



ITA

International Teachers Association

MODULE 24: Aging and long-term care

This module is about aging and long-term care as it relates to those on the autism spectrum. First you'll learn about what is known as the aging out crisis and how researchers are responding to what they're uncovering about the crisis. Then you'll find out about how the transition into adulthood affects those on the autism spectrum and about some of the challenges that those on the spectrum face during adulthood. The module then goes on to explore the support systems, including intervention programs and financial support, and housing options available to those on the autism spectrum, before closing with a section on emergency preparedness.

24.1 Aging out crisis

24.2 Functioning in society as an adult

24.3 Support systems

24.4 Housing options

24.5 Emergency preparedness

24.1 Aging out crisis

24.1.1 The problem

The 'aging out crisis' is the term used to refer to the huge drop in services available to those on the autism spectrum when they move from childhood into adulthood, particularly with reference to when they leave school or educational provision.

Paul T. Shattuck at A.J. Drexel Autism Institute has been the pioneer of research in this field, leading the Life Course Outcomes Research Program at Drexel University. He and his team of researchers have found, through analysing longitudinal studies, some disturbing trends in outcomes for the adulthood of those on the autism spectrum. Their collated findings led them to the conclusion:



ITA

International Teachers Association

Individuals on the autism spectrum are about three times more likely to be disengaged from employment or education than people with serious mental illness or severe cognitive impairments, five years after leaving high school.¹

When individuals on the autism spectrum leave school, the severe lack of services available can leave them and their families struggling to access further education and the workplace, as well as retaining the social skills they need to build and maintain relationships. While funding may have been easily accessible when the child was at school, with state-provided services and resources, the struggle to gain and retain funding for adult services may be too complex and time consuming for some families to go through. There may not be any funding available, leaving the families in the position that they have to pay for services themselves, which they might not be in a position to do. Health insurers may not pay for autism treatment cover, and, if they do, it is likely to be restricted to certain approved treatments, approaches or programs. These might not be the programs or services that those with an individual on the autism spectrum to care for want to use. The treatments might not be compatible with the treatments received or programs enrolled in during childhood.

24.1.2 Creating New Services to Respond to Need

Before Shattuk and researchers at Drexel began their research program, there was very little accessible information about the outcomes for adults on the autism spectrum, showing how underdeveloped this area of research is. The autism research field has a heavy emphasis on early intervention and services for children, an emphasis which Shattuk is intent on rebalancing until all age groups are given sufficient research attention.

The questions of how many friends people have, how many go to college or university, live on their own or have a job are questions that are extremely important to those on the autism spectrum and their parents and carers. This data set needs to be explored for the long-term results of early intervention to be understood. Shattuk and researchers plan to use this information to identify trends and also to identify the best educational and employment supports available that improve quality of life for those on the autism spectrum, both at a childhood and adult level.

This research can shape national policy. This kind of data demonstrates to governments and health bodies both that action is required to improve outcomes and also what kind of interventions and services are the most successful in improving outcomes. The Drexel team plans to use the research program to develop and add to the range of strategies and services offered to adults on the autism spectrum.



ITA

International Teachers Association

“People with autism are valuable members of our communities,” says Shattuk. “Like all people, they have dreams, roles to play, contributions to make. ... We need to know what experiences, beyond clinical interventions, promote positive outcomes and prevent negative ones — both for people on the autism spectrum and the families and communities they are part of.”

24.2 Functioning in society as an adult

24.2.1 Transition into adulthood

The transition from childhood to adulthood seems to be fraught with difficulties for many people. Teenage rebellion and depression could be a response to this transition. This time is characterized by change, particularly when individuals leave school and enter further education or the workplace. The transition into adulthood requires those going through it to adapt to changing demands and expectations from those around them, as well as new routines and activities. This can be a period of great excitement but also of distress and anxiety.

This is often exacerbated in the cases of those on the autism spectrum, though individuals will respond differently and be affected in different ways because autism is a spectrum condition. The consistent routine of school that lasts for about 10 to 15 years is abruptly broken and a new period of life begins. For some, this will mean going to an adult care facility. For others, the new transition may involve university or a work placement. For others, it means staying at home. Many young adults are expected to choose their own activities for the next period of their lives and are expected to be pro-active in applying to university, looking for a job or finding other avenues to pursue.

