

MAIN SECTION

Understanding Independent Living with Autism: The Role of the Housing Environment in the Experiences of Two Autistic Men

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ABSTRACT

Many autistic adults continue living with their parents rather than living independently, regardless of their IQ levels. In studies about adaptive housing, their perspective is still lacking. To address this gap, our research aims to offer insight into, first, autistic adults' experiences of living independently, and second, what role the housing environment plays in these experiences. A qualitative study was conducted to investigate what living independently means to two autistic men. The findings suggest that living independently for them means (1) living in proximity of public facilities, retail stores and family, (2) self-determining their apartment arrangement, daily living activities, and (3) having nearby social contacts to cope with regular domestic stress and anxiety. Comparing their experiences suggests that social and physical factors of the housing environment are not detached, but could strengthen each other in supporting their independent living. The combination of social and physical factors facilitates living independently for these men, which resonates with the paradigm of independent living. A better understanding of autistic people's lived experiences is crucial to develop housing options which enable them to live independently.

KEYWORDS

Autism; Housing Environment; Independent Living; Lived Experience

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Introduction

“The autism spectrum” refers to a range of conditions characterized by challenges regarding social behavior, communication and language, and a narrow range of interests and activities unique to the individual and carried out repetitively.¹ Autistic people² share certain difficulties, but being autistic affects individuals in different ways, some need much help in daily life, others less.

Different studies report that many autistic adults live either with their family or in some form of supervised residential setting.³ In the US, an estimated 80% of them (younger than 30, but having finished high school) remain in their family home, often being cared for by aging parents who, in most cases, will not outlive their children.⁴ In the UK, a study following 68 autistic people from childhood until adulthood found that, within the “normal” IQ range, 4% of autistic adults live separate from their parents, although some of those living with their parents have a high level of independence. The majority, however, remain highly dependent on their families or require some form of residential support.^{5,6} Furthermore, the rate of autistic adults living independently is lower than that of their peers. Compared to persons with other types of impairment, autistic adults are more likely to live with their parents and less likely to live independently after leaving high school.⁷

The observation that most autistic adults, regardless of their IQ level, are behind their peers regarding independent living raises questions as to what living independently means to them and the role of their housing environment therein.

Autistic adults and independent living

Autistic people face considerable challenges throughout adulthood.⁸

1 World Health Organization, “Autism Spectrum Disorders,” Fact sheets, April 2, 2018, <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>.

2 The term “autistic people” tends to be preferred by autistic adults, whereas professionals rather prefer “person with autism”. Lorcan Kenny et al., “Which Terms Should Be Used to Describe Autism? Perspectives from the UK Autism Community,” *Autism* 20, no. 4 (May 2016): 442–62, <https://doi.org/10.1177/1362361315588200>.

3 Kim Steele and Sherry Ahrentzen, *At Home with Autism: Designing Housing for the Spectrum* (Bristol: Policy Press, 2016).

4 Sherry Ahrentzen and Kimberly Steele, “Advancing Full Spectrum Housing: Design for Adults with Autism Spectrum Disorders,” *ASU Stardust Center* (Arizona: ASU Stardust Center, 2009), <https://sustainability.asu.edu/stardust/project-archive/advancing-full-spectrum-housing/>.

5 Patricia Howlin et al., “Adult Outcome for Children with Autism,” *Journal of Child Psychology and Psychiatry* 45, no. 2 (2004): 212–29, <https://doi.org/10.1111/j.1469-7610.2004.00215.x>.

6 Kristy A. Anderson et al., “Prevalence and Correlates of Postsecondary Residential Status among Young Adults with an Autism Spectrum Disorder,” *Autism*, August 30, 2013, <https://doi.org/10.1177/1362361313481860>.

7 Ibid.

8 Patricia Howlin and Iliana Magiati, “Autism Spectrum Disorder: Outcomes in Adulthood,” *Current Opinion in Psychiatry* 30, no. 2 (March 2017): 69–76, <https://doi.org/10.1097/YCO.0000000000000308>.

Many of them, including those with a “normal” IQ, are significantly deprived regarding social relationships, physical and mental health, and are at risk of isolation.⁹ As a result, the majority remains dependent on parents or caregivers for support in daily life when grown up.^{10,11,12}

Autistic people’s well-being seems to relate not to the characteristics of autism itself, but to their supportive services. A self-report study on satisfaction, competency, independence and community integration in 58 high-functioning autistic adults in Belgium, found these factors to relate to the characteristics of supportive services.¹³

Within this support, social factors play an important role: autistic adults’ well-being correlates significantly with social functioning, among other elements like age, intellectual levels, or autism severity.¹⁴ Based on a meta regression analysis of 17 studies which involved 1721 autistic adults, Kim et al. (2019) conclude that improvements in social functioning may enhance their well-being. However, autistic people have difficulty in social interaction – not only with non-autistic people, but also within autistic communities.¹⁵ Common complaints about non-autistic people are that they seem pushy and demanding, and waste conversational energy on meaningless small talk.¹⁶

Living separately from their parents shows numerous benefits for autistic adults, according to their mothers’ assessment,¹⁷ while living with their parents may negatively affect skills development.¹⁸ Moreover, autistic people who live separately from their parents, have an impressive amount of continued contact with their families.¹⁹ Researchers suggest

9 Patricia Howlin and Philippa Moss, “Adults with Autism Spectrum Disorders,” *Canadian Journal of Psychiatry* 57, no. 5 (05 2012): 275–83.

