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# **Training curricula** for people starting work with adult people with autism

## HANDBOOK 2018

Publication written in the Project 'Train the Trainers - Education for Social and Vocational Inclusion of Individuals with Autism Spectrum Disorders (ASD)', co-funded by the Erasmus+ Programme of the European Union.

Realised in the Partnership of the three organizations: SYNAPSIS Foundation, Latvijas Autisma apvienība, AS Mentoring Ltd.



Co-funded by the Erasmus+ Programme of the European Union





LATVIJAS AUTISMA

### Foreword

The professionals from three European organisations: SYNAPSIS Foundation, AS Mentoring Ltd and Latvijas Autisma apvienība have exchanged knowledge and experience during some trainings and discussions in the project from

Erasmus + Programme: 'Train the Trainers - Education for Social and Vocational Inclusion of Individuals with Autism Spectrum Disorders (ASDs)'. The result of this dialog is the Handbook: 'Training curricula for people starting work with adult people with autism'.

A team of trainers from the SYNAPSIS

Foundation, working with adults with autism spectrum disorders (henceforth ASDs), has prepared a curriculum for training staff who support adult people with ASDs. The curriculum was devised through every-day experience of clinical work, counselling, advocacy and training delivery. The Modules contain also description of trainings and some materials & bibliography prepared by British and Latvian teams of trainers.

You could ask, why should anyone prepare a special curriculum for training psychologists, job coaches, therapists and caregivers for adult people with autism?

It is our belief that the world needs a fresh look at adult

people with ASDs, that considers their personalities, pasts, perspectives and ways of thinking and perceiving the world. It is important to consider adults with ASDs as mature and fully developed people, with wide-ranging

experiences and characters, and who process things differently to the 'norm' due to autism.

The course stresses how important it is for adult people with an ASD to meet with psychologists, therapists and instructors in a shared environment. It is worth remembering that such

meetings need to be conducted with mutual respect and openness. If one bears that in mind, one can build a solid therapeutic/mentoring/training/caregiving/coaching relationship. It is this feeling of a good relationship that is key for growth and development, not only for the person with an ASD, but also for the therapist, trainer or psychologist as well.

What we want for people who complete our training is for them to be more open to people with ASDs. If this happens, these professionals can create opportunities and conditions for people with ASDs that will allow to resolve everyday problems and, in effect, improve their lives. This training focuses on experiencing oneself through communicating with others.

> We hope you enjoy reading this, Liga Berzina David Perkins Renata Werpachowska

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'I hear and I forget. I see and I remember. I do and I understand.' Confucius

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### Glossary

Autism: is a disorder in neurodevelopment that causes difficulties with social interactions. People suffering from it often demonstrate inflexible thinking, behaviour or interests, and difficulties in receiving and processing sensory stimuli. The first symptoms manifest very early (even when children are only a few months' old) and should be visible before the age of three. Despite the fact that small children can be diagnosed with autism, it is not uncommon for people to be diagnosed in their teenage years, and even in adulthood. Left untreated, it can lead to very severe functioning disorders later in life. Autism is often diagnosed in people whose speech development has been significantly delayed. Autism can be paired with other disorders, e. g. mental disabilities. However, autistic spectrum disorders can be very diverse. A simple description of symptoms and their severity does not exist. That is why, in world literature, the term 'autism spectrum disorder' is now used. In this publication, the word 'autism' will be sometimes used to describe the full range of spectrum disorders (ASD).

AS (Asperger's Syndrome): similarly to autism, Asperger's Syndrome is a disorder in neurodevelopment. People suffering from it have difficulty in understanding the intentions and behaviour of other people, in communicating, in sharing their interests and controlling their behaviour. It is often described as a mild form of autism. It was first introduced in the ICD-10 and DSM-IV diagnostic criteria. However, in the DSM-5 issue of diagnostic criteria, Asperger's Syndrome is no longer distinguished as a separate entity. People with Asperger's experience difficulties due to autism in a different fashion and with different intensity. Most of these people find communication, social interactions, abstract and emphatic thinking much easier. People with AS often demonstrate an average or above average level of intelligence and do not show any delays in speech development in the early years of their lives. These people often have skills that are valued in the workplace. Please note that not every person with AS thinks that his or her different way of thinking is a disorder. Some of these people simply think that their minds function differently, but not any worse than that of a 'normal' person. They sometimes describe people whose brains function 'normally' as 'neurotypical'. Just like autism, AS is a disability that often remains invisible.

**ASC** or autism spectrum condition is a term that describes individuals who displays autistic symptoms, including those with severe disorders, as well as those whose symptoms are of a milder nature. It is a term that, on the one hand, aims to underline the diversity of symptoms and the ways they can manifest in different people, and on the other hand, ensures that the mechanisms which determine their occurrence are the same. Contrary to the ICD-10 criteria still used in most European countries, the DSM-5 diagnostic criteria effective in many countries worldwide use the 'autism spectrum disorder' term and do not distinguish autism, Asperger's Syndrome or other pervasive developmental disorders as a separate entity.

**HFA, or High Functioning Autism** is a term describing people with autism who have a level of functioning and possible difficulties that are similar to people with Asperger's Syndrome. Their intelligence is average or above average; their speech development was significantly delayed.

LFA, or Low Functioning Autism a term describing people with autism with severe disorders. These people often do not speak or have obvious difficulties with communicating. One can observe that these people quite often have secondary problems, e. g. difficult behaviour. People with low-functioning autism might have an intellectual disability, but it is not necessarily true, even if they have limitations in communicating and difficulties in everyday relations, which might produce intellectual problems. More than often, these are people who require much support and cannot rely exclusively on themselves (in everyday life).

Meltdown – A meltdown is 'an intense response to overwhelming situations'. It happens when someone becomes completely overwhelmed by their current situation and temporarily loses behavioural control. <u>http://www.autism.org.uk/about/</u> behaviour/meltdowns.aspx

**Neurotypical** – Neurotypical is often used to refer to people who are NOT on the autism spectrum. It's a combination of the words "neurologically typical" and is often shortened to NT. http://musingsofanaspie.com/2013/01/10/what-is-neurotypical/

**Obsessive Compulsive disorder (OCD)** – Is a serious anxiety -related condition where a person experiences frequent intrusive and unwelcome obsessional thoughts, often followed by repetitive compulsions, impulses or urges, <u>http://www.ocduk.</u> org/ocd

SEN—Special Educational Needs

**Triad of Impairments** – The three main areas of difficulty which all people with autism share are sometimes known as the "Triad of Impairments", as first described by Lorna Wing: Social communication, Social interaction, Social imagination, <u>http://www.autismbedfordshire.net/about-autism/triad-of-impairments/</u>

### Chapter 1.

# The concept of the course, its assumptions, target audience

The main aim of the course is to prepare professional staff for work with adult people with an ASD in the field of gaining self-reliance and coping with problems in their professional lives, so that these individuals can enjoy their lives as much as possible.

The modules have been prepared for professionals who meet people with an ASD, that are of age, and for professionals who have not worked previously with children with ASDs. The form of the course and the way it is conducted are designed to help staff build openness and empathy for the way people with an ASD function and perceive the world. Through participating in this course professionals become sensitive to the needs of adult people with ASDs, learn about the tools that they can use and learn how to build relationships with people with ASDs that support their overall development.

The most common stereotype about autism is that 'it is a disease'. Hearing such a statement, one can assume that it can be cured. In modern science, it is explicitly stated that autism is a disorder of functioning modes and modes of perceiving the world, that lasts a lifetime. Through therapy, people with an ASD can learn to cope with their disability and being different (with different levels of success) and learn how to function properly, as understood by neurotypical people.

Taking that into consideration, it is important to instil in participants a stereotype-free view of people with an ASD. Why? Because stereotypes simplify understandings of ASD and label people with autism as sick people who mainly need care. Perceiving adult people with ASDs through the lens of stereotypes often results in neglecting their real needs. In effect such people receive only basic care. People with ASDs usually receive help in performing tasks related to self-reliance and do not receive support that is suited to their capabilities and needs. Often, people supporting those with ASDs lack knowledge and experience and believe in common myths about autistic people, e. g. that they are all geniuses with extraordinary skills. While this may be true in rare cases (the technical name for this is savantism, and it's not exclusive to autistic people) it is not necessarily the case.

Not only do both stereotypes simplify the characteristics of people with an ASD, but they also create difficulties in building relationships between professionals and individuals with ASDs that are based on mutual respect. That is why it is so important not to see autistic people as individuals who are simply sick. Looking at the rights of disabled people, demonstrating their possibilities and presenting the most typical life situations of people with ASDs from different countries will help you to show how strong an influence education and inclusion in society have on broadening the possibilities for their development.

The aim of the course is to show the variety of ways that ASD can manifest in people. This goal is achieved by delivering the necessary knowledge and skills to support people with ASDs in achieving their developmental goals. An important aspect of the training is to teach the participants to recognise the individual needs of such people, along with our own needs for help with our work. Without caring for each other's needs, a relationship based on mutual respect and openness cannot be built. It is important to realise the vast array of methods to help with development, functioning and self-reliance. Such an approach helps professionals gain greater self-confidence, even when working with people with great difficulties, and fosters greater commitment.

This training is aimed at professionals, namely psychologists, therapists, work trainers/job coaches, assistants and employees of Occupational Therapy Workshops, Vocational Development Centres, Communal Homes of Mutual Aid; assistants in higher learning, trainers of supported employment, trainers in protected households working with people with ASDs in different fields (from self-reliance to in their professional career). Other people who encounter people with ASDs in their professional work may also participate, e.g. in clinics, culture centres and restaurants, etc.

The first module is the core. Here, two main topics are presented: ASD as different ways of perceiving the world and adulthood as a stage in human life. Aside from theoretical knowledge about cognitive functioning and functioning in society, the module's aim is to teach the participants about the way people with ASDs function in relation to senses and perceiving stimuli from the outside world.

This module is for everyone working or wanting to work with adults with an ASD as it contains basic indispensable information on what ASD mean in adulthood. It can be used by both people working in supported housing and people taking care of individuals with ASDs. The training is aimed towards psychologists, therapists and trainers (of social skills, self-reliance, work) and assistants in Occupational Therapy Workshops, Vocational Development Centres or at schools of higher learning. Other individuals, who have contact with people with ASDs in personal as well as professional life and who are tasked with supporting these people, can also participate in this course.

Building an approach towards people with ASDs that is centred around commitment and openness, and free from stereotypes, is an important part of the course. An approach built on openness and respect towards the other person gives a chance to establish a relationship that positively impacts an autistic person's development and gives the therapist/trainer/assistant/psychologist satisfaction from his or her work. A good relationship encourages happiness and enables personal growth. These qualities, in turn, prepare us to gain new competences and overcome obstacles. It is only possible when everyone feels accepted, regardless of their behaviours and skills. This is the kind of attitude that people with ASDs need from individuals working with them, to be able to keep developing and work with their own limitations and difficulties.

An open attitude and empathy towards the other person form the basis for a strategy to work with adult people with ASDs. It provides you with tools to communicate, prepare tasks, adapt the workplace and surroundings in such a way as to develop an individual's potential in the most effective way.

The second module is for people who work with adult people with high-functioning autism or Asperger's. The third module is for people who work with individuals with more profound disorders. Both latter modules cover the topics of specific needs, communication possibilities, encouraging self-reliance at home and at work. To create the most suitable environment for gaining and developing specific competencies in adult people with ASDs, these modules are mainly conducted in the form of workshops. The concept behind the course and its assumptions are the same for all the partners of this project: organisations from Poland, the United Kingdom and Latvia. The modules set forth by each partner were addressed to similar recipients and were divided into one base module and two modules for advanced training. It is worth pointing out that the level of detail in the descriptions differs for each partner and reflects the experiences and demands of their countries. The characteristics of the groups that they are aimed at is also described.

All partners who developed the training curricula use mainly active training methods. The partners state that these methods are the best in terms of quality and effectiveness for educating staff working with people with ASDs. All partners emphasise that the participants should have the opportunity to relate to their own experience and devise helpful solutions during the course. An important aspect of how the curricula are constructed is that they ensure every participant develops openness and respect towards other people. To achieve that the course presenters use words that do not exclude anyone and encourage participants to do the same. All partners agree that interpersonal skills and a proper approach towards people with ASDs, regardless of how severe, are more important than qualifications and formal education.

Please note that the courses were designed for specific countries. The partner organisation from Great Britain involves people with high-functioning autism as experts. The partner from Poland, on the other hand, draws on participation and recorded statements from people with disorders of different levels, so that the participants can experience the diversity of the spectrum first-hand. Finally, the partner from Latvia concentrates mainly on the training process itself and the skills of the instructor, paying less attention to the content itself.

### Chapter 2.

## Established problems that the training can resolve and the situation of people with ASD

In some EU countries, especially in the post-communist ones, adult people with autism or Asperger's are often denied a social life and do not receive proper support while entering adulthood and during the later years of life. Disorders from the autistic spectrum often manifest themselves during childhood. They have various levels of intensity and cause disability for a lifetime. It is a social disability that encompasses communication and the ability to develop relationships with other people; it impacts on imagination and the understanding of social norms. With the right rehabilitation, therapy and social inclusion such people can function better, conform to society and, in effect, avoid spending several years in mental institutions or closed institutions of care.

SYNAPSIS, in 2013, prepared a report titled '<u>Autyzm – sytu-acja dorosłych</u>' which makes it clear that Poland does not

provide any state solutions that give adult people with ASDs access to education, therapy and psychological counselling that could prepare them for self-reliance and self-sufficiency at the highest possible levels.

In most European countries, the exact number of people with an ASD is not known. However, according to global indicators, between three and six children in every 1,000 have ASD. According to this indicator, there are currently 180,000 people with ASDs in Poland. However, many people have not been yet diagnosed or have been diagnosed wrongly (e.g. with obsessive-compulsive disorder (OCD) or bipolar affective disorder, etc.). According to the CDC agency in the United States, the number of people diagnosed with ASDs continues to rise. According to the latest research carried out in the USA, one child in 88 suffers from this disorder (every 45th boy and every 252nd girl).

The British National Audit Office estimates, that the number of people with ASDs living in England amounts to half a million (400,000 being adults). The spectrum of their disorders is very wide with severe cases requiring constant care. At the same time, it is known, that, in Great Britain, only 15 percent of people with an ASD find employment.

In Latvia, on the other hand, inclusive education is recommended by the Ministry of Education. Such actions promote the overall inclusion of people with an ASD into society. Despite this, headmasters, teachers and pedagogy representatives feel uncertain about the special education needs (SEN) of young people with autism. Taking that into consideration, access to practical knowledge and developing the skills of people working with young adults and adults with ASDs are all important.

In many countries, people with autistic spectrum disorders receive support tailored to their needs only until they finish school. Social weLFAre, health care and continuing education systems do not recognise ASD adults as a group that needs special support. Due to this fact, their mental health and ability to function in society during adulthood often dramatically deteriorate. Proper support can prevent this from happening.

There is a general lack of awareness (even among professionals) that such people require specialist and long-lasting support. On the other hand, there is a shortage of psychologists, physicians, work trainers, care givers and assistants who are trained to communicate with adult people with ASDs and to support them in various activities and social roles. Many countries do not offer degree programmes or courses that could educate staff in this regard. In the bestcase scenario, formal preparation relates only to children with ASDs, but working with adult people requires a different approach and perspective. In effect, adult people with ASDs live in solitude and isolation, cannot continue education or find work, and do not receive care or support in difficult situations. Some adult people with ASDs find themselves in drastically difficult situations.

If we are considering the provision of institutions that are designed to support adult people with ASDs, the obligation of training the staff rests on the facility's owner. There are too few trained professionals in the job market. People with autism and their families complain about not having access to professional care that could help their adult children. To prepare adult people with ASDs to function in society and in a work environment, we need properly trained professionals, who not only work in schools and clinics, but in work, rehabilitation, social inclusion, etc. as well.

We also need to work on how society perceives these people, as currently is a reluctance to accept them into schools and to hire them. Due to many stereotypes and out of fear of possible problems, people are afraid to have any contact with ASD adults. Working with people with autism is for many individuals a challenge — employees face stress and job burnout. Owing to this, most institutions avoid taking responsibility for such people or provide services that are of questionable quality. This very often leads to a deterioration in the wellbeing of people with ASDs.

As a response to these needs, three organizations (from Poland, Latvia and the United Kingdom) have decided to, as part of a project, to develop a specialist training curriculum for professionals working with adult people with ASDs in various organisations and schemes. Basing on the experience of people from Poland and Great Britain, it can be said that people working with adult individuals with ASDs need to understand the nature of autism spectrum disorders, the difficulties that arise while trying to communicate with such people, and their behaviour and ways of functioning. Professionals are currently discouraged from seeking information and gaining knowledge because of fear and reluctance. By training and transferring practical skills relating to the methods used, teaching ways of communicating and coping with new or surprising situations, we can raise the efficiency of the support, reduce the feeling of powerlessness and bring measurable effects in the form of improving the lives of people with ASDs. Measurable success and improvements motivate everyone to further work.

In recent years, we have observed an increased proportion of people with ASDs accessing further and higher education. More and more go to college, where some of them can work in protected environments or in normal circumstances, depending on their capabilities. People with ASDs, by participating in cultural events and doing sports, are more and more noticeable in social life. Thanks to the support of professionally trained staff, they can develop and be successful, feel needed and accepted. Some of them are self-advocates and spokespersons of not only their needs, but the community as well.

There are examples of good practice in terms of training professionals working with adult people with ASDs, but we still lack opportunities to share knowledge and experience in that field. This is what we aim to accomplish with the training modules of the 'Train the Trainers' project. We have decided that the first course will introduce the topic of autism spectrum disorders and a full presentation of how people with ASDs function. This will help understand, how their world is different.

The second module entails working with people with autism or Asperger's, whose disorders are hidden, not visible at first glance (such as people with what would formerly be described as high-functioning autism), but who very often cannot break the barrier of establishing interpersonal relationships, even though they have many skills and capabilities. As a result, they are unable to function in society in a satisfying way.

The third module tackles the topic of working with and supporting people with very diverse and deep autistic disorders, which very often coexist with intellectual disabilities. Maintaining cooperation and administering care are very difficult in this scenario and require specialist knowledge and experience. Please note, that this is the group that is most dependent on others.

### Chapter 3.

### Primary and secondary objectives of the course

**The main objective** is to bring the participants of individual modules up to date with knowledge pertaining to ASDs and issues relating to adult people with ASDs. Further modules will prepare the participants for work with such people. The participants will gain knowledge, competence and practical skills that are indispensable in supporting adult people with ASDs and maintaining a stance of openness and mutual respect.

### Secondary objectives:

- Building a stance of openness and respect towards people with ASDs through workshop activities and coaching;
- Gathering and comparing the participants' knowledge on the topic of people with ASDs;
- Introducing knowledge on the specific issues relating to how people with ASDs function while considering disorders characteristic to communication and cognitive processes;
- Teaching about the differences of how adult people with ASDs perceive the world and how it affects

their everyday lives;

- Analysing and understanding adulthood in relation to adult people with ASDs – the problems and opportunities it can bring;
- Revising the methodology of therapies particularly useful in work with adult people with ASDs with significant focus on improving communication, establishing interpersonal relations and developing cognitive functions;
- Teaching the participants how important professional work and social roles are to people with ASDs;
- Training participants how to use tools for improving communication with people with ASDs;
- Through the use of individual profiles, participants will be taught to understand the different traits, potential and constraints of people with ASD. The profile makes it possible to administer support tailored to the individual's needs.
- Gaining the ability to develop support strategies in the workplace (for people with ASDs);
- Giving the participants an opportunity to share experiences;
- Developing team work and team-building skills;
- Enabling participants to support each other after the course ends.

### Chapter 4.

### Course methodology

All modules are based on David Kolb's model of experiential learning. This means that the participants will have a chance to test their knowledge (transferred through lectures and PowerPoint presentations) in practice. They will also have an opportunity to think about their level of skill and build a stance of openness and respect towards people with ASDs. Doing so, they have a better chance at building relations with these people.

Stages of the course:

- <u>Gaining knowledge</u> presenting theoretical knowledge about the functioning of people with ASDs. Building a positive image of people with ASDs is also within this scope;
- Lectures;
- PowerPoint presentations;
- Moderated discussions;
- Feedback.

By learning the theory and gaining skills that relate to the relevant issues, the participants will understand the mechanisms behind the way adult people with ASDs function and rules for building positive and effective working relationships with them;

- 2. <u>Gaining experience</u> the participants will practice their skills, using methods such as:
- individual work;
- workshops in various groups;
- psychodrama activities in which participants act as adult people with ASDs;
- educational games;
- case studies;
- feedback.

The participants become a part of a process in which they

### Chapter 5.

### **Course structure**

For efficient use of the course book, modules have been described in accordance with a given structure. In this way, anyone, who uses it can quickly find the content that he or she needs. Note: it is recommended that you start and finish the base course first (Module 1) before continuing actively partake. Due to that, they have an opportunity to experience specific solutions used in work with people with ASDs. This makes remembering facts and developing new and useful strategies easier. The strategies are based on meticulous observation of the resources, needs and difficulties of people with ASDs.

- Contemplation the participants observe, analyse, discuss, draw conclusions, reflect. Participants are supervised by facilitators, who monitor their progress. In addition, the facilitators constantly provide feedback. Methods used at this stage:
- moderated discussions;
- brain storming;
- questionnaires;
- work sheets;
- tests.

The participants learn as an observer. By observing the trainers and other participants, they can memorise given strategies and draw conclusions relating to their own work with specific people with ASDs. In addition, at this stage, the participants, with the help of instructors, have a chance to reflect on their readiness, openness and motivation to work with people with ASDs.

- 4. <u>Planning</u> at this stage, participants have an opportunity to analyse and consolidate the conclusions drawn from previous work, and an opportunity to develop models of action that can be used in real-life situations of therapeutic work and building interpersonal relations with adult people with ASDs:
- individual activities;
- group activities;
- presentations;
- moderated discussions.

The participants, by using in practice the strategies, plans and solutions presented during the course, have an opportunity to develop their own models that can be used in their work. In this way, they will be glad that they took part in the course.

to Module 2 (people with High Functioning Autism and Asperger's) and/or Module 3 (people with Low Functioning Autism).

Every module starts with a description of assumptions. Owing to that, one can determine the course one should participate in, and explore the knowledge, skills and stance one could develop. Next, one can find a brief structure of the training module – the duration of the course and of its component activities. There is also a brief description of the qualifications that a facilitator should have to effectively conduct the course.

Each module also features a description of the target audience. This is the group that will make the most of the module. This does not mean that other people cannot participate. Further descriptions state the aims of a given module and a description of the topics covered, along with an indication of the day they are meant to be used in.

The introduction is followed by a detailed description of each module's curriculum. Here, one can also find descriptions of activities (e.g. their duration). Every activity features information about its form (lecture or workshop) and structure.

Lectures feature material used to convey knowledge that participants need to effectively work with adult people with ASDs, and to prepare themselves for further parts of the training. In addition, some lectures feature a lesson plan with a detailed description of the material that needs to be covered.

Workshop activities feature a list of materials that should be used along with a description of how the activity should be conducted. Plus, in Module 1, every activity includes goals that can be achieved through completing it. In Module 3, on the other hand, there are additional charts that help both facilitators and participants understand the learning outcomes. After the description of Module 3, there is a list of suggested literature. Every item on the list includes a suggestion as to which module it is best suited for (abbreviated as MI, M II, MIII).

# **MODULE**

Basic training curriculum 'Adult people with autistic spectrum disorders (ASDs)'







### **MODULE I**

Basic training curriculum 'Adult people with autistic spectrum disorders (ASDs)' SYNAPSIS Foundation



### **Assumptions**

Module 1 is a founding section that covers basic notions related to adult people with ASDs. These notions are crucial to anyone working with such people or having contact with people with autism spectrum disorders in everyday life.

Participants have an opportunity to broaden their knowledge about autism spectrum disorders in adult people. The course features many workshops that will help the participants gain and develop practical skills that enable them to act in accordance with people's needs and abilities. Taking that into consideration, lectures and workshops feature tools that are used in work with people with ASDs, for example: visualisation, structuring time and space and clear communication.

It is very important to focus on building an attitude of openness and respect towards people with ASDs, as it enables participants to establish a strong and mutual relationship. To help achieve that goal, there is strong focus on learning how to properly communicate with people with ASDs (for example: how to convey positive feedback).

During the activities, the facilitators foster integration, which is an important factor in workshop activities that require feelings of security and trust. Facilitators stress the need for precise communication between participants, to create an atmosphere in which participants can freely convey needs that relate to the activity, the content and the course itself.

### Course structure

Estimated duration: 16 hours

Day 1: 8 hours with a lunch break and short coffee breaks Day 2: 8 hours with a lunch break and short coffee breaks.

### **Facilitators**

The course should be conducted by two experienced facilitators who work with people with autism spectrum

disorders (ASDs) on an everyday basis.

### **Target Audience**

The course is for professionals who work with adults with ASDs and want to broaden their knowledge and qualifications. People with no experience, who want to start working with adults with ASDs, can also take part in the course. The course is also for any other individuals who have contact with people with ASD in the line of duty: for example in social weLFAre, at a Communal Home of Mutual Aid, Occupational Therapy Workshops workers, librarians, museum workers, plenipotentiaries for the disabled at college, etc. In addition, people closest to adults with ASDs who want to learn about the way they function and, as a result, better help them in achieving self-reliance, reaching goals and tackling everyday problems, can also take part.