Many people on the autism spectrum have difficulty with transitions. These could be transitions as minor as switching off the TV, going to bed, or going from one classroom to another, which are all short-term. The transition of stopping going to a place that the individual might have attended for more than a decade is a serious prospect, and this upheaval can be enough to cause extreme distress in an individual with autism. For this reason, conscious education providers, therapists and teachers often implement transition interventions to prepare the individual for the impending change.

The shift from the secure, timetabled environment of the classroom with teachers who understand the condition, into the wider world which expects self-determination, can be extremely challenging for those on the autism spectrum.



ITA
International Teachers Association



24.2.2 Challenges (1 of 2)

To be an adult who participates in society, there are many, mostly unwritten, requirements, that make this participation possible. Some of those on the autism spectrum may not be able to meet some of these requirements. Others may have the abilities to meet the requirements but have not used them because they were not aware of the requirements or that these requirements applied to them. Due to the fact that some on the autism spectrum have limited social creativity and imagination, meaning they can find it difficult to imagine life as different from how it is in the present, it may not occur to them that they can alter their situation or lifestyle by taking a pro-active approach.

Though every individual on the autism spectrum will experience things differently, there are some areas of difficulty that are common to many.



ITA
International Teachers Association



24.2.2 Challenges (2 of 2)

Social challenges that can affect employment, educational and relationship outcomes include the following:

- Some people on the autism spectrum do not communicate verbally. This will limit their employment, educational and relationship outcomes. However, if they learn sign language, Makaton, use speaking machines or pictures, they may still be able to communicate effectively with others who have the same skills.
- Because of the lack of theory of mind, some people on the autism spectrum find it difficult or impossible to know if someone is trying to deceive them. Neurotypical people can sometimes prevent harm from coming to them by picking up subtle social cues or using their imagination to know that people can have different intentions than what they portray, those on the autism spectrum might be unable to prevent themselves being manipulated or deceived.



ITA

International Teachers Association



- The difficulties those on the autism spectrum may have with empathy, whether that's a lack of empathy, a lack of understanding of the emotions of others, or difficulty expressing their empathy, can hinder social relationships.
- Many people on the autism spectrum find it difficult to make 'small talk'. If anxious about interaction, they may ease into conversation by beginning to talk about their special interest. This might interest others, but may also alienate others and prevent even-sided conversation.

24.3 Support systems

24.3.1 Treatments and support programs



ITA

International Teachers Association

Programs available for adults on the autism spectrum vary from area to area but can include state-funded, lottery-funded, charity-funded and private organizations. The programs available might be on a daily, weekly, monthly or ad-hoc basis. Alternatively, they might be courses that run for a particular amount of time and then conclude. Many people on the autism spectrum attend multiple support programs simultaneously. The programs available can include:

- Social learning programs – These programs should offer skills based training tailored to those on the autism spectrum, to help them improve their relationships, education and work prospects. These are likely to be held in a group setting that encourages the formation of new friendships.
- Leisure activity programs – These programs might offer games, exercise activities and excursions, to provide opportunities for those on the autism spectrum to broaden their horizons and make new friends.
- Skills programs – These programs are designed to teach those on the autism spectrum new skills. These might be practical skills to help with self-care and independent living, such as cooking, washing clothes or cleaning. They might be skills to improve employment prospects, such as CV writing and interview techniques. They might also provide activities that improve fine motor skills or coordination such as knitting or sports.
- Psychological therapy – Individuals on the autism spectrum may be referred by their doctor or other health professional to psychological therapy sessions to support their wellbeing.
- Medication – Medication may be offered to those on the autism spectrum to help them manage any difficulties or health problems they may have, though there is no medication to ‘cure’ autism.
- Other therapies – A huge range of therapies are available to those with ASD, though access to these services in adulthood can be difficult. These therapies include Speech and Language Therapy and Occupational Therapy.

