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ASSISTED LIVING FOR PEOPLE WITH AUTISM SPECTRUM DISORDER: A SCOPING REVIEW

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Eduardo Sacomori Ferraz[1], Carla Correa de Lima[2], Fabiane Correa de Lima[3], Inara Regina Frühauf[4], Rafaela Fernandes Gonçalves [5]

ABSTRACT

In the approach to individuals with Autism Spectrum Disorder, among the main areas that need further study, inclusive education, mental health, accessibility, employability, and autonomy stand out. In view of this, the present study aims to map and reflect on the state of the art on assisted living as a viable alternative for people with ASD, based on their particularities of each level of support and the best practices for the implementation of this housing model. To this end, it was considered pertinent to carry out a scoping review in the PubMed®, Elsevier Science®, and Scientific and Technical Literature of Latin America and the Caribbean (LILACS) databases. The state of the art of the scoping review shows that assisted living consists of a mode of housing that provides support to individuals with special needs, including those with ASD, who need continuous care. This housing model aims to promote independence and well-being, while providing the necessary assistance to meet the needs imposed by the disorder, whose manifestations are varied, which justifies the three levels of care: support 1 (mild), support 2 (moderate) and support 3 (severe). Therefore, in the context of ASD, assisted living, with its infrastructure, fundamentals and dynamics of care, represents a trend in the intervention of adults who aim to achieve autonomy, in view of its benefits. Therefore, the objective of this review is to point out the contribution of this type of housing to the repertoire of life skills of adults on the autism spectrum, providing the necessary tools to socially improve issues of coexistence, contact, adjusting social life strategies and encouraging the achievement of new achievements.

Keywords: Autism Spectrum Disorder. Assisted living. Autonomy.

[1] Specialization in Psychiatry
Abuchaim Institute
Porto Alegre, Rio Grande do Sul, Brazil
Email: dreduardoferraz@gmail.com
[2] Post-graduation in Applied Behavior Analysis – ABA
Dom Alberto Higher Education Center
Porto Alegre, Rio Grande do Sul, Brazil
E-mail: Carla@clinicalibertad.com.br
[3] MBA in Hospital Management
Lutheran University of Brazil – ULBRA
Porto Alegre, Rio Grande do Sul, Brazil
E-mail: Fabiane@clinicalibertad.com.br
[4] Specialization in Psychiatry
Abuchaim Institute
Porto Alegre, Rio Grande do Sul, Brazil
E-mail: inara.fruhauf@gmail.com
[5] Master in Principles of Surgery
Mackenzie Evangelical College of Paraná
Curitiba, Paraná, Brazil
E-mail:rafaelafernandesgoncalves@gmail.com

1 INTRODUCTION

Autism Spectrum Disorder (ASD), of neurobiological origin and onset in childhood, imposes on sufferers some specific characteristics that define them, among them, many are related to communication, social interaction, behavior, and sensory perception, which result in difficulties in socio-emotional reciprocity, communication, and restricted and repetitive behaviors (Ramos and Lopes, 2024).

Over the past few decades, the prevalence of ASD has increased dramatically, which has drawn attention to this neurodevelopmental disorder (Xiao et al., 2023). The Global Burden of Disease Study estimated its prevalence and years living with disability among the six most prevalent developmental disabilities. It was shown that in 2021 the number of autistic people, worldwide, was 61.8 million (uncertainty interval of 95% 52.1-72.7), which corresponds to one carrier in every 127 inhabitants (Global, 2025).

In Brazil, there are still no official data on the prevalence of ASD, but the 2022 Census of the Brazilian Institute of Geography and Statistics (IBGE), will release an updated panorama in the year 2025. However, this government agency, based on previous data, estimates the existence of approximately 2 million autistic people, which corresponds to 1% of the population. More recently, the study "Portraits of Autism in Brazil in 2023", presents an estimate of 6 million people with ASD in the Brazilian population, based on data from the Centers for Disease Control and Prevention, which points out that 1 in 36 people is on the autism spectrum in the United States (Rissato, 2024).

ASD was ranked among the top ten causes of non-fatal health burden for young people under the age of 20, denoting the need for early detection and developmental support for autistic people. Most epidemiological investigations on the autism spectrum have been predominantly centered on children and adolescents, leaving a gap in relation to adult carriers. The prevalence and health burden of the disorder persists throughout life (Global, 2025).

