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### **Module 26: Community living and supports**

This module begins by exploring how families can support their family member on the autism spectrum and any physical home modifications that might be made in this regard. Next you'll learn about early intervention, why it is seen as beneficial, and the early intervention programs available. Next, the in-home and out-of-home options for autism care will be described. After-school programs and their benefits will be discussed and the module will close with an exploration and evaluation of behavioural therapy, with particular reference to the ABA approach.

26.1 Family support

26.2 Physical home modifications

26.3 Early intervention programs

26.4 In-home and out-of-home care

26.5 After-school programs

26.6 Behavioural therapy

#### **26.1 Family support**

The family of a person on the autism spectrum can help their family member with ASD by implementing various social, behavioural and organizational strategies to support them. Though the ultimate goal may be to assist the individual on the autism spectrum in integrating successfully into their family environment, significant modifications may be required before this is possible.

##### **26.1.1 Family Support - Structure**

Those on the autism spectrum generally function best within structural approaches. Here are some ways that families might incorporate structure into their everyday lives:

- Ensuring consistency between therapeutic settings and home. Individuals on the autism spectrum tend to find it difficult to transfer what is learned in one setting to another. This requires parents and carers to engage in dialogue with therapists,



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educators and intervention providers to ensure consistency of approach in all areas of the individual's life, equipping themselves to continue techniques used by professionals within the home environment.

- Ensuring consistency in behavioural expectations, interactions and consequences. It may be necessary for parents and carers to explicitly lay out their standards for behaviour, perhaps visually in the form of lists of rules with pictorial representations. To provide additional structure, it is strongly recommended that parents and carers are consistent in their approach to interaction with the person on the autism spectrum.
- Creating stability through timetables. People on the autism spectrum have been shown to respond well when they are provided with timetables for the day or week, particularly with pictorial representations, informing them of the activities for that timeframe. Parents and carers are advised to prepare the individual on the autism spectrum as far as possible in advance in the case of unavoidable schedule changes.



### 26.1.2 Family Support - Communication



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Families are also advised to focus on communication in order to effectively support a person on the autism spectrum within their family.

- Families are reminded that those on the autism spectrum are communicating, even if they are non-verbal. Family members are encouraged to discern how the individual communicates and to respond to the individual in a manner they can understand.
- Non-verbal cues that are used by those on the autism spectrum to communicate include gestures, facial expressions and sounds. Family members are encouraged to be observant and to work out what messages these behaviours are intended to communicate.
- It is not recommended that tantrums are approached in the same way as they would be with a neurotypical child. They are differentiated by the term 'meltdowns'. Families may be informed that meltdowns are not a type of power struggle, but rather are a result of the frustration of inadequate communication channels that lead to the individual's needs not being met. Families are encouraged to view meltdowns as a signal that non-verbal cues are being missed and communication needs to be worked on.



- People on the autism spectrum may be hypersensitive, hyposensitive, or experience both these states at different times. Families are advised to work out what sounds, sights, sensations, movements and smells are enjoyable or distressing for the individual and monitoring their communication to see how these factors interact. Having knowledge of sensory triggers empowers families to increase harmony and communication.



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- Families are encouraged to foster positive relationships by scheduling time for fun and enjoyment. By focusing on the activities that the individual on the autism spectrum enjoys, families can forge closer bonds through time spent together outside of therapeutic or educational interventions. Sharing enjoyment improves family relationships.



### **26.2 Physical home modifications**

In addition to behavioural, social and communication measures, families are advised to modify their homes to help their relative on the autism spectrum. Doing so can provide order and sensory balance that may impact behaviour and relationships in a positive way.

The home environment can be overstimulating, frightening, confusing or restrictive for people on the autism spectrum. Families who use their knowledge of autism in general and in how it exhibits in their relative to adapt the living environment can improve outcomes in all areas of the individual's life.



