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Supporting young adults on the autism spectrum towards independence: Lessons from the Netherlands

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Introduction

How can service providers help young adults on the autism spectrum find their way towards successful independent living? What factors need to be taken into account, what promotes independence and a good quality of life, and what might barriers might there be? The researchers decided to gain views directly from six young men under the age of 30 who were living in different types of residential settings in different locations.

Literature review

In the research literature on autism and housing/independent living, the majority of published sources focus on specialist design or support mechanisms for segregated group homes or other institutional settings (e.g. Ahrentsen and Steele, 2009; Brand, 2010; Beaver, 2011; Harker and King, 2004; Resnick, 2009; Selcer et al., 2015). However, studies that consulted adults with autism themselves about their housing needs and wishes highlighted the desire for independent living rather than congregate “special” housing forms (e.g. PAS, op cit.; Kinnaer, Baumers and Heylighen, 2015; and Durbin-Westby, Ne’Emen and Topper et al., 2012). These authors and their research participants frequently mentioned a need for control and choice in any residential form, as did participants in another recent study (van der Veecken and van Rengs, 2012). There are still relatively few research studies that engage service users directly in finding out what is important to them. Many studies in the past have just taken the views of professionals and parents on the services provided and then designed provision accordingly. In contrast, this study involved one of the service users in designing the interview questions, and then interviewed six autistic adults individually to gain the data.

Method

The researchers conducted semi-structured interviews with six young men with an autism spectrum diagnosis, all of whom were under 30 years of age (see *Appendix A* for the questions asked). None had an intellectual disability, although some had additional difficulties, such as anxiety, depression or dyslexia/specific learning disability. All gave fully informed consent to take part in the project. Their names have been changed for this paper to Anton, Ben, Callum, Dieter, Erik and Frank to protect their identities.

All of the participants met the authors for the first time in a meeting with facility staff. After this initial meeting, individual interviews with one researcher and one participant were set up in locations chosen by the participants. In some cases interviews took place in the participant’s personal living space; others took place in private offices within the same

building. Interviews lasted for at least 30 minutes; some participants were interviewed twice.

Ben and Callum lived in a medium-sized supported living facility in a small seaside town, and Anton moved from that facility to a supported shared apartment next door during the study. Dieter, Erik and Frank lived in shared apartments with daily support in a nearby town. These facilities were managed by a disability service provider, Heliomare, as part of a residential programme assisting people with disabilities to gain skills and competencies for living independently.

Anton acted as a co-researcher. His role included suggesting improvements to interview questions, and commenting on the results and analysis. Results were also sent to three members of a Disabled People's Organisation (DPO), Personen uit het Autisme Spectrum (People on the Autism Spectrum, PAS), for additional comment. PAS was part of the national research consortium, and has itself conducted research on the housing needs of Dutch adults with autism (PAS, 2014).

Interviews covered a wide range of topics related to housing and independent living, including the respondents' current housing situation, their thoughts about Heliomare's residential programme, and their hopes and concerns about housing and independent living in the future. Their interviews were transcribed and a thematic analysis revealed common as well as less common issues (see Table 1, below). These data were further analysed via comparison with findings from a wide-ranging international literature review on autism and housing conducted for the national project (Waltz, Beltman and Cardol, 2015). The research findings have also been presented to Heliomare and to colleagues researching housing-related issues within the national project.

Findings

Eight themes emerged in almost every interview and additional themes were important to some respondents (see *Table 1: Themes Matrix*).

Table 1: Themes which emerged from the interviews with the six adults

(Note: Letters A to E are the initials of the 6 young men)

MAJOR THEMES	A	B	C	D	E	F
Importance of who delivers support	X	X	X	X	X	X
Importance of acting independently, where possible	X	X	X	X	X	X
Working in partnership with parents/pre-	X	X	X	X	X	X

independence skills training at home						
Heterogeneity of autism	X	X	X	X	X	X
Need for realistic, practical goals	X	X	X	X	X	
Importance of outside network		X	X	X	X	X
Potential need for floating support	X	X	X	X	X	X
Need to feel in charge of own life	X	X	X	X	X	X
Additional themes:						
(In)ability to choose who you live with	X	X	X			X
Location (proximity to desired activities)	X	X	X		X	
Communication between staff	X		X	X		
Staff changing too often		X			X	X
Need for extra time to think about decisions			X	X		X
Need to accommodate sensory issues in living space	X		X		X	
Concern about future loneliness				X		X
Prefer housing integrated with community				X		
Need to customise living space			X			
Anxiety			X			

Although the six respondents in this study did not always raise exactly the same points as other researchers and campaigners on the autism spectrum, they were clear that they did not wish to live in specialist, congregate housing, and they placed a high value on choice and control.