### **Objectives**

Module 1 provides participants with the necessary skills and knowledge that make it possible to support adults with autism spectrum disorders in creating a positive image of themselves That image is created with the help of self-awareness, valuing oneself and one's abilities through improving self-reliance and working on improving communication skills that can be used in different social circumstances.

The participants, by actively taking part in workshop activities, in pairs or groups of between three and six people will have an opportunity to gain deeper understanding of the material. The aim of every workshop activity is to enable the participants to look through the eyes of people with ASDs and strengthen their practical skills through, for example, building on their capabilities and resources, and identifying their difficulties and need. The focus is also on developing preparatory skills and creating the conditions that enable adults with ASDs to function in daily life and accomplish goals pertaining to their personal life, work and society, and subsequently improve their lives.

### Thematic scope

The material entails not only broad notions, such as the most important definitions, the so-called trio of autistic disorders, the difference in sensory perception, methods of therapy and communication tailored to the needs of adults with ASDs, but more detailed ones as well. Some of those definitions relate to individual differences that result from past therapeutic or educational experiences, and the support that people with ASDs received. These aspects can have great influence on the way these individuals function and on the type of needs they display.

The course focuses on adulthood as a stage of life entirely different from childhood and coming of age. The course also considers the challenges that this period in life can pose for individuals with ASDs and those supporting them. The course will cover the most important aspects of working with individuals with ASDs: raising their self- and law- awareness, stressing the importance of interpersonal skills, raising self-reliance and the feeling of own worth. The course will also tackle the topic of adults with ASDs as co-creators of services for their social group. The material covers: meeting the individual requirements of people with ASDs, supporting people who self-advocate and working with officials in improving the lives of people with ASDs.

The aforementioned topic will be covered by means of lectures, discussions and, for the greater part, active workshops. **During the first day** of the course, it is planned to discuss basic terms relating to autism spectrum disorders. At the beginning, participants have an opportunity to get acquainted and share their experiences in working with people with autism spectrum disorders. During the activities, the facilitators foster integration, which is an important factor of workshop activities (conducted later in the course) that require a feeling of security and trust.

Activities conducted during the second day will pertain mainly to the theme of adulthood in relation to people with ASDs. Aside from learning the theory, participants have a chance to take part in practical activities, that can strengthen their qualifications highly in demand in the work with adult people with ASDs.

### **Module I curriculum**

### Day 1:

### I.1.1. Intro:

<u>Aim</u>

- Explaining the aims and rules of the course;
- Getting acquainted with each other;
- Initialising the integration of the group.

### Materials needed:

 Flip charts, markers, work sheets with statement templates for every participant.

### Activity description:

- 1. Talking about aims, rules and the scope of the course.
- Participant introduction quick round (name, where they came from, place of work, goals and needs, mood). Every participant is given a work sheet that needs to be filled out without aid. Next, the group is divided into pairs, then participants exchange infor-

mation written on the worksheets. At the end, each participant describes his or her partner to the group. Duration: 45–60 min.

#### I. 1. 2. Workshop activity called 'Cloud' Aim

- seeing what the participants know about autism;
- discovering possible stereotypes about people with ASDs.

### Materials needed:

• Flip charts, markers, clean A4 sheets, post-it notes <u>Activity description</u>:

- 3. The group should be divided into teams of three to four people;
- 4. Every group writes about their understandings and associations of autism;
- 5. The results of their work, to create a map of associations, are then presented to the whole group;
- 6. The trainers moderate the discussion about the maps in such a way that they highlight not only the shared elements, but associations that differ between groups as well. They draw attention to possible stereotypes, the need to look at every case of ASD individually, the need to assess the individual's strong points, possible opportunities, resources, difficulties, constraints and limitations in comparison to neurotypical people at his or her age.

Duration: 45–60 min.

# I.1.3. Lecture: 'An introduction to the problems that adults with autism spectrum disorders might face while trying to function in society'

Suggested scope of material for the lecture:

- What are autistic spectrum disorders? An explanation of basic notions and differences in terminology;
- A definition based on diagnostic criteria describing the way people with ASDs function;
- The three main autistic spectrum disorders;
- Basic differences in cognitive processing;
- The individual character and diversity of each adult person with an ASD;
- Medical conditions and risks that relate to age and long-lasting pharmacotherapy.

Duration: 60 min.

### I.1. 4. Workshop activity: 'Senses'

<u>Aim</u>

- Explaining the complexity of disorders in sensory perception and integration that may affect individuals with ASDs;
- Explaining the many difficulties sensory disorders can cause in everyday life;

- Developing an awareness of the sensory problems that people with ASDs may have; developing the ability to notice and possibly interpret unusual behaviour displayed by people with ASDs that result either form heightened sensitivity or the lowered sensitivity to particular senses (for example: hand flapping, knocking, smelling unusual items, etc.);
- Developing problem solving skills in the subjects' environment that consider their heightened or diminished sensory perception.

### Materials needed:

 A set of items of a different texture, weight, scent, sound; bands/scarves for covering the eyes, statements of individuals with ASDs about their sensory problems, flip charts, markers;

### Activity description:

- 7. Depending on the size of the group, the activity is conducted either in one group or two groups;
- 8. The facilitators explain the activity and then ask the participants to cover their eyes;
- 9. The facilitators hand over the items one by one, and the task is to recognize the items but not say their names aloud;
- After the last item, the participants are asked to take off the blindfolds, check if they guessed correctly and determine what helped them to guess;
- 11. The facilitators encourage everyone to share their experiences. They also draw the discussion onto the topic of the limitations and difficulties that arise when one is not able to use all one's senses to the full. To illustrate how serious the problem is, in the conclusion, the facilitators may use statements from people with ASDs about their difficulties in relating to their senses.

Duration: 90 min.

### I.1. 5. Lecture: 'Sensory disorders in adults with ASDs' Suggested scope of material for the lecture:

- What is sensory integration and sensory distortion?
- What are sensory disorders?
- Statistics of sensory disorders in people with ASDs
- How do sensory disorders relate to everyday life
- Sense-friendly environment for people with ASDs Duration: 60 min.

### An example lecture plan:

- 1) What is sensory integration? The process of sensory integration:
  - It relates to everyone;
  - It gives us information about our body and the world around us;

- It develops as one becomes older;
- It affects experiences, definitions and learning processes.
- 2) What are sensory disorders?
  - These are errors in perceiving and integrating sensory stimuli;
  - Difficulties in connecting stimuli received through the senses;
- Basic senses and the three most important sense systems according to Jean Ayres:
  - Balance and proprioception (allowing us to receive stimuli from inside the body from our sinews and joints);
  - Touch, taste, hearing, sight, smell (allowing us to receive stimuli from outside of the body);
- 4) Statistics of sensory disorders in people with ASDs:
  - The percentage of people suffering from autism, having sensory disorders, with a distinction into particular senses;
  - The number of people with ASDs who, according to statistics, have sensory disorders.
- 5) The most important effects of sensory disorders:
  - Difficulties pertaining to social life and mental processing (lower self-esteem that seriously affects interpersonal relations);
  - Malfunctions of motor skills (difficulties in small motor skills: worsened graphomotoric abilities, speech impediment, difficulties with tasks that require precision; difficulties in large motor skills: disorders in feeling one's own body, high risk of injuries, developmental coordination disorder, a type of clumsiness);
  - Dysfunctions in cognitive development (difficulties in concentrating, paying attention, acquiring and using knowledge, difficulties in learning and speech development);
  - The effect of sensory disorders on behaviour (hyperactivity, lowered activity, evasive mechanisms, using items wrongly, too much or too little activity);

By introducing sensory integration activities at the youngest possible age, one can greatly improve the development of senses in people with ASDs. To stimulate or train sensory integration in not only professional environments but also private ones as well, one can incorporate everyday tasks. By introducing the proper stimuli, tailored to the individual's needs, one can improve his or her functioning and help him or her to perceive the outside world in a better way.

6) People with ASDs can process stimuli in an entirely different way, compared to neurotypical people. You might include statements from people with ASD that describe their sensory problems and show how they perceive the world. This should include positive examples of how heightened perceptual sensitivity can be beneficial to someone with ASD.

7) The last part of the presentation contains a few optical illusions that illustrate how difficult it is to process too many stimuli and illustrate the difference in perceiving images, depending on what a person is focusing on. Every part should be summarised. There should be information on the disorder; how they affect the development of a person with ASDs, and how one can help to foster that development.

### I.1.6. Lecture: 'Adulthood of people with ASDs'

Suggested scope of material for the lecture:

- Adulthood as one of the stages in life characteristics;
- Physical changes that relate to becoming an adult;
- Social expectations and roles of adult people;
- Adult people with ASDs similarities and differences connected with experiences, constraints, abilities and environments;
- The role of family for adult people with ASDs;
- Possible life crises for adult people with ASDs (illnesses, unemployment, death of someone close, violence, etc.);
- Is there something positive about adulthood for people with ASDs? What kind of challenges does it bring?
- The specificity of working with adults with ASDs entailing their needs, capability to be self-reliant, constraints and talents.

Duration: 60 min.

### I.1. 7. End-of-the-day sum up

 Gathering comments from participants in the form of positive feedback (positive statements that improve strengths: I liked.../thank you for.../thanks to you.../I still need...), asking for the things that the participants remember at the end of the day.

Duration: 30 min.

### Day 2:

### I.2.1. Intro:

Activity description:

 Greet the participants, ask for their mood: 'I am starting the second day...'

Duration: 30 min.

### I.2.2. 'Adult people with ASDs talk about themselves and their adulthood'—workshop activity Aim

- Discovering how people with ASDs understand adulthood;
- Talking in detail about the problems, challenges and possibilities that adulthood can bring

for people with ASDs;

- Confronting participants' own experiences of adulthood (looking for similarities, but more importantly for differences) through the lens of their individual situation and level of disorders;
- Developing sensitivity towards the needs of adults with ASDs, building an attitude of openness and respect towards their experiences.

Materials needed:

- A few video clips of interviews with adult people with ASDs talking about themselves and their lives;
- flip charts, markers

Activity description:

- Participants watch a few recordings of interviews with adult individuals with ASDs talking about their lives, about what adulthood means to them and what kind of challenges adulthood poses;
- After watching the video clips, facilitators start a discussion about the participants' impressions of the statements uttered in the recording. The facilitators ask questions about what drew the most attention, what kind of threats or chances can the participants see for the adults with ASDs from the video clips, etc;
- Basing on the film footage and conclusions drawn from the discussions, the facilitators help the participants establish four central aspects of the lives of adult people with ASDs – family, work, self (hobbies, personal growth), society. These aspects are the base for further activities;
- The participants are divided into four groups, each of which characterise one of the four aspects, considering the capabilities, skills, resources (that the adults with ASDs need to fulfil themselves in a given aspect), possible opportunities and threats. It is important that the participants have an opportunity to relate to their own experiences in developing themselves in a given area and sharing their experiences with the group. In effect, they can see their differences and similarities in relation to the experiences of people with ASDs;
- Each group presents the material it prepared;
- As a summary of the exercise, the facilitators gather conclusions.

Duration: 90 min.

### I.2.3. 'How someone with ASD can fulfil him- or herself in the four aspects of life'—workshop

Aim

 talking in detail about the problems, challenges and possibilities that adulthood can bring for people with ASDs;

- practising the skills of providing help and support for adults with ASDs. The support and help should cover the person's abilities and tasks related to adulthood in a way that enables individuals with ASDs to be selfreliant and seek solutions that could improve their lives. Materials needed:
  - flip charts, markers

Activity description:

- The group is divided into four subgroups one per area of life discussed previously;
- Each group receives one area and tries to establish how to support a person with an ASD in developing their lives in that area. Note that the groups should not work on areas that they explored during the previous exercise. For example:
  - Family knows the family members, works for the family, is responsible for specific tasks, actively participates in family life, is included in family life, etc;
  - Work has work/works regularly. For example, in Communal Homes of Mutual Aid, Occupational Therapy Workshops, Vocational Development Centres, protected environments, normal environments, voluntary services, places that offer internships;
  - Self the subject knows what he needs, knows his rights, preferences, knows how to address problems in meeting his needs, hobbies, hygiene, friends, new places, etc.;
  - Society social awareness, establishing interpersonal relations, working for others, norms and rights awareness, social responsibility, participating in social life, engaging in the work of different groups and organisations, etc.;
- Each group presents the material it prepared;
- As a summary of the exercise, the facilitators gather conclusions.

Duration: 90 min.

### I.2.4. Lecture: 'Methodology of therapies used in the work with adult people with ASDs – an overview' Suggested scope of material for the lecture:

- In general, the scope should have a multifaceted character:
- The approach should be person-centred;
- An overview of the methodology of therapies particularly useful in work with adult people with ASDs;
- Choosing the right method for satisfying the needs of an individual person with ASD;
- The attitude that should be adopted while working with adults with ASDs - openness, respect, help in making decisions and completing the tasks of adult life. Duration: 60 min.

### I.2.5. Workshop activity: 'Individuals with ASDs as socially disabled people – what such a person needs to reach the highest level of development' Aim

- Talking in detail about the problems, challenges and possibilities that adulthood can bring for people with ASDs;
- Practising the skills of providing help and support for adults with ASDs. The support and help should cover the person's abilities and tasks related to adulthood in a way that enables individuals with ASDs to be self-reliant and seek solutions that could improve their lives:

Materials needed:

Flip charts, markers

Activity description:

- The group is divided into four subgroups;
- Each group is to discuss what needs to be considered when trying to establish a support system for socially disabled people (for example: physically disabled people need a wheelchair, but what are autistic people's needs in terms of social disability?);
- Next, the participants work on establishing possible and specific support systems for socially disabled people with ASDs, that could be used in their workplace. As a next phase, the participants try to organize the systems that they have prepared, in terms of the possibility of implementation, workforce and funds needed, etc.;
- Every group then shares their ideas. The group talks about how the possibility of implementing these systems in different places;
- During explanation, the facilitators stress how important an attitude of openness and mutual respect is towards adults with ASDs and other employees. They highlight that without such an attitude, one cannot break barriers, debunk stereotypes and see new and sometimes unconventional solutions. The facilitators also stress the importance of cooperating with the people in the autistic individual's environment.

Duration: 60 min.

### I.2.6. The end and conclusion

- The facilitators check what the participants have learned from the course. They also summarise the theory and talk about practical skills as well;
- The facilitators answer the participants' questions;
- Participants talk about what they learned and what they found most valuable out of the two davs of the course.

Duration: 45-60 min.

### **MODULE I**

Basic training curriculum 'Adult people with autistic spectrum condition (ASC)' AS Mentoring Ltd



### 'Autism Awareness': course description

**Day one** of the course opens with the two presenters (one autistic, one neurotypical) introducing themselves in detail. We then asked the participants to create a name badge which introduces – in whatever way they feel comfortable with – who they are. We then give each of them a questionnaire to fill out, rating their knowledge about particular aspects of autism.

We then split them into small groups to ask each group to come up with 10 things they know (or think they know) about autism. In planning this course, we intended right from the start that they would be lots of activities, and that it would be very participatory. We follow this exercise with a discussion of 10 common facts (and/or myths) about autism.

We then give them an overview of what they are going to cover on each of the two days (with two separate sections on each day), together with the aims of the training. We then introduced the three autistic characters who we are going to focus the training around: Hari, a five year old schoolboy; Jane, a 19 year old student; and Bob, a 44 year old unemployed man. We divide the participants into three groups, and then allocate one of the characters to each group. The participants will be given exercises throughout the training which involve relating what they've just learned about to their allocated character.

Next, we go into detail about the history of autism, and the characteristics by which it is diagnosed. This is followed by an exercise where the participants are asked to visualise – and draw – their version of the autism spectrum. We discuss alternative ways to consider this latter, and the merits (or otherwise) both of obtaining a diagnosis of autism, and then of declaring/disclosing it in various contexts. Using our three characters as a focus, we discuss how each of them might do this. We look at the possible causes of autism and that commonly co-occurring conditions such as ADHD, dyspraxia et cetera. This is the end of section 1 of day 1.

We then break for lunch, and resume in the afternoon with section 2: breaking down the key characteristics of the autism spectrum, and giving the participants strategies to ad-

dress each of these with their clients. This begins with slides covering executive functioning, and then goes on to look at social communication and relationships in particular detail; again using our three characters as the focus in each case. We look at several different methods of alternative communication, over a succession of slides.

We go on to consider Theory of Mind and rigid thinking, and look at the importance of structure and routine for autistic people. We close with another exercise for the participants, getting them to consider their own schedule for the rest of the day, and communicating this to a partner non-verbally.

**Day two** of the course begins with a review of what we covered in day one, and then tells them what we will be looking at in the remaining two sections of the course. We start with a discussion of regulating emotions, and have an exercise for the participants where they have to draw themselves as emojis. We give them strategies to use to help their clients with this aspect of their condition.

We then go on to discuss anxiety, and again provide a range of strategies and approaches for dealing with this central aspect of autism. This is followed by a detailed look at the sensory aspects, including stimming. This includes showing the participants an embedded video ("Carly's Café", made by Carly Fleischmann as a vivid illustration of her own sensory experience and overload; Carly is fully credited in the video). Using our three autistic characters, we discussed with the participants the sensory issues that each of them might have. We give them a range of accessories to handle, and our autistic trainer describes how she relates to many of these. This ends section 3, and we break for lunch.

We resume the training with section 4, asking the participants to consider (and share with us) what they think the links are between autism and mental health conditions. We then spend several slides considering associated mental health conditions in detail, together with strategies which the participants can use to address these with their clients. As has been the case throughout the course, we invite each group of participants to consider the effects of these on 'their' character.

Next, we consider the effects of one person's autism on the wider family. After discussing these in detail, we show the participants another embedded video: "A Mum's Perspective", produced by the UK organisation Resources for Autism (who are fully credited at the end of the video).

We go on to discuss what funding is available to people with autism to support their needs. This is a detailed discussion, and includes another exercise where the participants have to consider these funding issues for their Hari, Jane and Bob. We discussed the need for advocacy support for many autistic people.

We then look at the differences between the medical mo-

del and the social model of disability, opting strongly for the latter. And after having spent the first three quarters of the course looking at the difficulties which autism can cause for many people, we look at its positive qualities and strengths. We ask the participants to consider the future for each of their autistic characters, and ask them both what they have learnt from the course and how they think they will apply this learning to their role. Finally, we ask them to go back to the questionnaires they filled in at the start of day one and to complete them again, in order to compare their 'before' and 'after' levels of knowledge and confidence.

We then closed the course by telling the participants that will be around for another 30 minutes or so to take any individual questions. (It has long been our experience that there will be people with a personal, often family connection to autism that they want to discuss with us).

Presentations from the 'Autism Awareness' training course: https://drive.google.com/drive/folders/1v7U4Nvtm8F1aYcwBHanS8xFsTfN3gFMx?usp=sharing

### **MODULE I**

Basic training curriculum 'Adult people with autistic spectrum disorders (ASDs)' Latvijas Autisma apvienība



### **Basic Training Programme. Train the trainers**

The difference between training and education can seem unimportant as both are forms of learning. The difference lies in their focus and scope. Training is focused on producing a particular skill or capability whereas education builds an overall aptitude, combining knowledge and skills to be applied and adapted to a range of life situations and issues. The significance of this is that training has a very clear, limited focus so that by the end of the training process a person is able to use specific skills, perform particular tasks or manage a particular type of function.

On the job training may take the form of picking up skills as you work, under the direction and guidance of someone else in the workplace. It often takes the form of being inducted onto a site or having a colleague teach you how to use equipment or follow procedures. This could also include indirect guidance in the form of manuals or workflow guidelines, with direct support coming from a supervisor or colleague as needed. On the job training is sometimes incorporated into off the job programs by assigning people work based projects, usually as part of their assessment. Off the job training usually takes the form of structured sessions or programs. This may be with a trainer or coach. It can also include individuals working through an e-learning package. Off the job training does not necessarily mean off site, as e-training shows, where a person can remain at their desk to do the program. Off the job means putting aside normal work for a period of time to focus on learning new skills in a dedicated training environment, even a virtual one. There are many criteria for deciding how to organize your training. Some of them are:

**Focus:** The level of focus required by individuals to learn will vary with the content of the training. Sometimes a group can help people explore a topic because participants can share a wide variety of ideas and experiences. However, some topics require a lot of individual concentration and practice. This could be compromised by training that has to adapt to the needs of a group. It may slow someone down as they wait for others to learn or it could leave someone behind as the group ploughs on and can't wait for them to catch up. **Environment:** Many types of skills can be learned in the artificial environment of a training room. For some types of training the artificial environment is necessary for safety or for creating a space to learn. However, the artificial environment may not prepare people for real world situations. Supervised field work may be necessary to ensure people can reliably apply their skills in a real world context.

**Repetition:** Some skills require repetition and practice. A once off training session will not achieve this. It may be necessary to program a series of shorter but frequent sessions to reinforce the content and troubleshoot issues.

**Stage of Development:** People have developed their skills to different levels. When planning a program it is important to match it to the level of the participants. Beginners may need a different type of program to experienced participants. For example, beginners may need a lot of background information before embarking on practical activities. Experienced participants may need a program focused on case studies and situations linked to what they are currently dealing with. These can help them move beyond introductory principles into more complex analysis.<sup>1</sup>

### **Engaging people to learn**

Its mandatory before you start training plan find out what actual training is needed or required and what those audience want from you. To do assessment and planning the training ask these questions to yourself:

- Is there a gap and do you require a training to fill these gaps?
- Which line or areas training needs?
- What does the company or organization want?
- What do the audience want?
- What type of training will best fill the specific gap?
- What training of delivery is best suited to the event?
- How long will the training take?
- How long will it take to organize?
- What facilities and materials will the trainer need?<sup>2</sup>

Some common engagement strategies are:

**Keep it jargon free:** Use language and concepts people are already familiar with. People need to be able to use old, familiar concepts to build new ones. If you need to use technical terms, make sure you define them when you introduce them and remind people of what they mean as you use them.

<sup>1</sup> Hegerty, Paul. The Occasional Trainer: Practical tips for busy people who have to train others (pp. 10-11). Five Clyde, Brisbane, Australia.

<sup>2</sup> Umar, Imran. Train The Trainer: Ultimate toolkit to become professional,Imran Umar.

**Balance how people process their thoughts:** Introverts prefer internal processing whereas extroverts like working things through with others. Check with your participants how they prefer to process things. You are likely to find a mix of both preferences in a large group, though not always. A simple way to balance preferences is to give people some individual time to reflect or work on an activity before moving into a group discussion or exercise.

**Physical activity:** Use movement, even two minute breaks for stretching, to help basic things like circulation and posture. The idea is to help people to concentrate by increasing blood to the brain. Evidence shows that a 10 minute brisk walk generates the same energy boost as sugar treats but the positive effects last hours longer.

**Share responsibility for energy levels:** As the trainer you may be too absorbed in the content to be fully aware of the energy in the room. You can nominate people in the group to monitor their energy levels and to interrupt when they think the group needs a stretch or break. While some people won't want to interrupt, other people will be more than happy to do so, especially if it is for the weLFAre of the group.

Keep in mind that learning and communication builds on the pre-knowledge of the learner. If they have no pre-knowledge of your content they will find it hard to learn. Make sure you link new material to content they already know so they can extend their knowledge. The good news is that you are training adults who come to training with a wealth of knowledge and experience.

A useful training method to quickly teach task oriented skills is.

**Explain:** Go through the concepts, steps and other pieces of information people need to know to develop the skill and do the task. This can include when to do the task and safety requirements.

**Demonstrate:** Show people how it's done so they can see how the ideas work in action. Do it step by step, making sure everyone can see what you are doing. For complex tasks, check along that way that they understand each step before moving to the next one.

**Do:** Get people to do the task themselves, under supervision, and give them feedback as they do or complete it. For complex tasks with groups, get the whole group to go through the process step by step, waiting after each step until everyone is ready to move onto the next. This way you can answer questions or trouble shoot issues as the group moves along. For simple, safe tasks it is easier to let people have a go and then solve issues at the end.

### Here are a few approaches to keeping training relevant.

**Get participants' learning priorities:** At the beginning of the session spend some time getting information from the group about what they want to learn that day and what they will use it for. Some trainers make a check list with the

group that they can refer back to during the training process to make sure the priorities are being addressed.

**Focus on applying it at work:** During the session ask people how they would apply the content in their workplace. This has two effects. One is it keeps people thinking about relevance and how the material can be used. The other is it generates meaningful examples. Some people understand issues better if the explanation is illustrated by examples.

**Monitor progress:** Check with people during the session whether they are getting what they need from the session. This is important because their needs evolve during the process as they learn more and become aware of new issues and opportunities.

**Invite questions:** Always encourage questions. Reassure people that questions are not an interruption but a way to keep the session focused on their needs. At the end of each segment of input, pause and ask people for questions or comments.

Keep in mind that people might not know what they need to learn as they haven't learned it yet. It's a bit of a relevance paradox – until I learn it I don't know what I need to learn! This is why focusing on the issues people are dealing with can help. Knowing the current issues enables the trainer to focus on material that will help people. When conducting an in-house training session, the trainer can get some of this information from the initial client briefing about the purpose and goals of the training program.<sup>3</sup>

### **Give people support**

There are some strategies trainers use to provide individual support in group settings.

**Use small group time to help individuals:** Spend time with an individual while people are working on group tasks or activities. Most groups will be fine without your help. As you scan the room you can see who might need some assistance.

**Use peer support:** Pair people so they can help each other. If all goes well they will complement each other. What one lacks the other can provide. At times you may even ask someone who is doing well to help someone who is struggling a little. Most people are happy to cooperate.