24.3.2 Benefits and grants in the UK



ITA

International Teachers Association

Individuals on the autism spectrum between the ages of 16 and 64 might be able to claim benefits through the Personal Independence Payment, known as PIP. The criterion of the PIP is that the individual has care needs or mobility difficulties, regardless of whether they are in education or work, or how much money they or their family have. This benefit is replacing the Disability Living Allowance (DLA) that used to support those on the autism spectrum.

Other benefits those on the autism spectrum and their carers may be eligible for include:

- Job Seekers Allowance, if the individual is actively looking for employment
- Employment and Support Allowance, if the individual cannot work or has a limited ability to work due to a disability or health condition
- Income Support, if the individual is a carer or lone parent of children under 5 and does not work or only does a small amount of work
- Carers Allowance, for people who earn less than £110 per week and care for someone who receives disability benefit of some kind
- Working Tax Credit, Housing Benefit and Council tax support, for people who are working for a low wage and have limited savings



ITA
International Teachers Association



Different rates apply to those below working age and above the age of 64.

24.4 Housing options

24.4.1 Independent living

Those on the autism spectrum who are able to live independently might consider the following options:

- Buying a home with a mortgage, either paid for by parents or from own working. It is advisable to make sure that ground rent, insurance, ongoing maintenance and service charges are affordable on top of the mortgage payment.
- Inheriting property. This means there is no mortgage to be paid but other service and maintenance must be affordable.
- Renting private property with a tenancy agreement with landlord. Some may accept benefits claimants but others will not.



ITA

International Teachers Association

- Renting a property owned by a parent or relative who will take up landlord responsibilities. Sometimes benefits will cover the rent payable to the relative in this arrangement.
- Renting social housing (council housing or housing association properties). Councils generally work through a points system which enables those looking for houses to bid on properties they like. Those receiving disability related allowances may have more points which makes them more likely to be housed. Rent may be subsidised by a housing association, which often also work on the bidding system.
- Buying a property through shared ownership, a scheme which allows a part-purchase, part-rent agreement.



24.4.2 Semi-independent living

Semi-independent living is for those on the autism spectrum who want to live as independently as possible, but may need some assistance in doing so, either in a general sense or in specific areas. A needs assessment by the local social services department will determine the level of staff support given.

Some semi-independent options are:



ITA

International Teachers Association

- Living in one of the arrangements described in 9.4.1, but with extra support from family, friends or carers for tasks such as managing finances, shopping or cooking. A carer or personal assistant might visit on a regular basis, live in to offer 24 hour support, or be on-call in times of need.
- Sheltered accommodation, which is usually for those aged at least 55, may be on a rental or owner-occupier basis. Others of a similar age housed around them, and there is a warden on hand who is kept informed of any need by alarm system and phones. There may be a communal lounge or other facilities.
- Cluster housing, which is a small block of self-contained flats with own kitchen, bathroom and bedroom facilities. There may be communal facilities, too, and support is provided by a team of support workers or wardens on site.
- Supported living networks are comprised of nearby flats or houses occupied by people on the autism spectrum or who have disabilities of some kind. A Community Living Worker lives in the area and supports those in the network with advice, information and support.

Any of these living arrangements might involve the following support, which might be provided by social services or arranged privately and paid for privately or by the local social services department:

- Cleaner or carer to take care of responsibilities such as cleaning, laundry, shopping etc
- Carer to take care of self-care needs such as bathing or dressing
- Support worker to assist in accessing services and therapy
- Any other support as deemed necessary in the needs assessment

24.4.3 Living with others

Family home

An individual on the autism spectrum might live in a family home and be cared for by their family. This could be the home of one of their parents or siblings, or a more distant relative like aunts, uncles or cousins. The local social services department carry out a needs assessment of the carers as well as of the person on the autism spectrum.

Residential home

Some people on the autism spectrum require 24-hour support and care to meet their needs. This care might also be relevant for those with ASD who previously lived



ITA International Teachers Association

independently but now suffer from age-related conditions such as dementia. A specialist autism residential home is recommended for people on the spectrum, unless their autism is mild and a particular illness is the reason they need round-the-clock care. Most residential homes will have between 5 and 20 residents of any age over 18.