The persistence of the health burden of ASD throughout life highlights several considerations on how health services can better adapt the available support. For this reason, in 2015, a line of care aimed at individuals with this neurodevelopmental condition was introduced, thus aiming to optimize early diagnosis, promote appropriate multidisciplinary interventions and offer continuous support to needs from childhood to adulthood, taking into account aspects such as well-being, improved quality of life, social inclusion, autonomy and independence (Brasil, 2015; Correa, Barbosa and Oliveira, 2023).

Among the main areas that need further study, inclusive education, mental health, accessibility, employability, and autonomy of people with ASD stand out. These are topics that

require a multidisciplinary approach and can generate significant results. The disorder requires an integrated and individualized approach. Therefore, lines of care and public policies in Brazil play a fundamental role in ensuring adequate and quality care for these individuals (Ho, 2020).

Through the implementation of inclusive policies, such as, for example, the Berenice Piana Law, No. 12,764/12, which instituted the National Policy for the Protection of the Rights of Persons with Autism Spectrum Disorder, equating autistic people with people with disabilities, which guaranteed and expanded their fundamental rights, such as, for example, access to early diagnosis and multidisciplinary treatment and protected residence, Brazil has made progress in promoting inclusion and strengthening rights (Brasil, 2012).

More recently, the Commission for the Defense of the Rights of Persons with Disabilities (CPD) approved Bill No. 1,466/22, which proposes the integration of assisted housing with the Unified Health System (SUS) in order to allow easy access to treatment and psychosocial support, thus expanding the rights of autistic people (Brasil, 2024).

As protected residences, assisted living facilities offer shelter to people who need monitoring and/or help to manage and maintain their own lives safely and autonomously. It is not a clinic or hospital, but a home where the facilities, tasks and routines are those of a house itself. In this sense, the purpose is assisted residential care for adults with the disorder who are unable to live independently without adequate family support, or for those who seek independence (Mason 2024).

In view of this, the present study aims to map and reflect on the state of the art on assisted living as a viable alternative for people with ASD, based on their particularities of each level of support and the best practices for the implementation of this housing model. It is intended, therefore, to deepen the understanding of how assisted living can improve the quality of life of people with a neurodevelopmental disorder, addressing public policies and the challenges faced in adapting and implementing affordable and appropriate housing solutions for these people.

2 THEORETICAL FRAMEWORK

ASD is a complex neurodevelopmental condition, caused by the altered expression of specific genes. Its identification was not a recent discovery, since in 1943 it was recognized in very young children, preschoolers, affected by biomedical and psychological problems accompanied by problems in communication and social interaction. Under the name of "autism", during the following three decades, studies continued to elucidate that neurons express chromosomal defects, including disturbed genes revealed during their structural

organization. In 1993, distinct components of the disorder began to be proposed and then recognized, becoming the most significant disease in the field of Psychiatry and widely debated; it is currently accepted as a set of disorders (Lamanna and Meldolesi, 2024).

It is important to note that in the fifth edition of the "Diagnostic and Statistical Manual of Mental Disorders" (DSM-V), of the "American Psychiatric Association", the following diagnostic criteria for ASD are established: deficits in communication and reciprocal social interaction and in non-verbal behavior in multiple contexts, with possible delays in language acquisition; ritualized patterns of behavior, including stereotyped and repetitive movements and language, attachment to routines, restriction of interests, and sensory disorders (APA, 2023). Abnormalities in sensory reactivity and cognition, particularly in executive function, are also described (Metwally et al., 2023).

The International Classification of Diseases (ICD), in its eleventh revision, included in the chapter on neurodevelopmental disorders, in analogy to the DSM-V, the diagnostic category of autism spectrum disorders on a dimensional basis, which allows for further specification through the two characteristics of an intellectual developmental disorder and the degree of functional impairment of speech. Difficulties in social interaction/communication. The previously separated symptom areas were combined into one: deficits in communication materially relate to social interaction and are not structural in nature (vocabulary or grammar). In addition, due to its frequent occurrence, hyper- or hyposensitivity to sensory stimuli was included as a symptom relevant to the diagnosis. In addition, there is clinical severity at different stages of life, including adulthood (WHO, 2022).

In the literature, ASD is approached as a complex disorder because it is commonly accompanied by morbidities that significantly affect the quality of life of its patients and family members, including epilepsy, depression, anxiety, obsessive and affective disorders, and attention deficit hyperactivity disorder (ADHD), which, depending on the severity, become challenging behaviors, such as self-harm, heteroaggression, and destruction of others' property (Maenner et al., 2021; Posara and Viscontia, 2022; Yang et al., 2022). Patients may present with atypical cognitive deficits, such as impaired cognition and social perception, executive dysfunction, and atypical information perception and processing, and motor deficits (Weir, Allison, and Baron-Cohen, 2022; Wang et al., 2023).