10 Howlin et al., “Adult Outcome for Children with Autism.”

11 Eva Billstedt, I. Carina Gillberg, and Christopher Gillberg, “Aspects of Quality of Life in Adults Diagnosed with Autism in Childhood: A Population-Based Study,” *Autism* 15, no. 1 (January 2011): 7–20, <https://doi.org/10.1177/1362361309346066>.

12 Patricia Howlin et al., “Cognitive and Language Skills in Adults with Autism: A 40-Year Follow-Up,” *Journal of Child Psychology and Psychiatry* 55, no. 1 (January 2014): 49–58, <https://doi.org/10.1111/jcpp.12115>.

13 J. O. Renty and Herbert Roeyers, “Quality of Life in High-Functioning Adults with Autism Spectrum Disorder: The Predictive Value of Disability and Support Characteristics,” *Autism* 10, no. 5 (September 1, 2006): 511–24, <https://doi.org/10.1177/1362361306066604>.

14 So Yoon Kim and Kristen Bottema-Beutel, “A Meta Regression Analysis of Quality of Life Correlates in Adults with ASD,” *Research in Autism Spectrum Disorders*, Growing older with autism, 63 (July 1, 2019): 23–33, <https://doi.org/10.1016/j.rasd.2018.11.004>.

15 Jim Sinclair, “Being Autistic Together,” *Disability Studies Quarterly* 30, no. 1 (February 22, 2010), <https://doi.org/10.18061/dsq.v30i1.1075>.

16 Ibid.

17 M. W. Krauss, M. M. Seltzer, and H. T. Jacobson, “Adults with Autism Living at Home or in Non-Family Settings: Positive and Negative Aspects of Residential Status,” *Journal of Intellectual Disability Research* 49, no. 2 (February 2005): 111–24, <https://doi.org/10.1111/j.1365-2788.2004.00599.x>.

18 Karola Dillenburger and Lynne McKerr, “Echoes of the Future: Adults with Disabilities Living at Home with Their Parents,” *Journal of Neurology and Clinical Neuroscience* 1, no. 2 (2014): 10.

19 Krauss, Seltzer, and Jacobson, “Adults with Autism Living at Home or in Non-Family Settings.”

the need to identify the individual, family or environmental factors that enhance autistic adults' well-being²⁰ and therefore facilitate independent living for them.

In disability studies, the independent living paradigm situates problems of impairment not primarily in the individual, but in the supportive structures offering solutions.^{21,22} To our knowledge, however, this paradigm has hardly been recognized yet in autism research. Supportive programs to facilitate autistic people's inclusion are frequently lacking, and little research exists into ways of developing more effective programs for their independent living.²³ Some psychiatrists and researchers do not even understand the role of the environment in causing disability.²⁴

Housing environment and user experiences

Autism research from the perspective of autistic adults is still limited.^{25,26} Moreover, most recent studies adopt medical models of autism, primarily relying on parental, sibling or healthcare provider reports.²⁷ Such third-person accounts provide limited insight into what autism means and how it feels to autistic people.²⁸ Their voice is lacking.²⁹ Without opportunities to discuss their experiences, autism research risks missing important aspects of their self-concept.³⁰

In summary, autistic adults' well-being is at risk, but is shown to correlate with support, in which social factors play an important role. Other factors, such as physical factors, have received limited attention. Our study therefore aims to offer insight into independent living from autistic adults' perspective: (1) what does living independently mean for them? (2) And what is the role of the housing environment therein?

20 Howlin and Magiati, "Autism Spectrum Disorder."

21 Gerben Dejong, "Independent Living: From Social Movement to Analytic Paradigm," *Archives of Physical Medicine and Rehabilitation* 60 (1979): 435–46.

22 Ingolf Osterwitz, "The Concept of Independent Living - a New Perspective in Rehabilitation" (HELIOS European workshop, Venice, 1994), www.independentliving.org/docs5/Osterwitz.html.

23 Howlin and Moss, "Adults with Autism Spectrum Disorders."

24 Sven Bölte, "Hey Autism Researcher, What's on Your Mind Today about Inclusion?," *Autism* 23, no. 7 (October 1, 2019): 1611–13, <https://doi.org/10.1177/1362361319870994>.

25 Michelle Teti et al., "Reframing Autism: Young Adults With Autism Share Their Strengths Through Photo-Stories," *Journal of Pediatric Nursing* 31, no. 6 (November 2016): 619–29, <https://doi.org/10.1016/j.pedn.2016.07.002>.

26 Marijke Kinnaer, Stijn Baumers, and Ann Heylighen, "Autism-Friendly Architecture from the Outside in and the inside out: An Explorative Study Based on Autobiographies of Autistic People," *Journal of Housing and the Built Environment* 31, no. 2 (June 2016): 179–95, <https://doi.org/10.1007/s10901-015-9451-8>.

27 So Yoon Kim, "The Experiences of Adults with Autism Spectrum Disorder: Self-Determination and Quality of Life," *Research in Autism Spectrum Disorders* 60 (April 1, 2019): 1–15, <https://doi.org/10.1016/j.rasd.2018.12.002>.

28 Ibid.

29 Bölte, "Hey Autism Researcher, What's on Your Mind Today about Inclusion?"

30 Teti et al., "Reframing Autism."

Methods and materials

We report on two case studies with two autistic men who live independently in two different housing projects in Belgium that adopt an inclusive residential model. In this model residents with an impairment are part of a community, have a fully-equipped apartment in a neighborhood or in a house on the street. The housing projects do not provide common living spaces and no professional caregivers are living in the building. Instead, volunteers/“good neighbors” who live in the same building are the contact persons in case residents need urgent support. The “good neighbors” are residents who have contracts with a coaching center that supports residents, and in return pay a lower rent. Both housing projects are rented by social housing agencies, and residents receive personalized support from the coaching center according to their requirements; e.g., meeting monthly with their psychologist(s) and coach(es), learning how to cook, or doing weekly outdoor activities with their coach(es).

