

Major Take-Aways from Feb. 19 Community Discussion Results

What parents are concerned about... *no matter if my adult child with autism is living in their own apartment, home, section 8 housing, or a residential setting for people with disabilities, or at home with family:*

1) Safety & Dignity of residents on the Spectrum

- In neighborhood and home/apartment complex – no matter what the residential setting
- Fear of victimization: Will they be taken advantage of?
- What risks/dangers will they encounter, be exposed to in the neighborhood?
- Meeting medical and health needs; managing medications, appointments
- Respect for individual with autism
- Stability and risk of homelessness
- Building natural supports

2) Staff Training & Capacity

- How well is staff trained? Knowledgeable about autism? Background checks
- High staff turn-over; low pay/low retention, low capacity/understaffed services
- Awareness of the unique needs of individuals on the spectrum?
- Handling of meltdowns and aggressive behaviors
- Communication between staff, family and residents
- Fear of abuse – physical, sexual, exploitation
- Personal assistants

3) What residential services do we have locally?

- How to find the right fit
- Scaling/adjusting supports according to needs (e.g., move from 24-hr support to 12 hr-support?)
- Availability, openings, wait lists, staff shortages

4) Do we have an On-Call 24-hr Response Service/Hotline?*

- Crisis response team, like PATH for people with autism
- Needs for night-time responses, after-hour needs
- Respond to more independent residents with autism
- Place to call for information (non-emergency & non-emergency)
- Help connect to services and resources; vetting autism-trained services

5) Compatibility with other Spectrum Residents

- Matching interests, capabilities, needs
- How to find the right roommate; how are residents matched?
- Keeping self and other residents safe if someone has meltdown, has aggression issues

6) Support and Respite for Parents

- How to connect with other parents
- What about support for family members living at home with parents/family?
- Ability for parents to go out of town, having someone to check in/support, respite

7) Quality of Life / Training Support for Residents

- Food/nutrition
- Socialization and Recreation
- Transportation
- Employment
- Managing finances
- Continuing Education/Life-long learning

8) Funding Streams & Navigating the System

- What are our financial options?
- How do we move through the system? Learn the rules/legal issues?
- SSI/SSDI, PUNS, HUD
- Trusts, Savings and Insurance, Special Needs trusts, ABLE accounts
- Microenterprises, employment
- Private supports, charities, donations



What can we do?

Suggestions for discussion, exploration and future planning

(feedback from Feb 19, 2019 Autism & Housing Community Discussion, Normal, IL)



Take Action!

- **What actions can we take?**
- How can we work **together**?
- How do we organize to get or create what we need?

What residential support/services are we missing?

- Who can help?
- Learn more – keep learning!
- Explore **models and services in other communities**
 - Bring in speakers
 - Go visit/report back
- What **partnerships** are possible?
- Work with local municipal CDBG Grants Writers and MCRPC?

Parent-to-Parent Support

- Who are the mentors, those who have navigated the system?
- Start a parent support group
- How can we connect?

Expand awareness and natural supports

- Become a more fully autism-friendly community!

Funding & Grants

- Explore if grants are available, what they could fund
- Help support our existing local agencies to grow their services

Create a 24-hour Autism Response Hotline

- Place to call for information and help (non-emergency & non-emergency)
- Crisis response team, like PATH for people with autism
- Access to help learning about what is available, call for information
- Help connect to services and resources
- Needs for night-time responses, after-hour needs, including independent residents with autism

Special projects

- What is needed?
- e.g., explore use of digital/electronic devices for support, monitoring, communication...
- e.g., Is there an “autism-match” site to help match residents to placement and roommate?