**Use session breaks:** It may be difficult to attend to people during the session. However, it may be possible to meet with them during breaks.

Offer tutorial sessions: When a training program has multiple sessions you can organize a tutorial between sessions for people who need it. You can also offer to review their work between workshops when they have to do work based projects or other activities between sessions.<sup>4</sup>

<sup>3</sup> Hegerty, Paul. The Occasional Trainer: Practical tips for busy people who have to train others (p. 35). Five Clyde, Brisbane, Australia. Kindle Edition.

Accelerate progress with feedback

Positive feedback is the most powerful performance enhancer you have. Negative feedback will clarify the expectation but won't build a person's capability to meet the expectation. Positive feedback focuses on all the steps and successes people take as they learn something. By giving positive feedback each time a person gets something right you reinforce the knowledge and actions that build competency. The key is to look for people doing the right things right. For someone who is struggling this can be hard. Patience, coaching and encouragement will help.

### The **NESTS** framework

You can use the NESTS framework as an easy framework for giving positive feedback:

Name: Identify and name what it is that they did right.

**Explain:** Explain what it was they did and how it was the right thing to do.

**Share:** Get them to talk about what it was they did and how it felt.

**Tutor:** Encourage them to continue, giving them tips and guidance about their next steps.

**Substantiate:** Keep track of and record if necessary their progress and what it is they have done. This way you can acknowledge their progress until they achieve full competency or learn what it is they have to learn.

### Preparing for the Training:

### Acquisition of Knowledge

Effective training requires knowledge of adult learning principles, subject matter content, practice and planning. This section offers tips on advance preparation activities.

Advance Preparation and Instructional Delivery.

The most effective trainings are not accidental – they are the result of the trainer spending hours familiarizing her/ himself with early childhood education content knowledge, adult learning principles, and instructional materials such as Teachers' Guides and Children's Workbooks.

### Take the time.

The recommended preparation time is three hours for every hour of training.

Learn the material. Be well acquainted with the material, and make your own notes, highlight portions that you want to focus on and stress. This will lend the impression that you are a competent and confident trainer. It will also facilitate effective instructional delivery, and will increase your ability to answer questions correctly that the adult learner might pose. Use your own words. The training will be better received and more interesting for adult learners and you will be more con-

4 Hegerty, Paul. The Occasional Trainer: Practical tips for busy people who have to train others (p. 37). Five Clyde, Brisbane, Australia..

fident if you know the important points well enough to be able to express them in your own unique style.

### Incorporate experiential learning.

Make connections between your own experiences as a former teacher and some of the main points. Make sure to also inquire about the classroom teacher's experiences. Personalizing information with your own anecdotes (stories) will assist in both stressing and expanding points. Remember, for the adult learner life experiences add enrichment to the learning process. And, it will enhance any handouts and/or power point presentations that you use.

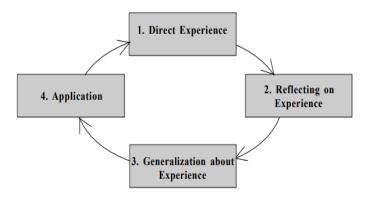
### **Reference Lesson Overview and Objectives.**

Be sure to incorporate unit overview and course objectives for each Teacher's Guide in your presentation (s) as they establish the framework and context for subject matter (e.g., Mathematics, Environmental Studies, Literacy).

Model and demonstrate at least two lesson plans from each Teacher's Guide.

Be sure to provide enough materials so that adult learners can experience age – appropriate curriculum instruction and delivery (e.g., hands-on learning, discovery learning, directs teaching-see Overview in Teachers' Guides). <sup>5</sup>

### THE ADULT LEARNING CYCLE THE ROLE OF THE TRAINER



Learning is the transformation of information into useful knowledge.

The learning cycle requires the learner to progress through four different phases of the learning process. Effective learning requires the ability to apply the things you learn in phase 3, where you form principles based on your analysis in phase 2 of an experience you had at phase 1. This does not come easily for everyone, especially those who are used to learning from lectures. Adult learning requires the active participation of the learner in the learning process.

The role of the trainer, then, is to help the learner through

5 Textbooks/Teaching and Learning Materials Program-Ghana. Jean C. Murphy, Ed. D. and Carol O. Carson-Warner, Ed. D. this process of learning. A good trainer must have the competence to understand what goes on at each phase and to facilitate the learning process.

### WRITING OBJECTIVES FOR DIFFERENT KINDS OF LEARNING

### KNOWLEDGE/INFORMATION/FACTS

Objectives for learning knowledge/information/facts use words like:

explain name describe tell list

### SKILLS

There are many kinds of skills, including manual skills, communication, cognitive, problem solving/decision-making, and leadership skills. Objectives for learning new skills use words like:

apply do use create differentiate generate compare decide evaluate plan analyze examine construct implement develop

### ATTITUDES

Attitude changes are the hardest to teach and evaluate; learning is measured indirectly by observing behaviors. Objectives for learning new attitudes use phrases like:

"demonstrates \_\_\_\_\_ by \_\_\_\_\_" (e.g. "demonstrates respect for patients by greeting them by their name, listening closely to their questions...")

Attitudes taught and evaluated often include:

- confidence in applying new knowledge and skills,
- respect for patients' sensibilities and fears,
- patience,
- accuracy,
- gentleness in performing exams,
- thoroughness,
- conscientiousness,
- curiosity,
- tolerance for opposing views,
- belief in the truth of importance or usefulness of something,
- integrity,
- diplomacy,
- tact,
- dedication,
- enthusiasm, and
- satisfaction.

### STEPS FOR A TRAINING SESSION BASED ON THE EXPERIENTIAL LEARNING CYCLE

### SET THE LEARNING CLIMATE

• Gain the learners' attention and interest.

- Create an informal rapport with the learners.
- Recall relevant previous experiences.

### PRESENT THE OBJECTIVES

- Provide a link between previous session/s and this one.
- Present behavioral objectives to the learners and check understanding.
- Let the learners know what they will do during the session in order to attain the objectives.

### **INITIATE THE LEARNING EXPERIENCE**

- Introduce an activity in which the learners "experience" a situation relevant to the goals of the training session. The "experience" might be a role play, case study, simulation, field visit or group exercise.
- The learners will use this experience to draw data for discussion during the next step.
- If you begin this session with a presentation, follow it with a more participatoryactivity.

### **REFLECT ON THE EXPERIENCE**

- Trainer guides the discussion of the experience.
- Learners share their reactions to the experience.
- Learners participate in problem-solving discussions.
- Learners receive feedback from each other and from the trainer on their work.

### DISCUSS LESSONS LEARNED FROM THE SUBJECT MATTER

- Learners identify key points that have come out of the experience and the discussion.
- Trainer helps learners draw general conclusions from the experience and reflection.

### DISCUSS HOW THE LEARNERS MIGHT APPLY WHAT THEY'VE LEARNED

- Based on the conclusions that were drawn during the previous step, the group discusses how the information/skills will be useful in the learners' own lives.
- Learners discuss problems they might expect in applying what they have learned.
- Learners discuss what they might do to help overcome difficulties in applying their new learnings.

### **PROVIDE CLOSURE TO THE SESSION**

- Briefly summarize the events of the training session.
- Refer to the objectives to determine how well they were reached.
- Discuss what else needs to happen for better retention or for further learning in the subject area.
- Provide linkages between this session and the

rest of the training program.

• Make sure the learners leave with a positive feeling about the session.<sup>6</sup>

### **Facilitating Discussion**

Trainings that are interactive tend to be more effective than lectures because the ADLs' involvement and experiences are actually a part of the learning process. Actively engaged participants are more likely to retain, recall, and remember information about the content of the Teachers' Guides and Children's Workbooks. The likelihood of the information being transferred outside the training session is great. And, this is the ultimate goal/outcome of the Train-the-Trainer sessions. However, leading an active training can be challenging; it requires the development of four key facilitation skills: Facilitating vs. Directing, Asking questions, Answering Questions, Facilitating Discussion

### Facilitating vs. Directing

The key to facilitating effectively is to remember that your roles are to lead the discussion, not direct it. As a leader, you should focus on drawing ideas out of the ADLs, rather than dominating with your ideas and experiences.

The following are tips to help you remember to facilitate rather than direct:

- Be respectful of the participants
- Be enthusiastic about the topic and the training program
- Ask and encourage questions and idea sharing.
- Be clear and direct
- Keep your own contributions during group discussions brief
- Use "Wait Time" time to think about an answer or response to a question before providing answers. Count to t 10. If you fail to get responses, rephrase the question.
- Invitation encourage the participation of those who have been quiet. State the participant's name and ask an open-ended question. For example, "What do you think about the materials?"

### **Asking Questions**

It is the TOTs's responsibility to pose stimulating and intriguing questions or topics for discussion. Discussion is a teaching strategy that helps learners to think deeply about information, to make answer queries, and to assimilate information into already existing knowledge. Below are some tips for asking questions that yield powerful responses.

• Use open-ended questions that encourage answers beyond yes or no. Close-ended question: Do you like the training manuals? Open-ended question: Which of the training manuals is the most teacher friendly?

- Use "think back" questions. Ask the ADLs to remember their previous experiences/past instead of imagining a hypothetical situation.
- Ask clear and concise questions. Make sure your questions only cover one topic or issue at a time.
- Responding to Incorrect answers. Do not shut down a person who gave an incorrect answer. This may freeze the discussion. To reduce the possibility of embarrassment, acknowledge the effort and then redirect the question to the whole group. For example, you might respond, "Interesting. I can see how you might come up with that idea."

### **Answering Questions**

- As a trainer, one of the most common questions you will ask of adult learners is, "Does anyone have any questions?" If, in response, you think the group can answer, redirect them to the group to encourage active learning for as we know one of the key principles of andragogy (adult learning) is that adults learn best when they are involved in diagnosing, planning, implementing, and evaluating their own learning.
- You're asked a question that you can't answer. Don't be defensive or fake it, just say you don't know, but ask if others in the group might have an answer. If no one does, simply say you'll research it and get back to them later.
- You're asked a difficult question. Break the question down into manageable parts and keep your answer precise without omitting key details.
- You're asked a question you don't want to answer. Be honest and say so. Offer to meet with the person after the session to provide your response.

### **Facilitating Discussion**

Adult learners have a need to have their voice heard; they have a reservoir of experiences that serve as a primary learning resource which enables them to contribute to and join in rich discussions on topics presented. The skilled TOT trainer recognizes this fact and builds on contributions made by the adult learners in her workshop. There are various types of discussion types the TOT trainer should keep in mind".

• **Discussion dominators**. If someone is doing most of the talking it may prevent others from contributing their thought. Although it may seem intimidating, it can be very easy to reduce the amount of sharing coming from one participant. - Wait for a pause in her speaking, respectfully acknowledge her contributions, and thank her. You can say something like, *"I appreciate your comments and ideas."* - Then make direct contact with other participants and ask

<sup>6</sup> The Centre for Development and Population Activities,1400 Sixteenth Street, NW, Suite 10, Washington, D.C. 20036, U.S.A.

something like, "I know someone else has good ideas too, I'm very interested in hearing how other people are feeling about this issue" or "It's very interesting to get a variety of perspectives especially since we are from different regions, I would think we can all benefit from the variety in this room." 20

• No Response. Many group facilitators have stood before a group that simply stares. Groups vary in responses. Even questions that stimulated the most interesting discussions with one can fall completely flat with another. It could be that people are tired of talking about the topics, or they might be bored with the questions and need more stimulating activities to help them think.

• Interpersonal Conflict. If two or more people begin arguing you must confront the situation before it spirals out of control. You can try to defuse it with humor, or give the participants an easy way out by reframing what they are saying and move on.

### Evaluation

It is important to provide closure in order to ensure participants leave feeling positive.

Information provided can be used to guide and inform future trainings.

Evaluating the training session is essential to getting feedback from participants on the effectiveness of the training. It is not only beneficial for the trainers of trainers (TOTs), who can use the feedback to improve subsequent trainings; it is a good chance for future trainers to express their thoughts so that they feel their voice is heard. Some guidelines for a successful assessment include:

Review key ideas covered during session. This approach aids in clarifying key ideas discussed during the session.

Written feedback. This can be accomplished through the completion of a written evaluation form which should include a section on constructive feedback related to the current training session.

#### PRACTICAL EXERCISES Sphere of influence

Think of your role as a trainer, a member of the organisation and your relationship to the change project team. List the things you can influence and the things you cannot.

l can influence	l can't influence

### Practical exercises of understanding autism

It is always great to check internet connection and sound

system before training. There are many internet resources for trainers to demonstrate examples of sensory overload, miscommunication etc. If the trainer sees there is a break needed between exercises or theory video demonstration can help.

### Playground<sup>7</sup>

During Vancouver's Hacking Health weekend hackathon in 2013, Taylan Kadayifcioglu and his team created *Auti-sim*, an unsettling first-person game that allows the player to experience hypersensitivity. *Auti-sim* features layered, deafening shrieks from faceless children and fuzzy visuals, causing the player to retreat in order to see and hear clearly.



https://youtu.be/DwS-qm8hUxc

### **Shopping at Walmart**



### **Remove/Reduce Stressors**

Work in groups. Remember a practical situation in your work and discuss how to

- Remove/decrease disliked activities
- Remove/decrease difficult activities
  - Simplify work
  - Reduce writing assignments
  - Simplify all tasks involving organizing, planning & sequencing
  - Eliminate discussions on feelings

### Balance the Agenda (con't)

7 http://mashable.com/2014/04/23/autismsimulations/#kCgYmlLLVaqO

- Assess the upcoming demands on the student for the day.
- Remove any stressful tasks/activities that are not essential.
- Do not remove tasks that the student enjoys.8

### UNDERSTANDING DIFFERENT ASPECTS OF AUTISM Being "autistic"

Trainer separates group into smaller groups. At the first stage groups defines what does it looks like to be characteristically 'autistc'. Each member is asked to repeat something from that list, for example make the repetitive movements, rip a piece of paper into tiny pieces and drop it on the floor, to be incredibly honest about the look of members of the group, make noises etc.

Share their experiences, thoughts, ideas afterwards how does each member feels, have they met such situations etc.

### **Preparing the checklists**

Giving the checklists is particularly helpful when person with AST has to complete short series of related activities or when they need to organize a group of materials. For a chore at home they might need a checklist for completing the steps necessary to clean their room.

Work in pairs. Set the goals for daily activities for a person with AST.  $^{\circ}$ 

### make your bed

put away your clean clothes \_\_\_\_\_ put your books on the shelf \_\_\_\_\_ put your school notebook in your backpack \_\_ put your toys in the toy bin \_\_\_\_\_ sweep the floor

### Communication

Tell members of the training group to mingle around the room for 20 minutes. If you have a large group, ask for six or more volunteers. Once selected, tell these volunteers to mingle around the room without speaking. They cannot use their voices for anything. They can only use body language or other techniques to gain attention. They will not be allowed to reach for anything on their own. They must tell someone else when they need something.

When 20 minutes is up, the volunteers will tell about their experiences. They will discuss the frustration of needing something but a helpful person may have handed them something different. They may have also experienced people ignoring them because they did not want to be bothered or felt uncomfortable trying to determine what the communication attempts really meant.

No one should be scolded for their actions during this exercise. The information should be expanded on to relate it to the frustration that many people with autism feel when their communication attempts go unnoticed or misinterpreted. The exercise will make people aware of the need to provide consistent communication options to people with autism.<sup>10</sup>

### Recommended literature and sources of electronic materials

### http://mashable.com/2014/04/23/autism-simulations/#kC-gYmlLLVaqO

Textbooks/Teaching and Learning Materials Program-Ghana. Jean C. Murphy, Ed. D. and Carol O. Carson-Warner, Ed. D. Hegerty, Paul. The Occasional Trainer: Practical tips for busy people who have to train others. Five Clyde, Brisbane, Australia.

Umar, Imran. Train The Trainer: Ultimate toolkit to become professional Trainer. Imran Umar.

Simple Strategies That Work! Helpful Hints for All Educators of Students With Asperger Syndrome, High-Functioning Autism, and Related Disabilities, Brenda Smith Myles, Diane Adreon, Dena Gitlitz, 2006

Bull, A., Brooking, K. & Campbell, R. (2008). Successful home -school partnerships. Report prepared for Ministry of Education by New Zealand Council for Educational Research. Available: <u>http://www.educationcounts.govt.nz/publications/</u>schooling/28415/3

Department of Education, Employment and Workplace Relations (2008). Family-School Partnerships Framework: A guide for schools and families. Available: <u>http://www.dest.gov.au/</u> <u>sectors/school\_education/publications\_resources/profiles/Family\_School\_Partnerships\_Framework.htm</u>

http://tfig.unece.org/pdf\_files/Training%20of%20Trainers%20 manual%20UN\_ESCAP.pdf\_

http://classroom.synonym.com/autism-awareness-training -exercises-5673097.html

http://www.scautism.org/

http://www.futurehorizons-autism.com/

http://www.tonyatwood.com.au/

http://www.thegraycenter.org/

http://www.paulakluth.com/articles/calmincrisis.htm

<sup>8</sup> Simple Strategies That Work! Helpful Hints for All Educators of Students With Asperger Syndrome, High-Functioning Autism, and Related Disabilities 9 Simple Strategies That Work! Helpful Hints for All Educators of Students With Asperger Syndrome, High-Functioning Autism, and Related Disabilities

<sup>10</sup> http://classroom.synonym.com/autism-awareness-training-exercises-5673097.html

# **MODULE II**

Advanced training curriculum 'Working with people with Asperger's Syndrome or high-functioning autism (HFA)'



### **MODULE II**

Advanced training curriculum 'Working with people with Asperger's Syndrome or high-functioning autism (HFA)' SYNAPSIS Foundation



### **Assumptions**

Module 2 is an advanced part that covers basic notions related to adult people with Asperger's Syndrome and High Functioning Autism (HFA). These notions are crucial to anyone working with such people or having contact with such people in everyday life.

During the training it is not only important to convey knowledge. It is also important to teach practical skills that allow participants to administer better care for people with Asperger's or HFA. Taking that into consideration, the lectures and workshops should feature tools that are used in work with people with Asperger's or HFA, for example: visualisation, structuring time and space, clear communication.

It is also important to assume an attitude of openness and respect when building interpersonal relationships. To help achieve that goal, there is a strong focus on learning how to convey positive feedback. During the activities, the facilitators foster integration, which is an important factor in workshop activities that require feelings of security and trust. Facilitators stress the need for precise communication between participants, to create an atmosphere in which participants can freely convey needs that relate to the activity, the content and the course itself.

### Course structure

### Estimated duration: 16 hours

Day 1: 8 hours with a lunch break and short coffee breaks Day 2: 8 hours with a lunch break and short coffee breaks. <u>Facilitators</u>

The course should be conducted by two experienced facilitators who work with people with Asperger's or HFA on an everyday basis.

### Target Audience

The course is for professionals who work with adults with Asperger's and HFA who want to broaden their knowledge

and qualifications. The course is also for any other individuals, who are preparing for work or have contact with people suffering from Asperger's or HFA in the line of duty, for example: social weLFAre workers, librarians, museum workers, plenipotentiaries for the disabled at college, etc. In addition, it can be attended by people closest to the adults with Asperger's or HFA who want to learn about the way they function and, as a result, be better-able to help them in achieving self-reliance, reaching goals and tackling everyday problems.

### **Objectives**

Module 2 aims to provide participants with the necessary skills and knowledge that make it possible to support adults with Asperger's and HFA to create a positive image of themselves That image is created with the help of self-awareness, valuing oneself and one's abilities through improving self-reliance and working on improving communication skills that can be used in different social circumstances.

Aside from the theory, the participants, by actively taking part in workshop activities in pairs or groups of between three and six people, will have an opportunity to gain a deeper understanding of the material. The aim of every workshop activity is enabling the participants to look through the eyes of people with Asperger's or HFA and strengthen their practical skills. This may involve, for example, improving participants' ability to help adults with Asperger's and HFA in terms of potential capabilities, resources, difficulties and needs. The focus is also on developing preparatory skills and creating the necessary conditions that enable people with Asperger's or HFA to fully function in daily life and accomplish goals pertaining to personal life, work and society and that can improve their lives.

### Thematic scope

**The first day** covers basic terms that relate to difficulties in functioning pertaining to people diagnosed with Asperger's and HFA. At the beginning, participants have an opportunity to get acquainted with each other and share their experiences of working with people with Asperger's/HFA. Next, the facilitators talk about the main issues connected with the diagnoses, similarities and differences between Asperger's and HFA in men and women (with their consequences), and about the specificity of the aforementioned group's cognitive processing, therapy methods and work priorities. The participants will have a chance to confront their own stereotypes about people with Asperger's Syndrome/HFA and to discuss their needs regarding their individual capabilities and difficulties. **The second day**, for the most part, will deal with establishing and planning work goals for individual people with Asperger's and HFA in relation to their circumstances, and planning strategies that can help accomplish those goals. Aside from gaining knowledge and receiving concrete tips, the participants will have a chance to take part in practical activities, that help strengthen the skills required to work with people with Asperger's/HFA. The scenarios include the possibility of analysing specific situations (of people with Asperger's/HFA) in different areas of life.

### **Module II curriculum**

Duration: 2 days ( $2 \times 8$  hours + breaks) Number of people in a group: 12-24Number of facilitators: 2

Note: the facilitators should incorporate the tools that are used in work with people with Asperger's or HFA, for example: visualisation, structuring time and space, clear communication.

### Day 1:

### II.1.1. Intro:

Materials needed:

 Flip charts, markers, work sheets for every participant. <u>Activity description</u>:

- 12. Talking about the aims, rules and scope of the course;
- 13. Participant introduction quick round (name, where they came from, place of work, goals and needs, mood). Every participant is given a worksheet that needs to be filled out without aid. Next, the group is divided into pairs, then participants exchange information written on the worksheets. At the end, each participant describes his or her partner to the group.

Duration: 45-60 min.

### II.1.2. 'The definition of Asperger's syndrome' – lecture

Suggested scope of material for the lecture:

- The history of Asperger's Syndrome;
- Diagnostic criteria;
- Similarities and differences between men and women with AS/HFA;
- Myths and stereotypes about people with AS/HFA (adults especially),

• The individual character of AS and HFA in adults. Duration: 90 min.

### II.1.3. 'The cognitive processing of adult people with Asperger's and HFA' – lecture

Suggested scope of material for the lecture:

- Cognitive processes (perception, attention, memory, language functions, cognitive control)
- Theory of Mind
- Central coherence
- Executive functions
- Cognitive distortion
- Attribution error
- The rigidity of cognitive processes in adults with AS/ HFA and the consequences of this.

During the lecture, the facilitator introduces a few interactive elements, thanks to which the participants may understand differences in the way people with AS/HFA function (for example: drawing a picture based on voice instruction without contact with the person who is giving the instructions). Duration: 90–120 min.

### II.1.4. Workshop activity called 'Suitcase'

Materials needed:

• A briefcase filled with items belonging to a person with Asperger's/high-functioning autism;

Activity description:

- The group should be divided into teams of five to six people;
- Working with the items from the briefcase, the participants are to:
  - 1. Create a profile of the briefcase's owner that should include the following information: age, preferences (likes, dislikes), strength and weaknesses, interests, the type of friends he has, if he uses the internet, etc.;
  - 2. Hypothesise about the briefcase owner's needs;
  - 3. Relate the hypothesis to their capabilities in their place of work (regarding the briefcase owner's needs);
- Every group presents the individual's profile on a flip chart;
- Every group presents a hypothesis that relate to the briefcase owner's needs. There is a discussion and participants draw conclusions about the possibilities for responding to these needs;
- Activity overview and impression sharing: what information did you need? What was easy? What was difficult? What helped? How to deal with frustration during the activity?

Duration: 120 min.

### II.1.5. End-of-the-day sum up

Gathering comments from participants in the form of positive feedback (positive statements that improve strengths: I liked ... /thank you for ... /thanks to you ... /I still need), asking for the best things that the participants remember at the end of the day.
Duration: 30 min.

### Day 2:

### II.2.1. Intro:

Activity description:

 Greet the participants, ask for their mood: 'I am starting the second day ...'

Duration: 30 min.

### II.2.2. Lecture: 'Methodology of therapies used in work with adult people with Asperger's Syndrome and High Functioning Autism'

Suggested scope of material for the lecture:

- In general, the scope should have a multifaceted character and include a person-centred approach;
- Methods of therapy that may be helpful in working with adults with AS/HFA;
- Choosing the right method to meet the needs of an individual person with AS/HFA;
- Other ways of supporting adult people with AS/HFA;
- The attitude that should be adopted while working with adults with AS/HFA openness, respect, help in making decisions and completing the tasks of adult life.

Duration: 90 min.

### II.2.3 Workshop activity: 'Instructions'

Activity description:

- The participants are divided into groups of five to six people;
- Every group, according to the hypothesis put forward previously about the briefcase owner's needs (a person with AS/HFA) creates clear instructions for a task, that requires concrete skills, actions and aids, in a way that makes it possible for the individual to complete

the task on his/her own (the instructions should take into account the person's capabilities, cognitive abilities, level of self-reliance, experience to date, etc.);

- Presentation of the compiled instructions;
- Assessment of the prepared instructions through the lens of their clarity, level of detail, accuracy; learning how to give each other positive feedback (the facilitators can moderate the discussion).

Duration: 150 min.