These cases were chosen because they fit with our aim to study independent living from autistic adults’ perspective. We contacted the coordinator of the housing projects through the information given in a publication about the projects. The coordinator found two autistic men, living in two different settings willing to share their lived experience of living independently. Steve,³¹ 32 years old, has been living independently for three years after moving out of his parents’ house. Leo, 28 years old, has been living independently for more than one year after moving out of his mother’s house.

The first author – henceforth the researcher – conducted a group interview with the coordinator, a coach and Steve for 1,5 hours. Semi-structured interviews were then conducted individually with each resident in their apartment for two hours. During the interviews, Steve and Leo were asked to draw their apartments and neighborhoods. After that, a walk-along-interview with each resident was conducted during a 2-hour outside promenade in the neighborhood and to the city center. Participants decided the trajectory of the walk according to their needs and daily routines. Steve wanted to activate his new bank card, then find a new book, and finally buy some food. Leo wanted to visit the park in the city center, as usually in the afternoon, yet decided to extend the walk. Along the way, he introduced the researcher to the city’s landmarks (library, cinema, casino, sport centers, shopping centers, square, beach, parks, well-known houses), his regular route to the coaching center, his secondary school, and his regular barber shop. Both Steve and Leo asked the researcher to accompany them as a friend rather than as a researcher, which meant they had spontaneous conversations along the way, and did things together like buying food and

31 To omit details that might allow participants’ identification, their names and those of their settings were pseudonymized. However, the illustrations may allow people familiar with the setting to recognize it.

looking at books in the book store. Sometime during the walk, Leo was playing Pokémon on his mobile phone while the researcher walked next to him. As he explained, he always keeps himself busy by playing Pokémon while going for a walk. Immediately after the walk, the researcher made thick descriptive field notes, including her impressions about the participants' feelings and actions and their meanings.³²

Data collected included drawings made by the residents, photos taken by the researcher, interview transcriptions, field notes, architectural drawings of two projects provided by the coordinator, and project descriptions from the internet. Analysis was conducted by roughly following the QUAGOL guide:³³ reading and rereading transcripts and field notes, identifying themes, coding, and analyzing coded citations.

Insight into living independently

Based on our analysis, the meaning of living independently for Steve and Leo can be apprehended by considering three themes: proximity, self-determination, and social contacts [Fig.1]. In their living practices, living independently does not mean living by themselves. Steve and Leo need support from their physical and social environments, which facilitates their daily activities and helps them to cope with challenges in their daily life. Both experience beneficial effects from their housing location. Also, both determined (many aspects of) their living activities. Both identified the need for social contacts, yet how they experience contact with their neighbors differs.

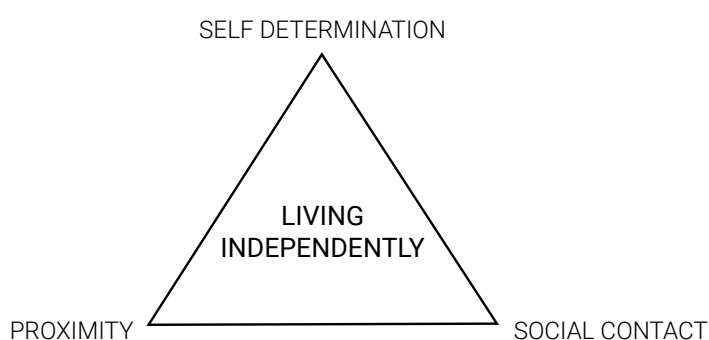


FIG. 1 Components of living independently for two autistic men

32 Claire Howell Major and Maggi Savin-Baden, *Qualitative Research: The Essential Guide to Theory and Practice* (London: Routledge, 2013).

33 Bernadette Dierckx de Casterlé et al., "QUAGOL: A Guide for Qualitative Data Analysis," *International Journal of Nursing Studies* 49, no. 3 (March 2012): 360–71, <https://doi.org/10.1016/j.ijnurstu.2011.09.012>.

Proximity

The housing location's proximity to public facilities and their parents' house plays an important role in the lives of both men. Their apartments are located in residential areas, close to their parents' house, the coaching center, public facilities and retail stores, e.g. a bus stop [Fig. 2], a hospital, a bank, parks, supermarkets, book stores, a barber shop, restaurants [Fig. 3]. They remarked:

I think living in the city where you're close to everything, I don't have a car, I have to do everything with public transport. But I like to be [here], as [it's] quiet, eh, you can get, come to rest in the evening, there's no voice from the street. In the evening you can really come to rest, that's [what] I like ... It's more living alone nearby my parents (interview Steve).

There's a lot of shops like, on the other side of the road ... if you need to go to a supermarket for anything, you get everything a pretty close ... You get actually everything you need here, like the drug stores if you need medicines or anything (interview Leo).

