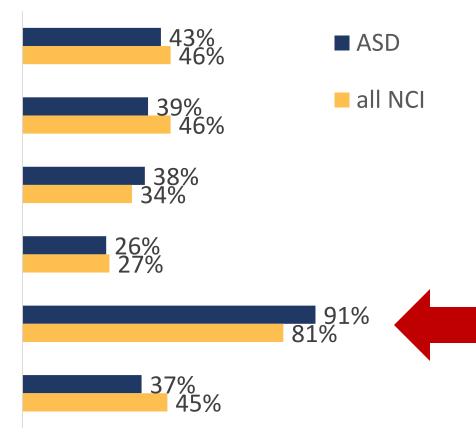
have a key to your home

rules about having friends or visitors in your home

like to live somewhere else

Can make changes to budget/services if needed

No guardianship







#### References

- Hewitt, A. S., Stancliffe, R. J., Hall-Lande, J., Nord, D., Pettingell, S. L., Hamre, K., & Hallas-Muchow, L. (2017). Characteristics of adults with autism spectrum disorder who use residential services and supports through adult developmental disability services in the United States. Research in Autism Spectrum Disorders, 34, 1-9.
- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from:
- Leigh JP, Grosse SD, Cassady D, Melnikow J, Hertz-Picciotto I (2016) Spending by California's Department of Developmental Services for Persons with Autism across Demographic and Expenditure Categories. *PLoS ONE 11*(3): e0151970.doi:10.1371/journal.pone.0151970

National Core Indicators. (2018). In-Person Survey FY 2015-16 Charts from



### Thank you & Other Resources

#### Residential Information Systems Project

- Heidi Eschenbacher hje@umn.edu
- RISP email <u>risp@umn.edu</u>
- RISP website <u>risp.umn.edu</u>

#### In process:

- A scoping study about new institutions and residential options that coming forward for people with autism, ID or DD.
- RISP FY 2017 annual report

## Additional resources at the University of Minnesota:

- raise awareness and understanding of Autism Spectrum Disorder (ASD) and of services available to Minnesota families within the African American, Hmong, Latino, Native American, and Somali communities
- Minnesota Autism
   Developmental Disabilities
   Monitoring Network (MN-ADDM), a part of the Centers
   for Disease Control ADDM
   project





# Trends & Insights Autism Housing Network



Interagency Autism Coordinating Committee
Housing Work Group
July 23, 2019



Desiree Kameka
Director of Engagement & Housing Networks
Madison House Autism Foundation

### **Setting Expectations**

AGE 0-21

AGE 21-80+

CHILDHOOD (SCHOOL)

ADULTHOOD

- Autism Housing Network (AHN)
   Welcome Video
- Trends from AHN reach of 250k+ people
- Local Market Analysis
   Data
- Opportunities for Research to Inform Policy and Increase Options





#### **AutismHousingNetwork.org**

Video Link:

https://videocast.nih.gov/summary.asp?Live=3

3279&bhcp=1&start=3025&stop=3145

### Housing is More Than a Basic Need

selfactualization morality, creativity, spontaneity, acceptance, experience purpose, meaning and inner potential self-esteem confidence, achievement, respect of others, the need to be a unique individual love and belonging friendship, family, intimacy, sense of connection safety and security health, employment, property, family and social stability physiological needs breathing, food, water, shelter, clothing, sleep

"A home is more than a roof over one's head or a financial investment. It affects the quality of a person's general well-being, one's confidence, relationships, and even one's health. It can provide a sense of security and comfort, or elicit feelings of frustration, loneliness, and fear."

Charles Durrent, The Senior CoHousing Handbook



#### **Trends & Pain Points**

- Understanding property types / service delivery models and navigating "the system" is unclear and overwhelming
- Increasing number of crisis calls from self-advocates, siblings or family members as primary caregiver is no longer there to care for them
- Autistic adults are experiencing homelessness
- Autistic individuals without intellectual disability often deemed ineligible for Medicaid LTSS, too "high functioning"
- Autistic adults with self-injurious or "aggressive behaviors" are often refused by service providers



### **Trends & Pain Points**

- Most people forced to stay in family home
- Scattered-site, market-rate rental housing is unaffordable, thus only choice is often "the next empty bed" in a providercontrolled setting and displacement from one's community
- Behaviors associated with autism can be known to destroy property and disturb neighbors, thus non-renewal of lease or eviction
- Medicaid authorities, local housing industry, and city/town planners are largely unaware of demographics or preferences of the local neurodiverse population
- MATE CRIME and ABUSE HAPPENS OFTEN



#### **Trends & Pain Points**



Five-part video series Virtual Tour of Housing & Service Delivery Models

#### What We Know

- ✓ Autistic adults want to move out and experience personal growth
- ✓ Groups are organizing to develop local solutions
- ✓ Not only parents; autistic adults are starting and leading autismoptimized projects
- ✓ NIMBY is not as prevalent
- ✓ Most communities want to become more neuro-inclusive



+60 opportunities "emerging" or "in development" could be studied as comparisons to existing models



#### ECI: Local Market Analysis - Colorado



# Empowering Communities Initiative

Educate neurodiverse community

Assess preferences and support needs

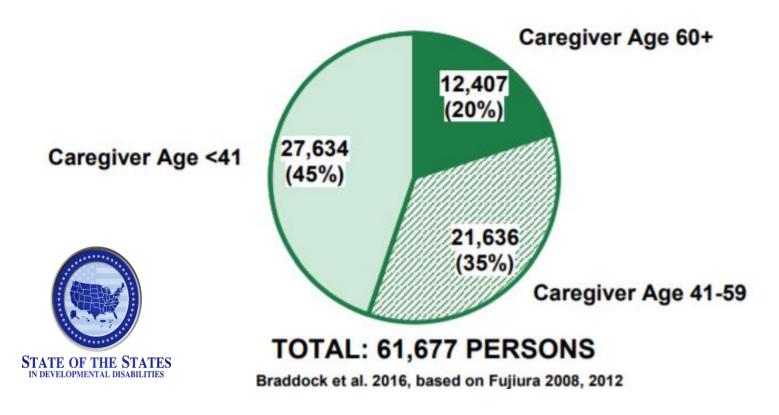
Approach housing industry with consumer data

Increase housing stock that meets the local needs



#### ECI: Local Market Analysis - Colorado

## ESTIMATED NUMBER OF INDIVIDUALS WITH IDD BY AGE GROUP LIVING WITH FAMILY CAREGIVERS: FY 2015

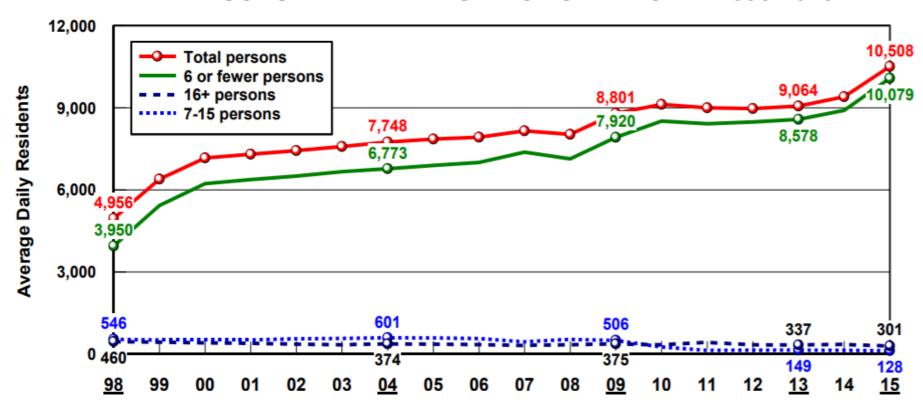


In CO, ~10,500 individuals live outside their family home with residential supports.



### ECI: Local Market Analysis - Colorado

#### PERSONS WITH IDD BY SIZE OF SETTING: FY 1998-2015







#### ECI: Local Market Analysis – Colorado

Fewer than 3,500 individuals have been given residential supports to move into any other setting in the past 15 years





## **ECI: Three Financial Roads**

#### 100% Public funding for home & support

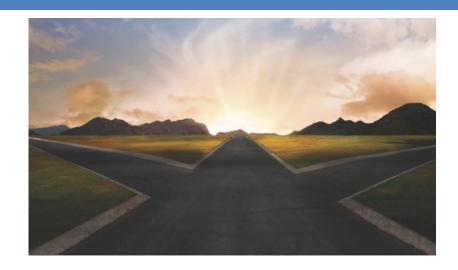
Institutional setting

ICF-ID

Host home/adult foster

Group home

Affordable housing + Medicaid waiver



#### Private housing & public funding for support

Property privately developed for ownership or rental (potential built-in supports and amenities)

Long-term support services funded by Medicaid waiver

#### 100% Private pay

Own home & hire staff or provider agency privately Tuition-based residential Transitional program



## **ECI: Service Delivery Models**

## Relationship between Housing and Services

- Provider-controlled
- Consumer-controlled

#### **Service Delivery Types**

- Agency-Based Rotational Staffing
- Consumer-Directed Services
- Host Family Home
- Shared Living / Roommates
- Paid neighbors





## **ECI: Property Types**

- Accessory Dwelling Unit (ADU) / Tiny home
- Bequeathed family home
- Scattered-site, single-family home, townhouse or apartment
- Cohousing Community or Intentionally Neurodiverse Neighborhood
- Planned Community (Built-in Support or Live-Work-Play)





#### ECI: Local Market Analysis – Colorado





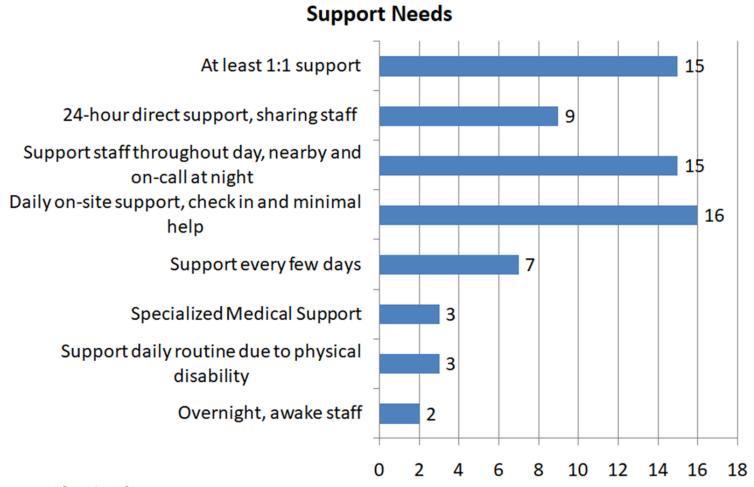


Survey includes demographic questions, property and service delivery preferences, and current barriers to community life