### II.2.4. Workshop activity: 'There here and now'

 The participants are divided into pairs. In pairs, they share impressions about the course and talk about their needs regarding their relationship with an adult person with AS/HFA. The participants answer the following questions:

Did you notice any new elements that could be important in your work with an adult person with AS/HFA?

- The facilitators gather the comments and write them down on a flip chart:
  What are the resources available to me in my work with adults with AS/HFA and the resources that I still need?
- The facilitators gather information about the participants resources and needs.
- A short discussion about the resources and needs of the participants.

Duration: 60-90 min.

### II.2.5. The end and conclusion

- The facilitators also answer the participants' questions;
- Participants talk about what they learned and what they found most valuable out of the two modules of the course.

Duration: 30-45 min.

### **MODULE II**

Advanced training curriculum 'Working with people with Asperger's Syndrome or high-functioning autism (HFA)' AS Mentoring Ltd



### 'Asperger's Syndrome Awareness': course description

**Day one** of the course opens with the two presenters (one autistic, one neurotypical) introducing themselves in detail. We then asked the participants to create a name badge which introduces – in whatever way they feel comfortable with – who they are. We then give each of them a questionnaire to fill out, rating their knowledge about aspects of autism.

We then split them into small groups to ask each group to come up with ten things they know (or think they know) about autism. In planning this course, we intended right from the start that they would be lots of activities, and that it would be very participatory. We follow this exercise with a discussion of ten common facts (and/or myths) about autism.

We then give them an overview of what they are going to cover on each of the two days (with two separate sections on each day), together with the aims of the training. We then introduced the three autistic characters who we are going to focus the training around: Charlie, 22 years old and lives with their mum; Mollie, a 15-year-old student who lives at home with her parents; and Bob, a 51-year-old who lives independently and until recently worked full time. We also introduced a 'Your person' box to encourage the trainees to keep in mind an individual they know. We divide the participants into three groups, and then allocate one of the characters to each group. The participants will be given exercises throughout the training which involve relating what they've just learned about to their allocated character.

Next, we go into detail about the history and characteristics of autism and discussed some of the theories as to what causes autism. This is followed by an exercise where the participants are asked to visualise – and draw – their version of the autism spectrum. We discuss alternative terminology and the characteristics by which it is diagnosed, and the merits (or otherwise) both of obtaining a diagnosis of autism, and then of declaring/disclosing it in various contexts. Using our three characters as a focus, we discuss how each of them might do this. We finish the end of Section 1 of day 1 with a discussion on Camouflaging and the negatives effects this can have on the individual.

We then break for lunch, and resume in the afternoon with Section 2: breaking down the key characteristics of the autism spectrum and giving the participants strategies to address each of these with their clients. This begins with slides covering executive functioning, and then goes on to look at social communication and relationships in detail; again, using our three characters as the focus in each case. We look at several different methods of alternative communication, over a succession of slides.

We go on to consider Theory of Mind and rigid thinking and look at the importance of structure and routine for autistic people. We close with another exercise for the participants, getting them to consider their own schedule for the rest of the day, and communicating this to a partner non-verbally.

Day two of the course begins with a review of what we covered in day one, and then tells them what we will be looking at in the remaining two sections of the course. We start with a discussion of regulating emotions and have an exercise for the participants where they are asked to draw themselves as emojis. We give them strategies to use to help their clients recognise, regulate, express and reflect on this aspect of their condition. We look at several different methods of managing and expressing emotions over a succession of slides. Using our three autistic characters we can provide 'real life' examples of how the strategies discussed can be adapted and used.

We then go on to discuss anxiety, and again provide a range of strategies and approaches for dealing with this central aspect of autism. This is followed by a detailed look at the sensory aspects, including stimming and self-injurious behaviour. This includes showing the participants an embedded video (<u>https://www.carlyscafe.com/index\_nf.html</u>, made by Carly Fleischmann as a vivid illustration of her own sensory experience and overload; Carly is fully credited in the video). Using our three autistic characters, we discussed with the participants the sensory issues that each of them might have. We give them a range of accessories to handle, and our autistic trainer describes how she relates to many of these. This ends Section 3, and we break for lunch.

We resume the training with Section 4, asking the participants to consider (and share with us) what they think the links are between autism and mental health conditions. We discuss in detail anxiety and depression as co-occurring conditions, together with strategies which the participants can use to address these with their clients. As has been the case throughout the course, we invite each group of participants to consider the effects of these on 'their' character.

Next, we consider the effects of one person's autism on the wider family. After discussing these in detail, we show the participants another embedded video: 'A Mum's Perspective', produced by the UK organisation <u>https://resourcesforautism.org.uk/</u> (who are fully credited at the end of the video).

We go on to discuss what funding is available to people with autism to support their needs. This is a detailed discussion and includes another exercise where the participants are asked to consider these funding issues for Charlie, Mollie and Bob as well as for the individual they have been keeping in mind throughout the training. We discussed the need for advocacy support for many autistic people.

We then look at the differences between the medical model and the social model of disability, opting strongly for the latter. And after having spent the first three quarters of the course looking at the difficulties which autism can cause for many people, we look at its positive qualities and strengths. We ask the participants to consider the future for each of their autistic characters and ask them both what they have learnt from the course and how they think they will apply this learning to their role. Finally, we ask them to go back to the questionnaires they filled in at the start of day one and to complete them again, to compare their 'before' and 'after' levels of knowledge and confidence.

We then closed the course by telling the participants that will be around for another 30 minutes or so to take any individual questions. (It has long been our experience that there will be people with a personal, often family connection to autism that they want to discuss with us).

Presentations from the 'Aspergers Awareness' training course: <u>https://drive.google.com/drive/folders/1YXoX-aS620E6GLtwUGzep-JCc80avl-z?usp=sharing</u>

### **Autism and Employment**

#### **SECTION 1**

### Recruitment: the advantages to the employer of recruiting an autistic employee

There are several persistent myths about employing autistic people. These might be collectively termed the '*Rainman* Fallacy': that autistic people never get bored with repetitive tasks, or never make mistakes when repeating them; that they always have one special skill ('if only you can find it'), are brilliant with numbers, and generally have a preternatural facility for all things IT.

One or more of these things may indeed be true for individual people, simplistic stereotypes are as inappropriate and unhelpful for this group as they are for any other. Nevertheless, it is often the case that people with Asperger's Syndrome (AS) are of above-average intelligence; and employers *are* frequently struck by their consistent application to their work.

The primary focus should always be on achieving a close match between the CV and job description. When there is an overlap between the skills, abilities and interests of somebody with AS and the requirements of the job, you are likely to be pleasantly surprised by his or her productivity in the role. A good match between someone's skills and experience is particularly important for autistic people, as a mismatch is likely to leave them struggling to adapt and to demonstrate their ability at the start of the job. The early period for anyone in any job is extremely important because it is when relationships are built, and first impressions formed. Spontaneous flexibility and adaptability are often areas where autistic people underperform compared to their neurotypical peers and a higher-than-typical degree of orientation and coaching might be helpful in the early stages of any new posting. Autistic recruits also tend to be less likely to speak out if they do not feel comfortable with aspects of the role, so if a mentor actively solicits such information it will be advantageous to both the employee and the employer.

When there is a good match then you are likely to find your recruit performing consistently well above average. As noted above, work tends to be even more important to autistic people than it is to the rest of the workforce, as it is likely to be their primary route to social inclusion. It also offers someone with autism an opportunity to engage with his or her skills and interests in a structured environment with clear rules and goals. Coupled in most cases with a preference for known routines and an aversion to change, this means that autistic people are invariably willing to remain in a role which suits them well and in which they can demonstrate their qualities. They are far less likely than their neurotypical peers to be looking to move on to other opportunities, either within your company or somewhere else.

#### 2. Reasonable Adjustments – recruitment

The statutory requirement to make Reasonable Adjustments for disabled employees mandated by the Equality Act 2010 in the UK applies to recruitment as well as employment.<sup>11</sup> An important point for employers to be aware of is that very few of the Reasonable Adjustments required by applicants, recruits or employees with autism cost anything to implement. They are predominantly procedural in nature, and - because these Reasonable Adjustments are invariably aimed at simplifying, clarifying and/or rationalising a process or procedure - they tend to be constructive contributions. Indeed, they are often subsequently applied more widely, simply because they work well: they are invariably examples of good operating and management practice. They improve the procedure for all applicants and recruits, not just for those with autism. For more on Reasonable Adjustments once employees are in a job, please see the 'Management' section of this handbook.

In the context of recruitment, Reasonable Adjustments most commonly pertain to details of the interview process, and to the phrasing/wording (not the content or nature) of the questions themselves: this is covered in detail on the 'interviews' page. The following section includes some aspects of an employer's recruitment procedure that could inadvertently exclude autistic people:

#### Telephone interviews

Some people on the autistic spectrum have an aversion to speaking on the phone, particularly to people they don't already know. This triggers a high level of anxiety that can prevent them from performing as well as they might otherwise do in a different situation – which makes sense when you recall that autism is above all a communication impairment. If your selection procedure involves a telephone interview, many applicants with autism will fail at this stage. This is not just a significant problem for them as individuals; it is also potentially disadvantaging you, as the employer, because you are inadvertently preventing yourself from accessing the right people. There are some very talented individuals out there, a great many of whom would dedicate themselves single-mindedly to these and other jobs, and as things stand they may find your recruitment process inaccessible.

<sup>11.</sup> See 'Equality Act 2010' for a detailed overview of this requirement.

### Group exercises

People with autism can struggle to read other people's body language and can take longer to think about a (verbal) response to what they perceive. Many are wary and hesitant in any situation requiring interaction with strangers, or in what they perceive to be a competitive rather than a collaborative situation. This means they can struggle to be heard or to assert themselves in group tasks. If your selection process contains any kind of group element – either a group exercise or a group interview – the applicants with autism are likely to be heavily disadvantaged at this stage.

Another option to consider is giving the person your interview questions in advance, so that he or she can prepare a response. This may seem like 'cheating' but it can help to level the playing field, by making the person feel less anxious and akin to their non-autistic counterparts. It also helps you see how the person will function in their job once he or she knows more about what is required.

### 3. The application stage: being autism-friendly

### Job descriptions and job adverts

Job descriptions and job adverts can sometimes inadvertently include content that contains wording which is likely to deter potential applicants with autism. Common examples include 'must be a strong communicator'; 'good communication skills required', or 'excellent written and spoken communication skills'. Many jobs require these; but many do not. Moreover, unless these skills are clearly identified and described (e.g. the ability to speak over the phone, to attend networking events and to speak and work appropriately with people of varying levels in the company), an autistic person will not necessarily know which particular 'skills' are required: the terms are too generic to be meaningful. In which case, he or she won't be able to work towards improving them, or demonstrate them at interview, even if they happen to be very skilled in some areas of communication.

Many job descriptions and job adverts are simply rolled over from one vacancy to the next and are rarely reviewed in depth. It is worth considering on a post-by-post basis whether these qualities are necessary, or even desirable. Even if an autistic person has acquired good communication skills, their tendency to exacting standards of self-reflection would mean they are unlikely to consider themselves 'good' and are frequently put off by such an advert, despite being well qualified and suited to the role. Furthermore, their tendency to take things literally means that they will invariably assume that they won't be considered for the job if they see this requirement, even though they have all the skills that are relevant to what are actually the essential elements of the job. The job description may even prevent someone from applying who has much stronger aptitude for the work than the majority of the neurotypical team-players who'll be applying. Employers should consider whether a junior IT support post really needs an outstanding communicator, or a back-office data entry role requires a committed team player? The unnecessary inclusion of this communication criterion is probably the biggest single factor which deters jobseekers with autism from applying for vacancies for which they are both qualified and well-suited.

### Job applicants

Many jobseekers with autism have had many negative experiences of applying for work, and they tend to be offered fewer interviews if they declare their diagnosis on the initial application than if they don't disclose their disability. Furthermore, many people with autism, particularly those with a diagnosis of Asperger's Syndrome or other high-functioning autism diagnoses such as PDD-NOS, do not consider themselves disabled. They view themselves as neurologically different, with this difference conferring advantages as well as disadvantages. This also means an employer should not view an autistic person's not ticking this box as dishonesty if the employee discloses later – many honestly won't view their autism as a straightforward disability.

In any case, many applicants with autism will not have declared their condition at the application stage.<sup>12</sup> However, they may well contact you following their selection for interview, to disclose and to discuss any adjustments they may require at interview. Alternatively, if they have been receiving pre-employment support and mentoring from the third-party organisation, it may be their coach/consultant who contacts you on their behalf to discuss these adjustments.

For a detailed discussion of the reasonable adjustments that are commonly implemented at interview for candidates with autism, go to 'Reasonable Adjustments at Interview'.

### 4. Unfamiliarity

One of the biggest obstacles that jobseekers with autism face is the recruiting employer's/ interviewer's unfamiliarity with the condition and its highly varied nature – autism is commonly misunderstood. It is important to bear in mind that autism is a spectrum covering a very broad range of abilities

 $<sup>12. \ \</sup>mbox{They of course have the absolute right not to disclose at any stage, if they choose not to. }$ 

and impairments, ranging from mild to severe. The 'label' in and of itself tells one very little about the individual.

If you are not familiar with the communication differences that are the signature aspect of being on the spectrum, or are unprepared for them, these differences can be subtly but powerfully alienating. This is because we all have expectations – instinctive for the most part – about how the people we meet will act, and react, in conversation and in certain situations. (An interview of course is fundamentally a structured assessment, but one in which these unspoken rules and unconscious expectations are a very significant factor.)

These expectations include eye contact (that it should be neither too hesitant or too sustained); tone of voice (not too high or low, nor not too animated or monotonous; 'normally' modulated, in short); speech patterns (not too halting or too fast); phrasing and terminology (there should be nothing unusual); and the nature of any observations or suggestions (these should be within the range of what is considered normal, and should not be in any way jarring - they should not be too left-field or nebulous). Body language is important too; many would view twitching or an inability to sit still as suggesting nervousness, but such movements could be involuntary.

All our expectations, therefore, tend to be 'Goldilocks criteria': no extremes and nothing out of the ordinary. And this is the problem, because the communication differences that characterise autism are by (neurotypical) definition out of the ordinary. And – particularly because we are for the most part unaware of our expectations – these differences have the capacity to feel uncomfortable.

If as an interviewer you find yourself internally distancing yourself from a candidate, the first thing to do is to recognise that you are developing an instinctive aversion to the way this candidate presents. The next thing to do is to ask yourself why. You should consider whether the person you're interviewing is on the autism spectrum. Here's a quick checklist: do any of the following apply?

- Too much eye contact ('He just stares at me all the time he's talking – it's making me very uncomfortable'), or little or no eye contact ('She won't meet my gaze at all – I don't trust her');
- Very little tonal modulation ('He's really droning on ... What he's saying makes sense, but it's hard to listen to');
- Long pauses before answering the questions ('I can't cope with what feel like long silences – I feel compelled to prompt');

- Very short answers not expanding them with any context or additional information;
- Longer answers than needed not responding to non-verbal cues or to verbal interjections to move on ('this person is unbelievably arrogant. They seem determined to finish their point and have the last word');
- Contravening the dress code (which is usually unspecified, but nevertheless is always expected to be understood and respected).

### 5. Recruiting candidates with autism – Reasonable Adjustments at interview

The main elements of autism to remember in this context are the differences in language-processing (taking it literally, and sometimes taking longer than others to process what's been said), and the difficulties that many people with autism experience when trying to imagine themselves in unfamiliar situations. Your key reference ideas throughout should be clarity and directness as is always the case if you want to communicate effectively with someone on the spectrum. The following points constitute the reasonable adjustments that are most commonly required when interviewing autistic candidates. As noted earlier, they work equally well for neurotypical people:

- Avoid open questions ask closed questions instead. For example, a gentle opening question such as 'Why do you want this job?' will leave some candidates floundering because they either don't know where to start ('Because I haven't got one') or, conversely, when to stop (all the pressing personal and family circumstances that make it imperative for them to find work within the next month). A closed version of the same question would be 'What are the elements of this job which appeals to you?', and this will be much more likely to elicit the information you want;
- Ask single questions; do <u>not</u> ask multi-part questions. A vague and compound question like 'Do you have experience of working in teams and, if so, what do you think makes for good teamwork?' will just confuse. You need to simplify and clarify. An initial single question – 'Do you have experience of working in teams?' ('Yes') – can be followed by another single question, phrased more specifically, e.g. 'What factors do you think make a team work well?'
- Avoid hypothetical questions, or ones involving abstract situations. A question like 'What would you do if you were faced by an angry customer who wasn't happy with the service he received and wanted you to fix it for him?' will leave many autistic candidates

completely stumped, as they will struggle to imagine this;

- Instead, break it down into single questions comprising concrete rather than abstract formulations. To continue this example, you might usefully ask 'Have you ever had to deal with an angry customer?', followed by 'How did you try to calm him down?'
- Give the candidate a few seconds longer than usual to think about their answer. They may need this additional time (and period of silence) to be able to respond. As a rough rule of thumb, allow up to about ten seconds;
  - Beyond this interval, be prepared to prompt the candidate gently in order to extract all the relevant information and gather sufficient information. You may need to rephrase the question for them;
  - Conversely, stop them if you need to when they've given you enough information: 'Okay, you've told us what we need to know about that, so we'll move on to the next question';
- Any slack phrasing in your questions is likely to be exposed. A standard 'soft' opening question -- 'How did you find your last job?' – has in the past prompted answers such as 'I looked online,' and 'I planned my route on TfL';
- Be aware that eye contact is likely to be different from that of neurotypical people. Autistic people are likely to make either significantly more eye contact (holding the gaze, staring 'through' people) or significantly less eye contact (occasional and/or fleeting eye contact, or none) than you are used to. It depends on the individual, and it can be unsettling if you're not expecting it. It's a very common aspect of being on the autism spectrum; the person you're with will do this with everybody, not just you;
- Facial expressions: many autistic people are difficult to read facially, and thus may appear to be unengaged or unenthusiastic. This will be misleading. Again, they're probably unaware of this – try not to be thrown by it;
- Speaking voice: quite a few autistic people have unusual speech patterns, vocal inflections, and/or turns of phrase. They are likely to be entirely unaware of this. Try to listen to what the candidate is saying, rather than the way he or she is saying it.

#### Interview support

If an interview candidate has been receiving pre-employment support from a specialist agency, they will sometimes request a supported interview from their consultant. This is recognised as a standard Reasonable Adjustment by the government's 'Access to Work' scheme, which regularly funds the consultant to attend in such circumstances. Their role is not to answer questions on behalf of the candidate. Rather, it is to prompt the candidate when necessary, as the literalness of many people's language processing will often prevent them from understanding the wider context of the question and from realising that more information is required, even if it hasn't been explicitly requested.

Thus, a question such as 'What experience do you have of using Microsoft Excel' may receive a factual but perfunctory answer such as 'I used it at university. And, also, in my last job'. At this point the consultant – who will know the candidate well – will intervene to suggest that they talk about their extensive experience of creating pivot tables, graphs etc. Conversely, if the candidate becomes excessively focused on a minor aspect of the question, the consultant may quietly intervene to prompt them to stop and move on.

#### 6. Work trial - an effective solution for both parties

There are some candidates who will never be able to acquit themselves effectively at interview regardless of how much practice and preparation they do. The ideal solution for these candidates in particular, but also for autistic applicants in general is for the employer to assess their suitability via an unpaid work trial. This typically lasts for a fortnight and gives the candidate the opportunity to show what they can do, not making them talk about it in an interview.

Whilst this is undoubtedly more time-consuming for the employer, it nevertheless confers the significant advantage of enabling the employer to assess, with much greater accuracy than at interview, how effectively the candidate will perform in the role and what, if any, personnel management adjustments might be needed to accommodate them.

From the candidate's point of view, the ideal would be to provisionally 'ring-fence' the vacancy, so that if the candidate performs well in the work trial they will be offered the job; it will not be necessary to interview other candidates. However, this is only likely to be a realistic possibility where there is an existing relationship between the employer and a specialist agency such as <u>AS Mento-</u> ring, Autism West Midlands or Prospects Glasgow, who will have prepared the candidate(s) and ensured that they are appropriate for the role. Without such a pre-existing relationship, the work trial will need to conclude at the same time or very shortly before the interviews for the other candidates take place. This will level the playing field with the interview candidates and will, hopefully, enable a fair and objective selection to take place across all the short-listed candidates.

### 8. Staff buy-in

If this recruitment is part of a company diversity initiative it is important to ensure that all those involved in the recruitment process - especially the recruiting manager - are aware of the initiative, and actively involved in it. There can often be a disconnect between a high-level (board, senior management, head of HR) policy initiative and what happens on the ground. The strategic intention is to recruit an employee with autism; the tactical outcome is that nothing changes, and a non-autistic applicant is recruited instead. Some of this is down to simple inertia: people stay within their comfort zone and do what they usually do, i.e. they recruit the type of candidate they usually recruit. If they're not familiar with autism, they can be taken out of their comfort zone by an autistic candidate - sometimes consciously, sometimes unconsciously – which is why it is essential to engage them with the process and brief them on what to expect.

It's also important that all those in the company understand the benefits the policy will bring, so that they are all invested in making it a success. This can include the importance of diversity to making good business decisions and therefore the profit of the business. While those who know people with autism likely have a more emotional reason to advocate these changes, many people will not be emotionally invested in this way. If they recognise how they and their business will benefit from these changes, they will be far more likely to personally support them.

### SECTION 2 Induction

One of the advantages of an early declaration of the new recruit's autism is that any reasonable adjustments that will be required can be identified and implemented so that they are in place when the recruit starts their new job.

### Reasonable Adjustments

Autism, including Asperger's Syndrome, is categorised as a disability under the terms of the Equality Act; the primary duty arising in an employment context is that the employer is required to implement Reasonable Adjustments to neutralise any disadvantages arising from the individual's condition/ impairment in the workplace. These adjustments

are specific to each *particular* individual, in their *particular* job, in that *particular* workplace. The criterion of 'reasonableness' is not defined, as it is specific to each individual situation. An adjustment which may be reasonable for a large corporate employer (e.g. transferring an employee to an equivalent role in a different part of the business if s/he had been recruited to an inappropriate job originally) may not necessarily be reasonable or indeed feasible for a small business with only a handful of employees.

Here's what Reasonable Adjustments are emphatically not: 'If we do it for you, we'll have to do it for everybody'.

Surprisingly, you still encounter managers who refuse to implement a Reasonable Adjustment on this basis; a recent example concerned noise-reducing headphones for an employee with acute auditory sensitivities, an adjustment which was (initially) declined on the basis that all her colleagues would want to wear them in the office.

Essentially, each adjustment is a reasonable response to a specific issue which has been identified as problematic in the context of an employee's disability in the workplace. If you approach the discussion with an open, can-do attitude – a spirit of pragmatism and flexibility ('okay, what can we do to resolve this effectively?') – then you can usually find an appropriate, effective solution.

For instance: in one company, the data-entry clerk sits as part of a large team in an open-plan office with a relatively high level of background noise. Their desk is nevertheless situated next to a large window and receives a lot of natural light. In another, smaller company, the clerk sits in a quiet office in the basement which is lit solely by fluorescent lights. If the recruit in the open-plan office is, like many autistic people, hypersensitive to ambient (background) noise, he or she will find it very difficult to concentrate on their work, and noise-cancelling headphones should certainly be considered as a reasonable adjustment (see for example here). Similarly, when it comes to someone who is acutely sensitive to fluorescent lighting who is working in an artificially-lit basement, then you should consider letting them move to a desk next to a window or - if this is not feasible - then replace the basement lighting with non-fluorescent units.

Clearly, if the people concerned do not have these sensitivities, no such Adjustments will be necessary. Adjustments may well be required, however to enable each employee to work to his or her potential.

What we find, time and time again, is that:

1. Reasonable Adjustments for employees with autism rarely cost much if anything to implement – they

are usually matters of communication, process and procedure; and

2. What works well for employees with autism, works well for all employees.

An example of the latter is the detailed written breakdown mentioned in the Information Box. It's often been the case when we've provided this for a new employee with autism, the employer has seen how useful it is in enabling the individual to settle quickly into their role. They have then included a copy of this document in the induction material for that role for all new employees.

**Be clear about expectations**, across the board. The employee will need to know:

- Who they report to (e.g. supervisor or line manager);
- How often their formal support/ supervision meetings will happen;
- Who they approach for informal information, advice and guidance – e.g. a workplace 'buddy' or mentor, whether internal or external to the organisation.

#### **Useful actions:**

- Write all such instructions down, so that the new employee has induction documentation to refer to;
- Consider breaking the job description down into bullet-point lists/ flowcharts ('decision points');
- Introduction to colleagues give the recruit a floor map of who's who/ who sits where/ who does what, together with their formal job title in each case;
- Provide a written schedule, with detailed timings: when you're expected to arrive in the office, when you can leave and when you can take breaks. These are often a source of stress and anxiety otherwise;
- Some autistic people can have difficulties with coordination and remembering the layout of the office/ building – for these people an orientation tour, coupled with a personal map of the area to help them find their way around, are useful;
- The anxiety (and, sometimes, the difficulty) which is triggered in some people with autism when someone speaks to them to give them information and/ or instructions can make it difficult for them to assimilate and/or respond to it. Thus, a new colleague who is on the spectrum may need to have this information and/ or instructions repeated to them several times, often on successive occasions, before they will be confident that they have understood and remembered them. Again, it will be better if these can be written down.