3 METHODOLOGY

It is a scoping study or scoping review carried out according to the methodology of the Joanna Briggs Institute (JBI), which establishes the following operational steps to be followed: elaboration of the research question; search for articles in databases; selection of articles in

accordance with the inclusion and exclusion criteria; mapping of pertinent data; and grouping, summarizing and presenting the results (Peters et al., 2020).

Based on the acronym population (P), concept (C) and context (C), the population selected for the study were adult individuals with ASD; The concept used as a phenomenon of interest was assisted living; and the context considered benefits as variable. Reconciling the key topics of the PCC with the objective of the study, the research question of the scoping review was constituted as: What are the benefits of assisted living for adult individuals with ASD?

This review was developed in June to November 2024 by the researcher involved who predefined the objective and stages of investigation. To identify relevant studies, articles indexed in full, in online journals, from 2014 to 2024 were selected. Repeated studies in more than one database were excluded from the selection, and only one was selected; and investigations whose results did not answer the research question of this review.

The search for articles was guided by the use of Health Sciences Descriptors (DeCs) and Medical Subject Headings (MeSH) terms in English and Portuguese, with the help of the Booleans AND and OR between the terms as follows: "autism spectrum disorder" OR "autism" AND "assisted living".

The following electronic databases were used as sources of information: PubMed®, Elsevier Science®, and Scientific and Technical Literature of Latin America and the Caribbean (LILACS). In the review, at first, the titles, keywords, descriptors and abstracts were explored in the identified records in order to confirm the approximation of the results with the object of the present study. Subsequently, the selected studies were read in full and answered the research question they were included in the present scoping review.

4 RESULTS AND DISCUSSIONS

ASD is a neurodevelopmental disorder with an early onset in life, whose pathophysiology involves several genetic, immunological, environmental, epigenetic, and neurobiological factors, which contribute to its various clinical manifestations, with different levels of severity explicitly elaborated to correspond to various degrees of functional impairment, namely: without support, deficits in social communication result in noticeable impairments (ASD level 1); social impairments are evident even with support in place (ASD level 2) and severe discrepancies in verbal and nonverbal social communication skills cause substantial functional impairments (ASD level 3) (Xiao et al., 2023; Zoccante et al., 2024).

Therefore, the characteristics of ASD range from milder manifestations and behaviors, which may go unnoticed by those who are not familiar with the syndrome, to more

exacerbated conditions that include significant challenges such as limited or non-existent verbal language, severe behavioral changes, difficulties in autonomy and performance of daily activities, socialization and maturity (Courte Júnior et al., 2024).

In addition to a wide range of symptoms and diverse developmental trajectories, since the needs of each person with ASD are unique, the presence of associated conditions is quite common, whether developmental disorders (intellectual disability, language disorders; attention deficit disorder) or psychiatric comorbidities, such as depression, anxiety, bipolar disorder, and schizophrenia (Al-Beltagi, 2021; Nader, 2024). Therefore, this disorder has become a public health problem in many countries, which deserves to be in the spotlight for policymakers to enable the delivery of targeted services, especially in developing countries where access to effective therapeutic services is limited or non-existent (Metwally et al., 2023; Shea et al., 2024).

However, in the area of research, scholars seek to discover effective and efficient approaches to treat people with ASD based on pathophysiology and syndromes, generally focusing on six main areas: sensory integration and sensory-based interventions; interactive relationship-based interventions; skills-based development programs; social cognitive skills training; targeted or parent-mediated approaches; intensive behavioral interventions (Xiao et al., 2023).

After decades of research, conventional interventions have increasingly been concerned with promoting a positive environment for social engagement and self-regulation in people with ASD, mitigating the negative effects of autistic traits and improving quality of life and well-being. Meanwhile, as the disorder is a multifactorial disease, the importance of a multifaceted approach adapted to the specific needs of each one is emphasized, comprising behavioral and educational therapies, speech and language therapy, occupational therapy, family support and training, pharmacological interventions, and complementary and alternative therapies (Zoccante et al., 2024).

ASD has a significant impact on the physical and mental health of sufferers, along with a higher risk of premature mortality, and higher annual health care expenditures than non-autistic adults and in almost all segments of health care, including outpatient care, follow-up in primary care, emergencies, mental health services, neurology, home health care, claims for prescription drugs, specialty care, and hospital admissions (Weir, Allison, and Baron-Cohen, 2022; Roy and Strate, 2023).