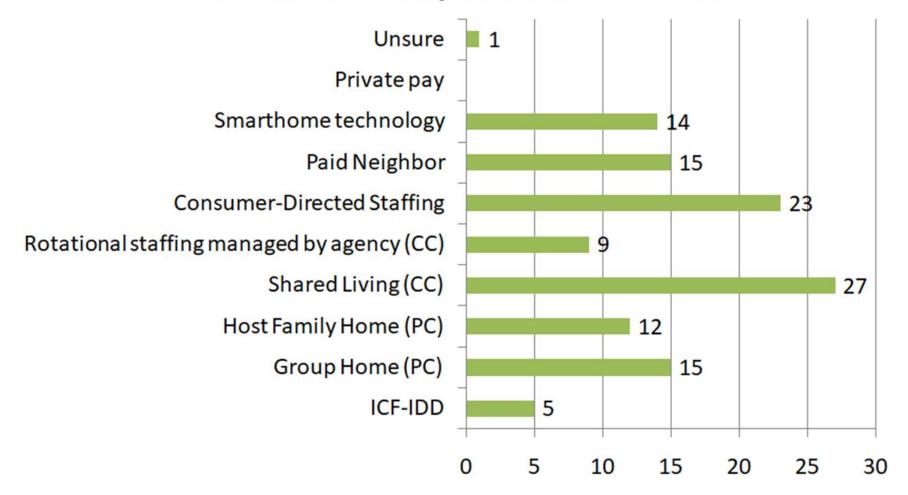






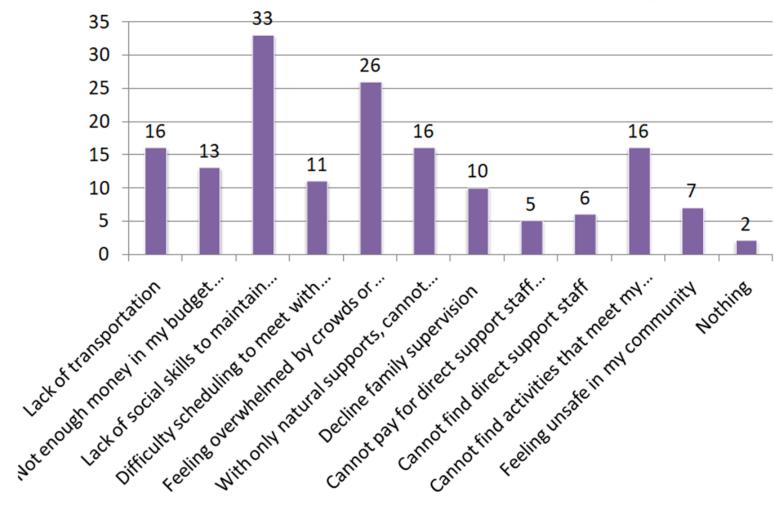


#### What Service Delivary Models are Preferred?



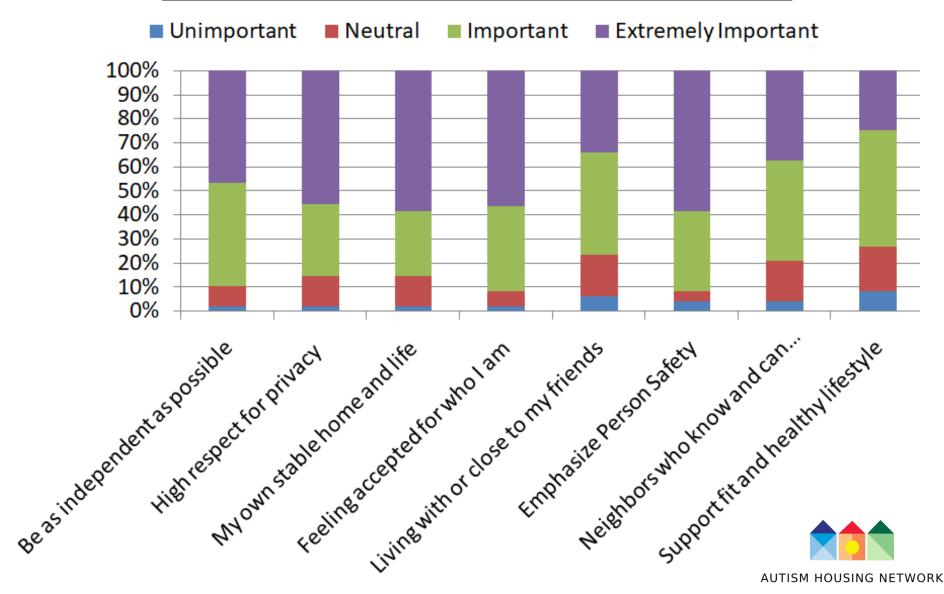




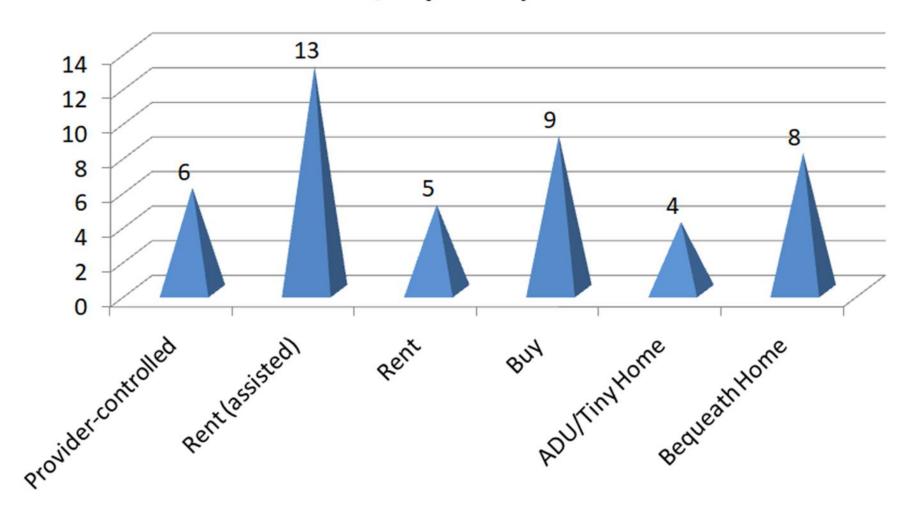




#### Importance to you for your future residential support

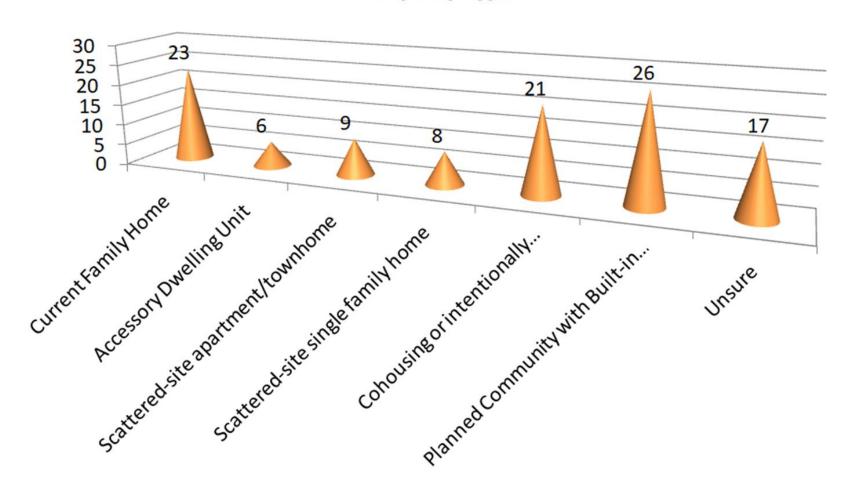


#### Rent, Buy or Bequeath?





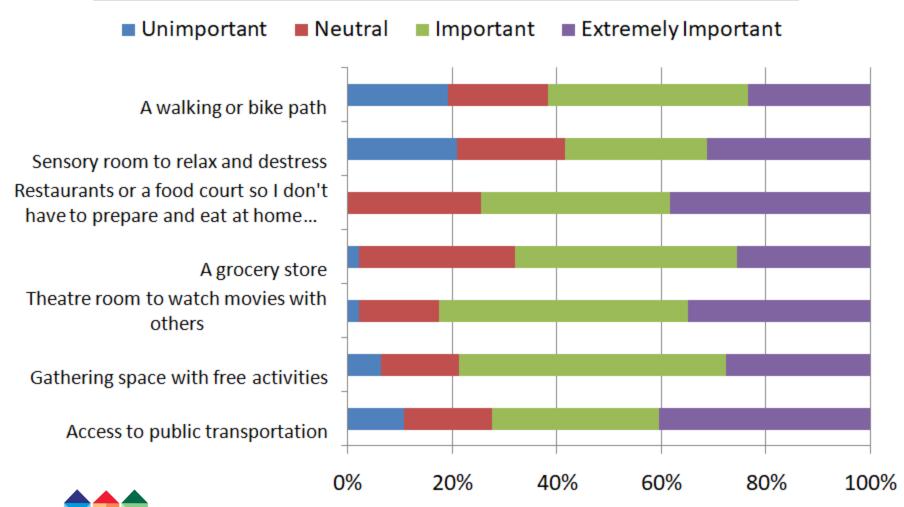
#### **Property Type**



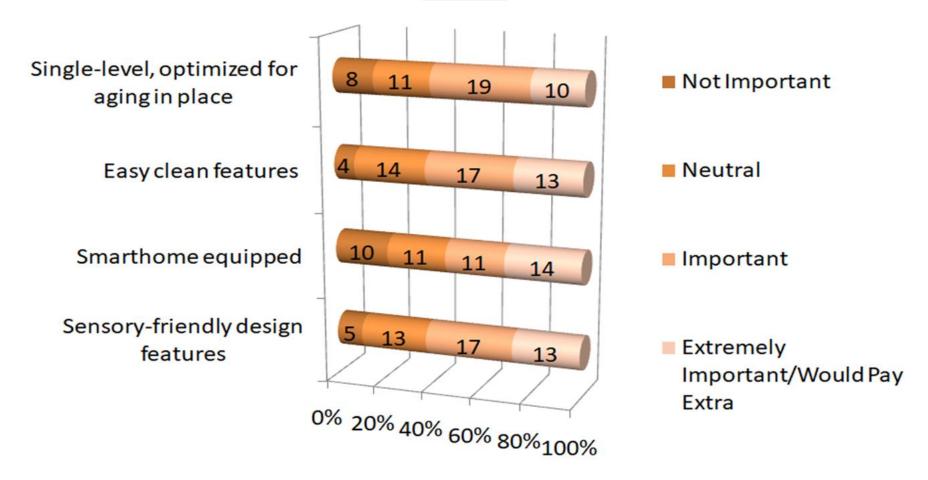


AUTISM HOUSING NETWORK

#### What community spaces would you like in walking distance?



## What type of built-in features would you like in a future home?





#### What type of built-in features would you like in a future home?

Housekeeping service to help keep my space clean

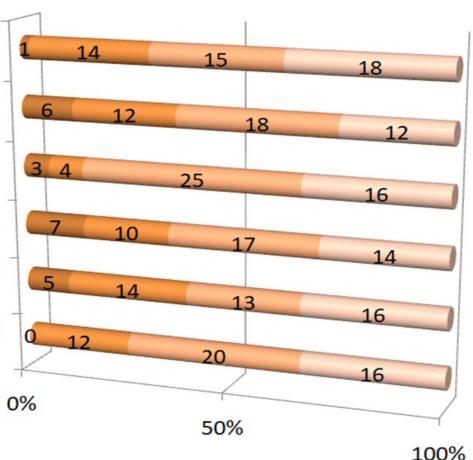
Shared dining area to buy mealplan or cook meals together

Ride-share or other affordable transportation

Community/Employment Navigator

24/7 help desk or on-call, in-person support

Emergency help intercom (voice or button activated)





#### HOUSING SUPPLY AND DEMAND

- Foundational nomenclature (2018 GLI/AHN Think Tank)
- State-specific assessments to meet demand
- Data collection and interpretation for evidence-based metrics must be person-centered and reflect various service delivery models
- Impact from remaining in the family home for decades of adult life



# IMPACT OF INTENTIONAL DESIGN, AMENITIES, AND OPERATIONAL DECISIONS

- Abuse mitigation
- Home design and physical accommodations for cognitive disabilities
- Smart Home and assistive technology
- Housing and high behavioral support needs
- Comparative study: private- vs. publicly-funded options



# DATA ON AUTISTIC PEOPLE EXPERIENCING HOMELESSNESS

- Percentage of autistic adults or families who become homeless
- Does autism-specific intake accommodations improve access to support?
- Does autism-optimized housing and built-in supports improve outcomes?
- What set asides or incentives could increase supply of housing for the autistic population?

# DIRECT SERVICE PROFESSIONAL (DSP) CRISIS: WORKFORCE, TURNOVER, QUALITY

- Effective strategies for stable direct service staffing
- Decrease repeat abuse offenders
- Impact of autism-specific training
- Impact and potential benefits for technology usage to supplement DSP workforce shortage



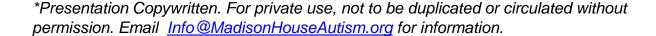
#### DISCRIMINATION

- Impact of Olmstead Decision in light of the lack of affordable housing leading to forced placement into more restrictive settings
- Legality of restrictions of LTSS in a setting that is consumer-owned or controlled by the individual
- Lack of appropriate supports leading to ER visits
- First Responders Issues
- Nuisance laws and autism



## **Autism Housing Network**

By working together, solutions are possible!





#### **About Desiree Kameka**



For the last decade, Ms. Kameka's work for Madison House Autism Foundation has focused on researching housing solutions, advocating on issues of autism in adulthood, and presenting her findings at local and national gatherings. Her passion is supporting autistic and other neurodiverse adults and their families to create a future that is full of promise and life-affirming.

A recognized disability housing expert and keynote speaker in conferences across the country, Ms. Kameka is cited in media outlets such as The Atlantic, Rolling Stone Magazine, NPR, Psychology Today and ABC News. In addition, Desiree's work in housing is included among international academics and professionals in the pioneering scholarly volume *Autism Spectrum Disorder in Mid and Later Life*, which covers the issues faced by aging individuals on the autism spectrum. She has been invited to speak at the UBS Global Autism Innovation Roundtable, the United Nations World Autism Awareness Day, Great Minds Coming Together on Autism International Conference. Ms. Kameka has a Masters in Theological Studies with a cross section of Theology and Disability from Wesley Theological Seminary and she attended, University of Miami with a B.A. in Psychology.

Contact: Dkameka@madisonhouseautism.org



## Thank You to Our Sponsors

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## American Airlines

Contact Desiree Kameka: dkameka@madisonhouseautism.org at Madison House Autism Foundation to learn how you can support the work of the Autism Housing Network.





# Discussion



# Break



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### **Meeting of the IACC**



#### **Morning Agenda**

11:00 Public Comments

Susan Daniels, Ph.D.

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Science Policy Analyst

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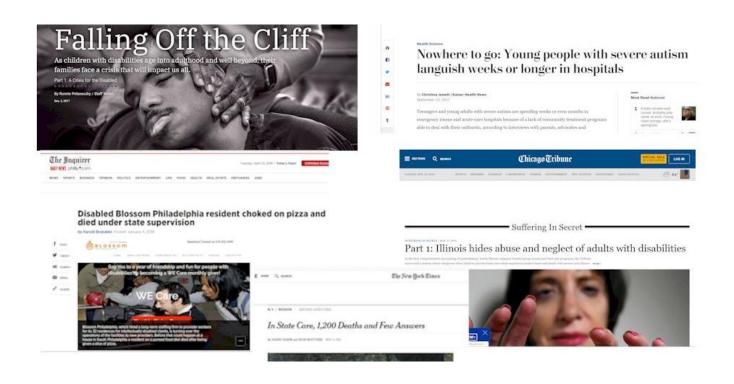
12:00 PM Lunch

#### **Oral Public Comments**



Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination Executive Secretary, IACC National Institute of Mental Health



"Even if some license if afforded to "hope" - a "hope" that history would not repetited to "hope" in the strings of the string

- Tamie Hopp

## ICF - needed attention, services, supervision, facilities for moderate to severe autism

Allegedly inclusive settings like small dispersed group houses and apartments can be the most isolated and segregated for all those with challenging behaviors that require more structure and support than can be provided by these environments.