Perfectionism can be a real issue for some autistic people. This can be a positive trait in terms of the quality of their work; but it has the capacity to be disruptive in terms of their productivity and prioritisation. Furthermore, the pressures of work, deadlines and the needs of managers and colleagues to receive completed work within an agreed timescale often make it difficult for the autistic employee to work to the standard they feel compelled to achieve. This can lead to acute stress and anxiety. The most effective way to address this is to give examples of the standard(s) of work they are expected to achieve and state the deadline by which they are required to have completed the work. Out of a desire for perfection, many will also not speak up if they don't quite understand something that's been explained to them. To counter this, let them know they can ask again if they don't understand and that it gets things done quicker if they ask earlier rather than later (or, worse, don't ask at all).

Disruptions to expected routine can also be disproportionately distressing for autistic people. An IT malfunction, an unannounced fire alarm drill, an unscheduled meeting, a cancelled train - all of these have the capacity to affect the employee's capacity to complete their work to the required standard in the stipulated timescale. If there is a practical way around the issue, suggest it in concrete terms ('The server's down and you can't access your working document, but you can boot up the laptop and draft the final section there while you're waiting for the system to come back online'). If there isn't - if, for instance, they've arrived 40 minutes late because of the train cancellation, and are very agitated – then reassurance is the best option (This happens to everyone sooner or later'). You can again follow this with practical suggestions ('You can make up the time later. Take a shorter lunch break and leaving at 6 pm rather than 5.30').

**The general case:** If an autistic employee runs into difficulties at work, it is rarely because of the technical aspects of their job. It is much more often the case that these difficulties arise from a misunderstanding with a colleague, or a misinterpreted comment on either side. Some struggle with unstructured time, and the perceived expectation that they should interact socially with colleagues when there is less to do. Many autistic people find informal conversations baffling and unnavigable. 'Small talk', implicitly understood by neurotypicals (non-autistic people) as socially cohesive, is often literally meaningless to someone on the spectrum.

**Explain the unspoken and unwritten 'rules'**: make them explicit. Write them down if necessary. Examples might include:

- A clean-desks policy; all filing to be done by the end of the day; all stationery items to be stored away in desk drawers, etc.;
- The rules around tea and coffee. Does everyone make their own or do people make 'rounds' of drinks? Is everybody expected to take turns? If so, how often should you offer to make them? And where do people drink them? Standing talking in the kitchen, sitting quietly at their desks, or taking them outside the immediate workplace?
- What people generally do for their lunch and other breaks. When do they go? Is it a packed-lunch culture? If so, where do you eat it? Do certain groups tend to sit together (e.g. managers on one table, supervisors on another, general employees on others) or is the culture less hierarchical?

An informal (non-managerial) mentor is often helpful in this unstructured, quasi-social context. Having a person in this role who you can go to – someone who understands autism and who can provide informal support and advice – is another anxiety-reducing measure that is often effective. The mentor can also have a quiet, explanatory word with colleagues to neutralise and resolve any misunderstandings. The mentor/ buddy and line manager should liaise wherever possible, to ensure clarity and consistency of advice and messages. Between them, they need to ensure that the recruit with autism is made aware of anything they're doing that has the potential to alienate colleagues. The recruit will almost certainly be unaware that they're doing this. Common examples include:

- Talking too much, especially about their own special interests;
- Not taking their share of expected tasks (e.g. making tea and coffee – the unspoken rules again);
- Standing too close to colleagues (especially when the latter are sitting at their desks) – and not recognising personal space in general;
- Interrupting excessively. If you do need to intervene to correct this, you will have to try to make clear for them what constitutes 'excessive' in this context. They may think what they're doing is reasonable;
- Not recognising and/or observing the distinction between 'professional' and 'private', either in direct conversation or via e-mail;
- Failing to maintain respectful professional language and terminology;
- Inadvertently causing offence by being very direct/ blunt in comments and responses;
- Telling inappropriate jokes or making inappropriate

political comments (trying to fit in with the perceived office culture, but misjudging the tone of it);

- Involuntary communicative acts which seem inappropriate, e.g. instinctively laughing nervously when they hear bad or sad news, but because of their tone of voice it can seem like they are laughing humorously;
- The autistic employee is likely to take what their colleagues say literally and will not necessarily understand that what is being said is sarcasm or banter. If this seems to be the case, just - literally - explain the joke or the context.

It is important to note that the need for such help for an autistic employee is likely to continue. The above issues are a feature of the person's autism, and while the individual may learn several strategies to reduce their incidence, they will be unlikely ever to eliminate them completely. To intervene effectively you will need to be clear and direct in everything you say and make a point of keeping it adult-to-adult: be aware of the risk of patronising your colleague.

#### Training -- induction and ongoing

- Ensure training is delivered in a format that is fully accessible to the employee with autism. Many (although not all) people with autism have a strong visual learning preference. Employees in this category will find it much easier – or, in fact, completely necessary – to have comprehensive written handouts with the training materials/ content in order to be able to assimilate them;
- Be prepared to offer training in a 1:1 taught format for those employees who struggle to receive information in a group-training environment. This will have the additional benefit of enabling the individual to ask questions which s/he may be afraid to do in a group situation.

#### Individuals: workplace support

Ongoing support and guidance in the workplace, from a provider which specialised in autism employment support, can be very effective in helping to develop the individual's skills, and in providing strategies to enable them to work as effectively as possible. Typical areas covered include stress and anxiety reduction and management, assertiveness, self-confidence, time and workload management, communication skills, and meetings skills and strategies. The external consultant can also advocate for them with their employer – often, in practice, their line manager/supervisor – and act as a mediator (in both directions, 'translating' between autistic employee and neurotypical manager) if appropriate.

Workplace support is very flexible and is often a short- to medium-term measure. These visits usually take one or two hours (depending on what has been agreed), and they will usually be scheduled weekly, fortnightly or monthly, according to individual need. The frequency of support can often be decreased as managers and colleagues become familiar with any reasonable adjustments which have been agreed, and as the employee becomes more familiar with – and confident in – their role.

The employer will often fund these visits as a reasonable workplace adjustment. Alternatively, the government's Access to Work scheme may fund some or all the costs of this support. It is the individual employee who must make the application: see <u>https://www.gov.uk/access-to-work/overview</u>. This is an overlooked source of funding, which always has a surplus left over each year because so few people make applications to it, and it should be seriously considered in cases where your business feels it cannot afford to make adjustments.

#### Initial briefing/ Q&A Session

It is strongly recommended that you commission an autism awareness session for the new recruit's line manager and immediate colleagues – *assuming he or she has given consent for the employer to disclose their diagnosis to this specific cohort of colleagues*. More than any other single factor, this briefing has the potential to make the biggest difference to the new employee's reception, and thus to the accessibility of the workplace overall. It can be the biggest determinant in whether the recruit perceives the employer to be helpful, and whether there is an inclusive culture in the workplace.

It will also be a real advantage to conduct an autism awareness session with relevant colleagues at an early stage. This will ensure that if for instance the autistic employee misjudges the tone of the conversation and says something that is perceived as jarring or inappropriate, their colleagues will understand that this is an aspect of their condition and will hopefully be less likely to take offence and/or withdraw.

**Example:** because of the communication issues which are at the core of the condition, and which manifest to a greater or lesser extent in different individuals, it is quite possible

that on their first day in the job, the recruit will feel anxious and overwhelmed about meeting their new colleagues and may find it extremely hard to know how or when to greet them collectively when they walk into their office or workplace for the first time. The upshot may be that they blush, put their heads down and lower their eyes, and walk over to the desk and sit down without saying anything.

If these colleagues have not been briefed about the condition, and/ or have no idea that the new colleague has autism and what the implications of that might be, they are likely to instinctively withdraw, without being aware that they are doing so. If they've been briefed about their new colleague's condition and have been told 'Jess finds it difficult to gauge when and how to say hello to people, particularly when they meet them for the first time, so don't be offended if they don't greet you when they first start. It's nothing personal, she's just feeling a bit overwhelmed'. The reactions in this case are very different: 'Oh, okay, the recruitment guide told us this might happen. Give it a few days'. First impressions are important, and the first scenario has the potential to open a small but immediate rift, which has the capacity to get steadily wider with time. The second scenario avoids this and buys time for the new recruit to settle into their new role in a much more tolerant and welcoming environment.

As with all disability issues, the key thing is to get to know the person as an individual. This is the surest route – the 'secret', if you like – to all successful diversity practice. People often perceive a person's disability as an enormous label, as their defining characteristic; but when you start to get to know someone as a person and begin to get a sense of their personality, their likes and dislikes, the quirks and idiosyncrasies, then the disability and the questions around it imperceptibly recede. After a while, you just see the person, just like everybody else.

Autism awareness training: In addition to accessing resources such as this website and reading more about autism, it's important for employers and fellow employees to receive, wherever possible, autism training to learn more about how autism can affect people in the workplace. Everyone with autism experiences their condition in a specific, individual way, so as wide an understanding as possible is important. Some people will be more affected by social difficulties; others will be more affected by sensory difficulties, such as being over-stimulated by light, sound or touch etc. For these people, other adjustments such as headphones to block out outside noise – even from things like fans which wouldn't affect most people – or a certain room to work in with brighter or darker lighting – would be appropriate.

#### **SECTION 3**

#### Management

Let's start with a reminder. Autism, including Asperger's Syndrome, is – in the way that it manifests in the individual – primarily a condition which affects the way people communicate and interact with the people around them. And since the percentage of communication that is non-verbal is significant, this offers ongoing opportunities for mutual misunderstanding – particularly in the workplace. This is because of the s host of unspoken rules and conventions that vary from one organisation to the next. This should be the primary consideration in all successful management strategies involving employees with autism.

#### **Communication**

The following considerations arise from these precepts, in no particular order:

• The 3 Cs: be Clear, Concise and Concrete in your communication with employees and colleagues with autism. This applies equally to written and spoken communication. Here's an example of how not to do it:

'That, uh, document that I asked you for a while back ... where are we up to with it?'

• How it will be heard by your autistic employee, who will be staring at you blankly while her stress spikes: *That, uh, document ... '* 

What document? Does he mean a report? Meeting notes?

'- that I asked you for ...'

Did you? Oh God. I don't remember any email –

'-a while back ...'

When? Last week? Month? Year?

'-where are we up to?'

We? Who's we? Must be a team thing. I don't know anything about any team task...

<u>How you should ask the question:</u> 'When we had our 1:1 meeting last week I asked you to prepare a detailed briefing document for this coming Friday's team meeting. How much progress have you made with it?'

The other main considerations in your management strategy are likely to be the employee's stronger-than-usual tendency to acute anxiety, a lack of understanding of the unspoken rules of the office, and (where present) any sensory difficulties.

You should also bear in mind the autistic person's general preference for structure, routine, and familiarity,

rather than change, particularly when any change is unexpected, unannounced or unplanned.

Approach these issues – and indeed all diversity issues – with an open and pragmatic mindset. Much better to have a 'Why not?' culture than a 'Why should we?' response. In practice, at least 90 percent of what many employees with autism need from their line manager is clear communication and clear expectations, together with the opportunity for regular feedback. Some people describe these as 'reality checks', albeit using the term in a much more literal way than is usually the case: to enable them to check that their perceptions of what is required, and of how well they're performing, matches their employer's perception in each case (where 'employer' usually equates to 'line manager').

#### The unspoken rules of the workplace

These are the social conventions: the collectively-established norms of what constitutes acceptable behaviour, dress, conversational topics, in-jokes, etc. Most of us are not even aware that we share these unspoken standards until somebody fails to conform to one of them, inadvertently or otherwise. At this point, we become sharply aware that somebody has transgressed – that they have said or done something we consider unacceptable. In most cases, when an employee with autism runs into problems at work, it is because they have inadvertently broken one or more of these unspoken rules. We looked at common examples of these in the 'informal mentor' section of the induction chapter.

Unstructured time (tea/ coffee breaks, lunchtimes in particular) can be very stressful. Again, the key is to make the implicit *explicit*. Explain what people tend to do at lunchtimes, where they go, where they get their food, who tends to go with whom, etc. Suggest what the employee with autism might do, at least in the short term:

'In the summer you can bring a packed lunch and eat outside, the benches in the park. Now, in the winter, you probably want to go to the canteen and get something hearty. The best time to go would be early, around 12.15, so you can choose a table. When the place fills up from 12.30 onwards, people will come and join you, and that's your chance for conversation if you want it. So, I suggest you take your lunch hour from 12.15 to 1.15 and see how it goes. If it doesn't work out, we can think of a different approach for you to try.'

People with autism tend to value clear rules and boundaries, so write as many of these down as possible. To avoid singling anyone out, this document could be designated a Code of Conduct, and form part of the general induction material for all new staff. Make it clear to your employees that they are required to follow these rules and observe these boundaries, and that there will be consequences if they don't. A strong induction programme – one which makes implicit assumptions explicit and which codified these unspoken rules and boundaries – is the most helpful prophylactic measure which you, as the employer, can implement in developing an autism-friendly workplace and working culture.

#### Autism awareness briefings for colleagues and managers

If an employee has (1) declared a disability and (2) confirmed that they are content for this declaration to be shared with a group of colleagues, then we always recommend a short autism awareness briefing session for those colleagues. This should be delivered by an external specialist who has a strong understanding of workplace autism issues; it has not generally worked out well in the past when such sessions have been presented by non-specialists, or by trainers from pan- disability organisations. Subsequently, when new recruits join the team, the autism awareness briefing should be part of their induction. This will maintain the inclusive ethos and will help to prevent any misunderstandings arising in the future.

#### Reasonable Adjustments

People with autism generally find it (much) harder than other people to engage in, and with, team activities. So, whether or not the individual has given their consent for wider disclosure, the line manager should make a point of ensuring that the employee with autism is involved in team activities whenever possible. This precept should be extended not just to work activities but also to any out-of-work social events and activities, to avoid the exclusion that can otherwise take place. While this is often unintentional, it can nevertheless feel like ostracism to the person concerned. A little thoughtfulness and facilitation really do go a long way in these circumstances. There are some persistent misconceptions about what 'Equality' means, and about Reasonable Adjustments in particular. In the context of employment, the objective of the Equality Act is for each employee to have equality of opportunity to achieve his or her full potential in their job. In the specific context of disability - and autism, including Asperger's Syndrome is categorised as a disability under the terms of the Equality Act - the employer is required to implement Reasonable Adjustments to neutralise any disadvantages arising from their condition/disability in the workplace. For a detailed consideration of these, see the 'Induction' section.

These Reasonable Adjustments are specific to each individual person, in their <u>particular job</u>, in that <u>particular workplace</u>. The criterion of 'reasonableness' is not defined, as it is specific to each individual situation. An adjustment which may be reasonable for a large corporate employer (e.g. transferring an employee to an equivalent role in a different part of the business if s/he had been recruited to an inappropriate job originally) may not necessarily be reasonable or indeed feasible for a small business with only a handful of employees.

#### Structure and routine

Employees with autism need regular, structured feedback. As the Information Box makes clear, it is important to have regular, timetabled 1:1 meetings with their supervisor/ line manager. This is the forum where the employee with autism can receive clear and concrete updates on what they're doing well, and on any areas for improvement.

Key points in this area are:

- Put the dates in the diary and stick to them! <u>Never</u> cancel one of these meetings at short notice, unless the building is on fire;
- Always make a point of noticing and praising good work and positive outcomes. If a manager only ever notices and comments upon – criticises – poor work and unwanted outcomes, the ongoing message received by the employee will be unremittingly negative. Do not, therefore, manage 'by exception';
- Always try to find a specific (i.e. rather than general) piece of work, action or outcome to praise. 'Just as flowers thrive when you water them, employees flourish when you praise them' - Richard Branson;
- Many employees with autism have had disproportionately negative experiences both in education and in previous jobs, and their confidence is often low. Help them to build their confidence and you will reap considerable returns both in productivity and employee retention.

Note that everything stated in this section can be seen to apply to all staff. This is another example of 'What works well for employees with autism, works well for everybody'.

#### Change management

Because of heightened levels of anxiety and a preference for structure, routine and predictability, most people with autism tend to be averse to change, sometimes strongly so. This version is compounded significantly when the changes are unexpected. Of course, it's not always possible to anticipate all change, but in those instances where you are aware of upcoming change that will in some way affect the employee with autism, it is important that you manage this change appropriately. Key points include:

- Flag the change up as far as possible in advance. Ideally, sit down with the employee in a one-to-one meeting to talk him/ her through the changes. Their anxiety is likely to spike, they are likely to register only some of what you tell them (because they are anxious); so, you should therefore have a pre-prepared briefing sheet to give them at the end of the meeting that sets out the key points of the forthcoming changes;
- Make a point of checking with them a couple of days later that they've understood these key points. Give them an opportunity to talk through any worries. Convene the second meeting in advance, i.e. rather than springing it upon them as an impromptu follow-up discussion. If they know about the meeting in advance they can plan what they want to say. Keep the employee briefed about progress, and let them know at the earliest opportunity about any changes to the plans;
- Be aware that apparently 'small' changes, ones which wouldn't normally be expected to be a problem for somebody, can be highly stressful and disruptive for an employee with autism. The most common example of this is a change of line manager, particularly when the existing line manager is known, familiar and trusted.

Be aware, too, that for the same reasons as set out in the introduction to this sub-section, change in life outside work for a person with autism can be very disruptive in terms of its effect on their stability, and thus their effectiveness in the workplace. If you do become aware of a sudden deterioration in performance which doesn't have any obvious causes at work, it's worth exploring with the employee – again, in a 1:1 meeting – whether anything has happened in their personal life which is having a knock-on effect at work.

#### What constitutes 'good'?

This is often difficult for employees with autism to assess and is another example of why clear and direct feedback and information is a prerequisite for their effective management. We looked at 'perfectionism' in the section on Induction; this trait often stems from trying to compensate for not understanding (in the absence of explicit instruction) what the expected standard is. Examples of similar work produced by colleagues or by predecessors in the role is very useful in this context. By giving the employee such examples, you are enabling them to see what you want them to produce and are also helping to remove some of the stress and anxiety. Explain clearly that there is always a trade-off, for everybody, between the standard of work and the time taken to do it. There needs to be a balance. Near-perfect work will not compensate for doing (far) less of it than required. Conversely, a very high production rate will not compensate for poorly -produced and/ or inaccurate work.

The perceived 'slippery' or nebulous nature of this trade-off, this hard-to-define balance, is likely to be a source of anxiety for the employee with autism. Like everybody else, they will have to get a feel for it over time, but unlike most colleagues they will need more, and regular, feedback from their manager on how well they are achieving this balance. Be attentive, be patient, be flexible: once they have settled into their role and are feeling confident, they are likely to be consistently effective.

#### Prioritising

This is a similar and sometimes linked issue. Particularly in the early stages of the job, an employee with autism – just as any new staff member - may benefit from regular help from you on what they should be prioritising. It is also similar in that respect to delegating: be as clear as possible regarding what you want done, in what order (as far as is reasonable/ reasonable), and by when. It is often helpful to break this latter point ('and by when') down into smaller chunks. Some autistic people struggle to conceptualise time accurately. Five days might initially feel like five weeks - no pressure - until they belatedly realise that there's only five hours left before the deadline. So, if they have 20 different things to do by Friday, and today is Monday, it's worth taking a minute or two to walk them through it. Basically, 20 tasks in five days implies four tasks per day, but you know that seven of the tasks are larger pieces of work, and that three of these are high priority. So, explain that the employee should do to, perhaps 2 1/2 of these things today, and aim to have all three finished by midday on Tuesday. Then perhaps they should aim to do three of the smaller tasks by the end of Tuesday, and five more on Wednesday. Finish the remaining longer tasks on Thursday and complete all the rest on Friday.

If as a manager you are reading this and thinking, 'I don't have time for that', consider:

- you probably already spend several hours each week 'fire-fighting' – trying to sort things out that have failed to go as planned. It is better to invest a couple of minutes upfront and achieve a successful outcome than spending a couple of hours later trying to rectify things;
- an informal workplace mentor may help in this regard;
- 1:1 non-managerial support from a specialist consultant tends to be very effective in addressing this kind of workplace issue.

David Allen's <u>Getting Things Done</u> is widely recognised as one of the most effective time- and task-management systems. It has the added advantage, from the perspective of any employee with autism, that when applied properly it can reduce work-related anxiety significantly. It is both clear and structured, which is the type of approach that is closely compatible with the preferences of most people with autism. See <u>www.gettingthingsdone.com</u>.

**Workplace organisation** goes together well with this. The physical work environment must be well-structured to implement time- and task-management strategies effectively. The employee with autism may need direct, practical assistance to set this up, and may need to have it checked regularly to maintain the discipline. 'Clear and tidy desk' and 'Do filing' should be recurring items on anybody's to-do list, as (at the minimum) weekly tasks.

Once again, these strategies work for all employees, not just those with autism.

#### Assessment and appraisals

These are often a source of anxiety for employees, autistic or not. But for employees with autism they can be disproportionately stressful, for all the reasons noted previously about predisposition to anxiety, confidence issues, negative experiences in school and/ or previous jobs, etc. Things that you as an employer can do to reduce this stress and make the assessment/ appraisal process as effective as possible for both parties include the following. Send the employee a copy of the appraisal proforma in advance, so s/he can consider their answers

- Explaining the format and process in advance (say, at the 1:1 session which precedes it); make sure they are clear who will be involved, exactly how they will be assessed, what will happen afterwards, etc;
- If they have a workplace mentor will receive specialist workplace support, considering allowing that person to attend the employee's assessment/ appraisal. This is not to answer on their behalf but prompts or remind them when necessary. Again, it is likely to make the process much more effective and satisfactory for both employer and employee.

#### Check the learning

Whenever you've had any kind of substantive conversation with an employee with autism – delegated a task, given some feedback, asked for some information – check that they have properly understood what you just told them. If you make the same assumptions about your autistic staff as you do about you and your typical staff in terms of communication and contextualising, you're likely to run into unexpected issues. If what you said to them contained any implied steps (and thus necessarily requires them to make inferences), you will almost certainly be surprised at how different those inferences will be from what you had expected.

Communication is a two-way process: it requires both the transmitter and a receiver. If the message was not received as intended, the problem is at least as likely to lie with the transmitter rather than the receiver. This might include using an incomplete message; an unclear message; business jargon and content-free buzzwords, rather than plain English and an assumption of common but unspoken reference points.

Always think how you can be clear, concrete, concise and direct.

#### SECTION 4 Ongoing support and problem-solving

#### Specialist workplace support from an external provider

As we saw in the list of typical Reasonable Adjustments, non-managerial workplace support from a specialist autism employment organisation is often implemented by the employer and funded as a job retention measure by the government's Access to Work scheme. The consultant will provide ongoing support and guidance in the workplace to develop the employee's skills and give them strategies to enable them to work as effectively as possible. Although the need for this varies greatly between individuals, some general points can be made. Typical areas covered include stress and anxiety reduction and management, assertiveness, self-confidence, time and workload management, communication skills, and meetings skills and strategies. Often, a kind of translation function is involved: explaining the actions and reactions of the employee with autism to the neurotypical manager and explaining the employer's/ manager's perspective to the employee. Such intermediation is generally extremely effective in achieving the resolution to issues which arise much more guickly than would otherwise be the case.

Workplace support is very flexible and is often a short- to medium-term measure. The frequency of support can often be decreased as manager(s) and colleagues become familiar with any Reasonable Adjustments that have been agreed with and for the employee; have adapted their communication styles accordingly; and as the employee becomes more familiar with – and confident in – their role. Others settle into a pattern of regular but less frequent support – say, an hour a fortnight, or an hour a month. This enables them to raise any issues of concern with their consultant, and to identify and tackle any problems at an early stage before they have had the chance to become entrenched.

Ideally, a three-way relationship develops (subject, of course, to the employee's consenting to this) between the employee, consultant, and the line manager. This has proven over the years to be a very effective measure to ensure staff retention.

#### Dealing with problems - dispute resolution

In any discussion – whether formal or informal – concerning the events and/ or details of a dispute involving an employee with autism, it is important for the employee to be accompanied by a mentor, consultant or colleague who knows them well. As noted above, most of these situations arise from a misunderstanding between the employee with autism and one or more of their colleagues/ managers. These initial misunderstandings are often trivial but can easily spiral and become entrenched. The 'translation function' – from autistic to neurotypical (non-autistic), and vice-versa – is particularly important here.

This is because:

- the individual's rationale for his/ her actions is likely to be entirely rational from his/ her perspective, but to appear notably irrational from a neurotypical perspective;
- the neurotypical (s) involved may well have expected their colleague with autism to have 'filled in the gaps' of what was said to them, or to have drawn a very different inference from the one that they did;
- the employee with autism is most unlikely to be aware of any hidden agendas, office politics, small 't' territorial issues – any sense that someone may feel that their toes have been trodden on, etc. It will be hard to achieve a positive resolution of the issues without someone accompanying them to explain and interpret all these hidden aspects of the situation and, where necessary and where consented to, explaining this on their behalf to the investigating manager. Furthermore, if the neurotypical/s involved it is/are not being entirely honest in their approach to the issues involved, it will be very easy for them to outmanoeuvre the employee with autism in social and emotional terms. For instance, they might play the victim, manipulate events to their advantage,

and attract the sympathy and support of colleagues (and managers) who are not aware of the underlying disability issues.

This is not to say that employees with autism who are involved in workplace disputes are always in the right; this is clearly not the case. It is, however, to state that they are *always* at a disadvantage when it comes to any investigative process in which those underlying issues have not been taken fully into account. It is why, perhaps intuitively, formal processes for dispute resolution tend to be much more accessible (and thus fairer) to them than informal ones. Mediation, in particular, almost always puts the autistic person at a significant disadvantage because they will not be able to 'play the game '. They will always be outflanked by a neurotypical counterparty who is seeking to gain an advantage or, at worst, is seeking to 'win' the dispute resolution process outright.