Although some literature purports to discuss what form of housing is “best” for people with autism, the six respondents were as different in their preferences as any group of six individuals could be. Autism is a heterogeneous condition, so this is to be expected. Two felt that a flat shared with roommates of their choice would work well for them, one hoped to eventually live with a partner and children, two would consider sharing but preferred to live alone, and one definitely wanted to live alone. Some stated a preference for an urban setting, others for a suburban area or smaller town, and one preferred rural life.

Interestingly, only Callum said that sensory issues were a major current or potential problem in housing. He and the two others who said they had experienced some sensory problems in their current residence did not feel that specialist housing design was the answer. They wanted mechanisms to give them greater control over issues such as lighting, noise, and temperature in their future homes.

When asked to define what “home” meant to them, each of the six said that home functions as a place of refuge from an outside world that could

sometimes be uncomfortable, whether that lack of comfort was perceived as due to sensory or social factors. When a place to live did not meet this need, (as some felt their current or previous living situation at Heliomare did not), it affected their ability to cope generally. For example, Callum and Frank mentioned problems with getting a balanced day/night rhythm, which they attributed to issues like noise, anxiety, or a lack of control over their daily routine. However, Anton added that the security of his current living arrangement outweighed some of the ways in which it was not ideal.

The importance of human factors

Rather than focusing on sensory-perceptual differences, the six respondents concentrated on interpersonal issues. They recognised that they did at times need support or advice, but felt this could not be properly provided by a revolving cast of support workers. They emphasised developing a rapport and trust with staff. Some noted that frequent turnover of staff on temporary contracts presented real problems for them. Anton said:

"I see new people constantly. It's our home, but I keep having to introduce myself! Trying to connect with those people is the biggest problem, trying to build a trust with them... People who have worked here a long time—[residents] are more comfortable with them, and more confident about talking to them."

Ben added that staff attitudes also mattered:

"Just respect the fact that this is my home, you know. [Some] really don't get the difference between work and home, because my home is their work, so they treat it as a work environment. But they shouldn't, they should treat it as a home environment."

This issue was made visible to researchers when members of support staff twice came through the front door of Anton's shared flat and walked out through the back door, using it as a short-cut to the larger facility next door. While Anton was not alarmed, as his bedroom was not entered, reviewers from PAS all flagged it up as a breach of privacy—and as creating a potential security issue in the future.

"This could make it hard for young people to learn that later they must not allow just anyone access to their home," said one reviewer.

It was clear that respondents saw support staff as people in a position of power over them, although they also said that most were competent and helpful. When asked to describe the “ideal” support worker, they said that a warm and caring personality, along with plenty of patience, was crucial. Interestingly, none felt that knowledge about autism was especially important. But here the researchers and the six respondents located a tension: warm and caring people also have a tendency to jump in too quickly to do things for residents, rather than supporting them to try themselves.

Dieter described what happened when staff get the balance right, supporting rather than controlling or taking over:

"At first they ... look at how you can handle things: If you can cook with support or without, if you can clean with or without support. And if you do things correctly, then they will only do a check. For example, for me it's with cooking. The first month I lived here, I ate with support every day of the week, but now I cook for two days of the week. One day is with the support—they are helping me—and one day it's on my own."

On the other hand, Erik said,

"some... don't know how to communicate with people. They're very pushy when they want something done—they're like little schoolteachers, and they treat us like children."

Some staff left residents out of the loop on issues that concerned them, such as whether a repair person was coming.

The issue of control also came up with regards to parents. Some respondents said it would have been helpful for their parents to have more advice on preparing them for independence, and for “letting go” and allowing them to make adult decisions. Erik said,

"I can't live with my parents, because they are very meddling."

Ben noted that his parents' behaviour towards him changed markedly following his diagnosis, as they made new assumptions based on what they had read about autism. For example, his mother began explaining metaphors to him, despite the fact that he had not had problems with them previously.