Since Steve uses public transport, the housing location is important for him. He remarked that he would prefer his apartment near the railway station. Within 10 minutes, he walks to the bus stop to go to work twice per week [Fig. 2]. Doing a small amount of shopping is easier

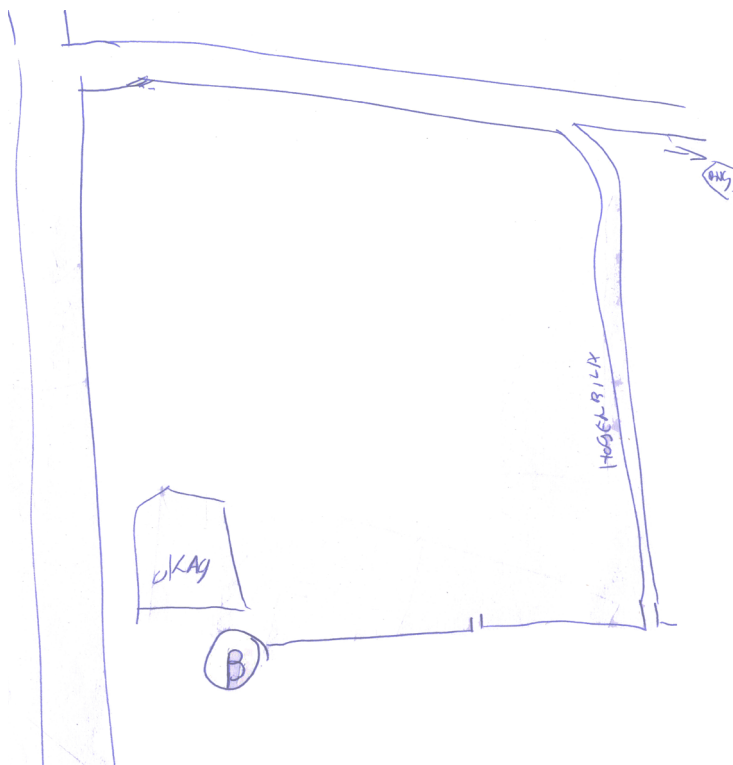


FIG. 2 Steve's drawing highlights a big supermarket next-door and a bus stop nearby

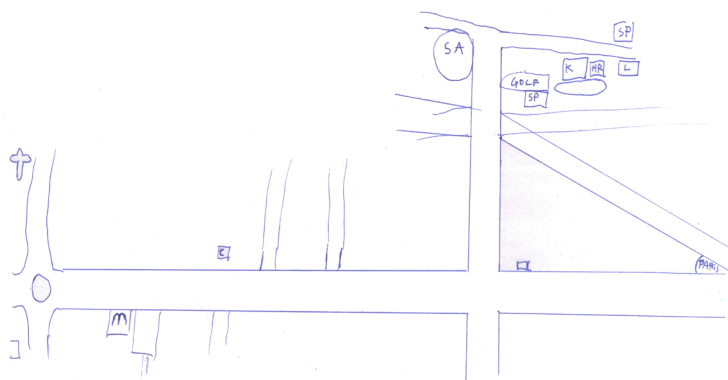


FIG. 3 Leo's drawing highlights public facilities near his apartment: different kinds of stores, supermarkets, park, and library

for Steve than buying many things at the same time. Living next to the supermarket [Fig. 2], he goes there every two days, sometimes every day.

Both Steve and Leo have intensive contacts with their parents even though they live independently. Steve's father visits him weekly, sometimes daily, and drives him to the railway station each time he needs to go to the airport. He lives at 20-minute driving distance to Steve's apartment. Leo uses a car. It takes him 15 minutes to drive to his mother's house for dinner every Monday and Thursday. His mother does his laundry weekly, cooks for him twice per week and cleans the windows in his apartment regularly.

Self-determination

Self-determination was identified as a significant theme in the lived experiences of these two men: it was one of the reasons for Steve and Leo to move out of their parents' house. Steve remarked "Living alone is doing what you want. It's your style. That's very important for me" and Leo mentioned "I want to live alone, to have my own space, and like independence myself". Living alone enables them to make decisions in several aspects of their lives: following their passions, having a sense of purpose, and having control over their daily activities.

Steve and Leo were very self-determined in what they wanted to do. They tried to have a paid job before. They are now both doing volunteer jobs which are directly related to their passions. Steve's passion relates to computers and travelling. His activities and trips are well-planned in a schedule on his computer, which he sticks to. Steve is developing an application for autistic people and designed a website for the coaching center. Leo is passionate about Star Wars and fictional heroes. He volunteers as a cosplayer in events and for children (at birthday parties or in hospitals). His volunteer work is more random as his cosplays depend on people's requests.

Both Steve and Leo were asked where they wanted to live in the building. Steve chose to live in a two-bedroom apartment [Fig. 4] on the first floor

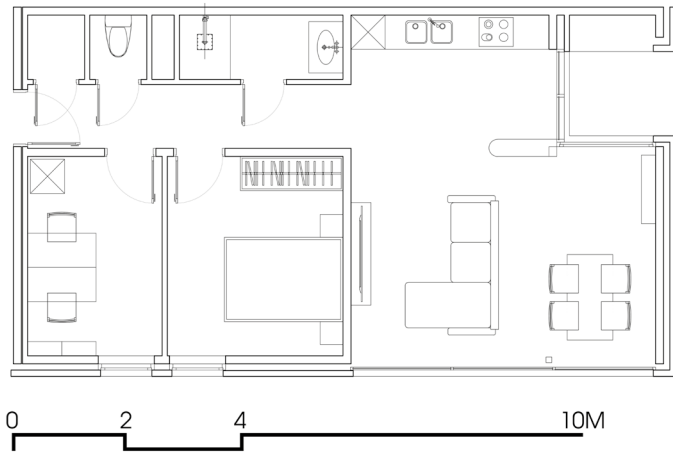


FIG. 4 Steve chose a two-bedroom apartment to have an extra room for his home-office