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### **26.2.1 Physical home modifications - Rooms, fixtures, fittings and design**

- Cool down space – A space with a minimal amount of objects, distractions and sensory experiences could be provided within the home to allow individuals on the autism spectrum to retreat when experiencing overstimulation or aggression. All objects in this space should be soft and dull coloured. The lighting should be dim and windows should have blackened curtains or blinds to allow light to be blocked should the individual feel it necessary. If space is a concern, a dark coloured tent erected indoors can serve the same purpose.
- Paint – Those who are sensitive to light may find the way some walls are decorated to be distracting or even distressing. Families can use soft colour tones and matt or eggshell textures instead of bright gloss paints to ensure minimum distress for the individual on the autism spectrum.
- Lighting – Many people on the autism spectrum have sensitivity to bright lights. Fluorescent lights are often flickering, too bright, and a source of distracting



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background noise. These should be replaced with incandescent lights, preferably with a dimmer switch.

- Doors – Some people on the autism spectrum enjoy slamming doors, which can damage the hinges and the doorframe as well as potentially causing injury. Families can replace traditional swing doors with pocket doors, curtains, bifold doors or weighted doors that close gradually and are impossible to slam. Those for whom replacing doors is not an option, can add bumpers to the wall to prevent wall damage or prop doors open with a doorstop to minimize slamming.
- Open plan design – When families are designing their homes or searching for a new home, they might want to opt for an open plan design. Good acoustic and visual connections are particularly important if there are medical issues, seizures or other safety risks that have to be considered. Families without these options are encouraged to create openings between rooms for optimal visibility, either with doorless frames or interior windows.
- Smooth edges – Selecting furniture and countertops with smooth edges minimizes the risk of head and brain injury, particularly for those who engage in headbanging behaviour.
- Soundproofing – People with sensitivity to sound will benefit from carpeting instead of wooden floors, as well as soundproofing windows to block out noise from outside.
- Furniture – Some individuals on the autism spectrum enjoy rocking, bouncing and other such movements. Purchasing furniture that accommodates these movements can help to reduce destructive behaviour.

### **26.2.2 Physical home modifications - Home maintenance**

- Organization of household objects – Household clutter should be kept to a minimum. Items for use by the individual on the autism spectrum can be organised into clear plastic boxes or other containers with labels that are understood by the individual, whether they include words, photos, symbols or textures.
- Sensory provisions – A box with sensory objects can be stored and retrieved at times when the individual on the autism spectrum is searching for stimulation.
- Locks – Some individuals on the autism spectrum have problems with understanding the concept of ownership, precious items and appropriate use of items. For this reason, it may be necessary to lock some things away, whether in a cupboard, box or storage area. The individual should then have a means of requesting the use of those objects should they need or want them.
- Odours – Odours can cause those on the autism spectrum significant levels of discomfort, distress or distraction. Ensuring that cooking odours are minimized through adequate ventilation and closing doors between kitchens and living areas can be helpful. Other odours such as roomsprays, perfumes and oil burners or



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incense can affect those on the spectrum negatively, though this is not always the case. Families are advised to keep an eye on the relationship between the odours in their home and the individual's behaviour.

- Allergies and sensitivity – Autism has a strong link with allergy, through the details of this relationship have not yet been fully established. Many people on the autism suffer with allergies, sometimes of a severe nature. These might include food allergies or allergies to products such as shampoo, chemical cleaners or soap ingredients. They may also have sensitive skin or eczema that is worsened by washing powder or synthetic materials. Families are advised to explore potential allergies and sensitivities and to update their household products in response.
- Sound sensitivity – People of the autism spectrum often have problems with noise. Beyond soundproofing the home structurally, families can avoid overstimulation by placing the TV, radio and computer in areas that the individual can avoid when they want to.
- Safety signs – Rooms, furniture or appliances that are off limits can be labelled with a 'STOP' or similar visual sign to alert the individual and prevent harm or damage coming to the person or the household.
- Airflow control – People on the autism spectrum can be sensitive to drafts, air quality and temperature. Air filtration and adjustable HVAC systems can be effective options for regulating airflow and temperature for maximum comfort.

### **26.3 Early intervention programs**

With reference to the autism spectrum, the term 'early intervention programs' usually refers to treatments that occur before a child attends school. In this section we discuss the benefits of early intervention, followed by exploring the early intervention programs available.



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### 26.3.1 Early Intervention Programs - Benefits of early intervention

*'A significant proportion of children receiving intensive intervention early in life make outstanding progress.'*<sup>1</sup>

This is a widely held view among the autism treatment community, but what are the scientific justifications behind this view?