Some respondents experienced over-protection, and had never been encouraged to do laundry, cook, or to make major decisions. Once ingrained, dependency can be difficult to reduce. Two in the study, including Erik, had been in a form of institutional care during some of

their teenage years, an experience that automatically limited opportunities for independence for them.

In contrast, two reviewers from PAS, both diagnosed as adults, said their families insisted that they took responsibility at an early age. One said,

"At home I was raised to think that asking for help is 'weak,' and I had better be independent!"

However, as another said,

"Looking back, I would have liked to have more support and a better understanding of my condition, because I would then have done many things differently and fewer things would have blown up in my face."

The right balance would mean creating a safe *"place to practice and fail,"* suggested Anton.

Having a choice of whom one lives with was another area where human factors mattered. None of the respondents living in shared flats were given a role in choosing their flatmates, although support staff did try to support them to solve interpersonal problems. For Anton, Dieter, Erik and Frank, living with people they would prefer not to sometimes led to conflicts and discomfort. All said they would be willing to share an apartment in future, but preferably not with strangers. Callum, who had the most marked sensory issues, was the only respondent who expressed a strong desire to live alone.

Choice about whom one lives with is an important issue for adults with disabilities generally, and is a right enshrined in the UN Convention on the Rights of Persons with Disabilities (United Nations, 2008). Durbin-Westby, Ne'Emen and Topper et al. (op cit.) noted that for young adults with autism or intellectual disabilities, choice was often denied in this very basic area. They called on service providers to move away from segregated congregate residences and towards facilitating individual choice and the integration of disabled people into communities.

Anton said,

"With people I know, I can relax and ask for help. With strangers, I feel uncomfortable and out of place."

Entering an established group can also leave the new resident feeling like an outsider for a long time.

The need for an outside support system

One key finding was that respondents who had a strong connection to a friendship, activity or work group outside of Heliomare felt much more confident about their ability to live independently. The advantages went beyond improved confidence, however. They described having people they could call on for typical adult problems, such as personal advice or help with a small repair. Some also mentioned the importance of maintaining close family ties, which can be a problem when service provision is clustered in lower-cost areas that may be far from residents' families. Those who did not have an outside network felt they would need to rely on professional support, and worried that it might not be available after they left the programme. Anton noted that while support staff did try to help residents find local sport or hobby opportunities, opportunities were lacking, and they should also attempt to link them with outside support organisations, including DPOs.

Although respondents noted that they might have a need for occasional professional support at a later date, especially with financial matters, getting organised, and handling difficult forms, the authors felt the evidence for supporting adults to develop and broaden their personal networks was robust. For some individuals, this could mean assisting them with locating people who share their personal interests; for others, that service providers must be careful not to limit their access to friendships, family members and activities of their choice. The somewhat remote location of the facilities worked against this for the six respondents.

Dieter, who had a busy social life with a job and a course to fill his time, said real-world connections were needed to give his life structure and support:

*"When I moved in here, I didn't know anybody, and it was very lonely here in my room. I didn't go to school, I didn't have any job. So I got a few tasks to do [but] for the most part it's, 'Well, what am I going to do today? I guess I'm going to do nothing.'... And now I have a real job, and I'm going to school, and I know people here.
[Nevertheless], when I go to work, it's just me going to work. When I'm coming home, there's nobody there to say 'hey, how was your day, here's your dinner,' like my parents did."*

He and some other respondents said they were worried about becoming isolated and lonely later in life, something that a strong personal network centred on hobbies, sport or work could prevent.

For Anton and Callum, the majority of their social contact was online. As one of the PAS reviewers said, online friendships can be a lifeline for

adults on the autism spectrum. Callum was for satisfied with relationships conducted via Skype and social media. Anton, who described being “stuck” in the programme due to lack of a viable plan for moving on to higher education at the time of the interview, spent most of his time playing video games in his room. Despite his keen interest in gaming, there was also a sense of him being in a holding pattern, circling interminably while he waited for his adult life to begin. Online friendships helped him stay connected to the outside world, he said, and have been a factor in preventing depression during this time.

The need for concrete, viable plans

While Dieter had only entered the programme recently and saw it as a means to an end while he completed vocational training, the other five respondents had all lived in Heliomare’s residential facilities for three or more years. Basic skills for independence (e.g. simple cooking, laundry, self-care) had been learned, and they had spent much time working through the service provider’s well-designed personal development programme.