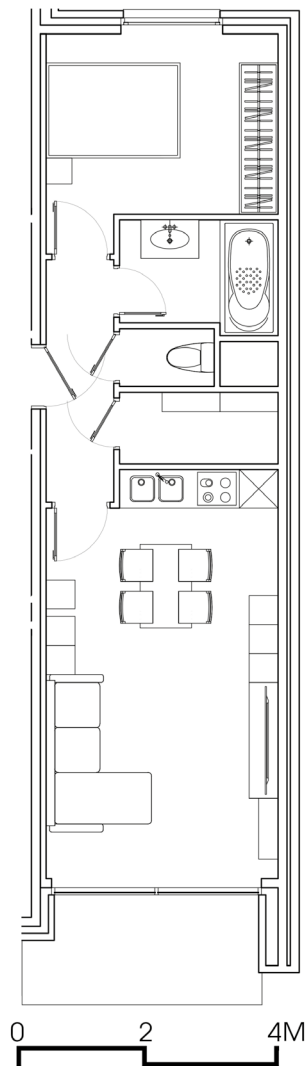


FIG. 5 Leo chose a one-bedroom apartment on the fifth floor so he could see his car on the back deck from the window of the bedroom



FIG. 6 Flashy colors for toilet and bathroom in Steve's apartment.



FIG. 7 Large desk with three screens and dark red color for home-office in Steve's apartment.



FIG. 8 Marvel and Star Wars collections and a home cinema in Leo's apartment

because he absolutely needed to have an extra room for his home-office. Leo chose to live in a one-bedroom apartment [Fig. 5] on the fifth floor because from his bedroom window he could see his car parked on the building's back deck.

I think, if there is a place that you like it, but you can't make decision ... because I was thinking, where my parents live, I don't want to go back, because of the home ... For me, it is also important that I could chose the furniture myself. That's all my style, mine. I like modern style. Like I knew what I want (interview Steve).

Making decisions was very important for both Steve and Leo in adapting the apartment to their needs and expressing their passions, decorating it the way that they wanted, contributing to their sense of self. Steve wanted to paint his apartment in multiple colors [Figs. 6-7].

I like mixture of flashy colors, it's my personal style, mixture of shiny colors. The toilet and the bathroom as flashy as me, my desk is in *bordeaux*, dark red. And my living room is in blue. Blue. My sleeping room, my bedroom is in blue. I like that. Some people say it's ugly. But I like the flashy, the idea of flashy. I like it. It's funny, It's flashy, it's optimistic of flashy color. The vision of my flashy (laughing) like me (interview Steve).

Having spaces for their passions in their apartment was essential. Leo needed place for glass boxes containing his Marvel and Star War collections [Fig. 8]: "I started to live here and designing all the stuff, like, I love Marvel, like Spider Man and Star Wars, because it's like the power of me". Steve needs a large desk with three screens in his home-office [Fig. 7], which is why he wanted an extra room. Having space for a "home cinema"

[Fig. 8] was important for Leo. That his apartment is small has the advantage that he finds it easy to clean.

Social contacts and different experiences

In Steve and Leo's lived experience, social contacts were identified as important to cope with many challenges throughout their living practices. In their daily life, they identified regular sources of stress. For example, Leo mentioned regular domestic stress like a light in the building's communal space that remained defective for a long time, calculating payments for electricity and water consumption, unwanted conversations with the next-door neighbor or noise from the upper neighbor in the evening, the disappearance of his neighbor's bike accessories in the bike storage, and his neighbors putting waste in the wrong place. Since some of the regular sources of stress could not be handled by Steve and Leo, they needed help through their social contacts.

Independence, but not that independence that they don't need anything. They need a little bit support, like, it's social, they need also neighbors, for example ... The concept of good neighbors is for us, eh, so, for a job, you could call it a job, small things are practical things like electricity issue, the heating whenever it went wrong, something like that. But the more important thing is the social thing, having talk with everyone here: How's about your feeling? How's about your day? How's your work? That's the most important thing that they do here (interview coach - Sarah)

The role of good neighbors is to facilitate small talk with residents with special needs and help them in case of emergency. One of Steve's good neighbors helped him when his electricity was shut off last year. They meet and talk sometimes. Leo knows he can count on his good neighbors in case of emergency, although he has not asked for help yet.

Both Steve and Leo meet the psychologist once per month, mostly related to anxiety and stress issues. Apart from that, their coaches help them as go-between with the social housing agencies and energy suppliers for electricity bills, broken lights, and other technical or garbage-related issues. The coaches also facilitate meetings between residents, especially when they moved in. Both Leo and Steve referred to friends who share the same interests. For Leo, it is hard to meet his friend because he lives far away: a 1,5-hour drive without traffic. For Steve, it is rather easy and his friend sleeps over sometimes.

Not all social contacts are appreciated, however. Social contacts they want to avoid seemed to relate to the concept of self-determination. For example, Steve does not always appreciate contact with a neighbor who used to come to him in the evening and asked questions he could not understand. This led him to make a "do not disturb" sign for his door. Leo

stated his interest in having social contacts with his neighbors, however at the same time his interest is very specific.

Room for social interactions

Steve and Leo have different experiences in social contacts with their neighbors. Differences seem to relate to the buildings' physical characteristics, the number of neighbors on the same floor, and where the good neighbors live. While Steve appreciates small talk with his good neighbors, Leo communicates with his good neighbor by sending messages without meeting. Steve is satisfied that he lives among nine other residents, while Leo feels isolated from the other 13 residents living in the same block in his building.