- ► ICF must meet rigorous standards to achieve and maintain certification with CMS - Appendix J is 257 pages long. No such requirement for HCBS settings.
- ICF required to provide Active Treament. No such requirement for HCBS and they seldom do.
- ICF provide a level of service HCBS almost universally lacks on-site nursing, clinicians, highly trained staff, behaviorists, supervisors, therapy rooms and pools, nutritional services, developmental training
- ICFs are required to report all critical incidents of abuse and neglect to the state, HCBS providers self-report

## Systemic Shortcomings of Waiver Houses for the severely autistic

- Group Home businesses have delegated frontline care to inexperienced caregivers with negligible training, a cost cutting combination that leads to harm.
- Frontline caregivers have minimal supervision and support for assistance in difficult medical or behavioral situations, no other staff, clinicians or supervisors on-site.
- Nursing homes, state institutions and other extended-care facilities are required by law to employ on-site registered nurses
- ▶ The Non-Contiguous Rule To meet community group home regulations, group homes must be located at a distance from one another. Consequently, supervisors can spend the entire day just driving from one group home to another, offering less time to actually supervise employees or interact with residents. Statistics show that abuse rates are alarmingly high in isolated settings.
- In an ICF (Intermediate Care Facility), there is a centralized kitchen, which is capable of 4 levels of food preparation for residents, so special dietary needs can be faithfully carried out.
- Frontline caregivers are expected to handle life and death situations at fast food wages. High turnover and staff shortages result. Two out of 5 DSP workers quit their jobs every year. 20% of needed positions remain vacant.
- Reliance upon powerful psychotropic medications for behavioral management less costly than skilled training or a humane therapeutic environment
- In an age where 50% of neurotypical Americans do not know their own neighbors, living in a group home is even more isolating for a developmentally disabled person.

#### The Economy of Scale

". . . Large institutions are, in most instances, less expensive than community residences for these challenging populations

- Schalock and Fredericks

There are fixed costs at the Centers. Fewer professionals to serve more patients, keeping costs down. Heat, Build, Light, Maintain Thousands of Small

Clinicians, Nurses, Doctors and Supervisors are available to serve a large number of

residents on the premises



**Dispersed Settings** 

Each group house will not have its own supervisors nurses, clinicians on premises



"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 institution may ever be appropriate...for these persons, institutional settings are needed and must remain available."

Olmstead v. L. C., 527 U.S. 581, at 604-605

#### **Oral Public Comments**



#### Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination Executive Secretary, IACC National Institute of Mental Health

#### **Written Public Comments**



Oni Celestin, Ph.D.

Science Policy Analyst
Office of Autism Research Coordination, NIMH

#### Live Feedback



#### Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination Executive Secretary, IACC National Institute of Mental Health



# Discussion



# Lunch



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#### **Afternoon Agenda**

1:00 PM Intentional Community Models

Live. Learn. Lead. We're the place for that...First Place AZ

#### **Denise Resnik**

CEO and Co-Founder, DRA Collective Phoenix, Arizona

1:10 Benjamin's Hope: a "Live, Learn, Play, Worship"
Community Where People with Autism Enjoy Lives of
Dignity and Purpose

#### Krista Mason

Executive Director, Benjamin's Hope Holland, Michigan



#### **Afternoon Agenda**

1:20 From House to Home: Thriving with Autism at The Center for Discovery

Terry Hamlin, Ed.D.

Associate Executive Director, Center for Discovery Harris, New York

1:30 Organizing for Inclusive Community: Leveraging Partners and Policies to Make More Possible

**Lindsay Johnson** 

Director of Policy and Partnerships, The Kelsey

2:10 Afternoon Break



#### **Afternoon Agenda**

2:25

**Apartment/Dispersed Community and Service Delivery Models** 

The Arc Jacksonville Village

Jim Whittaker

President/CEO, The Arc Jacksonville Jacksonville, Florida

2:35 The Faison Residence: Highlights of An Inclusive, Semiindependent Housing Community for Adults with Autism

Matthew Osborne, M.S., BCBA

Director of Adult and Residential Services, Faison Center Richmond, Virginia



#### **Afternoon Agenda**

2:45 How Integrated Living Opportunities Creates Supportive Communities & Full Lives for Individuals with Developmental Disabilities

#### **Maedi Tanham Carney**

Integrated Living Opportunities
Maryland, Northern Virginia, and Washington, DC

#### 2:55 **ABLE's Journey with Housing**

#### **Mary Anderson**

ABLE Inc.

Dickinson, North Dakota



#### **Afternoon Agenda**

3:35 Personalized Adult Services and Housing Navigation

Gail Godwin, M.A.

Executive Director, Shared Support Maryland Maryland

4:05 Final Discussion and Wrap Up

Susan Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH and Executive Secretary, IACC

Alison Singer, MBA

**IACC Member** 

President, Autism Science Foundation

4:30 Closing Remarks and Adjournment

Video Link:

https://videocast.nih.gov/summary.asp?Live=3

3279&bhcp=1&start=8835&stop=8956





Ensure housing and community options are as bountiful for people with autism and other neuro-diversities as they are for everyone else.

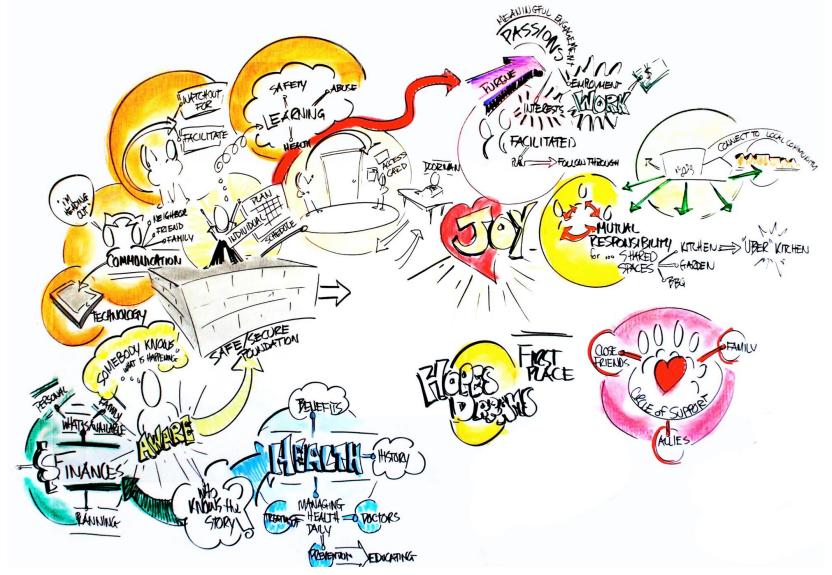


#### WHO WE'RE NOT

- Licensec
- Medical home
- Assisted care/ congregate housing
- For those needing
   24/7 care/support
- For those with self-injurious/ violent behaviors

"There is not a one-size-fits all approach. Societal costs can be dramatically reduced and quality of life, increased, when the right lifelong living and learning opportunities are available and accessible."



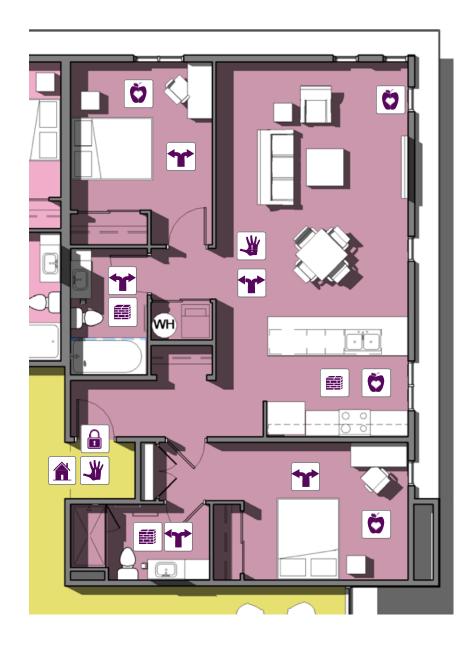


"Our residential model will demonstrate a variety of best practice, replicable housing options for adults with ASDs and related disorders; scalable frameworks through public/private/nonprofit collaborations; and community integration/engagement, safety/security and the comforts of home." -- 1999 SARRC Housing Strategic Plan



#### First Place-Phoenix

- Informed by two decades of research, evaluation & exploration
- Backed by public, private, non profit & philanthropic collaborations
- Designed for replicability, scalability, financial sustainability and impact
- Sister Study to Opening Doors now underway in collaboration with the Autism Housing Network, Urban Land Institute, ASU Morrison Institute, among others.



#### First Place Features

- Ensure safety & security
- Maximize familiarity

#### **Construction Features**

- Foster health & wellness
- Ensure Durability

#### Design Features

- Provide adequate choice & independence
- Minimize sensory overload

Natior Well Res Facu

Catalyst & Leader for Research Collaborations

#### MULTI-USE DEVELOPMENT

Innovative Residential Model

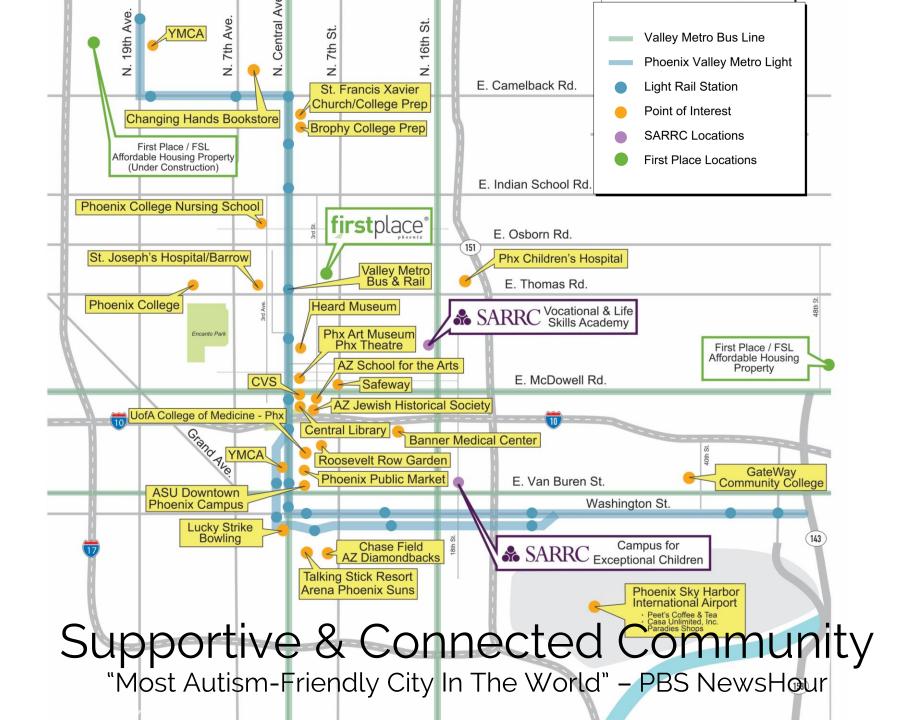
Advancing National Standards & Public Policy

For Deserchers & Policy Leaders Leadership Inst. firstplace phoenix **Transition Academy** (For Participants/Students)

Applica Acceptance for Stu

#### KINTSUGI: JAPANESE ART OF GOLDEN REPAIR







HOME

**APARTMENTS** 

TRANSITION ACADEMY

GLOBAL LEADER

#### We're the Place for That. That. The Place for That. The Place for That. The Place for The P

A supportive, inclusive community where you can make friends, have fun & live independently. A place to call home!

**EXPLORE** 





## Building confidence in the future™



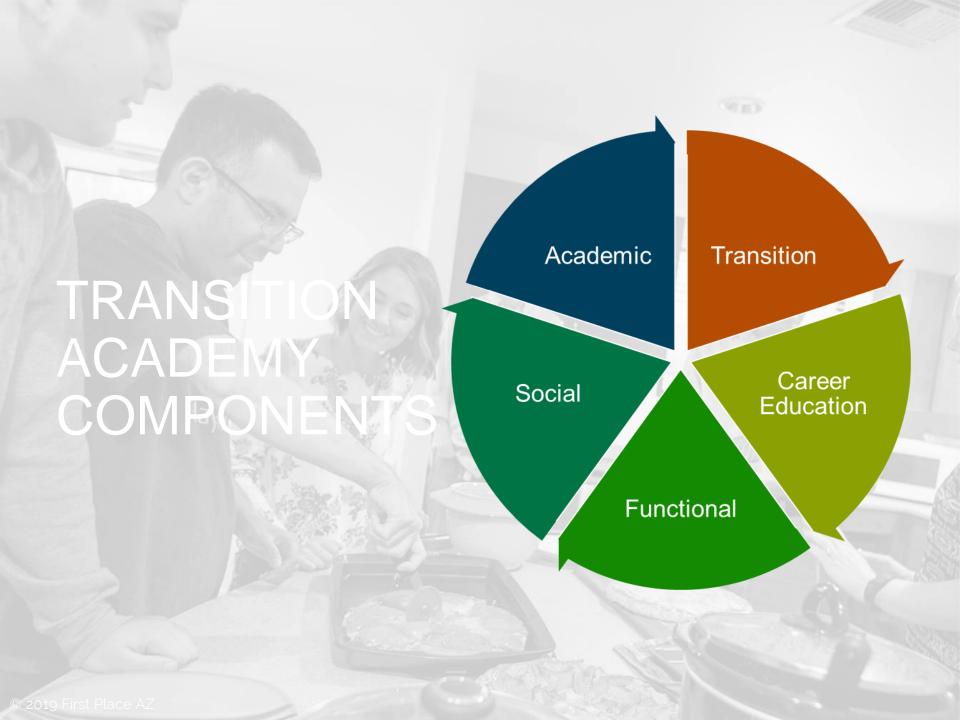
GLOBAL LEADERSHIP INSTITUTE FALL 2019 SYMPOSIUM

OCT 13 - 15

REGISTER

Including Think Tank in collaboration with the Autism Housing Network









Roommates & community apartment living



Courtesy & manners



Money basics & personal finance

. . . .



Physical & mental health

. .



Personal & community identity



Creating a life of independence



Safety, meal planning & prep



Friendships & family relationships



At home & in the community

. . . .



Conflict, coping & personal management



Travel planning, budgeting & etiquette



Getting a job & navigating the workplace

. . . .