One important term in relation to this area of study is 'increased neuroplasticity' in young children, which refers to the scientific fact that young children's brains have a greater ability to change than older children's or adult brains. Since autism has correlations with neurological differences, neuroplasticity is relevant to the treatment of autism. In young children, behaviours have not had long periods of reinforcement as they would in older children, leading to the view that behaviours in young children are easier to change.

A 2014 pilot study<sup>2</sup> brought 7 children between the ages of 7 and 15 months who exhibited signs of autism together with a behavioural modification therapist who engaged children and their parents in a 12 week therapy program. When the children were tested at 38 months against a control group who had no behavioural intervention, they were found to have much lower rates of autism. Five of the children showed no symptoms, one showed mild symptoms and one exhibited severe symptoms. Associate professor of psychiatry at Columbia University, Dr Veenstra-VanderWeele said of this pilot study, "It is exciting to think about an intervention that could change the developmental outcome for babies at risk of autism spectrum disorder."





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### **26.3.2 Early Intervention Programs - Programs available**

The vast majority of programs available as early intervention are simply modifications of programs available to all ages, but which are administered to preschool age children (up to age 4) for the reasons set out in 10.2.1. Here are a selection of programs which are available for early intervention and brief descriptions of their respective approaches:

ABA (Applied Behaviour Analysis) – This approach, also known as EIBI (Early Intensive Behavioural Intervention), includes PECS (the Picture Exchange Communication System) and will be explored further in section 10.6.

TEACCH (Treatment and Education of Autistic and related Communication handicapped Children) – This approach trains its therapy providers as generalists rather than specialists, offering treatment to those with autism in all different areas. Focusing on reducing ‘autistic behaviours’, TEACCH offers diagnosis, assessment, individual treatment plans, social skills education, special education, counselling, group services, school consultations and vocational training.



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**Son-Rise** – The Son-Rise approach aims to foster deep bonds and understanding relationships between children on the autism spectrum and their parents and carers, with the latter joining in autistic behaviours in order to improve communication and relationships. Rather than rewards or punishments, the approach emphasizes a child’s motivation and teaching through interactive play, in addition to enthusiastic and nonjudgmental interaction.

**Floortime** – The Floortime approach encourages parents to follow the child’s lead by engaging in their play and enjoining their emotional flow, followed by utilizing different exercises to spark creativity and spontaneity in the child, and engaging multiple senses, motor skills and emotions.

**Nurtured Heart Approach** – This relationship-based approach can be used with other therapies simultaneously. The parent is empowered to improve language, social communication and positive behaviour through engagement and relationship building.



### **26.4 In-home and out-of-home care**

Care for those on the autism spectrum is provided in a vast array of different settings. Here we discuss residential care and services offered to those who live with their families.

#### **26.4.1 In-home and out-of-home care - Residential care**

**Residential services** – Adults who present with severe autistic symptoms that mean they are unable to live independently might live in residential settings that provide specialized 24 hour care.



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Group homes – Generally for children who are in the care of the state, or whose parents cannot care for them, group homes provide a home-like atmosphere with a limited amount of children and staff living together in a normal, residential house. In addition to kitchen, dining room, living room and bedrooms, the house will usually have a quiet room and a sensory room, in addition to educational facilities to support with homework or children who cannot be educated in a school setting.



Supported living – Those on the autism spectrum who live in their own homes, whether as owner occupiers or tenants, and need extra assistance to stay functional, might live in a supported living setting. How much support received varies depending on the individual, ranging from occasional visits or a number to contact in case of emergency, or 24-hour care.

Special needs schools with boarding facilities – A large proportion of special needs schools offer boarding facilities, and many of them offer full-time residential care. Children on the autism spectrum may divide their time between home and school, which is often known as flexi-boarding.

Respite care and short breaks – Respite care offers those on the autism spectrum new experiences as they spend a few hours a week, or occasional weekend or weeklong breaks, in a different location and often with different carers.



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**26.4.2 In-home and out-of-home care - Day services**

Schools – In a mainstream classroom, in an autism unit or in a special educational needs school, children from the age of 4 to 19, or into the 20s in some SEN schools, will be supported during the day by educational and therapeutic professionals.





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Support centres – Catering for adults and children, support centres provide support, social interaction and the opportunity to develop social skills through groups, classes and activities.