#### What if it's the job itself that is problematic?

An imperfect fit between an employee and their job is an issue which can potentially affect all employees, whether they are categorised as disabled or not. In the latter case, though, you with their employer have the duty under the Equality Act to make Reasonable Adjustments.

In that minority of cases where the problematic issue for the employee with autism concerns the job itself rather than a misunderstanding in the workplace, you and the employee should work together to consider what adjustments you can implement to make hundred percent of the role accessible to them. If you have attempted this, and have sought external specialist advice, and there yet remain aspects which - it is clear - will in practice remain beyond the grasp of that employee, you should consider what is sometimes known as 'job-carving'. This entails removing the problem elements from the individual's job description and replacing them with other, equivalent tasks. Such adjustments may necessitate task reallocation between the employee with autism and one or more colleagues within their team. For instance, quite a few autistic people dislike speaking on the phone, particularly when they haven't been able to plan the conversation beforehand. If a minority aspect of someone's job is to take turns answering the phone to deal with external enquiries, it should be a straightforward matter to take that out of their list of duties and replace it instead with the responsibility to answer a fair proportion of the incoming email queries. in the worst-case scenario, where the job itself is simply the wrong one for that individual, and where no amount of Reasonable Adjustments will render it suitable, then you as the employer should consider transferring the employee to a more suitable role. (Subject of course to your company being large enough, with sufficient appropriate vacancies, for this to be a 'reasonable' rather than an 'unreasonable' adjustment.)

#### Workplace assessments

A formal workplace assessment conducted by a specialist autism employment organisation can be an effective way to resolve these kinds of problems. They are often commissioned when an existing employee has just declared their diagnosis to their employer for the first time, declarations which in turn may have been triggered by the individual concerned being notified that s/he will be facing a disciplinary procedure. Alternatively, they can be requested to resolve an entrenched and sometimes polarised problem involving an employee with autism, where the employer needs to find a way forward that fully addresses their responsibilities under the equalities legislation. Ideally this kind of specialist intervention will not only enable the employer to be sure that they have met all their Equality Act other statutory obligations but will also enable them to achieve best practice in terms of diversity.

A workplace assessment typically involves a specialist consultant visiting the workplace for a series of one-to-one meetings with all the key players involved in the situation: the employee with autism, the line manager, any other relevant colleagues and managers, and any HR representatives who are involved. The consultant will subsequently prepare a report setting out their assessment and analysis of the issues involved and specifying their recommendations for any Reasonable Adjustments to address those of the issues which are disability-specific. In most cases, this external intervention and advice enables a positive resolution to be achieved. In the minority of cases where this is not possible – where whatever you do as an employer, this will remain the wrong job for that individual – the consultant will enable you to identify this, and thus allow you to action any appropriate internal transfers or external outplacements. A list of specialist providers can be found in the signposting section.

#### Checklist

Summarising from the 'Management' and this current 'Ongoing Support' sections, we have the following key points for managers of employees with autism:

- Be Clear, Concise, Concrete, Consistent and Direct in your communications. Remember that people with autism tend to take what you say very literally.
- Follow up all spoken instructions and information with written summaries – bullet-point lists are ideal.
- Provide as much structure as possible: timetables, schedules, plans, etc.
- Have regular, timetabled one-to-one support and supervision meetings at an appropriate frequency. Give clear and regular feedback at these meetings, positive as well as negative.
- Provide autism awareness training for the relevant team(s) and, subsequently, for any new recruits to those teams.

Identify and explain the 'Unwritten Rules' of behaviour in your workplace. Write them down for the employee's reference, so that they are no longer unwritten!

Adapt your internal training as necessary for the employee's learning style. Be prepared to provide written versions of all information, and to convene one-to-one training/ learning sessions for the employee with autism if s/he struggles to process learning in a group situation.

Finally, keep a pastoral eye out for your employee. Try to ensure that s/he is consistently included in team activities, informal as well as formal.

# **MODULE III**

Advanced training curriculum 'Working with low-functioning (LFA) adult individuals with autism'







#### **MODULE III**

Advanced training curriculum 'Working with low-functioning (LFA) adult individuals with autism' SYNAPSIS Foundation



#### **Assumptions**

Module 3 is an advanced section that covers basic notions related to adult people with low-functioning autism. These notions are crucial to anyone working with such people or having contact with such people in everyday life.

During the training it is not only important to convey knowledge. It is also important to teach practical skills that allow participants to administer better care for adult people with LFA. Taking that into consideration, lectures and workshops feature tools that are used in the work with people with LFA, for example: visualisation; structuring time, place and space; supported and alternative communication. The course uses visual aids in the form of PCS signs created in Boardmaker:

*Examples of signs used during the lecture. Source: Boardmaker* It is also important to assume an attitude of openness and respect when building interpersonal relationships with adults with LFA. To help achieve that goal, there is strong focus on learning how to convey positive feedback and how to communicate with people with LFA. During the activities, the facilitators foster integration, which is an important factor in workshop activities that require feelings of security and trust. Facilitators stress the need for precise communication between participants, to create an atmosphere in which participants can freely convey needs that relate to the activity, the content and the course itself.

#### Course structure

Estimated duration: 16 hours

Day 1: 8 hours with a lunch break and short coffee breaks Day 2: 8 hours with a lunch break and short coffee breaks.

#### **Facilitators**

The course should be conducted by two experienced facilitators who work with adult people with LFA on an everyday basis.

#### Target audience

The course is for professionals who work with adults with

low-functioning autism (LFA) and want to broaden their knowledge and qualifications. The course is also for any other individuals who are preparing for work or have contact with people with LFA in the line of duty: for example, at a health centre, community centre, museum, social weLFAre and Municipal Family Support Centre employees, etc. In addition, the course is for people closest to the adults with LFA, who want to learn about the ways they function and better help them in achieving self-reliance, reaching goals and tackling everyday problems.

#### **Objectives**

Module III aims to provide participants with the necessary skills and knowledge that make it possible to support adults with LFA in creating a positive image of themselves. That image is created with the help of self-awareness, valuing oneself and one's abilities through improving self-reliance and communication skills that can be used in different social circumstances.

Aside from the theory, the participants will actively taking part in workshop activities in pairs or groups of three to six people and will have an opportunity to gain a deeper understanding of the material. The aim of every workshop activity is enabling the participants to look through the eyes of adult persons with LFA and strengthen their practical skills, through assessing potential capabilities, resources, difficulties and needs. Important elements of this module include developing knowledge and skills connected with methods of communicating and structuring time, place and space. The focus is also on developing preparatory skills and creating the necessary conditions that enable people with LFA to function in daily life and accomplish goals pertaining to personal life, work and society, and which can subsequently improve their lives.

#### **Thematic scope**

The first day is focused on establishing interpersonal relations with people with LFA with the use of information that they can impart. To make it possible, various methods of alternative and supported communication, that can be used with adults with LFA, will be explained. At the beginning of the course, participants have an opportunity to get acquainted and share their experiences in working with people with LFA. In later parts, by means of workshop activities, the participants will learn how to create and use tools that can help improve communication with people with LFA. With the help of suitable activities, the participants have a chance to experience a situation where one cannot use verbal communication or may use it in a limited and simplified way. By experiencing such a situation, the participants can discover their own needs and constraints in thinking about how people with limited ways of conveying their needs and preferences can communicate. The participants will have a chance to confront their own stereotypes about people with LFA and discuss their needs regarding their individual capabilities and difficulties.

As for the second day, this will include discussing issues from day one in more detail. Furthermore, there will be a discussion about the TEACCH model and the rules of structure that take into account the individual needs, preferences and abilities of specific people with LFA in relation to their individual situation. Aside from gaining knowledge and receiving concrete tips, the participants will have a chance to take part in practical activities that help strengthen skills necessary to work with people with LFA. The scenarios include the possibility of analysing concrete situations (of people with LFA) in different areas of life.

#### **Module III curriculum**

Duration: 2 days (2 × 8 hours + breaks) Number of people in a group: 12–24 Number of facilitators: 2

Note: the facilitators should incorporate tools that are used in work with people with LFA, for example: visualisation; structuring time, place and space; alternative and supported methods of communicating.

#### Day 1:

#### III.1.1. Intro:

Materials needed:

 Flip charts, markers, work sheets, PCS, pictograms, clean sheets of paper for every participant.

Activity description:

- 14. Talking about aims, rules and the scope of the course.
- 'Names'- participants get acquainted with each other through verbal and non-verbal communication;
- Preliminary tests of the participants' knowledge;
- Quick round the participants talk about their present mood and the aims and needs that the course should help them accomplish and satisfy. As a conclusion, the facilitators discuss the participants' needs and expectations and point out what can be accomplished during the two-day module.

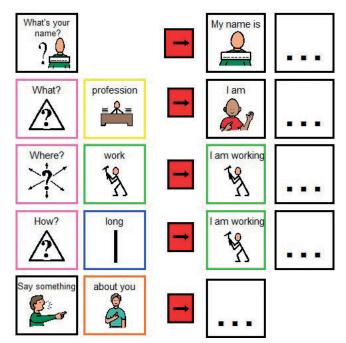
Duration: 45–60 min.

### III.1.2. Workshop activity: 'Let's get to know each other better'

Materials needed:

 Worksheet created in Boardmaker. The sheet contains simple questions in the form of PCS images (*Picture*) *Communication Symbols*) that can help an individual talk to the group. In addition, the worksheet also contains an answer key in the form of PCS images.





Worksheet for use during the workshop. Source: own material

#### Activity description:

Aim: an introduction from participants and facilitators, gathering experiences from participants' professional work. Worksheets and visual communication aids as means of working with people with ASDs in terms of self-reliance and communication.

- Every participant, using the PCS sheets and tips therein, introduces himself, talks about his profession, workplace, seniority, experience in working with adult people with LFA;
- The participants then pass the sheet to the next person in the group;
- In the end, the facilitators ask for the participants' impressions about working with PCS images and state the aim of the exercise.

Duration: 30 min.

#### III.1.3. Workshop activity: 'What defines me?'

Materials needed:

 Worksheets with instructions. The sheets contain random images and icons that relate to different areas of functioning. The materials used in the workshop can be modified. You can use emoticons, PCS symbols or pictograms.

#### Activity description:

Aim: presenting ways of information coding in a visual form and the differences they might pose depending on how they are used, on personal aspects and the information one has about a given person.

- Every participant receives a worksheet with instructions;
- He or she then marks the symbols that best describe him. The important aspect is that the participants use only the symbols from the worksheets and only communicate visually;
- The participants form pairs and exchange worksheets. The task is to decode information about the partner;
- Conclusion: explain, how important it is to be aware of the different manners of decoding visual information that depend on the experience and skills of both partners; talk about the possibilities and challenges that come with using visual aids in supporting communication with people with autism.

Duration: 30 min.

#### III.1.4. Lecture: 'Augmentative and alternative communication methods as a foundation for working with LFA people.'

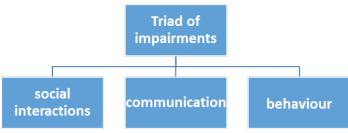
Suggested scope of material for the lecture:

- Communication skills of adults with ASDs;
- Description of augmentative and alternative communication methods (AAC);
- AAC methods most frequently used in the line of work with people with ASDs;
- Nine crucial communication skills;
- Good practices in communicating with adult people with LFA.

Duration: 60 min.

#### An example lecture plan:

1. COMMUNICATION as an area that autistic people have a problem with.



- Verbal communication difficulties:
  - quantitative (inability to speak, speech development delay, speech limitations – stimulus-reaction);

- qualitative (echolalia, reversing pronouns, neologisms, inaccurate utterances, disorders of prosody and articulation);
- Non-verbal communication:
  - difficulties in using eye contact, gestures and facial expressions as means of managing interpersonal relations;
  - inability to properly read facial expressions or gestures the importance of context;
- 2. Communication skills difficulties with:
  - Starting a conversation incentive;
  - Asking questions (maintaining a conversation) SMALL TALK;
  - Asking for help;
  - Formulating requests;
  - Understanding metaphors/comparisons;
  - not taking things literally.

3. AAC (Augmentative and Alternative Communication) Manual systems: sign language, finger spelling, natural gestures;

Graphic systems: Blissymbolics, PIC (Pictogram Ideogram Communication), PCS (Picture Communication Symbols), images and photographs;

Tactile and spatial systems – Premack's word tiles; Joint systems – MAKATON.

4. PECS and FC – AAC systems especially useful for adult people with LFA

PECS – Picture Exchange Communication System Nine crucial communication skills:

- asking for items/actions
- asking for help
- asking for a break
- responding 'no' to the 'Do you want to...?' question
- responding 'yes' to the 'Do you want to...?' question
- reacting to 'wait' commands
- reacting to activity changes
- performing functional instructions
- acting according to plan
- FC facilitated communication

5. Good communication practices – what to do to better understand each other:

- Talk to us instead of our facilitator;
- Value our attempts to communicate;
- Be patient—this will take time;
- One question at a time;
- Feel comfortable in silence;
- Do not ever pretend that you understand;

- Do not be afraid to ask me to repeat;
- Do not ignore things that you do not want to hear.

#### III.1.5. Workshop activity: 'Augmentative and Alternative Communication in work with adult people with low-functioning autism'

Materials needed:

- 'Work day fact list' name, timetable, task list of a given person with LFA;
- Visual materials and communication aids used on an everyday basis in facilities for autistic adults: for example blackboards, whiteboards, photos, books with PCS images.

Activity description:

- The facilitators assign roles to people attending the course – everyone acts out the role of a given employee from the Dom i Praca facility in Wilcza Góra. The facilitators act as class supervisors in the facility;
- Every participant receives a 'Work day fact list' of the person he should act as – including their name, timetable, task list;
- Incorporating the 'Work day fact list' and visual aids for communicating, the facilitators talk to every participant about important dates, the weather, classes and tasks (the participants use the fact lists handed to them earlier; everyone tries to communicate non -verbally);
- Gathering impressions, with great focus on discussing the extent to which the messages transferred during the workshop were understood and the type of support that helped the most in utilising ACC.

Duration: 45 min.

#### III.1.6. Moderated discussions: 'Why do we need communication?'

Materials needed:

• Post-it notes, flip charts, markers, clean sheets of paper. <u>Activity description:</u>

Aim: to show, how important communication is in building relations, to show the ways one can communicate. Creating an image of inter-human communication; reflecting on its role in adult life. Looking through time at different forms of communication; looking at the evolution of communication:

- Every participant then thinks about the roles and different forms of communication and writes down ideas on a piece of paper;
- The next step is brainstorming the participants exchange ideas about: 1. the roles of communication;
  2. different types forms of communication. Ideas are written on a flip chart;
- Conclusion: discussion about the ideas collected.

Overview: the focus is on the role of communication in meeting one's needs and relating to participants' own experiences in communicating and establishing relations with people with low-functioning autism – what form of communication does one use when 'talking' to such a person; what forms of communication do individuals with LFA use; to what extent does communication meet requirements and lead to constructing a positive self-image?

#### Duration: 60 min.

III.1.7. Workshop activity: 'Integrative activities incorporating PCS images – a game called "Crazy foreheads"" <u>Materials needed:</u>

 Headbands for everyone with a Velcro fastener to attach a PCS image; a set of images for drawing;

Activity description:

- The facilitators explain the rules;
- Everyone receives a headband and then draws an image;
- Participants try to guess the image that is stuck to their foreheads;
- Depending to the rules or time constraints, the game lasts until every participant guesses what the image is or until a single person guesses;
- Conclusion: quick collection of comments, underlining the importance of such games while working with adults with LFA.

Duration: 45–60 min.

#### III.1.8. End-of-the-day sum up

 Gathering comments from participants in the form of positive feedback (positive statements that improve strengths: I liked.../thank you for.../thanks to you.../I still need...), asking for the best things that the participants remember at the end of the day.

Duration: 30 min.

Day 2:

#### III.2.1. Intro:

Materials needed:

- A set of PCS signs, that can be used to convey the past and present mood: 'Today I feel...', 'Yesterday I felt...'.
  Activity description:
- Every participant, using the previously defined method of non-verbal communication, introduces himself (for example: writes his name on the board, points to his name on his badge). Next, with the help of PCS signs that represent mental states and types of mood, the participant tries to tell the group how he felt during the previous day of the course, and how he is feeling now. Duration: 30 min.

## III.2.2. Workshop activity: 'Passports of autistic people as sources of information'.

Materials needed:

• A 'passport of an autistic person' for every participant (these are documents created by the therapists from

the SYNAPSIS' 'Workshop of Versatile Things' that can be used to exchange important information about the person with ASD; it is particularly useful when incorporating volunteer workers and when employee turnover is high, etc.).

Passport					
About me? What's My Name?	How do I communicate? EXAMPLES: speak, write, wave, shout, mumble etc.				
How to call me? How old I am? What's your age? I'd rather not to tell What's my family members? How do I move around the city? Am I on a diet? If so, which one?	What's the best way to communicate with me? How to help me communicate? EXAMPLES: uk, first- then, gesture etc., How do I say "no"? NO I DON'T LIKE:				
	Passport				
What do I like/dislike to do?     I LIKE	KE				
FOODACTIVITYAT WORKAT HOME	How to help me then?				

**Other:** 

Passport				
Parent's/ caregiver:		Therapists		
Who are my significant people?		How long per day can I work ?		
What are my home duties?		How often and how many breaks do I need?		
Other:		Other:		
What does my work organization system look like?	What is my payment?		What do I need while working?	
		<b>\$</b>		

#### Activity description:

- Each participant is given a clean 'passport', which he then fills out with information about himself, according to the facilitators' instructions;
- Next, in pairs, the participants exchange information from the 'passports';
- The instructors show real 'passports' of adult people with autism and ask the group about the usefulness of such a document in supporting the afore mentioned people and compiling data about them;
- In the end, the participants share information with each other about the difficulties that they found when filling out the documents – what could be added, what would they want others to know if they had limited abilities in communicating. The conclusion should incorporate comments gathered about what could be done to make it easier for individuals with LFA to fill out the 'passports'; about how they can be used in the participants' workplaces (in which situations, to what end, etc.).

#### Duration: 90 min.

### III.2.3. Lecture: 'TEACCH – a work model. A positive attitude and structure'

#### Suggested scope of material for the lecture:

- Main assumptions of the TEACCH models;
- Possible ways of organising space for people with ASDs;
- Structuring time, space, classes and tasks for people with ASDs;
- Work plan as a tool helping adults with autism to organise work.

#### An example lecture plan:

- 1) **TEACCH:** Treatment and education of autistic and related communication handicapped children;
- The culture of autism. In other words, what is important while working with adult individuals with autism;
- 3) The definition of structuration (the action or process of acquiring or creating structure (a precisely defined system compiled out of the elements of a whole) and why it is used when working with adult people with autism;
- 4) Structuration of time, space and activity;
- Types of plans: concrete objects, symbolic objects, photographs, images, pictograms, labels, hand writing, print-outs;
- Single-box tasks and multi-box tasks designed in such a way that to complete them is self-explanatory;
- 7) Working on flexibility special signs (classes one can choose: surprise, change, new classes, no classes).
  Duration: 90 min.

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### III.2.4. Workshop activity: 'Task structuration in workshops'

Materials needed:

• Cards describing low-functioning people with autism. Flip charts, markers. Aids for task completion according to prepared plans.

#### Activity description:

- The participants are divided into groups of five to six people;
- Every group receives a description of two individuals. The group then prepares a plan of classes and tasks pertaining to those classes. The description includes information such as: attention span, break duration, the way the break is spent, etc.;
- Basing on the lecture, the groups prepare, according to the tips they received, a class schedule and lesson plans;
- The instructors monitor their work and give feedback, if need be;
- Every group tests the plans it has prepared in terms of their clarity, level of detail, completeness, adding the missing material, if need be;
- As a conclusion, the participants share impressions and experiences. The instructors moderate a discussion about the aims for preparing schedules; the issues that can be encountered in that process; the ways to resolve those issues, and the profits that adults with LFA can gain when using those schedules.

Duration: 90 min.

### III.2.5. Workshop activity: 'Conveying emotions with the help of visual and non-verbal communication aids'

#### Materials needed:

 A set of PCS signs, pictograms, boards conveying emotions, that can be used by adults with LFA to communicate;

#### Activity description:

- The participants use PCS signs to describe their mental state (like in the activity at the beginning of the course day);
- A summary highlighting how important it is to communicate with people with autism (including those with low-functioning autism as well) in order to improve their self-esteem and to assume an attitude of openness and respect to other individuals.
  Duration: 30 min.

#### III.2.6. Workshop activity: 'There here and now'

- The participants are divided into pairs. In pairs, they share impressions about the course and talk about their needs regarding their relationship with adult people with LFA. The participants answer the following questions:
- Did you notice any new elements that could be important in the work with an adult person with LFA?
- The facilitators gather the comments and write them down on a flip chart;
- What are the resources available to me in my work with adult individuals with LFA and the resources that I still need?
- The facilitators gather information about the participants resources and needs;
- A short discussion about the resources and needs of the participants.

Duration: 60-90 min.

#### III.2.6. The end and conclusion

- The facilitators answer the participants' questions';
- Participants talk about what they learned and what they found most valuable out of the two modules of the course.
  Duration: 30-45 min.

#### **MODULE III**

Advanced training curriculum 'Working with low-functioning (LFA) adult individuals with autism' AS Mentoring Ltd



# 'Autism with a Learning Disability: course description

**Section 1** of the course opens with the two presenters (one autistic, one neurotypical) introducing themselves in detail. We then ask the participants to create a name badge which introduces – in whatever way they feel comfortable with – who they are. We then give each of them a questionnaire to fill out, rating their knowledge about particular aspects of autism.

We then split them into small groups to ask each group to come up with ten things they know (or think they know) about autism. In planning this course, we intended right from the start that they would be lots of activities, and that it would be very participatory. We follow this exercise with a discussion of ten common facts (and/or myths) about autism.

We have a brief discussion about the terminology associated with autism and a learning disability. This is followed by an overview of what they are going to cover on each of the two days (with two separate sections on each day), together with the aims of the training.

We then introduced Leon at three different stages of his life; aged four, 18 and 44. We divide the participants into three groups, and then allocate one of the characters to each group. The participants will be given exercises throughout the training which involve relating what they've just learned about to their allocated life stage. We will ask the groups to swap their given life-stage throughout, so all participants experience the different age groups.

So, for example, in the first activity group A will spend some time considering Leon's experiences of having an invisible disability / being diagnosed with autism when he is four; then for the Section 2 activity, they will think about Leon's experiences of communication difficulties and relationships when he is 18; and then for the third activity, they will think about how autism affects Leon when he is 44. We also asked participants to keep in mind an individual they know on the spectrum and, where possible, to link the theoretical knowledge to both Leon and the individual they have in mind. We spend some time discussing the characteristics of autism and a learning disability and ask participants to visualise – and draw – their version of the autism spectrum. We discuss the challenges and reasons behind seeking a diagnosis and who autism affects. Following on from this we spend some time discussing the difficulties and challenges of having an 'invisible disability' using Leon to help us bring to live some of these points.

We then break for 15 minutes before starting Section 2. This begins with slides covering communication and relationships in particular detail; again, using Leon across the three ages as the focus in each case. We look at several different methods to support communication and offer alternative methods of communication.

We finish this first day with an activity and discussion on the consequences, both short and long term, of not being understood. In the activity, we hope to give a brief insight into the frustrations of not being able to communicate your wants and needs and, at the same time, the difficulties faced by support workers to understand and help the individual.

Section 2 of the course begins with a review of what we covered in day one, and then tells participants what we will be looking at in the remaining two sections of the course. We start with a discussion about any changes in behaviour the participants have been able to put into place over the last week with regards to how they communicate with the autistic people they support.

Next, we move on to discussing challenging behaviour. Describing what it is and how it can manifest and some of the potential reasons behind the behaviour. Using Leon as an example, we ask participants to discuss in their groups how they would respond when Leon is demonstrating challenging behaviour. We then have a group activity with a 'nonverbal' individual in a chair and his or her two 'support workers' standing very closely and talking between themselves. We ask how the nonverbal individual would get the support workers out of their space without being able to speak. To finish this section about challenging behaviour, we discuss and provide several strategies to use to help minimise and reduce difficulties, again using Leon to help bring to life these strategies.

Section 3: Next, we consider the effects of one person's autism on the wider family. We show the participants an embedded video *A Mum's Perspective*, which is produced by the UK organisation Resources for Autism (who are fully credited at the end of the video). We also discuss the impact on siblings and provide a quote to give a greater insight into the effect of having a child with a disability on the family as a whole. This is the end of Section 3 and we break for 15 minutes.

To start Section 4 we begin with a detailed look at the sensory aspects including stimming and self-injurious behaviour. Using Leon as an example, we discuss with the participants the sensory issues that someone with autism might have. We give them a range of accessories to handle, and our autistic trainer describes how she relates to many of these.

We go on to consider Theory of Mind and rigid thinking and look at the importance of structure and routine for autistic people. This includes an embedded video (PowToon – Theory of Mind). We discuss the role rigid behaviour has and a number of strategies to support routine in everyday life. We then have a brief discussion on special interest and the importance of it to an autistic individual. Using Leon's example, we ask the groups to think about and discuss how a special interest can be used to gain skills. We finish with an activity asking participants to create a social story to prepare an individual for a change or new activity.

