Housing for People with Intellectual and Developmental Disabilities: How do We Ensure a Home of Their Own?

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Overview

• Emerging issues in housing
• Trends in housing for people with intellectual and developmental disabilities
• Where do people live today and what outcomes do they experience?
• What do we know about demand in the future?
• Challenges to expansion of housing options
• Next steps
Emerging Issues and Factors Affecting Housing

• New HCBS Rules
• Pressure from some families to support more structured/congregate settings
• Impact of FSLA rules (changes in companionship exemption)
• Increasing cost of housing and competition for low income housing
• Limited supply of direct support workers
Change in the size and type of residence for people with IDD who did not live in the home of a family member: US estimates between 1998 and 2012

- Own home
- Group home (4 to 6 people)
- Group home (1 to 3 people), host home, family foster
- IDD, nursing, or psych facility (16+ people)
- Group home (7 to 15 people)
Where do People Live?

2013-14 data (N=14,380)

- Institution (16+): 4%
- Community-Based Setting: 32%
- Own Home: 20%
- Family: 36%
- Foster Care: 8%
Millennials at Home

**Pew Research**

- All Millennials 18-31: 36%
- 18-24 years old: 56%
- 25-31 years old: 16%

**NCI**

- All Millennials 18-31: 60%
- 18-24 years old: 65%
- 25-31 years old: 56%
Relationships by Living Arrangement

- Has Friends
- Can Date
- Can See Family
- Ever Feels Lonely

Institution: 56%
Community-Based Setting: 43%
Own Home: 43%
Family: 33%
Foster Care: 38%
Choice by Type Living Arrangement
(Respondent had at least some input in the following choices)

- Institution (16+)
- Community- Based Setting
- Own Home
- Family
- Foster Care

Legend:
- Home
- Roommates
- Staff
- Schedule
- Free time
- Day Activity
What About the Argument that People with More Severe and Profound Disabilities Benefit from More Structured Settings?

• In general, outcomes for individuals with severe disabilities are not adversely affected by where they live

• Some outcomes for these individuals are in fact more positive in less structured settings – specifically rights and respect, communication inclusion and satisfaction.

• Previous research shows that individuals who were deinstitutionalized from custodial settings

• No clear evidence in NCI data that individuals with more serious disabilities do better in more structured settings
Rights and Respect
(Individuals with severe or profound ID)

- People let know when entering home
- People let know when entering bedroom
- Has enough privacy at home

Institution (16+)
Community-Based Setting
Own Home
Family
Foster Care
Satisfaction
(Individuals with severe or profound ID)

- Likes home
- Would like to live somewhere else
- Likes day activity
- Would like to go or do something else

Institution (16+)
Community-Based Setting
Own Home
Family
Foster Care
Community Inclusion
(Individuals with severe or profound ID)
What do we know about the character of future demand for housing?

National Core Indicators (NCI)
What Does the Data from the NCI Adult Family Survey Tell Us?

• Mail-out
• Respondents are families of a random sample of all adults 18 and over receiving at least one service (if a person is receiving only one service, needs to be something other than case management) who live in the family home.
• Designed to assess family access to and satisfaction with services—at a systems level.
• 13-14 data collection cycle: N=8,271 (includes CA)
AFS Primary Caregiver Age

Average Age of Family Member Receiving Services: 36

- Under 35: 9%
- 35-54: 11%
- 55-74: 52%
- 75 Plus: 28%
44% of respondents reported an annual household income of less than $25,000/year.
AFS: Health of Primary Caregiver by Age Group

Under 35
- Excellent
- Good
- Fair
- Poor

35-54
- Excellent
- Good
- Fair
- Poor

55-74
- Excellent
- Good
- Fair
- Poor

75 Plus
- Excellent
- Good
- Fair
- Poor

National Core Indicators (NCI)
What Does Data from the NCI Children/Family Survey Tell Us?

• Mail-out
• Respondents
  ▪ families of a random sample of all children 18 and under (22 and under, if still receiving ‘child’ services) receiving at least one service (if a child is receiving only one service, needs to be something other than case management) who live in the family home.

• Designed to assess family access to and satisfaction with services--at a systems level.
• 13-14 data collection cycle: N=2,199
2013-14 Children/Family Survey

- ASD Diagnosis: 65%
- Need help to manage behavior: 64%
• 23% of respondents reported having more than one child with a disability at home.