PowerPoint Presentations



Instructor's Manuals



Reading Notes



Supplemental Materials



#### firstplace Transition Academy outcomes



Inly 28% of graduates have experienced living outside family home prior to enrollment.

89% live outside of family home after program completion.

50%



94% were employed

upon graduation.

39% of graduates are from out of state.



55% of graduates live at First Place properties.

Outcomes are based on First Place Transition Academy program operated by the Southwest Autism Research & Resource Center (SARRC), including the Learn4Independence® curriculum.



© 2019 First Place AZ











# FIRST PLACE APARTMENTS AMENITIES & FEATURES

© 2019 First Place AZ





















## SUPPORT

© 2019 First Place AZ



Transportation



Personal Management



Money Management



Household Management



#### AREAS OF SKILL BUILDING, PROMOTING INDEPENDENCE



#### **Time Management**

- Making schedules
- Setting alarms
- Planning ahead

#### **Shopping**

- Groceries
- Household needs
- Clothing & accessories

#### **Money Management**

- Budgeting
- Tracking
- Safety

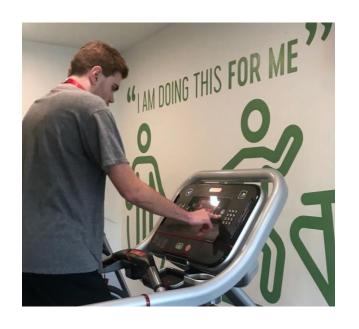
## Transportation & Navigation

- Public transportation training
- Transportation app training
- Transportation safety

#### Safety Support

- How to respond to strangers
- Awareness of surroundings
- Understanding signs/signals

#### AREAS OF SKILL BUILDING, PROMOTING INDEPENDENCE



#### **Culinary**

- Meal planning
- Preparation
- Diet and nutrition

#### **Personal Care**

- Hygiene
- User friendly products
- Prompts / reminders / routines

#### **Health & Wellness**

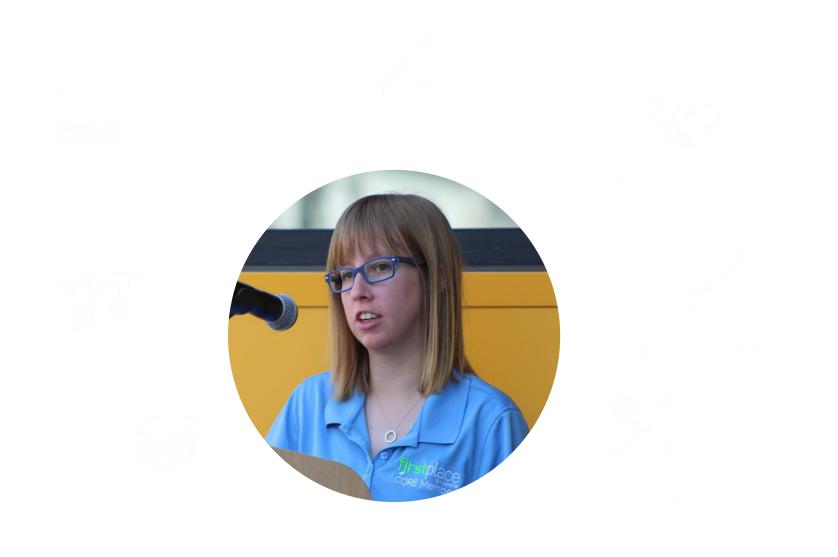
- Medication management
- Appointment preparation / scheduling
- Exercise

## Household Management

- Cleaning
- Organizing
- Understanding appropriate products

#### **Self-Determination**

- Confidence
- Decision making
- Empowerment



## ASKING TOUGH QUESTIONS



## FIRST PLACE GLOBAL LEADERSHIP INSTITUTE FIVE CENTERS

- Maricopa County IDA Center for Education, Training & Employment
- Center for Real Estate & Community Development
- Colonel Harland Sanders Center for Applied Research
- Mulzet Center for Expression/ Communication
- The Daniel Jordan Fiddle Foundation Center for Public Policy





#### **BUILDING THE SUPER HIGHWAY**

"We must restructure the way existing government funding is allocated to housing resources in order to grow a sustainable real estate supply over time."









### CELEBRATIO N OF FIRSTS













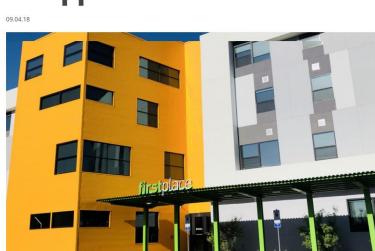
#### **Lessons Learned: Lesson #1** - Build a trusted team that can agree—and agree to disagree

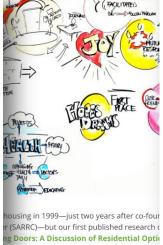
**Lessons Learned: Lesson #4** - Don't fall in love with (or marry!) your plan too soon



**Lessons Learned: Lesson #2** - Invest early in research and discovery to inform your vision

**Lesson Learned: Lesson #3** - There's no one-size-fitsall approach.





ers." This groundbreaking study represents ecial populations across the U.S. It also pres **Lessons Learned: Lesson #5**  Timeouts aren't just for kids!



## HOME IS...

a nurturing place that makes me feel better when I'm sick, grounds me when I'm well and brings forward the warm memories of fun times and cherished people in my life. where I can be the same and different.



a place I can cook a meal just the way I like it.



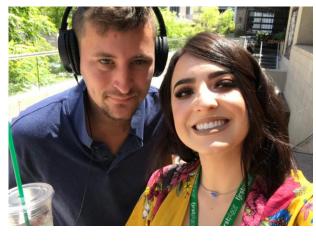
a place that makes me happy and a place where I find comfort when I'm sad.



a powerful, very special place.



Home is a place where I feel good and look good no matter what I'm wearing.



where I can speak any language and be understood.



that has rules so others can enjoy their privacy and be comfortable--and I can, too.



a place where I can dream with or without a pillow.



my most sacred space and place.



© 2019 First Place AZ

### Plugging the Holes: Taking note of what Matt can—and can't—do

06.20.19



Small Steps and a Big Team: The benefits of high- and lowtech solutions

06.25.19



# Test Run: Celebrating Matt's growing independence—and a 35th-anniversary celebration in paradise

07.09.19



## Gradually Building on Success: Taking stock of the little stuff, too

07.02.1





"Introducing a new wave of residential and community options, leading with sound market principles and what works for people with and without autism."



#### **BENJAMIN'S HOPE | WHO WE ARE**

A "LIVE, WORK, PLAY, WORSHIP"
FARMSTEAD COMMUNITY WHERE
PEOPLE OF ALL ABILITIES ARE
TRANSFORMED BY THE LOVE OF CHRIST







Video Link:

https://videocast.nih.gov/summary.asp?Live=3

3279&bhcp=1&start=10155&stop=10301

#### **BENJAMIN'S HOPE | WHAT WE LOOK LIKE**



#### **BENJAMIN'S HOPE** | WHAT WE OFFER

- ✓ 24/7 High Quality Care for 33 adults with I/DD
- ✓ A loving and safe Christian environment
- ✓ Monday Friday Life Enrichment Day Program
- ✓ A beautiful apartment within farm-style home in a neighborhood of friends
- ✓ Nutritious food
- √ Family Support
- ✓ Church of Ben's Hope serving 300+ people
- ✓ Community destination for families, school, youth and volunteer groups
- ✓ RPM: emerging method for non-verbal communicators





WE FOCUS ON WHOLE PERSON DEVELOPMENT IN AND THROUGH:

- ✓ THE ARTS
- ✓ BARN & GARDEN
- ✓ HEALTH & WELLNESS
- ✓ COMMUNITY ENGAGEMENT
- ✓ SPIRITUAL ENGAGEMENT

**BENJAMIN'S HOPE | WHAT WE DO** 

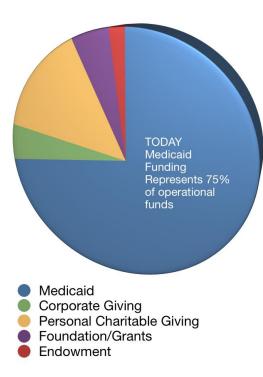




	Type of Use/Users	#'s of People Served Weekly
Life Enrichment Day Program	Mon-Friday 9 - 5	28
Residents	All the time	30
Recreational Visitor	Sunday - Sunday	50
Rapid Prompting Method Student	Mon-Friday by appointment	12
Staff	All the time	90+
Worshipers	Sunday	250+
Educational Seminars	1/per month	40+
Volunteers	all days	25+
Internships	all days	25
Visiting Students/Schools	1/per week	25+
Visiting Students/Youth Groups	1/per week	25+
Total Persons Served Weekly (estimation)		575+

#### **BENJAMIN'S HOPE | WHO WE SERVE**

#### Funding Sources for Ongoing Operations | 2018



Ben's Hope is a debt-free public private partnership. The men and women who live at Ben's Hope are funded through Medicaid Waiver dollars. Contracted Community Mental Health systems determine eligibility for specialized residential services.

- 1. How are fees determined? Person Centered Planning dictates staff ratios, which in turn informs a daily per-diem rate.
- 2. What are the staff ratios? Per PCP's staff ratios range from 1:4 to 1:1, depending on medical necessity. Ben's Hope provides 24/7 wake staff.
- 3. What funding do people have? SSI (rent), Bridge Card (food) and Community Living Supports (staffing).
- 4. So what is the fee range? Medicaid covers about 75% of the cost of care. Monthly rates range from low \$4,000 to twice that much for individuals in need of high acuity care due to behaviors and/or medical needs. We rely on charitable giving to address the gap.
- 5. Would you consider a private pay? Yes.

#### BENJAMIN'S HOPE | HOW WE'RE FUNDED & WHAT IT COSTS



#### BENJAMIN'S HOPE | WHY IT MATTERS

"Ben's Hope is a place where everyone is welcome not only to residents but to 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 Bens Hope. I don't have to hide anything ever, I don't have to worry about not fitting in."

Written by Lucas September 2014

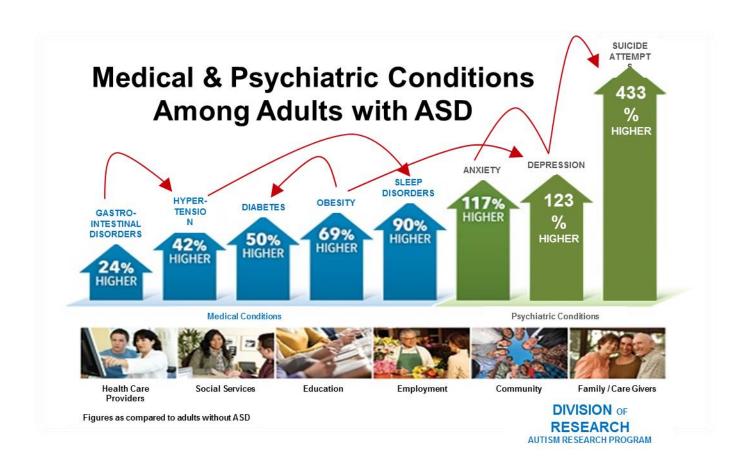


#### From House to Home: Thriving with Autism at The Center for Discovery

Dr. Terry Hamlin Associate Executive Director The Center for Discovery



#### **Retrospective Study of Health Conditions in ASD**



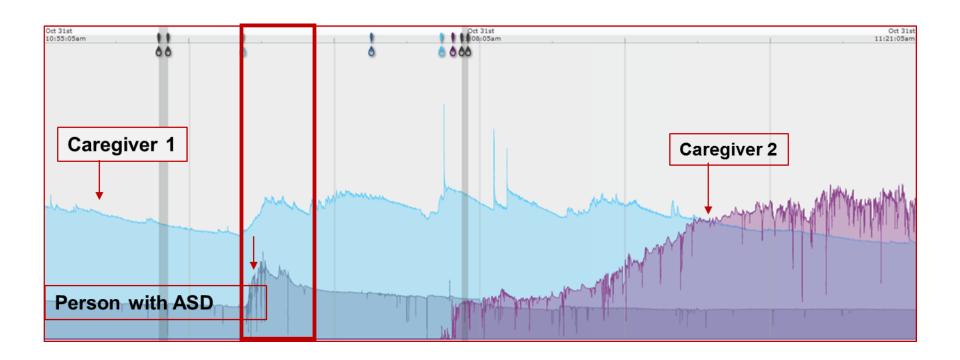
#### **Health Conditions in Adults with ASD**

255 Adults ages 18-71 years with ASD **substantially higher prevalence** of:

- seizure disorders,
- depression,
- anxiety,
- hypertension, and;
- allergies

Robert Fortuna, MD, MPH, et al., University of Rochester School of Medicine and Dentistry, 2015

#### Social Transfer of Stress in the Environment





To view the video that was played during the meeting, please contact the presenter.