The problem for Anton, Ben, Callum, Erik and Frank was the next step: leaving the programme and embarking on the adventure of adult life on their own terms. But here they encountered multiple barriers.

Two reviewers from PAS who were older than the research respondents noted that work often adds structure and meaning to the lives of adults with autism. It is also an important venue for social interaction. However, respondents were aware of high levels of competition for jobs and increased employer insistence on social skills and meeting stringent targets, leading some to worry that they would be unable to secure adequate employment. The dearth of local work experience opportunities and support into work was also a concern.

Access to housing was also blocked. Free-market housing costs in the Netherlands are high. Without a high income, respondents needed social housing. Social housing in the Netherlands is controlled at the municipal level, and in 2015, the typical waiting time was 8.5 years, although in some areas applicants must wait for up to 20 years (RTL News, 2015). Social housing providers also do not take any particular notice of the needs of tenants with autism, so many live in unsuitable accommodation (PAS, *op cit.*).

The benefit system also presented a barrier, with perverse incentives for remaining in supported accommodation longer than absolutely necessary. As Callum said:

"The first part is finances. I am tied hand to foot to the Government, and I don't know where I can find a place where I can pay the rent and my food and everything at short notice."

It can be hard for people on the autism spectrum to imagine what might happen in the future, because there are so many possibilities. The executive functioning challenges they face can make choice and forward planning problematic. But our respondents were also acutely aware that they lacked decision-making power for systemic reasons like those just outlined. Feelings of disempowerment and uncertainty can precipitate inertia, anxiety or even fear.

For some, a long trajectory towards independence was not a concern: these respondents stated that they were happy for now to continue without taking on greater adult responsibilities, although they knew that typically developing people in their 20s were doing so. However, some did feel ready to move on, but could not see a way forward. As Erik put it:

"I prefer this way over every place that I have lived before... [but] I would like to have my own home, with a garden and a fence, so I can say 'this is my home, this is the rest of the world.' And now I'm actually stuck in a little room in an apartment block."

Discussion of the findings

While respondents felt that their personal bedrooms were generally acceptable, shared spaces were seen as problematic. For example, Anton said,

I would like a place to just chill out, maybe somewhere for a family member to stay if they have to travel to visit. I should not be making appointments for a room to be opened so I can sit with my family."

Indeed, congregate housing was itself perceived as a barrier to independence. For example, those in the largest facility could not cook as and when they pleased, as kitchens had recently been replaced by a café for group meals. While for Frank the café presented an opportunity for gaining work experience, others resented having to cook and eat at scheduled times. Facilities, instruction and opportunities for practice were desired. Anton said,

"It would be great to have proper cooking classes... where you could learn simple things like how do you cook potatoes, scrambled eggs, cookies, sprouts."

Conflicts with housemates also detracted from feeling “at home.”

Rather than backing specialist design for autism, our respondents’ words gave credence to researchers who call for including cognitive differences when formulating Universal Design (UD) guidelines (e.g. Maslin, 2012), and for the implementation of UD principles when developing or renovating housing units. They also suggest an unmet need for products that can be used to adapt and improve the accessibility of existing housing units for residents with sensory-perceptual differences.

Questions emerged about the potential negative impact of earlier diagnosis on independent living as an adult. Diagnosis ideally acts as a signpost, indicating that an individual needs direct instruction and extra support to gain necessary competencies. On the other hand, it can result in young people being disempowered, overprotected, or “captured by the system,” with parental or professional support and control reducing their chances to act independently, to gain increased competence, and even at times to learn from the experience of failure. Service providers should therefore consider sharing their expertise with families and educators before young people reach the age of 18.

Limitations of the study.

All respondents were male and under 30. Women on the autism spectrum and adults over the age of 30 years may have very different issues, aspirations and priorities.

In addition, as the PAS reviewers cautioned, the six respondents had not attempted to live fully independently. They cannot anticipate whether their experience of sensory issues in future housing could be a more significant problem than expected, or whether they will have needs related to social difficulties, such as problems with neighbours, crime in the neighbourhood, or loneliness.

Concluding comments

This study suggests that service providers can play a vital role in preparing young adults on the autism spectrum for independent living. Success, according to the six respondents, depends more on the ability of staff to develop one-to-one relationships with the young people they support than any other factor. It is within relational interactions with staff, parents, and others in their social circle that young adults learn skills, gain confidence, and find solutions to problems.