A good neighbor also *motivates* each other. It's not about therapy, it's about the first step to help me to feel better. It's motivating "Tomorrow everything will be okay, tomorrow you have to go to Peace of Mind and everything will be *okay*" [laughing] okay (interview Steve).

Steve lives in a small three-floor residential building accommodating ten residents [Fig. 9]. The shared outdoor space [Fig. 10] and the large welcoming entrance, and the 1.8 m wide, light-filled and spacious staircase [Fig. 12] offer residents opportunities for encounter. During the walk-along-interview Steve met one of his neighbors on a pathway (a shared space) outside the building. Two good neighbors live on the upper floor, which allows for spontaneous encounters with Steve. Steve has three other neighbors on the same floor [Fig. 11].

The building where Leo lives offers residents few opportunities for encounter. It is a middle-sized residential building with 52 residents divided over four blocks [Fig. 13]. Leo lives in a block of seven floors with 13 residents. He is the only resident in his block who has a car and parks it on the back deck of the building [Fig. 14]. Leo has only one neighbor on the same floor [Fig. 15]. He remarked that his neighbor tended to talk with him about suicide, a topic Leo wanted to avoid. This is the reason why Leo did not want to talk to this neighbor. There are two good neighbors living in this building but different blocks. In the block where Leo lives, one good neighbor lives on the ground floor. The entrance of the building is relatively dark and narrow, 1.2 m wide [Fig. 16]. Leo does not use the shared bike storage because of his feeling of insecurity there. He commented on his lack of social contact with neighbors in the building:

Well, only [when] I have a building meeting ... That's the only chance where we meet each other or on the street when we walk to the surrounded. So, we're actually pretty isolated from each other. I know my neighbors, the one below me, his girlfriend lives



FIG. 9 There are ten residents living in the building where Steve lives. He lives on the first floor. Two good neighbors live on the second (top) floor.

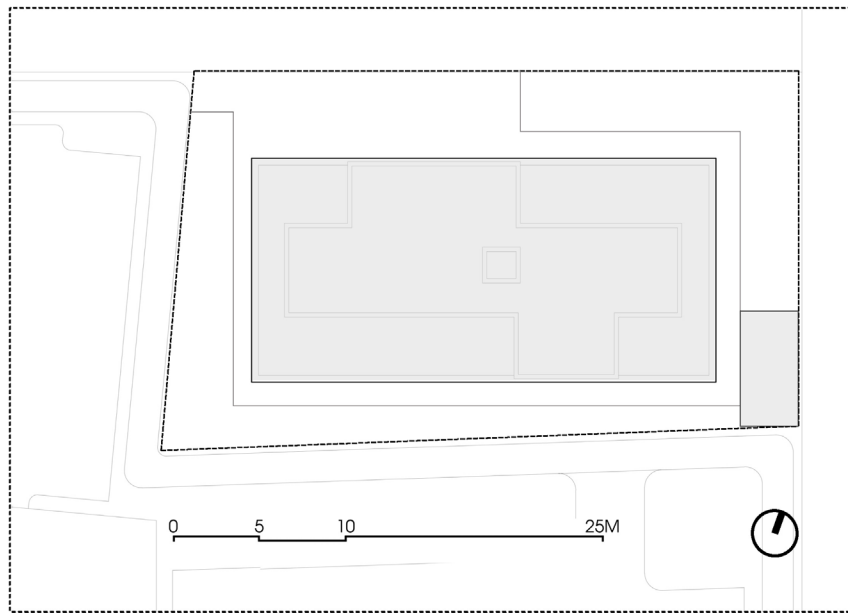


FIG. 10 The building where Steve lives, is located in the center of the site/plot. The residents share outdoor lawn, pathway around the building and bike storage.

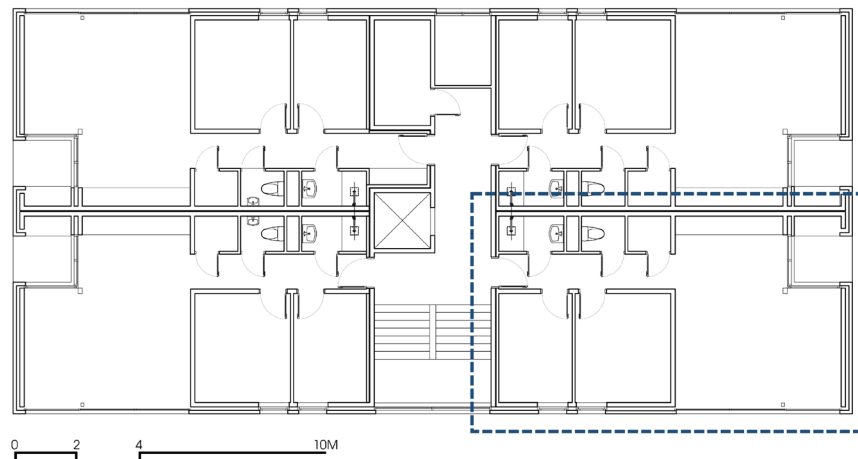


FIG. 11 The layout of the first floor, where Steve has three neighbors. Residents use the staircase.

in just below him, and below his girlfriend is actually his brother. So, it's pretty handy for him. And on the other side, there are also two friends living above each other. So, it's handy for them. I know like my below neighbor, he's gonna meet his brother every-day like for breakfast or stuff. And with his girlfriend they are



FIG. 12 The entrance of the building, where Steve lives, is filled with natural light.

doing a lot of stuff together and with his brother. *But I don't see much people* (interview Leo).