#### **Built Environments Can Either Support or Hinder Well-Being**

Features that reduce stress and anxiety help to make home *a safe place of serenity* 





#### 9 Design Features that Promote Health

Strategies to support physical and mental health and well being:

- 1. Single bedroom with own bathroom (privacy)
- 2. Calm, naturalistic and local artwork and photos
- 3. Muted southwestern color pallet (pale orange, blue, gray, green)
- 4. Plants (non-toxic)
- 5. Acoustic ceiling tiles or carpet to dampen noise
- 6. Window with a view of nature/greenery
- 7. East-facing window for morning light (circadian rhythms)
- 8. A place to retreat to
- 9. A place to meet with others

(Linebaugh, 2013; Hamlin, 2015; DuBose, 2016)









#### **Additional Health Supports**

- Organic whole foods diet
- Regular exercise routines
- Social connectedness
- Sleep hygiene routines
- Non-toxic environmental cleaners and building products







Feeling safe and connected



Fast Facts about
The Center for Discovery
MONTICELLO, NY

#### Contact:

Dr. Terry Hamlin
Associate Executive Director
The Center for Discovery
mediastudio@tcfd.org
www.thecenterfordiscovery.or
g

1200

ADULTS AND CHILDREN SERVED ANNUALLY 12,000

PEOPLE IMPACTED BY PROGRAM ANNUALLY 1650+

FULL TIME STAFF

**23** 

PEDIATRIC RESIDENCES

23

ADULT RESIDENCES

336

PEOPLE LIVING IN TCFD RESIDENCES

**55** 

TRAINING CONTRACTS WITH SCHOOL DISTRICTS 12+

MAJOR UNIVERSITY AND RESEARCH PARTNERS 90

MILES FROM NYC























### THE KELSEY

more housing | more inclusion | more community





















Because housing can be more

+ together we can domore.

www.thekelsey.org

All Content © 2019 The Kelsey®





## <u>Video Link:</u> <a href="https://videocast.nih.gov/summary.asp?Live=3">https://videocast.nih.gov/summary.asp?Live=3</a> 3279&bhcp=1&start=11838&stop=11874



## The Kelsey creates mixed ability, mixed income residential communities and partners with organizations and entities who seek to do the same.

- Published leading disability housing research at Harvard.
- Incubated at the Harvard iLab.
- Initial seed funding from Chan Zuckerberg Initiative. \$11 million in city funding. Secured \$7+ million in land for first projects.
- Developing first communities in the Bay Area with focus on defining scalabledevelopment approach.











### Convened 300+ cross sector stakeholders in a three part workshop series







- Project approach: Identify the Problem, Align the Resources, Design the Solutions, and Plan for Next Steps
- Focus on cross-sector awareness and actionable commitments
- 10Interventions ID'd
- Read full report at <u>www.thekelsey.org/togethermore</u>



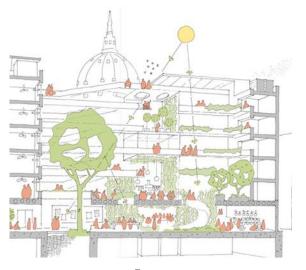
## Our first projects are in development in San Jose and San Francisco that include ~25%homes for adults with intellectual and developmental disabilities.



#### San Jose

SARES REGIS

- 115 homes
- Mix of I/DD, affordable/moderate income, and market rate homes.
- Rental project. Transit-oriented.
- \$11 million city funding.



#### **San Francisco**

mercy

- 102 homes.
- I/DD included in affordable, moderate, and middle income housing.
- Co-living. Sustainability focus.



# Our model aims to address the primary housing barriers for adults with IDD around affordability, accessibility, and inclusivity.

Financing Issue

Design Challenge

**Operations and Culture** 

**Affordability** 

Accessibility

Inclusivity



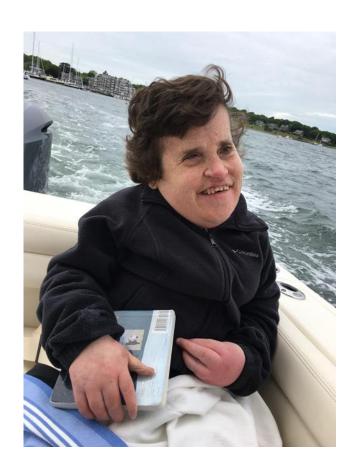






#### Kelsey's favorite sign was more.

- More (and new!) partners and resources can and must leveraged to address the shortage of housing for adults with disabilities.
- More individuals can be served when we collaborate within in our disability sector.
- **More** inclusion is desired by *all* people.
- **More** is possible when communities include people with disabilities.







# Discussion



# Break



**TUESDAY, JULY 23, 2019** 

IACC WORKSHOP:
Addressing the Housing
Needs of People
on the Autism Spectrum





# Meeting of the IACC



### **Afternoon Agenda**

2:25

**Apartment/Dispersed Community and Service Delivery Models** 

The Arc Jacksonville Village

Jim Whittaker

President/CEO, The Arc Jacksonville Jacksonville, Florida

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Alison Singer, MBA

**IACC Member** 

President, Autism Science Foundation

4:30 Closing Remarks and Adjournment



# The Arc Jacksonville Village

Jim Whittaker, President/CEO
The Arc Jacksonville



# The Arc Jacksonville Village

### Video Link:

https://videocast.nih.gov/summary.asp?Live=3

3279&bhcp=1&start=13308&stop=13576



# The Arc Jacksonville Village









## Dream – Answering What's Next

### Creating a vibrant community and lifestyle

- Concept was the result of input from persons served and families
- Independent living with staff supports
- Affordable long-term housing
- Opportunities for social engagement onsite and in the broader community
- Job placement support for community employment
- Safe living environment with access to 24 hour staff assistance
- Promote community inclusion without restrictions





























## Project Development

### Public, private, nonprofit partnership

- Affordable Housing Federal Tax Credits
- Government Grants
- Capital Campaign
  - Individual Gifts
  - Private Foundations
  - Corporate Grants

#### Long-Term Affordable Housing

- Support for employment and independent living
- Community inclusion and natural supports
- Replicate in other communities





# The Arc Jacksonville Village

Construction Development

#### Source of Funds

The Arc Jacksonville	\$2,898,328
Grants	\$1,500,000
SAIL	\$1,230,000
SAIL	\$1,790,000
Tax Credits	\$11,312,064

Total \$18,730,392

#### **Application of Funds**

Land	\$0
Construction	\$13,413,905
Soft Costs	\$1,808,692
Reserves	\$1,819,280
Developer Fee	\$1,688,515

Total \$18,730,392

#### Source of Funds

Start-up Expenses

#### **Start-up Costs**

Т	otal \$2,900,000
Endowment	\$1,000,000
Staff Training/Start-up	\$350,000
Equipment	\$300,000
Vehicles	\$250,000
Furniture	\$1,000,000
'	



### Village Personnel

### The Arc Jacksonville Village (Services - Private Pay)

### Management

Village VP-Director (1)

Director of Services(1)

### **Supported Housing**

Supported Housing Coach (4)

Live-In Coach (2)

### **Activity/Fitness Team**

Activity Coordinator (1)

Activity Coach (2)

### **Enhanced Personnel**

Personal Enrichment Counselor (1)

Nursing Student Training Project Manager (1)

### AmeriCorps/VISTA

AmeriCorps Members (4)

VISTA Volunteer Coordinator (1)

VISTA Research Coordinator (1)

### **Xplore – Offsite Team**

Community Lead Coach (1)

Community Coaches (1)

# Royal American Personnel (Housing Management)

### Management

Community Manager (1)

Assistant Manager (1)

#### Maintenance

Maintenance Supervisor (live-In)

(1)

Assistant Supervisor (1)

### Security

Courtesy Officer (1)

Courtesy Officer (1) PT

### **PT Villager Positions**

Janitorial Aide (2) PT



## The Arc Jacksonville Village

#### Rental Rates

Unit Type	Total Units: 120	Rent	Utilities
One Bedroom – Low/low*	19	\$326	Not included in rent
One Bedroom – Regular**	49	\$606	Not included in rent
Two Bedroom – Low/low* Split with apartment mate	13	\$326	Includes utilities: electric and water
Two Bedroom – Regular** Split with apartment mate	37	\$577	Includes utilities: electric and water
Two Bedroom – Low/low* No apartment mate	1	\$545	Not included in rent
Two Bedroom – Regular** No apartment mate	1	\$751	Not included in rent
Total Residents	121		
Two Bedroom - Staff	2	\$0	Not included in rent

### Services Rates - Private Pay

Level I - Basic - \$900 monthly (includes auxiliary) | Level II - Advanced - \$1,300 (includes auxiliary)

Auxiliary - \$270 monthly

<sup>\*</sup>Eligibility for a low/low rent is based on having a maximum of \$16,170 in combined annual benefits, wages and other sources of income. A total of 19 one-bedroom units and 13 single-bedrooms in a two bedroom unit are available. All remaining units are leased at the regular monthly rent

<sup>\*\*</sup>Income eligibility for a regular rent unit is a maximum of \$29,400 annually which includes a combination of benefits, wages and investor income.



# Apartments







# Apartments







# Apartments







# The Arc Jacksonville Village

#### **Quick Facts**

- Opened April 2016
- 100% occupied
- 97 apartments
  - 67 One bedrooms
  - 34 Two bedrooms
  - 2 Fulltime, live-in staff
- 120 total resident bedrooms
- 121 total residents
  - 65 male
  - 56 female
- 61 private pay residents
- 60 Medicaid Waiver residents
- 37 Medicaid Waiver with auxiliary services residents
- 79 residents employed in community
- 75+ activities offered monthly
- Dinner meal can be purchased
- 4 Village vehicles- shuttle service

#### **Amenities**

- Pool
- Hot tub
- Game room
- Movie room
- Fitness room
- Activity rooms
- Dining room with stage
- Commercial kitchen
- Basketball court
- Garden
- Gated
- Overnight, onsite security
- Arc personnel assistance call system





## **Amenities**







## Amenities







### Connectable | Overview

# CONNECTable

ENGAGING PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DIFFERENCES

Connectable is an awareness campaign to enhance connections within the Northeast Florida community with people who have intellectual and developmental differences.

#### Goals

- Compelling people to educate themselves and take a pledge to be more connectable
- Increasing interactions between individuals with IDDs and the typical community
- Encouraging employers to consider hiring individuals with IDDs
- Evolving terminology from "disabilities" to "differences"

# Connectable | Tactics & Outcomes

### PSAs | Website | Vignettes | Public Relations | Events | Social Media

The three-month campaign exposed hundreds of thousands of First Coast residents to these ability-focused messages. In addition to paid advertising, media outlets donated an average of 50 percent in free PSAs or added value.

Feedback from agencies and people in the IDD community included:

- A feeling that there was a community-wide increase in embracing those with IDDs
- A shift in the vernacular more people saying "differences" than "disabilities"
- A desire to continue to move the campaign forward









# Connectable | Resources

### Connectablejax.com

### CONNECTABLE

#### WHAT IS IDD?



Intellectual and developmental disabilities (IDDs) are a group of disabilities that begin at birth or in childhood that can affect a person's intellectual, physical and emotional development. People with IDDs have problems with both intellectual functioning and adaptive behaviors, which are everyday life skills like self-care communication and

common causes are genetics, problems during pregnancy or childbirth, and childhood liness - but the cause of IDDs are unknown in two-thirds of cases.

#### What Conditions Fall Under IDD?

- What Conditions hall under IDD?

  IDD is a term that encompasses a variety of diagnoses.

  While some DDs have physical signs and symptoms, others can be invisible to the eye. Some of the most common ones are:
- Autism spectrum disorder
- Down syndrome
- Fragile X syndrome

#### How Dravalent are IDDs?

How Prevalent are IDDs?

IDDs can happen in any family. There are no radial, educational, social or aconomic boundaries when it comes to IDDs. An estimated 6.5 million Americans have an intellectual or developmental disability, and approximately 1-5 percent of the ejiobal population is affected - or as many as 200 million people.

#### What Limitations Do People with IDDs Have? People with IDDs are like everyone else – they have unique interests, values and personalities. They cherish their family and friends, and they are capable of contributing to the community.

Since there is such a broad range, the abilities of people Since there is such a hicket singe, the abilities of people with 10Ds can vary geastly. About 85 procrat of people with 10Ds have a mild form and can succeed in school and work. However, in more severe cases, they may only be able to communicate on the most basic level. Regardises of abilities, people with 10Ds are not "aternal children" - lids with 10Ds become adults with 10Ds.

#### What Language and Terms Should You Use?

venue. Lenguage is an important part of acceptance and Language is an important part of acceptance and undestanding. Experts in the IDI community have outlined forminology that ensures people with IDIDs are treated with individuality and dignity. Some of the best practices include:

- Use "people-first language." This means you refer to a person with IDD rather than an "intellectually disabled person."
- Say a person has an IDD rather than "suffering from,"
   "a victim of" or "afflicted with" an IDD.
- . Avoid the word "unfortunate" when referring to a person with IDD.
- . When discussing IDDs, people without one are referred

### mean they aren't paying attention.

### CONNECTABLE

#### **APPROACHABILITY**

CONNECTING WITH PEOPLE WITH IDDS

People with IDDs can form strong personal connections like anyone else, but many people feel uncomfortable about or don't know how to approach them. When you do take the time to connect with a person with an IDD, you'll that can last a lifetime.

#### Treat them like you would any other friend

- or acquaintance.

  The most important thing to remember when interacting with people with IDDs is that they are interacting wint people wint Libb's that they are generally just like everyone else. They are individuals with their own opinions, passions and thoughts. Show them respect and kindness. Use open body language and a smile.
- Approaching someone with an IDD for the first time is just like other first meetings. Introduce yourself, ask questions, listen and share your thoughts. Unless you know specifics about them, there's no need to behave

#### Don't speak slower or change your communication style unless they ask.

- Many people with IDDs can understand regular speech, and slowing down or modifying how you talk can be and slowing down or modifying now you task can be condescending to them. For example, baby talk or a singsong voice should not be used for teenagers and adults with IDbs. Talk at your normal speed and volume, and they will let you know if you need to change.
- Give them time to express themselves at their own pace. Some of them may stammer or have trouble connecting words, if they get frustrated, upset or distracted, don't take it personally. Stay calm and enjoy

#### Speak directly to people with IDDs, not to other people

- Most people with IDDs prefer to be directly addressed. even if they seem quiet or withdrawn. A frustrating, if common, experience for people with IDDs is when people hold entire conversations about them as if they
- You shouldn't assume people with IDDs aren't listening based on their body language. For instance, people with autism can fidget and look elsewhere, but it doesn't



- but do so in an open-ended way such as, "If you ever need any help, just let me know."
- If you see someone struggling, you can ask "Do you need help?" or "Would you like me to help?" Then, lister to their answer. If they say no, remember that they know themselves and what's best for them. They can tell you if there is a problem with which they need help

#### START A CONVERSATION TODAY.

- It's always a great feeling to establish a genuine connection with someone. So never be afraid to have connection with someone, so never be arraid to nave a friendly conversation with someone with an IDD. Ask them about themselves. For example: "How are you?" "What are you doing today?" "What are your favorite things to do?"
- If you're ready to connect with people in Northeast Florida who have IDDs, learn more ways that you can get involved by visiting ConnectABLE Jax.com

#### EMPLOYING PEOPLE WITH IDDS:

WHAT YOU NEED TO KNOW

People with intellectual and developmental differences (IDDs) are often reliable, hardworking employees who can contribute to your team, but many employers are uncertain about what hiring a person with an IDD might mean for their business. Here are the answers to some commouguestions you may have about employing people with IDDs.