Support programme managers and developers need to be careful about factors that could limit personal growth. Respondents stressed the need to feel in charge of their own lives, and mentioned many areas where this objective can be furthered or hindered by service providers, as follows:

- The relationship between residents and support staff should not be overly hierarchical.
- Individual plans and goals should be aligned with personal preferences and abilities rather than “what’s available locally,” whether that relates to education, housing or work. Strength-based programmes are much more likely to have success than interventions that target weaknesses (Mills, 2013).
- Plans should be practical and realistic, with clear steps and end-points.
- Facility locations and forms need to be carefully thought through, including impact on family relationships and friendships, opportunities to access education and work, opportunities to develop individual competence, and the personal comfort of residents.
- Service providers should actively open up the wider community for residents, and focus on helping them build a lifelong support network beyond professional help.
- Involvement with Disabled People’s Organisations can be important for both young people and service providers: their practical experience and knowledge of both systemic barriers and potential ways around them is invaluable.

Service providers are also in an influential position to lobby government funders, alongside DPOs, to eliminate policies and practices that can incentivise dependence. For example, funding restrictions can encourage facilities to serve pre-cooked meals in a group setting rather than encouraging residents to learn to cook for themselves. Lack of access to independent housing options in the community and poor support for moving into adequately paid work can inadvertently trap young adults in congregate supported living, resulting in inertia, depression and lost potential.

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Appendix A: Interview Questions

During an initial meeting with the researchers and staff, three participants discussed their thoughts about future living situations and plans. These questions were used to spark freeform discussion:

1. *What is/would be important in a living space?*
2. *What do you like about where you live now?*
3. *Where do you see yourself living in the future—real, and ideal?*
4. *What would you like the interior of your future home to be like?*
5. *Where would your future home be located, and why?*

As participants did not find a meeting with staff to be a good venue for open discussion, for the remaining three participants these questions were asked in individual interviews.

Individual interviews focused on the participant's current living situation and the support he felt would be needed for him to move towards independence. Participants had been told in advance what the topic of the interview would be, to give them time to think about what they would like to say.

The following questions were asked of all participants, but the semi-structured interview design permitted the interviewer to reformulate questions or add follow-up questions as needed.

1. *What would you like to change to improve your current living situation?*
2. *Can you describe the home you would like to live in?*
3. *Have you experienced a lot of problems with your disability in school, with parents, work, or in the community?*
4. *What do you feel you need help with to live independently?*
5. *Is there anything about living independently that worries you?*
6. *What does "good support" in supported housing look like?*
[participants were asked to give specific examples of positive current or recent support experiences]
7. *What kind of support do you think works to help you move towards having your life the way you want it in future?*
8. *In terms of who provides support, what qualities does a good support person have?*

9. *What kind of training do you think support staff need?*
10. *About the people you live with here (in shared accommodation): Is there anything Heliomare could do to make living together easier or better?*
11. *About the training programme that's supposed to help to move you towards independence—is there anything about it that should be changed?*
12. *We are going to write a report for Heliomare about our research results. If you could give advice to a company like Heliomare about making things better for people with autism who live in their facilities, what would you say?*
13. *We are planning to write a guide for social housing corporations and other landlords about how to make sure people with autism get housing that is accessible and comfortable for them. If you could give advice to a social housing corporation about making housing more accessible for people with autism, what would you say?*
14. *If you could give advice to parents of a teenager with autism who want to make sure he or she has a good chance to live independently as an adult, what would you say?*
15. *If you could set up a service that supports adults with autism to live independently, what would that service do?*
16. *What things get in the way of you living independently?*
 - a. *Things other people do? [if no answer was forthcoming, specific prompts were used, such as bullying or miscommunication]*
 - b. *Things about the built environment (the house/building itself)? [if no answer was forthcoming, specific prompts were used, such as size, materials and location]*
 - c. *Things you find difficult to do or things that are difficult to use? [if no answer was forthcoming, specific items were mentioned, such as cookers and washing machines]*
 - d. *Things that bother you, e.g. sensory issues?*
17. *What if anything have you done, or do you do now, about these things?*
18. *What do you think could be done to solve these problems?*

19. *What people (family members, friends, mentors) do you look to for help and advice who are outside of Heliomare?*