Leo feels isolated and seeks informal "interaction" with the pizza seller on the street instead. Waving or smiling to him and/or asking "how are you today?" became a part of his walking routine. He appreciates the small talk with people on the street.:

One of the first times I passed here, they said like "Hi, how are you?". I was like "okay he is talking to me, so I have to talk back". Because it's like a [commitment] to join. Actually, it's pretty nice, most of people just say "Hi", and ask how you are is a good thing. Not everyone did it but- if one person did it, it, likes, makes your day easier (interview Leo).



FIG. 13 The building where Leo lives is a high-rise building on the street. The building is split into four blocks. The block, where Leo lives, accommodates 14 residents, among them one out of two good neighbors lives on the ground floor.

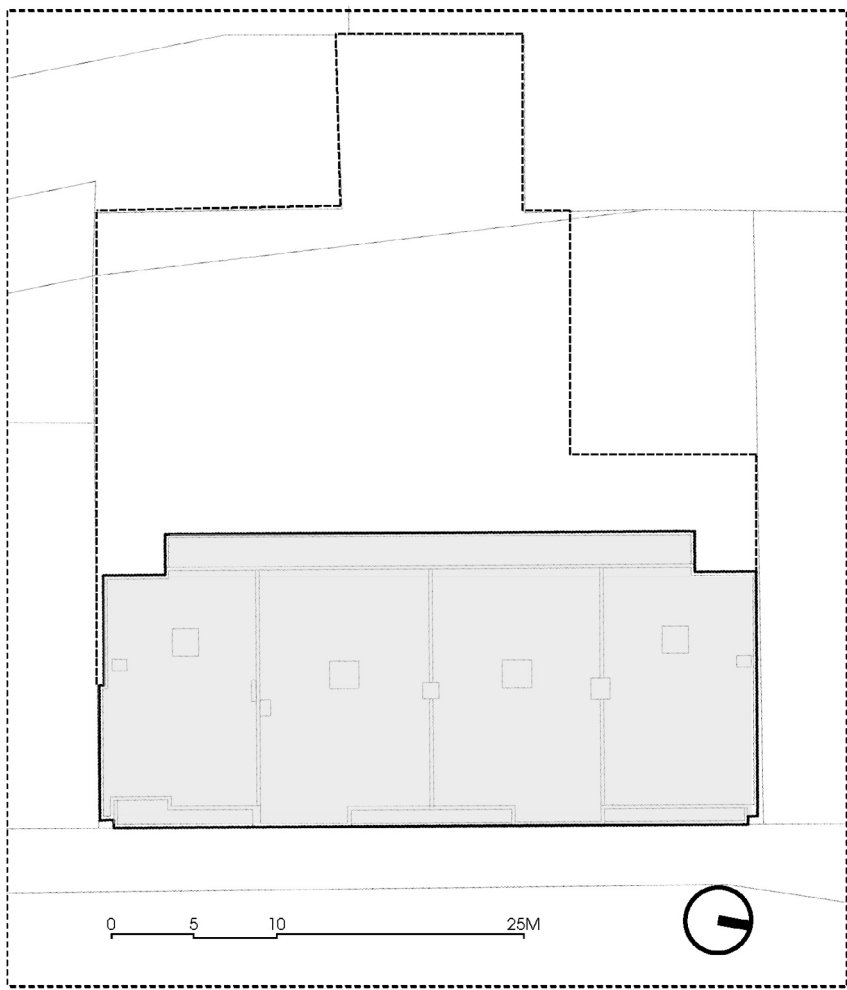


FIG. 14 The building where Leo lives, is located on the street. The residents have their parking lots at the back of the building

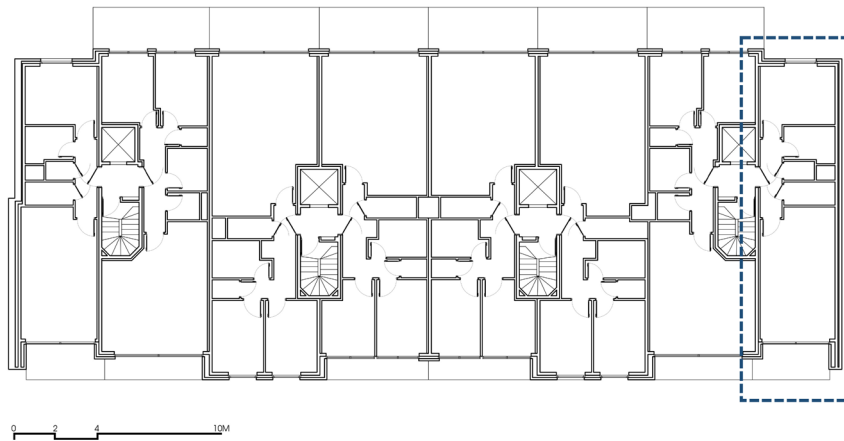


FIG. 15 The layout of the building, split into four blocks. The fifth floor where Leo has one neighbor. Leo uses the elevator only.



FIG. 16 The entrance of the building, where Leo lives, is narrow and relatively dark.

Discussion

Living independently for these two men means

1. living in proximity of public facilities, retail stores, and family;
2. self-determining their apartment arrangement and daily activities; and
3. having nearby social contacts to cope with regular domestic stress and anxiety.

Through the paradigm of independent living, their lived experiences are better understood: these two men would not live independently without their supportive housing environments, which involve social and physical factors.