What are IDDs and who is qualified under the definition? functioning level (IQ) is below 70-75, has significant limitations in adaptive skill areas as expressed in conceptual social and practical skills, and the disability originated

#### What are the federal laws?

The Americans with Disabilities Act (ADA) prohibits discrimination against qualified individuals with disabilities by private employers with 15 or more employees as well as

#### What are the laws in the state of Florida?

For public employers in Florida, under Florida Statute 413.08 section 5, employment can't be refused based on a disability alone, unless it has been proven that the disabilit

What can you ask during an interview?
An employer should be prepared to ask questions related to the position's essential tasks. You cannot ask about the applicant's medical condition, but you may ask questions like:

- Can you put things in alphabetical order? Can you place items in numerical order?

You can also ask an applicant to demonstrate or describe how they would be able to perform a specific job function.

can then inquire if they will need any accommodations and what type. You can't ask if they need an accommodation unless the information is volunteered or it is visually obvious that they have a disability.

#### What can you ask a new hire?

new employee's health if the same questions are asked of every new hire. You may also ask for documentation from a health professional answering questions designed to assess



the new hire's ability to safely perform the job's functions. You may not withdraw a job offer based on the applicant's IDD if the applicant can perform the essential functions of the job with or without a reasonable accommodation

#### Will my insurance rates go up?

Will my insurance rates go up?
A popular misconception is that if you hire an employee with an IDD, your insurance rates will increase. However, according to the U.S. Equal Employment Opportunity Commission, studies have shown that hiring a person with an IDD won't lead to higher insurance rates or more

DISABLITY DISCUSSIONS
What can you ask a memployee?
Generally, an emcloyer may ask disability-related questions
or result an employee to have a medical examination
or result an employee to have a medical examination
condition, has observed performance problems, and
reasonably believes that the problems are related to a
medical condition. An emcloyer may also ask for medical
reformation if they have received related information from that is causing performance problems. However, most of the time job performance is unrelated to a medical condition and should be handled according to company policy.

LEARN MORE AT ConnectABLEJax.com | #IAmConnectable | f 🖾 💺

### The Faison Residence

Highlights of An Inclusive, Semi-independent Housing Community for Adults with Autism



Pioneering Possibility

Video Link:

https://videocast.nih.gov/summary.asp?Live=3

3279&bhcp=1&start=14347&stop=14692

### Faison Residence

- \* 45-unit apartment complex in Richmond, VA (1-, 2- and 3-bedroom options)
  - \* 1/3 units for individuals in our program
  - \* Majority of units for members of the community
- \* Access to 24/7 supports (Live-in Counselors)
- \* "Smart home" technology (safety, privacy, dignity)
- \* We accept VA Medicaid Waiver, housing vouchers\*, private insurance, private pay

### Faison Residence

- \* Average age: 28-y/o (22- to 39-y/o)
- \* 72% competitively employed; at least 20-hrs/wk
- \* 88% SSI/SSDI; 83% Medicaid Waiver
- \* Since 2014, two "graduated"; 3 ready to transition (regulatory barriers)
- \* Out of 18 individuals: two earned learner's permit; 90% mastered public transportation (GRTC & Pulse); 100% ride sharing

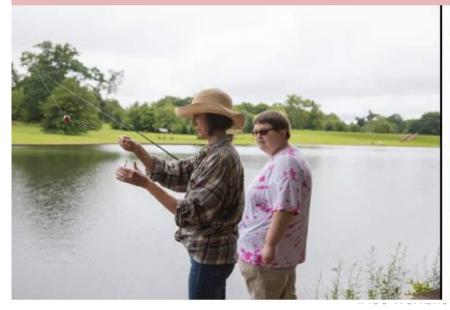
### Lessons Learned

- \*Open, self-managing system (Reporting results, accomplishments, and progress at least monthly)
- \*Proactive communication (e.g., Program Handbook; SOPs; monthly newsletter)
- \*Consultation
- \* Preference Assessments

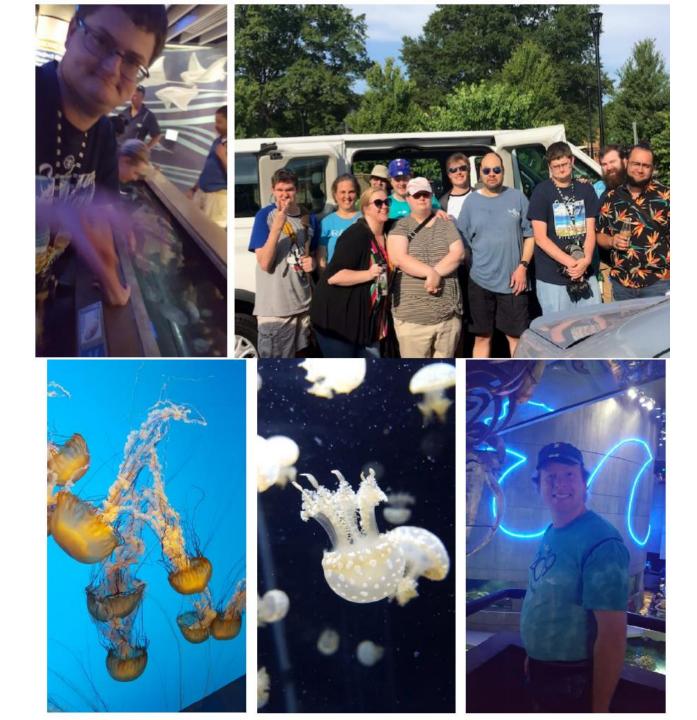




Fishing with Beyond Boundaries at Byrd Park

























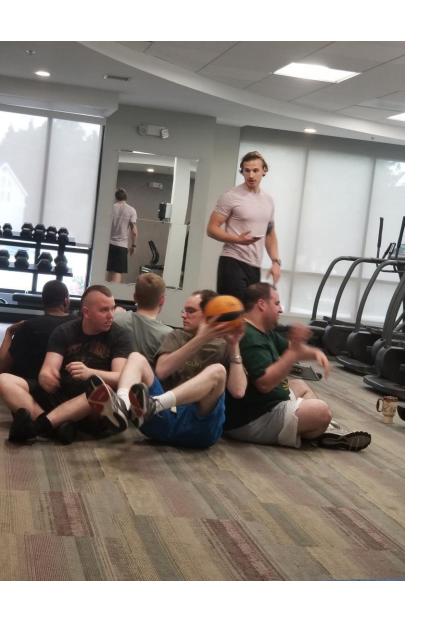




Saturday in Nature!
Cleaning up Bell Isle
Visiting Crump park
and taking a photo of
some sheep.







### **Mission**

ILO helps 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 Link:

https://videocast.nih.gov/summary.asp?Live=3

3279&bhcp=1&start=15200&stop=15315



## Four walls do not make a community, nor does it create independence



### **About ILO**

- •ILO was founded in 2014
- Today ILO supports 28 individuals, 17 have moved in to their own places in one of ILO's five communities:
  - Upper Montgomery County
  - Gaithersburg
  - Bethesda
  - Washington DC
  - Northern VA







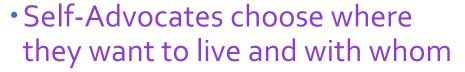
### Community-Based Independent Living

ILO's community builders (staff) help

- the self-advocates build relationships
- develop networks of support
- maintain and develop daily living skills



### **Inclusiveness**



- ILO facilitates peer to peer relationships between selfadvocates and with neighbors and the wider community
- ILO fosters the full inclusion of the self-advocates and provides the supports that ensure success





### **Affordability**

- Services are selected by the families and the self-advocates
- ILO is a DDA approved vendor for individuals who self-direct.
- ILO is a resource to families on public and private funding sources





### Sustainability

- ILO provides guidance to families for funding resources
- ILO has grant and foundation funding and individual donors
- Facilitation of long-term funding and care management when parents are unable to do so





### Program

- ILO Family Training
- Full Life Process™ Skills Inventory
- Establishing Supports and Staffing
  - Community Life Coordinator
  - Community Builder
  - · Life Coach
- Long Term Planning and Facilitation





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### **Integrated Living Opportunities**

Creating Communities for a lifetime...





### Thank you! Join Us Now!

Integrated Living Opportunities www.ilonow.org 202.248.7113



# ABLE's Journey with Housing

may your walls
know joy:
may each room
hold laughter,
and may every window
open to great possibility
-Mary Anne Radmacher



### Introduction of Mary Anderson

- Bachelor's of Nursing from the University of North Dakota
- ABLE, Inc. was formed in October 1984
- Mary joined ABLE, Inc. in October 1985
- Executive Director for 21 years
- ABLE serves 100 people with ID in SW ND; Hettinger 75 miles away, Bowman 90 miles away. Many medical services are 100 miles away.
- RURAL provider
- Mainly support people with intellectual disabilities.
   We are interested in serving adults on the autism spectrum and believe that the housing considerations are similar.



### ABLE, Inc. Values & Beliefs

#### WE VALUE RELATIONSHIPS

- We believe that ABLE, Inc. has the power to weave lives together making our communities more interesting and more beautiful.
- We believe that we are all keepers of people's reputations and that we must be vigilant in understanding and promoting each other.
- We believe and have witnessed the power of positive relationships through side by side walks with people.
- We believe that by transforming one life, you transform many.

#### WE VALUE COMMUNICATION

- We believe in hosting deep continuous conversations and observations to reveal people's true spirits and dreams.
- We believe that by being careful listeners we can hear how to help someone with their life journey.

#### **WE VALUE STORIES:**

- We believe that every person has a story to tell which are masterful ways to speak to the universe.
- We believe that those stories are the force of connectivity that ties us together and helps us understand that we are more alike than different.
- We believe that life is about choices, which evolve into moments, which evolve into stories, which evolve into journeys.

#### WE UNDERSTAND, APPRECIATE AND EMBRACE CHANGE

- ABLE, Inc. is the entrepreneurial spirit that is not satisfied with what is but delights in creating what isn't.
- We believe that all people have the power to change the world in big and small ways.
- We believe that in order to teach others you must be taught. We are lifelong teachers, we are lifelong learners.

#### WE VALUE HEALTH CARE PROMOTION AND REMEDIES

- We are dedicated to promoting the physical, spiritual and emotional well-being of people we support and invite our general community and health care community to encircle people with care, kindness and hope.
- We believe that well-kept health histories are paramount in keeping and promoting good health.



- Our support of people was not in alignment with our values
- ABLE had three group homes; each home had 8 residents who were not all compatible



### We had to get creative.



### Everyone should have choice of where to live.

The reality for all people is:

Choice is limited to affordability

For most people with intellectual disabilities, choice is limited to the umbrella of affordable (low income) programs.

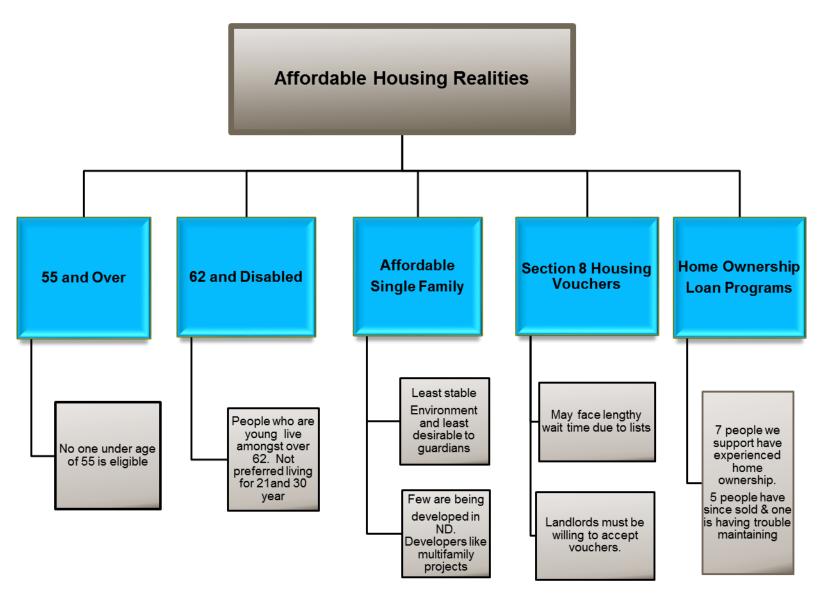
Here are the options as we know them...



### Affordable Housing Options

- 55 and Over
- 62 and Disabled
- Affordable
- Single Family
- Affordable
- Multifamily
- Section 8 Housing Vouchers
- Home Ownership
- Loan Programs







Affordable- Multifamily was available in 2006 in Dickinson. ABLE used this program to help reduce group home living. 16 people moved out of 2 group homes to apartments in one day.