Outreach services – This covers a huge range of services, which might include assisting those on the autism spectrum to attend a course or to join a sports team with a dedicated member of staff.

Student support – Many organizations assist children, young people and adults in accessing and getting the most out of their education through providing tailored support.

Employment support – Those on the autism spectrum may be supported in gaining skills to improve their employability, in writing their CV and interviewing and with attaining qualifications that will advance their career goals.

Social groups – Social groups offer opportunities for ASD individuals to learn social skills, meet new people and make friends.

Befriending and mentoring – Some organizations offer a service whereby those on the autism spectrum are paired with befrienders or mentors to improve their social or practical skills.

Enterprise – Those on the autism spectrum might be encouraged and supported in using their skills and talents to start businesses.

### **26.5 After-school programs**



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Some children and young people on the autism spectrum, particularly those with high-functioning autism and Asperger's syndrome, attend after-school programs. Unless the school the child attends has an autism unit, it is unlikely these programs will be held at the child's school. Rather, special educational needs schools may open their doors in the afternoons for children who attend mainstream school during the day, or the program may be provided by a community organization or autism charity or treatment provider.

These clubs are likely to provide activities to improve social skills, educational outcomes, practical skills and a wide range of opportunities. These activities might include cooking, sports, computer games, web design, animation, dancing, team games or excursions.

## **26.6 Behavioural therapy**

### **26.6.1 Behavioural therapy - The history and practice of ABA**



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ABA, which stands for Applied Behaviour Analysis, is one of most widely accepted autism treatments and one of the very few treatments that has attracted state funding. It is based on the principles of behaviourism, which postulates that positive reinforcement increases desirable behaviour and negative reinforcement decreases behaviour.

Developed in the 1960s, it was originally an adult-led, regimented approach that included corporal punishment but has since become more flexible and enjoyable for the child. The approach no longer uses negative reinforcement or punishment in response to unwanted behaviours, but rather offers no reinforcement for the behaviours.

Decades of research have produced numerous techniques for reducing unwanted behaviours and increasing desirable behaviours. ABA implements these techniques with an aim to bringing about behavioural change. This could be in the classroom or any other environment such as the home, the playground or out in public, delivered one-to-one or in a group setting. Primarily a skills-based method, ABA aims to equip those on the autism spectrum with social, practical and academic skills that will enable them to become increasingly independent and successful. Each individual will have their own skill plan tailored to them depending on the behavioural observations of their assigned analyst. Success is also measured by observable behaviour.





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### **26.6.2 Behavioural therapy - Criticism of ABA**

Criticism for the ABA method and wider behavioural therapy in general comes from many sources, some of whom are proponents of other methods, parents with difficult experiences of ABA, children on the autism spectrum who've gone through ABA treatment and scientists and psychologists.

Ido Keddar, a non-verbal teenager on the autism spectrum, attended ABA sessions during his childhood. Later he was taught to use an iPad and wrote a book detailing his experiences with different autism therapies. He wrote of ABA that 40 hours a week of repeated drills to teach concepts and to test understanding frustrated him. This is because he understood what was being taught but had no means to communicate his understanding. He felt the ABA experience was not helpful for him and his behaviours were frequently misinterpreted.<sup>3</sup>

Other critics say that the ABA method is intolerant of autism and views autism as a list of deficits that should be corrected. Dawson<sup>4</sup> put forward that, in ABA's view, 'autism equals tragedy, suffering and doom... Autism is incompatible with achievement, intelligence, physical and psychological integrity, dignity, autonomy and learning: either you are autistic *or* you have access to these possibilities.' She goes on to say that ABA and its supporters have compared Autism with cancer, strokes and AIDS, which illustrates their view that there is nothing beneficial about autism. 'Either you are autistic *or* you are human,' she says of the approach.

Others have concerns that ABA targets behaviours that are harmless and may even be helpful or necessary to the child on the autism spectrum, such as rocking or flapping, for extinction, and they also insist on activities such as joint attention and eye contact which may be unnecessary, stressful or even painful for the person. Psychologists and former ABA parents have criticized the approach for its perceived determination to assign a model of neurotypical behaviour to children on the autism spectrum and to coerce them into complying with rewards.

**[EXAM LINK](#)**