To end the training, we close with a summary of the key points we would like them to take away with them.

We ask them both what they have learnt from the course and how they think they will apply this learning to their role. Finally, we ask them to go back to the questionnaires they filled in at the start of day one and to complete them again, in order to compare their 'before' and 'after' levels of knowledge and confidence.

We then closed the course by telling the participants that will be around for another 30 minutes or so to take any individual questions. (It has long been our experience that there will be people with a personal, often family connection to autism that they want to discuss with us).

Presentations from the 'Autism Awareness' training course: https://drive.google.com/drive/folders/18SHXSxjTopyWwdxFUy2w26ER21jmYPHH?usp=sharing

#### **MODULE III**

Advanced training curriculum 'Working with low-functioning (LFA) adult individuals with autism)' Latvijas Autisma apvienība



#### Sexuality of person with ASD. Autism and teaching basic personal care skills

1: Introduction and the body Understanding one's body Self-care: guarantee of security Toilet Menstruation / periods Shaving 2: Communication Principles of communication skills training Skills that are important to teach 2.3. Public and private behaviour 3: People circles and social circles 3.1. People circles 3.2. Distance and touch in communication 3.3. Understanding emotions 3.4. Prevention of violence

#### **Appendices**

A visual guide for changing sanitary towels Human circles Categories of people, table Images: distance in communication, touch Images of different people Public / private, table Images: Public / private cases Images: public / private places Images: Public / private activities Suitable and inappropriate touch Social story 'Bibliography: recommendedBibliography: recommendedBibliography: recommendedPeriods' Social stories about distance and private activities (for a boy) Social story 'How to tell a boy to stop touching' Bibliography: recommended literature

### Introduction – the body

Adolescence is a difficult time for everyone. The body is

going through rapid changes and peer relationships and social situations become more complex. Autism creates additional challenges: children who have difficulty with bodily awareness find it harder to understand changes to their bodies. Due to puberty and age-related body changes, there are new requirements for self-care skills: girls need to learn to live with menstruation and sooner or later boys will have to start shaving. Autism-specific sensory issues can create additional difficulties: it can be difficult to withstand the sensation of an electric shaver or the feeling or sound of a razor.

Unlike during childhood, teenagers are more likely to be in situations where they are alone with their peers, since parental supervision is no longer constant. Consequently, a teenager with autism must solve a variety of challenging situations. These include difficulties with understanding social situations, with recognising other people's emotions and with engaging in appropriate communication.

Behaviour, which seemed endearing in the childhood (for example, hugging strangers) or at least innocent (walking around the house naked) may cause difficulties during adolescence. In some cases, typical behavioural problems such as searching for sensory stimulation (for example, touching and smelling other people), or difficulty in maintaining an appropriate distance in communication can lead to the child finding him- or herself in dangerous situations. Also, certain behaviours, without proper understanding or empathy, can be perceived as sexually intrusive (for example, when a boy approaches a group of women and touches their sweaters).

Many of these difficulties are related to a lack of specific skills and can be addressed by teaching the child appropriate behaviour. Often, preparation for a child with autism's adolescence should start much earlier and, if the forerunner of the problem is identified in a timely manner, the problems may be avoided.

This guide is intended for parents, caregivers, educators, psychologists, day care centres and social care workers, as well as other people who care for children and young people with autism. The guide summarises ideas, suggestions, useful resources and pedagogical methods that can be useful in preparing a child with autism for puberty.

The first chapter of this guide is devoted to changes in the body and self-care skills, which are extremely important parts of growing up. The second chapter focuses on several key issues related to communication skills: teaching teach kids to maintain the right distance in communication; how to talk about appropriate and inappropriate touching; how to discuss public and private behaviour; recognising the emotions of others, and more.

While writing the first chapter of this book, the authors focused more on autistic children with limited language skills and who have low self-esteem as adolescents. The ideas, methods and suggestions mentioned in the chapter on communication skills can also be useful for high-functioning children with autism. Some of the methods will be suitable for children who have other challenges instead of autism.

The appendices include examples of social stories [link to later mentions] and images that you can copy, cut out, laminate and use in schools, day centres or in the home.

#### 1.1. Understanding one's own body

In her book <u>Sexuality and Severe Autism: A Practical Guide for</u> <u>Parents, Caregivers and Health Educators</u> (2013), Kate Reynolds stresses that preparations for puberty should begin much earlier for young people with severe autism and/or learning difficulties.

For children with severe developmental disorders it is important to help them become aware of and understand their bodies as much as they can in early childhood. This can include various tactile games, massages, crayons, finger games, play at the mirror – everything that may help to feel, comprehend and understand their body.

For instance, it is very important for children learn to name their body parts. This knowledge will help them to talk about sensations and pain, and for the subsequent explanation of puberty.

Kate Reynolds recommends teaching children also words that denote different processes in the body. The words 'clean / dirty', 'wet / dry' as well as 'hard / soft' will help children to learn self-care skills and to explain what is happening in puberty.

Like their peers, it is also important for adolescents with autism to understand that the human body will grow and change throughout life. You can use images on the internet about a person's life cycle – how a person becomes a toddler from a baby, then a child, a teenager, a young adult, an adult and then how they will eventually age and become elderly.

Choose images suitable for the child's abilities <u>and</u> age. If you're talking to a teenager you should not use booklets aimed at pre-schoolers, for instance (even if the teenager's intellectual development is limited). You can create photo stories about the child him- or herself – putting their own pictures in a line and comparing him or her at infancy, early childhood and now.

Show and describe, using the pictures, how a child will change during adolescence. Avoid metaphors that can be frightening for a teenager with autism (for example, using the phrase 'breaking voice' to describe adolescent male vocal changes can be scary because the child can imagine that something in him will break).

When you are talking about changes in the adolescent's body, it's worth emphasising repeatedly the importance of

hygiene, both from the aspect of health and for the sake of having a social life (with the understanding that people like to be friends with those who keep themselves clean).

A good resource may include books published in Latvia for young people with intellectual disabilities – *Leva*, *Aleksis* and *Aleksis un leva*. These books are intended for young adults, and they explain changes in body when growing up, going through puberty and intimate relationships in the easy language. Booklets have also been published by the 'Easy Language Agency'.

#### 1.2. Self-care: guarantee of security

For some students at some special schools, self-care skills might be more important than reading or counting. A young adult with severe communication difficulties and/or learning difficulties who cannot count money independently in a supermarket might be able to solve the situation, for example, with the help of the cashier. However, if the same young person is not able to go to the toilet in the supermarket independently the consequences will be more severe for the individual's comfort. Therefore, using toilet skills, washing, dressing and eating should be given attention and should be in the child's individual curriculum.

Being able to care for oneself is also important from the point of view of safety. A teenager who can dress, use a toilet and wash him- or herself will be accustomed to seeking privacy when exposed and reduces the need for anyone else to touch his or her body. This is an important experience that can protect the young person from abuse. In the same way, this experience helps him or her to understand that other people need privacy and freedom from unwanted touch.

Self-care skills are those that can make a young person independent or, on the contrary, completely dependent on carers if they are not grasped. There are different approaches around the world on how to teach self-care skills to teenagers with developmental conditions such as autism when they affect communication, and/or they also have learning difficulties. Specialist help may also be required.

<u>An ergo therapist</u> (occupational therapist) can provide a lot of help and advice if self-care is hampered by poor motor skills. The therapist will be able to assess fine motor skills (hand and finger movements), help train the movements needed and, if necessary, can also suggest various adjustments to make self-care activities easier.

<u>Behaviour Analysis</u> (ABA, Applied Behaviour Analysis), has a wide range of applied techniques for helping people acquire new skills and new behaviours. The ABA approach has introduced the 'chaining' method, in which a longer process (like hand washing or dressing) is split into small steps. It is important that all carers teach this activity in the same order. The ABA approach uses various types of help or inducement to assist a person in learning new activities without error (for example, starting to perform the activity holding the child's hand, then gradually reducing physical help and switching to a gesture as helping out, etc). There are aspects of this approach that are controversial among the autism community, at least in part because of its association with sometimes coercive treatment and the idea that autistic people's behaviour is unacceptable unless it is entirely conventional.

<u>The TEACCH approach</u> (Treatment and Education for Autistic and Communication Handicapped Children) uses a lot of visual support and visual plans. A visual plan means that each step is captured in a picture, and the child is taught to do the job independently by following the sequence of images. Visual plans increase independence and help to offset procedural memory difficulties. It should be remembered that the use of visual plans should be taught; hanging them on the wall does not help. During the action, show the child the illustrated step. At first it may be helpful to take away the pictures of steps that have already been taken, so that the child sees how the action is moving forward.

You can find ready-made visual plans and images on these internet web sites: <u>www.do2learn.com</u> and <u>www.visualaidsforlearning.com</u>.

Visual plans for self-care can also be found in the book 'Daily Skills and Activities for People with Autistic Spectrum Disorders' published by the Latvian Autistic Association (2014). The book is free to download at <u>www.autisms.lv</u>.

It is important in all these activities to avoid shaming the individual when they make mistakes. Be pragmatic and do not assume that any mishaps are deliberate or intended to upset you.

#### 1.2.1. Toilet

The ability to use the toilet independently significantly reduces the likelihood of sexual abuse. The child who goes to the toilet by him- or herself has automatically mastered several important things:

He knows that he has parts of the body that are not usually visible to others;

He repeats the experience of having private places and private behaviours that others do not look at and He is accustomed that no one is watching him naked, and that no one else touches his intimate body areas.

When someone accompanies a teenager to the toilet, every time he indirectly receives the information: 'There is no privacy. Some people can always watch and touch on my intimate body areas (*that means, there are no intimate body areas*); in my intimate activities, someone is always present (*that is, there are no private behaviours and activities*), some-

one is always present in the private room (that means, in essence, there is no such thing as private rooms or private places). In this situation, it may be much more difficult to teach a teenager that there are private things, places, and activities in the world.

Ideas and recommendations for toilet training:

It's never too late! Even a teenager can learn to stop using a diaper. At that very moment the quality of life for all (both the young person and his carers) improves so much that it is worth trying;

Evaluate potential health problems that may make bowel evacuation difficult and create anxiety. Work with your general practitioner if you feel going to the toilet appears to be causing pain or discomfort for the child. Constipation, parasites, metabolic or digestive disorders and other health problems can be the reason why it's difficult for a young person to learn toilet skills;

For people with verbal communication <u>and</u> learning difficulties, it may be very important to give a clear message about what the toilet facilities and bathroom are for. Ideally, toilet facilities should only have things in it that are directly connected with self-care;

Changing diapers and washing oneself should only be done in the toilet or in the bathroom. If this happens in the toilet, then we convey the message that bowel evacuation is an activity done in the toilet only. We also convey a clear message that this is a private activity: trousers are pulled down and the diapers are replaced only in the toilet (or in the bathroom), and at such moments no unauthorised person is there. No one else watches the teenager, and no other activities are performed there;

Assess potential sources of sensory irritation in the toilet: are there any sounds, lights, smells, or other sensory irritants that can make a toilet visit unbearable for a person with autism? Maybe there is a loud fan that must be turned off, or a washing soap or a disinfectant with a strong scent that makes the child nauseous? There are children who cannot withstand the sound that the water from the shower handset makes when it hits the floor and therefore refuse to enter the bathroom. Evaluate everything your child might react to. Many of these things can be changed;

Both in school and at home there should be a strict rule that after entering the toilet, the door is closed and not halfway open;

If the toilet is connected to the bathroom, it is not used by several people simultaneously;

It's important for employees at boarding schools and social care centres to understand that having clear privacy rules in childhood reduces the probability of problems for their clients and students during puberty. The rules should ensure that young people know that washing, using the toilet and changing diapers are private activities that are performed only in rooms that are intended for these activities without others watching;

There are various tactics for teaching toilet skills: one is to 'grasp the moment when you need to go', which is to get the child to react to his own inner sense, body signal. However, there are children who hardly feel their body or who take very strongly against using the toilet. In their case, it may be easier to introduce a toilet image in the visual day plan and to teach 'following the plan'. This might seem 'unnatural', but in fact, typically developed peers are taught to 'follow the plan' and only use the bathroom during an intermission between classes, not during the class, or when on a journey and stop at service stations, not whenever you want;

As soon as possible, the child should start learning to use public toilets independently. Otherwise, this can lead to confusing situations when the young adult is out of the house with an opposite sex parent. If a little boy can be taken by his mother in the woman's toilet, she can't take a fourteen-year-old;

If a boy has severe developmental problems, it is safer to teach him to use a toilet booth instead of a urinal in a common room. (There are many unwritten social rules that can be violated in a common area, especially if a young adult with autism is not clear when he may or may not watch others, and when others may and may not be touched);

There are children who find it difficult to use toilet paper, because they are not able to coordinate their movements, and the activity takes place behind them, so their vision cannot help to correct it. To help prepare for this, there are games that put the 'tail' of toilet paper or fabric behind the belt of the trousers on the back, and the child can be trained to find the 'right place' by catching it;

There are children who find it difficult to understand how much toilet paper to use. The simplest rule is: if the paper is dirty after wiping, take another piece. When the paper is clean, that's enough. There are children who need a visual reminder (for example, a pictogram attached to the toilet, on which three pieces of paper are drawn).

Useful resources can be found <u>http://www.autisms.lv/index.php/lv/</u> (social stories about toilet use). A very good book for parents and professionals is <u>Eve Fleming and Lorraine McAlister's Toilet</u> <u>Training and the Autism Spectrum: A Guide for Professionals (2016).</u>

#### 1.2.2.Menstruation / Period

It may be difficult for a girl with autism to get used to menstruation / period for several reasons. It's hard for some people with autism to get used to a new routine and changes in daily routine, such as the need to change sanitary towels. The new sensations may be frightening – both the bodily sensation and discomfort caused by the sanitary towels. The appearance of blood can also cause fear and, just as for anyone, insufficient information and understanding about what is happening in a girl's body can be very frightening. When there are communication difficulties this can lead to other problems, including pain and confusion, and not being able to ask for help.

#### Ideas to help a girl prepare for her menstruation:

If the girl has good language skills, start telling her about puberty several years before it expected. Many people with autism take a while to become accustomed to these changes. A new experience is less intimidating for anyone if it is known about in advance;

Consider the nature of the child and her sensory or perceptual issues. If the girl is afraid of blood, you might need to tell her what is going on in her body, where the blood appears from (explain very specifically) and that the bloodless is actually very little to help reassure her. You can show it with a teaspoon of red gouache colours;

Discuss what a period looks like, how long they last, how often they repeat and what they feel like: from possible abdominal pain and cramps, accompanied by irritability. Also mention that each girl experiences this differently and that there might not be any unpleasant feelings at all; you can describe and represent bleeding colours and changes to volume over the cycle. It will help the young woman to report to her mum, guardian or nurse if any problems appear – such as excessive or prolonged bleeding. Describe and demonstrate how to change sanitary towels or use tampons. Pay attention to details: such as wiping blood from hands before leaving the toilet and wrapping the package in paper before tossing it out. Tell her that towels and tampons are not to be thrown into the toilet but should be placed in a bin where possible. Remind her about washing her hands before and after changing the product for hygiene reasons;

If the girl has good verbal skills, social stories may be a great help. A social story is a situation described in a step-by-step method, with explanations in simple language of what is happening in and why and, finally, a brief explanation of how the situation might be handled. You can find examples of social stories on the internet for different occasions. An example of social story appears below ('My period started') [hyperlink to appendix item];

Use visual support if this is an individual's best learning method. A visual plan placed in the toilet can be useful in helping someone to independently change a sanitary towel. Ready-made examples of the visual plan for menstruation / period and other puberty issues can be found on the website www.visualaidsforlearning.com; A social story or a visual plan can also be created as a book to read together with the girl before the start of the puberty and later as well, when menstruation has already begun, and the young adult needs help remembering what should be done;

For girls with more severe developmental problems it may be difficult to use diagrams. It may help to use a story, created with photos;

There are children who find it difficult to acquire information from photos. Mothers who are raising daughters with severe developmental problems recommend showing girls what a period looks like and how they or a sister change sanitary towels. As confusing as it may be, such experience can greatly help a girl prepare for her time;

For many people with autism, it can be very difficult to get used to new sensations - there are young women who are unable to get used to the sensation of a sanitary towel. If a girl has significant sensory issues, it is worth starting to think about menstruation several years before puberty. It may be useful to help the girl to get used to the sensation of towels with everyday pads. At the beginning, you can wear them for a very short time;

Try products from different companies. The surfaces of sanitary towels are different and some of them may feel very irritating, while others may cause much less discomfort; some women may feel more comfortable with tampons;

There are girls who are only able to cope with pads made from natural material or who may feel better with fabric strips that are sewn inside underwear (like during the time of our grandmothers);

Even before the start of menstruation, it might be worth teaching an autistic adolescent how to change a sanitary towel. Use the visual plan and try the whole process from start to finish. Repeat this several times – learning new skills takes time. Give the girl a lot of praise and reassurance during this process;

During the training process, you may be asked to join someone from the school staff if the girl attends a special school, most likely a teacher's assistant (or carer or nanny) or a nurse who will be the person who will help in future. It is good if there is a common goal and a plan to teach about changing sanitary towels independently;

If a girl with autism attends a regular school, it may be harder to find staff who are able to deal with these issues. Talk to the school staff to find out who your charge could turn to if there are any difficulties (such as a school nurse or a social educator);

It may be helpful to note with a marker where the sanitary towel should be placed in underwear;

There are girls who will learn to assess for themselves when it is time to change a sanitary towel (show the girl what the full towel looks like); There are girls for whom such assessment may be difficult to master. If a girl uses a visual day plan, it may be necessary to indicate on the plan when sanitary towels need to be changed;

People on the autistic spectrum usually appreciate predictability and clear information about upcoming events. If your charge can count, tell her that a period usually recurs after about 28 days (though the cycle may be irregular at first) and lasts between four and seven days. Create a healthy habit of encouraging her to mark the period in the calendar;

Also, for a girl who cannot understand complex explanations, you can mark the calendar on her behalf to show how long the period could last. It could be a great relief for a girl to understand that it will not last forever;

It is also worth marking the calendar with approximate time when the period might occur again;

Support the girl in making it a habit to take sanitary products with her. You can prepare a special pencil case or a small makeup bag of her choice and put extra sanitary towels and clean underwear in the bag. Keep track of the content regularly and stock up with what is needed. Later, teach the girl to pack the things she needs herself;

Talk to the girl about neurotypical social rules – that although a period is perceived as a positive thing because it shows that a girl is becoming an adult, it is also a very personal event that can only be discussed with a few people because it is considered private because of taboos around women's menstruation. Explain that girls usually talk about this only with girls (and even then, only with their best friend), as well as with her mother or a nurse;

Discuss what to do in case of a mishap like a blood stain on clothes in school. Tell her that usually a woman tries not to show it to others, but most likely, it has happened to every woman. Tell her what can be done in such cases, for example, ask a friend for help, wrap a sweater around your waist or go to the school nurse. For girls with autistic spectrum disorders, it can be difficult to make decisions independently and to come up with a flexible solution to the problem. Build a positive attitude. It is for a reason that in many cultures the first period is a celebrated event, which is accompanied by special rituals. Tell the girl that this is a positive event, which shows she is growing up and becoming an adult. Growth means something good: greater independence, more choices. Celebrate the start of the first period. You can go on a special trip; this may be the moment when the girl moves into her own room, etc. You can introduce other new, positive and maturity-related rules - for example, allowing the girl to go to bed at night 15 minutes later, and spend a little longer time on the computer. In any case, let her know that this is a GOOD event.

A great resource on reproductive health and choices about gender and sexual identity is Girls Growing Up on the Autism Spectrum by Shana Nichols (and published by Jessica Kingsley).

#### 1.2.3. Shaving

Shaving is not usually a matter that a teenager's parent is particularly worried about, and for an adolescent and others a growing beard or moustache can be proud a sign of the adolescent's maturity. However, when shaving must be done every day it is a big step towards self-reliance if a young man can shave himself.

<u>Kate Reynolds points</u> out that shaving can be particularly difficult for boys who have high sensory awareness. Many children with autism in childhood express discomfort when someone or something touches their head, hair or mouth area. There are also people who can be intimidated by the feeling of an electric shaver – the buzz, vibration and sensation on their skin.

She makes a few suggestions on how to prepare young adu-Its with heightened sensitivity for shaving and using a razor: It is worth paying attention to this issue in childhood. A barbers or hairdresser's salon is a very good environment in which to practise getting used to different sensory experiences around shaving. If a boy can have his hair cut at a hairdresser's, it's worth asking for the shaver to be used on each occasion for a short period of time, for example, to shave edges of hair;

To help boys get used to the feeling of shavers gradually, let him listen to and hold the shaver without a razor, and touch his hand and cheek with the shaver;

At first, try the shaver on his hand.

Young people who find it difficult to master any new manual activities can have a hard time learning to shave. Shaving is complicated because the person cannot see his hands and can only control the process by looking in the mirror. Shaving can be taught like any other self-care activity:

With the help of model (modelling): let the boy observe how other family men are shaving themselves; With physical help: at the beginning, the caregiver keeps his hand on the boy's hands and guides his movements, gradually reducing physical assistance; Split the shaving process into steps, which can be taught in a certain order; Using a visual plan, show the sequences of actions to be performed during shaving in pictures.

#### Communication

Teaching communication skills is a very broad topic: all of us learn and improve them throughout our lives. In this guide, we will only look at some aspects of teaching communication skills, which are those most closely related to safe behaviour. For both low and high functioning children and adolescents with autism, it is difficult to maintain a suitable communication distance. Some children approach others very closely and may even strive to embrace strangers and even kiss them. Sometimes parents of a younger child are very happy about it, saying: 'see – my autistic child is open to other people!' However, at adolescence, people and others can perceive such behaviour as sexually intrusive and very unpleasant. There are children who seeking sensory stimuli and want to touch and feel, smell or even lick other people. It is difficult for many children to understand the social rules that determine the difference between private and public behaviour: what may be done in the presence of everyone and what may be done only while no one watches. Like all social rules, these aren't necessarily that easy to explain.

Teenagers with autistic spectrum disorders will seek friendships, love and close relationships. However, to a significantly greater degree than their non-autistic peers, they are liable to misunderstand or confuse different social situations and signals from others. A teenager with autism may not perceive any non-verbal or implied verbal signals: 'Do not touch me, I do not like that!' and may find him- or herself in a situation where he or she is perceived as a threat. On the other hand, he or she may miss the 'signal': 'I want to sleep with you' and not suspect that he or she is in a potentially dangerous situation and should leave it.

A large part of the problem-provoking behaviour is related to a lack of skills and awareness. It is much easier to eradicate inappropriate behaviour by teaching people how to use other, more suitable behaviour instead. Often, the behaviour itself is not bad at all, but it is happening in the wrong place and at the wrong time.

In this section, we will look at some general principles for teaching communication skills, as well as methods for teaching a child about public and private behaviour. This will include how to teach someone to maintain a suitable distance in communication and how to teach to understand other peoples' emotions. At the end of this chapter, we will discuss principles that are important in protecting the child from violence.

#### 2.1. Principles of communication skills training

Communication skills are essentially the same skills that ought to be learned and used in school and at home, such as counting, buttoning up, gluing with a glue sticking, cooking soup or finding countries on a global map. They can be taught just like any other skill. In fact, they must be taught like any other skill in a direct, structured way, split into parts that must be learned one after the other.

There is a myth among both parents and specialists that communication skills can be taught in a 'magic', indirect way, for example, while swimming in the pool with dolphins, and then they suddenly 'happen'. Many people believe that an autistic child is 'closed' and some sort of special, magical action is required to 'open him / her up'. And then he will suddenly be able to do everything: share a toy, apologise, take his or her turn in a conversation and recognise emotions. But this is not true. For the child to be able to share his toys, apologise, take his turn in conversation and recognise emotions, he must be taught to share toys, be taught to apologise, taught to follow his turn in a conversation and taught to recognise emotions. It is important to know that therapists who use dolphins in their work, don't work on the basis of magic, but on certain, structured methods of teaching certain behaviours. The good news is that all these techniques are available to everyone. Even without dolphins.

But start by understanding what you want to teach:

Clearly identify what exactly you want to teach the child. Which skill? Try to describe it as accurately as possible. What should the child do? In what situations? Where? When?

If the skill is very broad – for example, 'maintaining a conversation', – divide it into smaller skill components, such as 'taking your turn in a conversation', 'choosing a suitable conversation topic', 'listening carefully to a conversation companion', 'making appropriate comments', 'asking questions to clarifying the opinion of the conversation companion', 'maintaining eye-contact during conversation', etc.;

It is very likely that each individual skill will need to be taught individually, and then these should be combined in due time.

Remember, this is the same as with all other life skills. You cannot learn anything at once, all in one go. However, many skills can be learned by dividing them into the themes and mastering them step-by-step. For example, when teaching musicians to play in an orchestra, the conductor does not try to get the musicians to play the music just after they have received their sheet music, all at once. The conductor first allows each musician to master their scores, then slowly puts them together, then rehearses for as long as necessary, etc. It is thus also possible to teach such large and complex skills as engagement in a game, maintaining a conversation, understanding other people's emotions, responding constructively to the emotions of others, etc.

Think about how you would motivate your child to do something new and complicated:

There are adolescents with autism spectrum disorders who are socially open and are pleased if they receive help and explanations on how to deal with a situation; However, there are adolescents who need external motivation – such as awards, praise, special attention from parents and caregivers. Remember that for a child with autism and learning difficulties, learning something new is sometimes hard work because of the extra burden of understanding neurotypical communication styles. Both carer and individual deserve help and recognition for this.