#### What we knew

Forced people into roommate situations

### What we later understood----

Designed for one

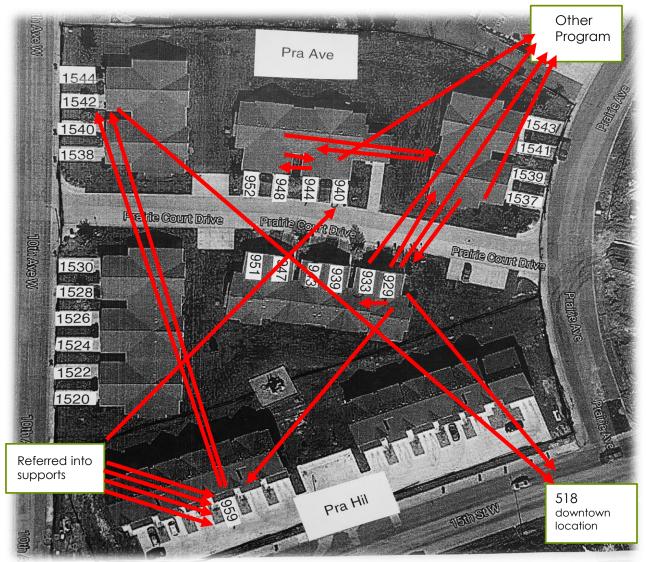
wage earner & child -Thus the large bedroom and the smaller bedroom/s

### What we later understood—

Based incomes on combined income, not per person.



### From 2006-2015:



21 moves
were
completed
mostly to
address
roommate
incompatibility

Including the incompatibility of the 4<sup>th</sup> roommate...



#### His owner called him Foxy...

### We called him **KILLER**:



Foxy loved to protect her new owner and would often nip at visitors and bark in a loud, shrill bark every time that anyone entered the home.

One roommate was sensitive to sounds and made it clear that either the dog goes or she goes.

Despite all efforts by support staff, the roommate was the one who had to go...

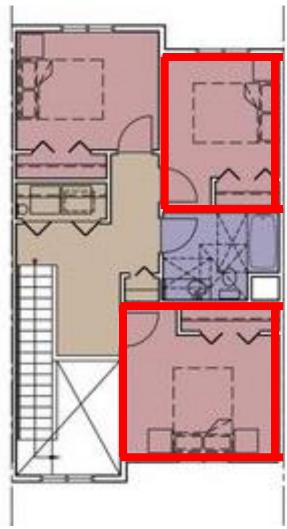


### Other Incompatibility Issues:

Stairs...



Different bedroom sizes...





### Other Incompatibilities...

Income Qualifications (Combined Household)
Stark County, ND

Income Levels for People Supported		Stark County Income Limits 2019		Combined Income	
AS	\$20,580	1 bedroom	\$35,250		
SS	\$11,341	2 bedroom	\$40,250	AS/SS	\$31,921
СН	\$16,958	<mark>3 bedroom</mark>	<mark>\$45,300</mark>	AS/SS/CH	<mark>\$47,905</mark>

**NOTE**: Roommates combined income may not qualify for housing **NOTE**: Income variations are a consideration for roommate choice.

 Because of the 4<sup>th</sup> roommate, Killer, CH left. AS/SS remained. With equal rent split:

AS rent = 24% of annual income , SS rent = 43% of annual income

If not equal, who decides how rent is split?

**NOTE:** even with 43% of rent share, SS didn't qualify for heating assistance or any programs that considers joint household income



### **Housing Creativity**

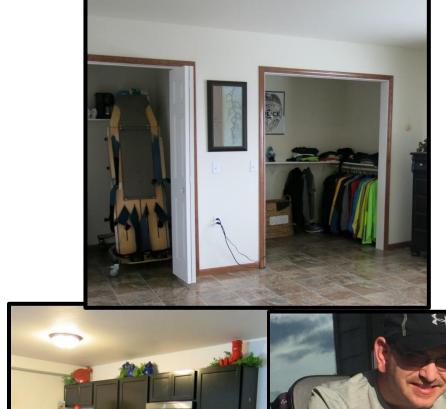
Housing 101 -----know thy people

Then build for them





The fully accessible unit has room for equipment, a whirlpool tub as well as adequate room to maneuver.







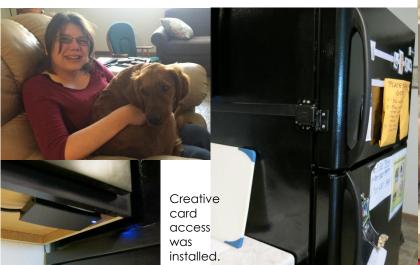


"THE MAGIC THING ABOUT HOME IS THAT IT FEELS GOOD TO LEAVE, AND IT FEELS EVEN BETTER TO COME BACK"



Wendy Wunder

Modifications were made such as larger bathrooms, card access for easy entry to locked areas, as well as a fully accessible unit.







### Results of our housing initiatives

- Increased personal preferences and desire for social connections
- Increased self-determination and pride. In 2018 people said that they were "living in a palace" and "feel like a queen in a castle"
- Increased <u>family involvement</u> and natural connections
- Increased security in knowing that support is nearby
- Was less intrusive and more natural
- Decreased challenges in daily life
- 12 people who had rights limitations due to roommates were now able to exercise freedoms. A total of 15 rights were reinstated



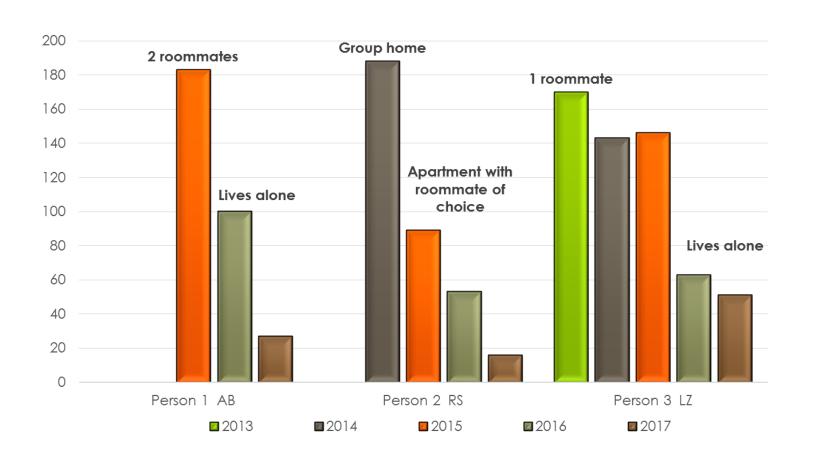
### CMS sees scattered housing as optimal: However.....

- Many housing programs force roommates.
- Roommate combinations are NOT identified in CMS bullets for heightened scrutiny.
- Yet, roommates are often incompatible.



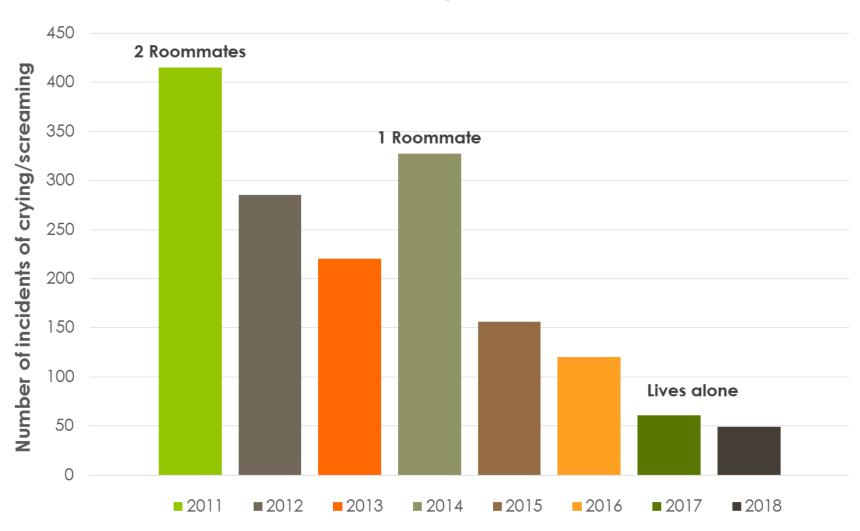
Sampling of 3 people's behavioral data after moves:

### Frustrations Decreased in Relation to Housing Changes





### Another woman's journey ...



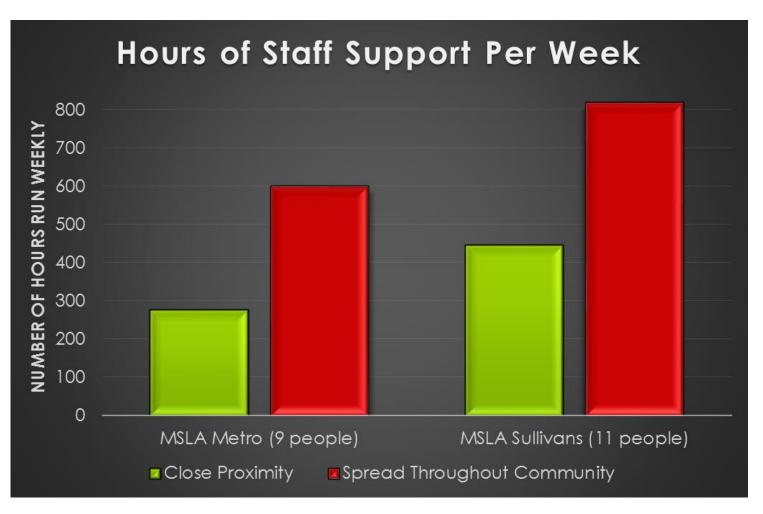


### CMS sees scattered housing as optimal: However...

- Scattered housing increases the need for more staff hours.
- o For example, at ABLE, 20 people who are currently living in apartments within proximity receive intermittent supports throughout the day. If scattered throughout the community, 14 of the 20 people would need 24-hour supports!
- 24-hour supports are highly restrictive. i.e. many people find it undesirable to have someone constantly in their homes. Ask about LB. Ask about MH.
- 24-hour supports have a high fiscal note



### Fiscal Note of proximity housing versus scattered housing





#### **ABLE, Inc.'s Human Resource Crisis**

 ABLE has 20 DSP positions open out of 63 since 2012. If scattered housing, where would we find the staffing support?



# ABLE believes people need multiple housing options...

- Scattered housing
- Apartments that are in close proximity for people who need on-site 24-hour support
- ICF/IID homes where 2-3 DSP's are readily available to support one person.
- Campus environments where people have free movement without fear of traffic or neighbors who would not understand people's communication styles
- Modifications that accommodate accessibility, sensory, etc.



#### In Conclusion:

- We have other solutions to housing that are very successful
- We have created several unique technological advances that have promoted more freeing environments for people
- We would love to answer questions and are excited to hear of other's experiences in the journey of housing understanding

# Thank you for this opportunity to join the conversation!



## Discussion

# Personalized Adult Services and Housing Navigation



Workshop: Addressing the Housing Needs of People with Autism Tuesday, July 23, 2019

Shared Support Maryland, Inc. sincerely thanks The Interagency Autism Coordinating Committee and the Panel for selecting us to present

#### Inc. Resources

- SSMD has no assets ~ nothing to fall back on.. for anyone...
  - no housing, no spaces, and no money in the bank to buy housing if we wanted to! Service is 100% separate from house
  - Our time and resource is best spent assisting people to gain their own assets rather than holding them for them...
- Our relationships and resources are there for the taking and using.
   Meaningful and enduring relationships are fruitful and necessary in

life.

#### Control, Power, Sense of Self Worth

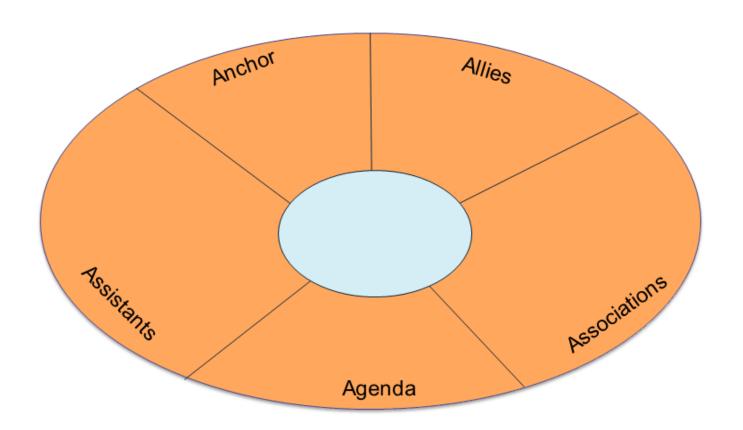
- Three times we co-signed a lease....
  - SSMD was in control ~ we co-signed and we paid
  - we lost our money because people were used to a culture was "that it will be taken care of..."
  - we ultimately asked everyone to leave and go on their own
- People with disabilities shall be in control, learn like everyone else about being responsible for their homes

#### Natural Everyday Tactics?

- Treating people with the same level of respect and as if (in fact) we are on the same level playing field. People are valued ~ the assumption is everyone wants the same things ~ in the way that they want them.... We start with the person first
- Naturally, one of our tactics would be to support people at all cost to want to and to become employed ~ which naturally opens doors financially, gained resources (movers for example) and connections.
- Knowing and connecting people to housing experts like landlords, real estate agents ~ not human service

#### Planning and Executing

Maryland Person Centered Housing Collaborative. Gathered resources and developed a plethora of tools for people on planning for and obtaining housing of choice. When people are looking for places to live ~ they have resources (people, natural support, \$) or they need the resources.



The  $\underline{resources}$  people need are not a team of human service professionals  $\sim$  but housing and home professionals.