Group home

Group homes are similar to residential homes in that they may specialize and generally offer 24 hour care, but they may only provide care for between 2 and 5 people at any one time.

Shared Lives

Some social services offer shared lives schemes, where people on the autism spectrum live with families other than their own to receive the support they need.

Homeshare



ITA
International Teachers Association

A young person with housing needs comes to live with a person on the autism spectrum and provides them with services such as household maintenance or chores in exchange for an affordable rental rate.

24.5 Emergency preparedness



An individual on the autism spectrum is more likely to have an emergency encounter with fire, police or ambulance professionals than a neurotypical person.³

Those on the autism spectrum may have a tendency to wander or run away, or a heightened sensitivity to touch, sirens, flashing lights. They may not be able to follow verbal direction. This is likely make any interactions they have with emergency responders difficult and fraught with misunderstandings.

24.5.1 The Six Actions (1 of 2)



ITA

International Teachers Association

The Autism Society of Minnesota produced a document called Six Actions to empower those on the autism spectrum to get the help they need in an emergency and to improve understanding with emergency services personnel. It can also be used by friends, family or carers of an individual on the ASD spectrum to improve emergency responses and outcomes.

Action 1: Assess Your Risk

You know your environment, personal health, and behaviors best. Think through your unique circumstances, what you need to do to ensure your safety, and be prepared.

- Live near water, train tracks, other potentially dangerous conditions
- Flooding or extreme weather
- House or wild fires
- Escalating or other dangerous behaviors that might lead to an encounter with professional responders
- Medications
- Nonverbal
- Mobility challenges

Action 2: Identify Yourself

ASD presents unique challenges in an emergency with police, fire, and EMS professionals. Professional responders can be more effective if they know you are a person with ASD. There are many ways to self-identify—find the solutions that work for you.

- Register with your local police
- Carry a card about ASD in your pocket, wallet or pouch
- Wear an ID bracelet or other identifier
- Have contact numbers in case of emergency in your phone or in a diary
- Place a sticker or magnet on your house or car window with ASD and contact information

Action 3: Educate your support network

Our friends, families, co-workers, and neighbors are a great source of support and assistance in emergency situations. Make sure your support network knows your situation, who to contact, and how to help.

- Introduce yourself to neighbors and co-workers
- Explain your situation and concerns to family, friends, neighbors and co-workers
- Ask others to check on you in the event of an emergency and help as needed



ITA

International Teachers Association

- Include contact information in your plan
- Share tips, medical information, and “who to contact”

24.5.1 The Six Actions (2 of 2)

Action 4: Make a plan and practice

Everyone needs a plan. Planning and practice are even more essential for persons with communication challenges, who do not deal well with a change in routine, or are likely to become confused or anxious in an emergency situation with police, fire or EMS professionals

- Consult resources about emergency preparedness
- Prepare a checklist
- Ready kit and Go Bag
- Practice test your plan
- Emergency drills
- Social stories
- Role play
- Videomodeling
- Visit with police, fire and ambulance services before an emergency occurs

Action 5: Prepare for wandering

Many individuals with ASD are at risk of wandering or running away. If this is a concern for you, you may want to participate in tracking and recovery programs in your local community (e.g., Project Lifesaver). Consult with local law enforcement for a recommended solution. If necessary, test some technology devices/tools or contact 3rd party call center services for further support

- If available, utilize a tracking device and protocol already supported by your community (e.g. Project Lifesaver).
- If there is no locally supported protocol or it does not work for you, consult with local law enforcement for potential solutions.
- As needed, turn to phone apps, other technology devices, and/or 3rd party call center services for support.

Action 6: Be an advocate



ITA

International Teachers Association

Part of making your own plan is getting to know local law enforcement, fire, ambulance and emergency managers. Make your voice heard! They need your help to learn more about ASD, how to plan and respond effectively, and design programs and protocols that protect you and the community at large.

- Meet with local emergency responders BEFORE an emergency situation happens
- Meet with local professionals BEFORE an event occurs
- Police
- Fire
- Ambulance
- Emergency call responders
- Share information about ASD and provide tips
- Ask for help
- Encourage training and better preparedness

[EXAM LINK](#)