Due to the complexity and severity of ASD, a growing phenomenon has stood out in recent years: the approach to individuals with the disorder in adulthood. This trend reflects an increased awareness of the spectrum and an improvement in diagnostic and therapeutic

practices. Therefore, there is a great interest in elucidating the difficulties faced by adult patients, characterizing it as an emerging area of research and clinical concern, particularly assistance in the face of the possibility of absence of parents or other caregivers, since a significant proportion of autistic people need some form of support to deal with different facets of daily life, especially when they opt for assisted living (Mason et al., 2023; Nader, 2024; Shea et al., 2024).

Ghanouni et al. (2021) conducted one of the first empirical studies involving relevant stakeholders, including adults with ASD (mean age 40 years, range 27–53 years), to explore their perspectives and experiences around barriers to independent living. The results obtained pointed out three areas considered critical: psychophysical stability, such as characteristics of the disorder and associated challenges, such as sensory overstimulation and medical conditions and the ability to perform tasks of daily living; financial issues pertaining to being underemployed and not being paid well, or not being eligible for disability funding due to having a high intelligence quotient (IQ), or financial management issues, such as managing personal finances; and access to integrated community living environments, such as living independently in the community rather than in segregated or protected housing. However, it has been shown that the needs of some autistic people may require alternative accommodations, such as living in assisted living facilities.

The discussion about housing in assisted living facilities falls within the scope of Mental Health, Well-Being and Social Security and concerns young people and adults with ASD, as well as their families and caregivers. Programs in Brazil, such as the Therapeutic Home Service of the Ministry of Health and the Inclusive Residence of the Ministry of Social Development, have the potential to help in this regard. Both public policies are considered of great relevance, considering that the transition to adulthood is often a source of stress for both the autistic person and their family, since there is usually a cessation or significant reduction in the services provided so far (Nader, 2024).

Assisted living consists of a mode of housing that provides support to individuals with special needs, including those with ASD, who need continuous care. This housing model aims to promote independence and well-being, while providing the necessary assistance to meet the needs imposed by the disorder, whose manifestations are varied, which justifies the three levels of care: support 1 (mild), support 2 (moderate) and support 3 (severe) (Faria and Borba, 2024).

In long-term care residences, an interdisciplinary team is made up of health professionals, such as occupational therapists, psychologists and educators, who work to meet the specific needs of residents. Commonly, the environment is designed to be safe and

welcoming, with structured routines that help promote stability and well-being for residents, thus providing opportunities to live in a dignified way, with access to daily activities, education, and community integration.

Many institutions have been offering therapeutic and recreational activities, with the aim of developing social, motor and cognitive skills, with the aim of ensuring autonomy, inclusion and social interaction. In addition to caring for residents, some locations also offer support and guidance to family members, helping them cope with the challenges of ASD.

Regarding medical practice in the assisted residential care for autistic adults, as it is a model that combines autonomy with the necessary support, it provides a safe environment adapted to individual needs. In fact, the study by Nguyen et al. (2021) reported that living independently with support was a positive opportunity for autistic individuals to develop their abilities.

Assisted living offers several benefits, which enable the autonomy and independence of individuals with ASD, from the adaptation of the environment, so that they can carry out their daily activities independently, but with support available when necessary; in addition, residents are guaranteed safety and emotional support in order to reduce stress and promote mental health (Olszewsk, 2022).

Social and educational integration are also benefits of assisted living, since in this environment socialization is fostered, with activities that encourage interaction and continuous learning. The model aims to improve the quality of life by adapting individual needs and providing a welcoming and inclusive environment (Vedovate, 2022).

For individuals with ASD who fit into support 1, who are autonomous in their daily lives, but adept at routine and have a closed thought, being resistant to initiating social interactions, assisted living is organized in order to allow greater independence. To do so, two options are given: live in environments closer to a conventional residence, with minimal supervision, such as in apartments or houses shared with other individuals. Assistance may be limited to social support situations, community activities, or regular consultations to monitor progress and adaptation to the process of change (Faria and Borba, 2024).

Support 2 in assisted living for individuals with ASD, who have speech delay or communication failures, in addition to socialization difficulties and restricted and repetitive behaviors more frequently, requires greater supervision, with a dedicated team to support daily activities, such as routine management, domestic activities and social interaction. This housing can include specific programs for the development of life skills, such as financial control, healthy eating, and emotional management. The structure can involve more controlled environments, with individualized support according to the needs of each resident.

Individuals who fit into support 3, on the other hand, due to the severity of the disorder, have little autonomy, may be non-verbal, tend to isolate themselves and have restricted interest and in stressful moments may be aggressive, requiring highly structured assisted housing, with constant support for all areas of life. In this model, professionals from the interdisciplinary team are active, who provide uninterrupted care, with specific therapeutic resources, intensive training and socialization programs that help residents develop basic coexistence skills. These residences need to be adapted to the specific needs of each individual, with a focus on safety and constant well-being (Faria and Borba, 2024).