• 26% of those with a household income below $15,000/year reported having more than one child with a disability at home.
Competition from Other Groups – Preliminary Data From NCI-AD Survey
Respondent Likes Where They Live By Where Person Lives

- Own/family home/apt: 86% Yes, 7% No, 8% In-between
- Group home/foster home: 85% Yes, 7% No, 7% In-between
- Assisted living: 73% Yes, 11% No, 16% In-between
- Nursing home: 64% Yes, 18% No, 18% In-between
Why the Respondent Doesn’t Like Where They Live

- **Own/family home/apt:**
  - Accessibility, feels unsafe, repair needed, layout/size, problems with other residents/neighbors, feels isolated/lonely

- **Group home/ foster home:**
  - Accessibility, repair needed, doesn’t feel like home, layout/size, problems with staff, wants more privacy, wants to be closer to family/friends

- **Assisted living:**
  - Doesn’t feel like home, problems with other residents/neighbors, problems with staff, wants more independence/control, wants more privacy, feels isolated/lonely

- **Nursing home:**
  - Doesn’t feel like home, problems with other residents/neighbors, problems with staff, insufficient staff, wants more independence/control, wants more privacy, wants to be closer to family/friends, feels isolated/lonely
Respondents Wants to Live Somewhere Else by Where Person Lives

<table>
<thead>
<tr>
<th>Location</th>
<th>No</th>
<th>Maybe</th>
<th>Yes</th>
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</thead>
<tbody>
<tr>
<td>own/family home/apt</td>
<td>77%</td>
<td>18%</td>
<td>5%</td>
</tr>
<tr>
<td>group home/ foster home</td>
<td>75%</td>
<td>2%</td>
<td>24%</td>
</tr>
<tr>
<td>assisted living</td>
<td>59%</td>
<td>9%</td>
<td>32%</td>
</tr>
<tr>
<td>nursing home</td>
<td>51%</td>
<td>7%</td>
<td>42%</td>
</tr>
</tbody>
</table>
Challenges to Expanding Housing Options
Priced Out in the United States

I am a person with a disability

My only income is $750 per month from Supplemental Security Income (SSI)

There are 4,933,731 people like me in the United States

The average monthly rent for a basic one-bedroom apartment is $780

That is 104% of my monthly income

I have no money left for food, transportation, clothing, and other things I need

It's no wonder that there are...

362,163 homeless individuals living in shelters on any single night

Too many people stuck in expensive institutions at a cost of $243 - $643 per person per day

The system is broken

This is not affordable

See Priced Out 2014 at www.tacinc.org to learn more about these alarming statistics
People with ID/DD Have Minimal Buying Power

Paid Community Jobs (ACS)
• 15% of sample in paid community job
• NCI Average hourly wage: $7.63/hr
• NCI Average hours per week: 13.3

Paid Facility-Based Jobs (ACS)
• 25% of sample in paid facility-based job
• NCI Average hourly wage: $2.72/hr
• NCI Average hours per week: 30.5
Sustainability of DSP Workforce

• Escalating demand for MLTSS Services in community based settings
  ▪ DSPs are critical to increasing services in least restrictive settings
  ▪ The quality of life of individuals with ID/DD in the service system is inextricably linked to the quality and stability of those who are paid to support them – recent research at ICI reinforces that point
  ▪ Demographics are definitely not on our side
NCI Staff Stability Survey 2014

- Average hourly wage for DSP providing:
  - Residential supports: $10.55/hour
  - In-Home supports: $10.93/hour
- Average Turnover Rate: 45% (across support settings; residential, in-home, non-residential)
- FSLA will increase wages of some home care workers but states may also cut back on services in order to fund that increase

*10 states: AZ, DC, GA, KY, ME, OH, SC, TX, UT, VT*
Where do we go?
Revisit Generic Housing Options

• Community Development Block Grants
• Section 8 rental subsidies
• Non Elderly Disabled rental vouchers – for people with disabilities and “disabled households” (NED vouchers)
• National Housing Trust Fund – subsidies for extremely low income (ELI) individuals
• Section 811
Additional Policy Options

- Case managers should explore housing security issues with families and individuals with disabilities in person centered planning process
- Find ways to expand shared living and other less conventional housing options
- Work with families re: future financial planning
- Take advantage of the ABLE act → tax-free savings accounts to help individuals and families finance disability needs
- Support innovation with greater use of individual budgets and self-direction
- The Arc Center for Future Planning: https://futureplanning.thearc.org/
What did she say?

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