Firstly, social factors support them in dealing with regular domestic stress issues. The nearby social contacts are important in supporting them practically and emotionally, providing a secure feeling of knowing a nearby and available person, good neighbors in this case, to count on in case of

emergency. Both Steve and Leo also rely on their parents, who live nearby, for weekly activities. This aligns with Krauss et al.'s (2005) finding that even when living independently, autistic adults may have an impressive amount of continued contact with their families.³⁴ Both men rely on support from their coach for domestic issues, technical problems, and housing maintenance. They also need monthly psychological counseling. Their living in proximity of social contacts is one physical factor which allows them to obtain support.

The finding regarding the role of social factors in the housing environment confirms previous research. As Venter et al. (1992) suggested, the availability of a supportive social network or local support may significantly affect the well-being of autistic people.³⁵ Access to specialist and appropriate support to develop social relationships,³⁶ and minimize psychological distress,³⁷ provides them with more opportunities to live independently.

Among the social factors, small talk was identified by both Steve and Leo as being important. This contrasts with Sinclair's (2010) finding that small talk is meaningless. In our study, small talk with the good neighbors emotionally encourages Steve when he is stressed and small talk with the pizza sellers makes Leo feel less isolated.

Secondly, for these two men, the physical factors identified are not only directly contributing to the success of living independently, but also indirectly facilitating access to social contact. Their housing location's proximity to their parents' houses, the coaches and the psychologist play an indirect role in facilitating access to social contacts. Its proximity to daily living facilities like public facilities, retail stores, and work-related and leisure activities makes living independently possible.

The housing type could facilitate residents' access to social contacts. Leo might be at risk of being lonely because he lives in a building on a street with little room for social interaction between residents. He has only one neighbor who lives next door, but wants to avoid him. Leo rarely meets his friend who lives far away, whereas Steve's friend comes over sometimes and stays with him. The housing type where Steve lives differs from the housing type where Leo lives. In Steve's situation, there is room for social interaction between residents. Room for social interaction consists of shared, common spaces for example, an outside lawn and pathway around the building, an outside bike storage, and a large light-filled entrance and staircases.

34 Krauss, Seltzer, and Jacobson, "Adults with Autism Living at Home or in Non-Family Settings."

35 A. Venter, C. Lord, and E. Schopler, "A Follow-up Study of High-Functioning Autistic Children," *Journal of Child Psychology and Psychiatry, and Allied Disciplines* 33, no. 3 (March 1992): 489–507, <https://doi.org/10.1111/j.1469-7610.1992.tb00887.x>.

36 Patricia Howlin and Pamela Yates, "The Potential Effectiveness of Social Skills Groups for Adults with Autism," *Autism*, June 29, 2016, <https://doi.org/10.1177/1362361399003003007>.

37 Digby Tantam, "Psychological Disorder in Adolescents and Adults with Asperger Syndrome," *Autism*, June 30, 2016, <https://doi.org/10.1177/1362361300004001004>.

The number of units per floor is a physical factor which could increase the spontaneous contacts between residents on the same floor. Leo lives on a floor where he has only one neighbor. Living on a floor with more people would offer options to meet other neighbors. Additionally, the good neighbors' location in the building also plays a role in increasing the spontaneous contacts between them and other residents. That Steve's good neighbors live on the top floor, may increase his spontaneous meeting with them. The housing environment's physical factors facilitate neighborly contact for Steve while they make Leo feel isolated.

Lastly, self-determining physical factors – making decisions in choosing the apartment size, and finishing their apartments in response to their needs – were essential for both. Leo found his apartment small but at the same time enabling him to manage his homecare, while Steve decided for a two-bedroom apartment to have a home-office. Both Steve and Leo have a strong sense of self-determination and want to express their personal identity and interests in finishing and decorating their home environments. Self-determining their apartment arrangement built up their personal identity and self-esteem. As we suspect that autistic adults may vary in this respect, housing design should allow different degrees of self-determination for independent living of autistic people.

The paradigm of independent living^{38,39} helps to better understand how the housing environment supports these two autistic men in living independently. Neither of them would live independently without support from their nearby family, good neighbors, coaches and other social contacts. This support is affected by the location and type of housing, the apartment's position within the building, its relation to the good neighbors' apartments and the number of neighbors per floor. Our findings suggest that their independent living is enabled by the combination of social and physical factors of the housing environment.

Limitations

Firstly, the English used for communication during the interviews was not the first language of either the researcher or the participants, which can be considered posing a challenge. At the same time, this challenge in verbal communication created opportunities to slow down the conversation. Participants had time to reflect and the researcher had opportunities to observe non-verbal communication, which added to and confirmed the meaning of the spoken words. Secondly, this research studied the cases of two autistic men with a "normal" IQ, who are not representative of the diversity on the autism spectrum.

38 Dejong, "Independent Living: From Social Movement to Analytic Paradigm."

39 Osterwitz, "The Concept of Independent Living - a New Perspective in Rehabilitation."

Conclusion

In conclusion, this research aimed firstly, to offer insight into autistic adults' experiences in and about living independently, and secondly, to understand the role of housing environments in their independent living practices. Analysis showed that these two men need supports from their housing environments to live on their own. For them, living independently means (1) living in proximity to public facilities, retail stores and family, (2) self-determining their apartment arrangements, daily activities and many aspects of their life, and (3) having social contacts assisting in living alone. We identified the importance of the supportive role of the housing environment, which includes social and physical factors. Those social and physical factors are not detached from each other, they could indeed strengthen each other to make independent living feasible for these two men. In line with the paradigm of independent living, the housing models of these two men may inform an effective long-term program for living independently with autism. A better understanding of autistic people's lived experiences is crucial to develop housing options which enable them to live independently.

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