Assisted living for people with ASD requires a careful and personalized approach, considering the specific needs of each individual, especially in relation to the daily routine and adaptations in the residential environment. For people with autism, especially adults, the structure and predictability of routine are key to ensuring well-being, safety, and a sense of control over the environment around them (Vedovate, 2022).

Routine is considered an essential element for individuals with ASD, since predictability offers security and reduces anxiety that can be triggered by unexpected changes or lack of structure. In the residential environment, the routine must be clear, consistent and easy to understand by the resident. In many cases, this involves creating a visual schedule, with images, icons, or even specific signs to indicate day-to-day activities, such as meals, leisure activities, personal hygiene, and rest times (Ho, 2020).

Routines in assisted living should be adapted to each level of support needed, considering cognitive and communication skills and the need for supervision. Thus, for a resident with support 1, the routine may be relatively simple, with more emphasis on self-sufficient tasks, while for someone with support 3, constant monitoring may be required to ensure that each step of the routine is followed safely (Ho, 2020).

In addition to establishing a well-defined routine, physical and sensory adaptations in the residential environment are considered essential to promote comfort and ensure functionality. In this sense, assisted living for autistic people should be organized in a simple and functional way, with well-defined areas for different activities, such as rest, food, and leisure. The use of soft colors, adequate lighting, and reduction of visual and sound stimuli are key to avoiding sensory overload (Vedovate, 2022).

Individuals with ASD may have hypersensitivity to sensory stimuli, such as loud sounds, touches or specific textures, resulting in avoidance reactions, irritability and stereotyped behaviors, on the other hand, others may exhibit hyposensitivity, seeking intense sensory stimuli or demonstrating an unusual tolerance to unfavorable sensations, such as low temperatures or uncomfortable environments. Due to the significant differences in

sensory processing, in the residential environment it is important to ensure that stimuli are minimized, such as the use of soft lighting, acoustic insulation, and room temperature control (Ferreira et al., 2024).

The environment must be safe and accessible, with spaces that promote the resident's mobility and autonomy, avoiding the risk of accidents. To do so, it may be necessary to adjust furniture, install grab bars, use non-slip floors, and ensure the absence of dangerous objects within reach (Ramos and Lopes, 2024).

The use of assistive technology can be essential to facilitate communication and the performance of daily activities. Devices such as tablets, desktop computers, notebooks, mobile telephone devices, communication boards, and audible or visual warning systems can be integrated into the routine to help individuals with ASD understand and interact with the environment more efficiently (Proença et al., 2019).

The care of autistic adults requires an even more personalized approach, given the unique challenges in relation to the lack of verbal communication or severe difficulties in social interactions. The main challenge faced, especially for those at higher levels of support, concerns the inability to express their needs, feelings and desires verbally.

This absence of verbal communication demands the adoption of alternative methods of communication. The use of alternative and augmentative communication (AAC) systems is considered essential to help these individuals express themselves. Tools such as communication boards with images or tablets with speech software can facilitate dialogue and the expression of basic needs, such as hunger, thirst, discomfort, or the desire to perform specific activities (Silva and Rossato, 2023).

In addition, the approach to care should be more attentive to the observation and interpretation of non-verbal signals, such as gestures, facial expressions, and body behaviors, which often indicate what the individual feels or needs. The team responsible for assisted living must be trained to identify these signs and respond promptly appropriately, using adapted communication methods (França, Morais and Rocha, 2024).

Another crucial aspect is the care with emotional and behavioral issues. Lack of verbal communication can result in frustration and, in some cases, challenging behaviors such as aggression or self-harm. Therefore, Applied Behavior Analysis (ABA) is indicated for the planning of strategies, including therapeutic interventions, social skills training and emotional support, aiming to encourage the development of social, communicative, adaptive and cognitive skills, to achieve active inclusion in the lives of individuals with ASD and, thus, improve quality of life (Oliveira e Silva, 2021).

5 CONCLUSION

It was concluded from this study that, in the context of ASD, assisted living, with its infrastructure, fundamentals and dynamics of care, represents a trend in the intervention of adults who aim to achieve autonomy, in view of its benefits. Therefore, the objective of this review is to point out the contribution of this type of housing to the repertoire of life skills of adults on the autism spectrum, providing the necessary tools to socially improve issues of coexistence, contact, adjusting social life strategies and encouraging the achievement of new achievements.

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