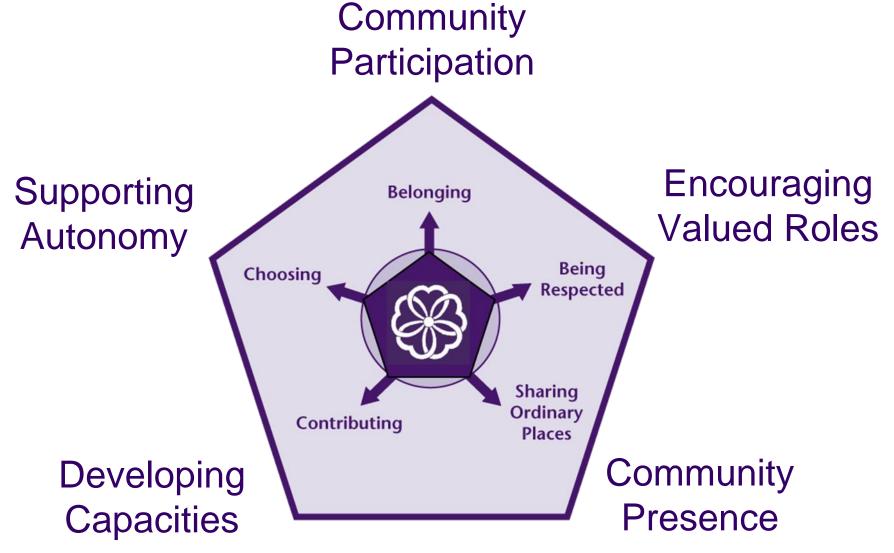
- they need to know the housing stock and the neighborhoods
- they need to know the housing programs (financial)
- they are landlords
- they are realtors

resources....

Pulling this group together in and of itself increases the likelihood of someone successfully obtaining housing of their choice  $\sim$  to gain housing near people you want to live, where you need to live based on needed resources or WHERE you have the most

#### Then "We" Get to do our Job

#### **Service Accomplishments**



O'Brien

#### LOU

Planning and execution centered around:

Lou's exceptional sensitivities,

neighborhood in Baltimore City.

- being near his father (the apple of his eye) but not on top of,
- possibilities not probabilities based on his reputation and actions living in an institution.

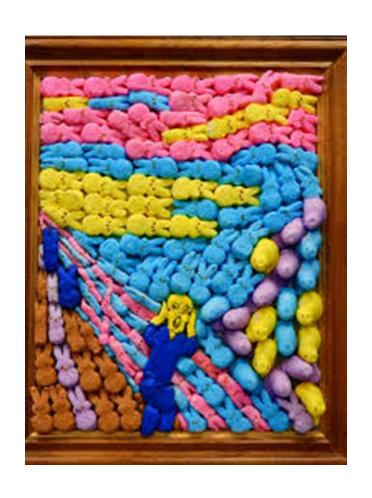
Lou was the last to leave this institution before it closed and 10 years later he still lives in his row home back in his old

#### Jacquie

Involved in 100 pilot projects that "did person centered planning" and had a huge team of people that believed nothing other than inclusivity... yet the provider could not execute anything but group homes and inaccessible boarding homes. When she had a team that could plan together with her and execute ~ she began knocking things off of her bucket list – 41 – she said she got to do  $40 \sim$  this included

choosing her place, living there and painting a wall purple....

#### Wait - no voucher?



#### **Tony**

- History of control, punishment and 24/7~ email from Tony's provider that said I was making the biggest mistake I ever made
- Plan for and go get:
  - Real JOB ~ multiple jobs to be able to afford
  - Increased resources ~ he had none, always teetering)
- Issues along the way roommate, landlord, subsidy to no subsidy
- Roommate, no roommate, no where to live, shared spaces
- Team ~ coordinator versus direct support
- "Would never go back" ~ no matter what these were always his own places...



Who I am is where I live... Where I live is who I am...

# Safety, Behavior, Risks ~ the Concerns that Stop the Movement and interfere with continuity and security

 Stability – How is support structured?, Does the person want the support?, Real life back up plans and risk planning ~ is the risk. Planning for risk, are the risks really different for people because they have autism, another or multiple disabilities?, are the results resolvable, dangerous?

#### Welcome to Sean's Plan ~

#### PRESUME COMPETENCE

It is important that a new provider understands that this is Sean's plan and it goes with him and stays (fluidly) throughout his life. They should be equipped and committed to implement this plan and use the plan in it's form, or something very close, to it to follow it and it's success. This is a core – all pieces of plans, special plans and other wonderful things belong together ~ here ~ one plan.

Sean is one person...

PRESUME INTELLIGENCE

#### A Vision for Sean's Future!

- (Margaret) Sean will evolve and become a more individualized person and will have a job making sandwiches, doing something with landscapers like at the Christmas tree farm! and learn to read. He will blossom... (let's keep all of these things in our head). If he has the supports he needs it will relieve him of all of the anxiety he has he'll focus... there will be no missing pieces... Jet skiing!!!
- (Amy) Sean having a job outside would be amazing and he would be motivated to do it (as long as he's outside he will do great)
- (Earle) Sean is an adult that has control over his destiny and what goes on in his life. Whatever happens is driven by Sean this is fundamental to his successful future.
- (Laurie) Seeing Sean on a boat fishing!!! He needs to be out on the water.
- (Mary) Support is plentiful for his success and his satisfaction!

#### Thinking about Sean's NEW! Home

- Ideal Location Baltimore County 10 minutes from mother, park like / serene setting, someplace where we can access the water and go fishing, where we can access the extra support that Sean will need to help him, near an Amore's and a good sushi joint. A house (vs apartment) would be best where the neighbors are a mile apart with a little bit of wooded area and if he could do yard work. He needs to take care of where he lives.
- Pet friendly. Sean would like a cat from the SPCA.
- Where he could do a lot of recreational things scooter, swim club locally YMCA close.
- Entertainment in the house so that he can watch DVD's and listen to his music. (when he watches his DVD's he wants to be by himself he has a whole set up). He likes his private quiet time needs to have an area where he has time to be alone more space than bedroom)
- Bubble baths ~ bathroom must have a tub or a Jacuzzi
- Allergies are seasonal nothing major so no accommodations are neccessary
- Open layout big window he can look out it makes him feel less confined

#### Safety needs of the home

- Plexiglass in the windows
- Pictures no glass
- Recessed lighting no lamps
- Fenced yard
- Secure doors entrance ways fire safe and doesn't have quick access to leave (alarms maybe, bell...)
- Furnishings nothing glass, very sturdy furniture that's tough, large appliances, TV and furniture should be secured well so that they don't move. Built in's are great. Now there is plexiglass in front of the TV. He hasn't broken glass from TV's in the past.
- No glassware, plates, etc.
- No coffee makers, toaster ovens, all appliances away
- Cabinets support to use and make sure they are secure
- Safety protectors on all outlets or covered entirely (so that he can't grab or pull them out)
- Bathroom water temp low enough so that he can't burn himself
- Bathroom mirrors & vanity lights need to be VERY secure to the wall so that they cannot be torn off (built in)
- Non skid stickers
- Toilet lid lid is an issue toilet without detachable lid
- Zip tied down lid of the basin
- Bed and bedding bed heavy enough not to be able to lift (platform bed), mattress secured, blankets to be really warm – heavy blankets
- Chairs bean bag chair, futon chair (nestling)
- Rocking chair or a swing calming
- All cleaning supplies away

#### Thoughts on Roommates

- He has a roommate now... and it's ok...
- What kind of person is Sean's ideal roommate?
  - Someone that is similar to Sean in many ways... positive influence...
  - One housemate or none no more, not a group home
  - Close in age
  - Perhaps someone that does not have complex medical needs?
  - Similar or less support needs
  - Someone he can communicate with (important TO Sean that the person talks and he can have a relationship with them
  - Someone that has the same interests or a few things that are in common
  - Male
  - He likes people that are DO'ERS that like to ride scooters, interacting together
  - Many different types of people are accepted by Sean

#### People around Sean...

- Having people around Sean is important.
- Those that are in a paid support role shall remember that they are there because of Sean and not let their attention slip.
- The roommate and Sean shouldn't be passively living together –it's important to Sean that they have a relationship and are able to interact
- Sean's staff ~ Jeremy, Kevin and Ian ~ are examples of people that would be perfect roommates
- Everyone needs to understand his intuition...

#### Tips to Be Successful in Supporting Sean

- PRESUME COMPETENCE
- PRESUME INTELLIGENCE
- Balancing adulthood and supporting Sean as an adult is essential. Making mistakes is part of life and having no punishment outside of natural factors are part of adulthood. This is going to be a major transition.
- We need do a separate list of antecedents "day wreckers" so that we can build a good positive support plan. (Amy is helping here)
- The best time to redirect him is right away use the support plan. Communication and consistency is really important.
- Understanding the cues prior to Sean getting highly upset and anxious are extremely important and will be successful
- We can't always predict when Sean gets upset which makes things more difficult ~ plan needs to wrap around this
- KNOW that there are mental health components that need to be supported and appropriate medication and following it is essential to his wellbeing (anti psychotic and anti anxiety medications for impulse control, mood disorders) understanding where it comes from is essential in building the support plan different tactics are going to be needed.
- Understand that what we view as Sean's negative behavior is a response to the inability to control his life and environment this can take over his world. He is gaining this back slowly... he needs to be kept on this track...

#### Tips to Be Successful in Supporting Sean

- Some issues for Sean that lead to high levels of anxiety
  - He likes to initiate conversations with others (vs. people initiating with him) he is in control it works for Sean and is VERY important to remember...
  - "too much attention" can be discouraging... remember he should be the initiator of conversations and activity as much as possible
  - Overstimulation ~ regular crowds are not a problem. Sean gets very anxious when all eyes are on him. Sean does not like to be the center of attention
  - Broken promises. The factor isn't that an event or activity was cancelled it's because he builds up so much excitement and anxiety about it it's a major crash. Anxiety itself can be a problem and can set him up for failure.
  - How one speaks to Sean is a major factor non demanding, easy going, not a hard approach, non-authoritative, subtle approach ~ balance all of this with stern/serious.
  - Any negative energy or conversation about Sean around him. Do not talk about Sean in front of him.
  - He is very observant and is often underestimated.
  - Interrupting him mid "task" could be a trigger
  - When Sean's mom needs to leave... he gets upset. Help him get back to his school work, something positive and talking about future plans that he's very excited about and looking forward to. Point out the next fun event on the calendar. Help him get his mind off of it.

#### Tips to Be Successful in Supporting Sean (continued)

Some issues for Sean that lead to high levels of anxiety

- Phone calls (after a phone call), having knowledge of an upcoming visit or doctor's visit (these produce tougher mornings), novelty and newness speaks to a having a real support structure around him....
- Responding following his lead when he says he's done. (he will use this to get out of things he doesn't want to do)
- Same setting same target. Targets things that will crash or make a loud noise...
- Newness is exciting for Sean he gets very anxious.
- Holidays and birthdays are so exciting for him!!!

### Absolute Support ~ Try New or Better Ways of Doing Things – Sean is Worth IT!

- NEW! Daily schedule in a calendar he writes in the schedule. He keeps a schedule for the day, he carries a planner in his book bag, staff has a copy.
- NEW! Visual planner helps in planning and processing. He likes pictures best mom would like to try words he can write them he can learn to read (he likes to take pictures of birds this could be fun in developing the schedule). Too much information on the calendar (right now it's 15 minute increments) also causes anxiety. He likes to write notes.
- NEW! Staff trained in positive behavioral supports. Potentially training from Bill Stillman can be worked into his plan. Picture cue training ~ anything related to a system that increases happiness and decreases anxiety.
- NEW! Sensory blanket
- NEW! Medical appointments, blood work, all follow ups MUST be on time never late
- Sean will have a pop up tent to sit outside in his own space... it will protect him from the sun and this will help him be calm.
- List of things he must have bike, scooter, tent, fishing pole, roller blades...
- Sean wants to make earrings he ha asked for an earring kit.

#### Matching Staff

Supports wanted & Needed	Skills Needed	Personality traits & characteristics	Shared common interests
	Commitment to positive approach to behavior (not to use mat) and capability to implement a good plan	No worrying Keep things on a positive note Help Sean get excited (like for the prom or fishing)	In tune to Sean's needs
	Redirecting skills Let things go Tell Sean he's doing well when he's doing well!	Understand that people get off track Do not dwell on Sean making a mistake or having a bad moment or day	
	Organized, keep things on track, keep items in their places, help when things are lost	Introverted vs. extroverted. Get to know Sean on his terms and pace.	Have these so that you have something to talk about that matters
Job Development / Job Coaching (the community learning services)			

#### To Do List for the New Providers

- Attend training in July with Earle
- Know that the transition details need to be in place we will work together on a transition so that all of this can be included
- Staff are and stay trained in Positive Approaches to Behavior, Picture Scheduling
- Please (must) have a Community Learning Services waiver to your day hab.
   program
- Go to a Bill Stillman training www.williamstillman.com
- Provider will be supported in transition needs, training, accommodations...
- Work on Sean and his mother interviewing and hiring staff prior to the move. They all need to time together prior. They should begin working for Sean at least 6 weeks prior to the move. We need to work 6 weeks prior to the move date if there are not 6 weeks prior to the move date we need to move the move date.
- ....shall be part of the transition plan and shall also start when the new staff start. The support plan shall be based off of Sean's Person Centered Plan
- Two people supporting Sean when he is in the community... transporting and in case anything happens is essential.
- Reminder this is Sean's plan.... It's fluid and can change when things in his life change but this is something that stays with him.
- Check out technology... IPAD, etc...

# Impact on Long Term Planning

- What you do now <u>impacts</u> long term planning and major changes
- When people have their own  $\sim$  control, resources, support not contingent on housing service or ownership, etc. when a major life change happens ~ the loss of a family member, anchor or one resource will not affect the structure of the rest. Going through one or few transitions during this time is more palatable...



# **Among, A Part, A Real Member of Community**

- Civil Right
- Social Responsibility
- Medical Necessity
- Combats Isolation



"Community is tangible; community is cohesive; community brings people together in ways that allow them to do things they couldn't have done in isolation."



#### The Informal Support Network



## Discussion



# Final Discussion



# Adjournment

#### **Next IACC Meeting**



Wednesday, July 24th 2019