Teaching communication skills can be part of a curriculum in both regular and specialised schools. If communication skills are taught in structured sessions (individually or in groups), a good skill-teaching plan would include the following four points:

Explaining Modelling Training Positively reinforcing.

Explanation: For some children with autism and Asperger's Syndrome, it can be very important to clearly and precisely define and explain what is the 'internal logic' of the skill – why should this be done? Under what circumstances? Where? What are the exceptions to the law? It is important for these children to create an 'algorithm' of the skill. To achieve this, you can use social stories, visual plans, or draw a skill's 'algorithms' step-by-step. At this point, you can propose a group discussion to discuss how everyone feels when others use the skill.

<u>Simulation</u>: an adult demonstrates an example of a skill, where appropriate. This point is very important in everyday life – we cannot ask the individual to comply with the rule that others violate in front of his eyes on a regular basis.

<u>Training</u>: to learn a new skill, it is not enough to just talk about the skill. It is necessary to give someone many opportunities to learn to use the skill. This can include using role plays during a structured class. On an everyday basis, this will mean taking every opportunity for the child or adolescent to use the new skill and to encourage him/her to apply it. It would be helpful if all the staff in a school or day centre, or other carers, know which skill the individual is currently working on and help him or her to achieve it.

<u>Positive reinforcement</u>: As soon as the individual starts using the new skill, it is important to acknowledge and praise it. Again, it is good if all staff involved in care are aware of this rule. If a token system is used (where a child is given tokens for which they can receive a prize) it's important to tell the them exactly what he or she is actually getting the token for.

2.2. Skills that are important to teach

There are several 'key skills' that help your child to be safe. For instance:

The ability to say 'no'. Of course, parents don't want to hear

this word. But a child who does not say 'no' because he is very shy, very submissive or very striving to be good, can easily find himself in situations when others use him/her or are violent against him/ her;

**The ability to accept a rejection,** i.e., comply if someone says 'no'. Accept that others do not want to play or talk right now.

**Ability to express a request.** Even a non-speaking child can be taught to make a gesture that indicates a request or uses an image or eye contact and a sound to indicate a request. It is important that the child or adolescent first addresses others with the request rather than taking things straight away or touches other people without their permission;

Ability to ask for help. For a non-verbal child this may also be a gesture or sound. With a talking child, one can discuss and decide precisely in which situations and to whom he can turn if something happens. Teach your child to call parents at once. Make sure he /she knows more people he/ she can approach and try to approach them together at first. For example, the school psychologist or the warden may be people with whom the child feels very shy at first, but they can be a useful aid in difficult situations;

**Ask for permission.** For any activity affecting another person, for example, sitting at their table or embracing another person;

**Teach good ways to show attraction.** For example, expressing a compliment, sharing, helping, comforting if the other person is sad, starting a conversation, inviting to a cafe or cinema, etc. You can create lists of 'what can you do' and 'what you are not to do' when a teenager likes (fancies) someone and what you expect them to do / not to do in return;

**Teach how to argue.** Refuse to do things that others are suggesting if the child does not like it. Get away to a position of safety if someone makes a child or adolescent feel bad or uncomfortable. Disagree. Tell others what is wrong. Tell others what he/she wants. Discuss options for solutions;

What are public actions (what we do when others see) and what are private actions (what we do only when we are alone); [hyperlink all instances of the discussion of public and private behaviour]

What is an appropriate physical distance for communication and what is appropriate physical touch; How to recognise the emotions of others.

#### 2.3. Public and private behaviour

As one of the methods that helps a child with autism to understand other people's behaviour is distinguishing 'private' and 'public' behaviour. The internet offers a variety of options of social stories that explain how public and private behaviour, as well as public and private places, differ. The appendix of this guide provides materials that can be used to explain this rather difficult skill at school or at home. Our experience shows that it is easier to start by explaining the notion of behaviour but then following on to teach about private / shared things, and then private / public places. Then, it is easier for the child to understand what kind of behaviour is public and what's private. Print and paste a table labelled 'Public / Private'. Cut and laminate pictures with private and public places, things and activities. Attach a Velcro sticker to the squares in the table and on the back of images. Now you can sort them out and talk with your child.

<u>Things to tell your child:</u> Simply put, the word 'public' means that it is related to other people, but the word 'private' applies only to oneself.

Publicly shared items are those that are used by everyone: for example, a lamp, a coat hook, a toothpaste tube, a sofa, a dining table, etc. Private or personal objects are those, which are just for your use. You do not share them with anyone. Private things are one's comb, toothbrush and underwear. Mum's private things are her handbag and purse or wallet (note for mothers: do not allow children to rummage through your bags without your permission! That is the way to teach your children that there are private things in the world). If an elder sister writes a diary, that is her private thing. Only one person uses private things.

Public places or common places are where other people are around. Many people can use these places at the same time. If you are in a public place, other people can see you. A public place is a classroom, a street, church, bus stop, dining room, shop, etc. At home, it is the kitchen, living room and maybe also a backyard. Private places are places that people use alone. No one else is present when a person uses a private place. A private place in your home is the toilet and bathroom. If the child has his own bedroom, which he does not share with others, this is also his private place. If the child shares a bedroom with a brother or sister, this room is no longer private. It is common. However, each has his or her own private bed.

Public actions are actions that we can do when others see us. We do it in public places. Public activity is to eat, take off your coat, shake hands, wash hands, draw, and write, and so on. Private action is an action we do when nobody sees. Private activities are done in private places, such as the toilet. Private activity is peeing, evacuating one's bowel, showering, and taking off underwear. Private actions are also actions that look or feel unpleasant to others, for example, picking your nose, farting and burping. It is worth telling the child that it is not a bad thing in itself, because all adults will fart occasionally. However, they do it in the toilet when no one is present. Everyone picks their nose at some point, if something is stuck there or it itches, but people do it when others do not watch them. This is a private action.

And there are also the private parts of a body – those that others do not see, which others do not touch and which we do not talk to others about. We can only touch them in private places, such as in the bedroom or the toilet. We can undress them only in private places, such as in the bathroom, when we wash ourselves or on the beach when we are changing. A dressing room is also a private place.

Activities you can do: It is advisable not to rush and not to give the child or adolescent too much information at any one time. It is best to let him/ her try to practise every piece of information, experience, play and talk about it for a long time. Remember the skill modelling – you must show a good example. In addition, for a positive boost, you must give the child the opportunity to use the new knowledge and immediately praise it when the child does so.

#### A good plan can be as follows:

1) Tell the child about public (commonly used) and private items. Allow him to sort the objects in a table. Then, for a certain period (for example, a week) daily, draw the child's attention to different things, and then discuss whether they are commonly used or private subjects. Praise the child when he uses his private items – a comb or toothbrush. Tell him that you can share public things or use them in turns. Praise when he shares. Show a good example – if you have told your child that the comb is private for each person, then do not use someone else's comb.

For smaller children or adults with severe learning and/or communication difficulties, it may be easier to deal with real objects than pictures.

### You may also try this activity for a small group of children: <u>Game 'Things to share'</u>

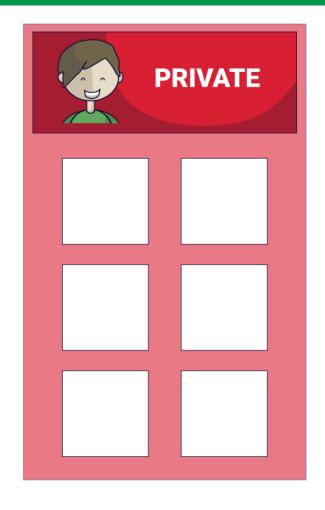
Tell the children that we each have things we can share, for

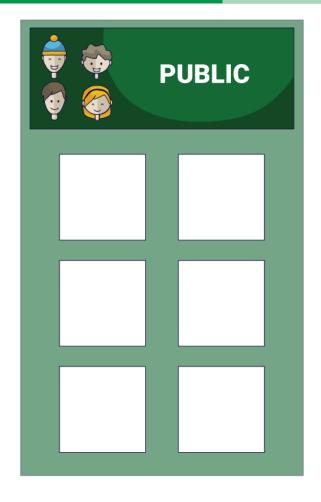
example, a snack or a toy, but there are also things that are only for our own use – private things – which we do not share with anyone. Prepare a basket containing a variety of private things such as toothbrush, underpants, comb, hat, slippers, and commonly used items such as pencil box, biscuits, toothpaste, Lego toys and a TV remote control. Invite the children to take things out of the basket one by one and split them into two boxes: private and common things. Discuss the reasons why this thing is private or shared.

In the second part of the game, you can learn the ability to share in a friendly way: invite the children to choose a thing from the 'common things' box and offer them to others. Tell them what to say when offering and teach others to say 'thank you'.

2) Once the child understands the difference between common and private things well enough, discuss in the same way private and public places. Allow your child to categorise pictures of public and private places in a table. Then, for a certain period and on a daily basis (for example, for a week) draw the child's attention to different places and discuss whether they are public or private. Praise the child immediately if he uses the private space properly -- uses them at the right time, closes the door behind him. Praise the child if he observes your private places: for example, a parents' bedroom may be a private place where he/ she can go in only after knocking and waiting for permission to enter. The teachers' lounge is a teacher's private area where one should knock on the door and wait for permission to enter. You can make 'STOP' or 'KNOCK' signs together as a reminder of what to do. Maybe you need to make a 'close the door' sign inside the toilet or the bathroom, because someone regularly forgets to close it. Promptly observe and congratulate if someone who has been forgetful remembers to close the door behind him/her. Demonstrate the right behaviour: knock at the child's bedroom door. Ask for permission to enter if you want to help your child wash their hair when they are in the bath. Show that at your home (or at your school) private places and things are respected.

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<u>Kate Reynolds</u> notes that for low-functioning children it is best not to use pictograms or generic images to teach about private spaces, but to use pictures of their own bedroom or their own toilet. Otherwise, a child with severe learning disabilities and / or communication differences may think that any bed means a 'private place', including a bed in a house they are visiting, or in a furniture store.

3) Discuss the same and do the same (sort pictures, pay attention to everyday situations, praise a suitable behaviour in a suitable place, show a positive example, etc.) with private and public activities. Use humour: it is usually funny for kids to think that adults may pick their nose sometimes, or burp. Draw a child's attention to the fact that none of these activities is bad: washing is very important, peeing and pooping as well, and letting out wind are not bad. However, they are only right for doing in a private place. It is bad and wrong for others to see our private activities. Then others are sad, angry and do not want to talk to us and be friends, because we have broken the rules of sharing public places.

When you have come all this way, it will be much easier to explain to a teenager that pleasuring oneself is a very, very private activity that should take place exclusively in a private place. Because it involves a completely private body part.

4) Discuss what a private body part is. As a rule, children are well aware of the 'swimwear rule': that the parts covered with a swimsuit are private. We do not show them to others and others do not touch them. The only exceptions to the rule are for the parents if they need to help their child to wash or dress him or herself, and the doctor if the child is being examined. A lot of useful materials, worksheets, books and suggestions can be found on this topic on the internet. You can use different books on the body, puzzles, and other materials. The Centre Against Abuse 'Dardedze' <u>http://centrs-dardedze.lv/</u> provides very good materials.

#### 3.1. People circles

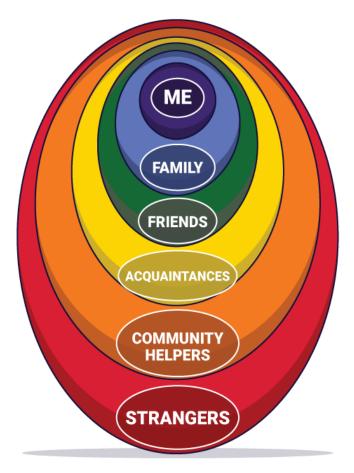
'People Circles' or 'Social Circles' are methods based on principles founded at the end of the last century (.L. *Walker -Hirsch and M.P. Campagne, 1991, Stanfield* – see for example <u>http://www.ascd.org/ASCD/pdf/journals/ed\_lead/el\_199109</u> <u>walker-hirsch.pdf</u>), and they have since been widely used around the world to help children and adults with intellectual disabilities or autism to understand relationships between different people.

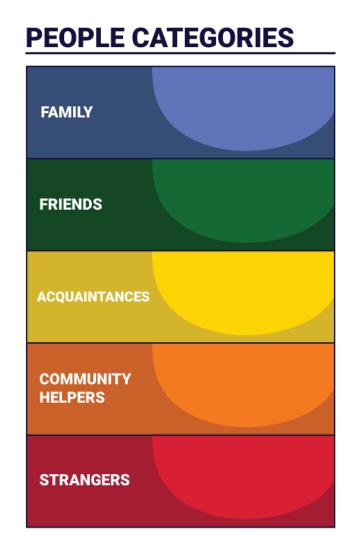
This method has various options and can be tailored to each child's or student's needs. In this material, we offer coloured circles (we chose the most frequently used colour code, but it also has variations). It may also happen that a child is distracted by the colours or they have other associations. In this case, black and white circles can be used. Each circle represents a certain group of people and has its own title. The child is at the centre and the circles located away from the centre denote the degree of proximity to each group of people.

Experience shows that it is best to work with this method individually or in a small group. In this case, each child needs his own sheet with circles. It is more convenient if the circles are large (at least an A3-sized sheet). You can find pictures attached of different types of people (family members, different occupations, etc.). These are suitable for using with the most able children. If the child is smaller or less intellectually developed, real photographs of people in his or her life should be used.

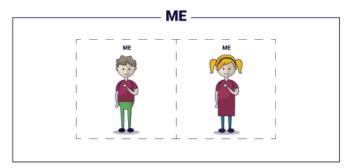
Attach a child's photo in the centre of the violet circle – that's his circle.

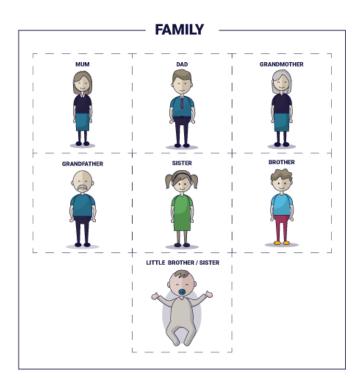
# **SOCIAL CIRCLES**





The blue circle is the family. Discuss with the child who is a member of his family and attach pictures of family members in the blue circle. These are people with whom the child has close relationships. If the method is used by a teacher or psychologist, talk to the parent about the family's situation beforehand. This circle must include people with whom the child has a close relationship. If one of the parents does not live with the child and they practically do not meet, the parent will not be included in the Family Circle. In turn, the aunt or cousin, who for some reason lives with a child and replaces parents on a daily basis, can be counted in this case as a 'family'.



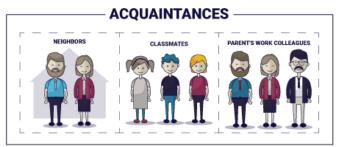


The green circle is for friends. Before you discuss this circle, you need to identify the child's real friends. You can explain to the child that friends are those people who care about each other, who trust each other, who have shared interests and who spend time together. Usually people have two or three close friends. Sometimes, we have only one close friend. And sometimes there are none, in which case leave this circle free. You may want to attach photos of your child's friends in this circle or write the names of your child's friends on a drawing of them.

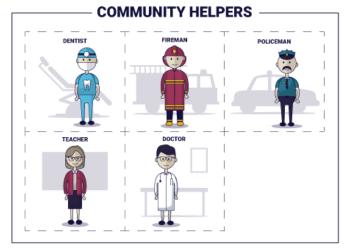


**The yellow circle is for acquaintances.** It is often quite extensive. The acquaintances are all the people we know (we meet them regularly, sometimes know their names, sometimes we do not, we do things together, etc.), but they are not close friends. Discuss the child's circle of friends and put pictures or photos of a friend in this circle. Examples of acquaintances include classmates, fellow members of a sports team, members of the art group, a choir, neighbours (if a child meets and knows them every day), well-known children from other classes, playground children, cousins, relatives,

parents' colleagues (if the child is sometimes taken to work), a school bus driver (if the child meets him/her each morning and knows), and so on.



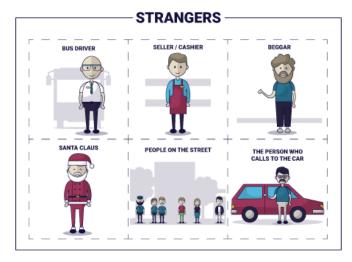
The orange circle is for authority. This is more complicated, but very useful when the child understands it. In English, it is commonly referred to as 'authority' or 'community helper'. The term 'authority' is used in this material, but you can use a different word if your child understands it better. In this circle there are people who are not familiar to the child, but unlike other strangers, they are responsible for looking after and listening to a child as part of their jobs. They might be a doctor, a police officer or a firefighter. Even the school principal and child's teacher may be in this circle. The child can turn to these people for help, if something happens, if family members aren't available. For example, they can ask the police for help on the street, even if they do not know the policeman in guestion. In case of a fire, we should immediately listen and do what the firefighters say, even if this firefighter is unknown.



**The red circle is strangers.** These are all the people a child can meet but does not know. For example, people on the street, people in public transport, service staff in the canteen or hotel, schoolchildren of other classes, unknown neighbours, etc.

Remember that these circles will not help if this conversation starts and ends in the counselling room. To generalise this knowledge, that is, to begin to understand and apply it in different situations, they must be applied in different environments. Once you have drawn the circles, take a moment in everyday situations to draw the attention of the child to different people and to discuss the groups to which they belong, their relationships with the child, etc.

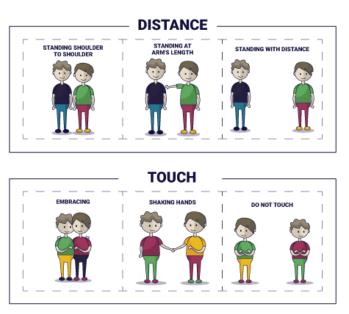
When you have grouped people together, it is easier to discuss the rules of communication with people in each group. These circles can also be used to understand the appropriate communication distances in each group, appropriate touches, suitable topics for conversation, and more.



#### 3.2. Distance and touch in communication

Understanding the appropriate distance and touch in relation to different people is not easy for a child with autism. It can be quite common for children with autism to come close to others or aspire to embrace them, as well as children who avoid touching at all and can behave aggressively if someone touches them. This is because of difficulties understanding social rules.

# **DISTANCE AND TOUCH**



It is good if we can help the child 'systematise' the complex unwritten communication and social rules. There are different ways we can do this:

Explaining private distance: in psychology textbooks this is labelled 'private space' and it describes a certain area around the body of each human being. Most people perceive this area as completely private. Whenever possible, we only let people in this area, that is, let them sit down or stand close to us or touch us, if they are family members or close friends. If someone enters someone else's private or intimate space, it causes discomfort to most people. Tell the child that it is unpleasant to others and that can scare them or insult them.

The idea of private space can be visually displayed with gymnastics circles or plastic hoops. Children can be asked to stand in the middle of their circles or hoops and tell them that the distance around the circle is a private area or a personal space for each person. Do not use the words 'private place' if you have already used that title to indicate a toilet or bed: use the terms 'personal space' or 'private area' instead. Ask them to walk so that the circles do not touch. You can offer for children to describe what they feel like when someone enters their circle? Compare how each one feels. Tell people that you can feel differently: some children may feel good while standing very close. However, most people do not feel good and so we aim to follow this distance rule. Invite the children to remember this distance, even when the hoops are put away.

**The distance of a stretched arm** is a distance at which it is convenient to stand to have a conversation with someone. When standing at the distances of a stretched arm, we can be quite sure that we will not break the boundaries of the other person's private space / area. If you are working with a group of children, invite each child to take turns showing the distances of a stretched arm. On the first occasion, the child can stretch his arms to check that the distance is correct. When repeating this game or task, it is best that the child no longer stretches his arms to check – the child with autism may mistake the method for the rule.

**Use of People Circles.** Remind your child about the 'People Circles'. Now that a child knows the concepts of 'personal space' and 'stretched arm distance', it is easier to understand how to treat people in each group.

You can create a table to insert images with the appropriate distance and touches for each group of people. If you laminate them and stick with Velcro, they will last longer, and the child will be able to work with them repeatedly. Discuss with the child what the right distance with each person is. Also think about exceptional situations. For example: we can stand or sit close to family and friends. The child can sit in Mummy's lap and cuddle. Close friends can sit on one chair. We can touch family members – we embrace them, caress or kiss them. We can put our hand around our friend's shoulders or embrace him/her, while sharing joy or comforting them in sorrow. But close friends and family members should be listened to if the other person says 'no' and does not want to be touched or for us to stand close.

With friends, we notice the distance of a 'stretched arm'. We can touch acquaintances when greeting or saying goodbye. When greeting our peers, we can 'give them a high-five'. Adults tend to shake their hands. Occasionally, adults can shake the hand of a teenager as well.

With authorities, we usually observe the rule of keeping the distance of a 'stretched arm'. However, the doctor may ask you to stand up and touch you for examination. It is OK. In addition, a police officer or security guard may, in special cases, stand near and touch, for example, at the airport during security checks. It is OK if a police officer or security guard is doing his job.

We try not to touch strangers. If it is possible to choose, we try to observe a bigger distance with strangers. There may be exceptional situations when we stand near to strangers and also touch them. Discuss those everyday situations that are typical of your child's daily routine, such as driving in public transport, queuing at a store or canteen, driving on an elevator, etc. In these situations, we must stay calm. But even in these situations, nobody has the right to touch private parts of other people's bodies.

<u>Social stories</u>: You can use social stories about distance and touching. You can search the social stories you have on the internet. You can also write your own social stories that are tailor-made specifically for your child's needs. [hyperlink to explanations of social stories#]

<u>Role playing</u>: Remember to practise – give the child the opportunity to try different types of distances and touches. You can prepare a group of children for different situations (with a family member, with a friend, with a football team after a victory, with a stranger on the street, etc.) and invite the children to play the situations in pairs.

**Consistent adult behaviour.** Remember about modelling appropriate behaviour – you are the child's model. Demonstrate the correct communication distance in different situations. Respect the child's private area – do not hug and do not kiss if the child shows dislike. Do not let the child embrace

strangers or come too close to others; correct this behaviour right away and show your child a suitable distance. Praise immediately if the child is at a suitable distance.

#### 3.3. Understanding emotions

Understanding other people's emotions in communication is like understanding road signs on the road – a vehicle driver who lacks the ability to follow and understand road signs quickly gets into dangerous situations with serious consequences. The same goes for people with autism in contact with other people when they are unable to understand what the surrounding faces, poses, voices and words are about. A teenager with autism experiences a lot of stress and can easily get into very unpleasant and even dangerous situations because of not being able to intuitively 'read' other people's emotions as many other people can.

For the sake of social relationships, it is sometimes important for a teenager to understand whether others like or dislike what he does at any given moment. It is also important to know how to tell: is someone particularly fond of me; how can I know if someone wants to be friends with me; or if someone is in love with me. In turn, a teenager might need help recognising their own thoughts and feelings towards others. How do we know that someone is our friend? How do we know when we are in love? This isn't easy for the wisest of us, but there are clues that can help and which we can look out for.

The psychologist talks to a teenager who has an autism spectrum disorder. The boy wants to discuss his relationship with the girls and falling in love. At some point in the conversation, the psychologist asks: 'How can you tell if someone is in love?' The adolescent's answer: 'Then, small hearts appear in their eyes ...'

Schematic images are often used to convey emotions in online and printed media. Unfortunately, psychologists' worksheets and the tasks used in educational books and computer games draw on the same schematic emotion pictures. Children with autism can easily learn to recognise schematic pics, but it's hard to recognise the facial expressions of real people. It may cause misunderstandings that typically do not occur for their peers.

Recognition of 'smileys' is a basic skill. There are young people with autism who are uncanny in sorting out and naming the emotions of a 'smiley', but this does not help them in any way to understand whether the classmate is sad, happy or in love. Suggestions for teaching children to recognise emotions: During a structured class, it is more useful to use photographs of real people rather than schematic drawings. In addition, consider that emotional photographs included in psychology

textbooks are often unintelligible in teaching you to recognise real emotions: they are most often depicted by fictitious, exaggerated facial expressions. More useful are pictures of accidental situations, which you can search for in Google images. Even family photos may be more useful; you can watch a film together with a teenager, pause and discuss how human faces, poses and gestures represent their emotions and relationships;

Researchers emphasise that people with autism may have difficulty perceiving the social context of the situation. Namely, a teenager can be able to decode emotions ('The person looks angry'), but fail to understand the situation ('What happened? Why is he/ she angry?');

The best way to teach an understanding of emotions is to name them in everyday situations. First, the adult names the emotions of the child ('I see you're glad') and helps them tie them up with the situation ('you like your new computer game!'). Then the adult names his own emotions and the emotions of people around him / her, ('Your brother is tired'). It may be helpful to draw the attention of the autistic child to how you can recognise someone's emotions ('You see - your brother went to bed and crawled under the blanket. He said that the football training was very difficult'), and to what the others want from him in such a situation ('Your brother would like to be left alone and take a nap in peace. It would be friendly if you would go to listen to your music in the other room'). Praise the child immediately if he acknowledges other people's emotions and acts accordingly ('It was very good that you immediately turned your music off. This way you show you care about your brother'). It is wise to teach a child a simple skill: ask others how they feel. We can always make mistakes, misinterpret or misunderstand another peoples' behaviour. The safest way to find out about other peoples' feelings is by simply asking.



When talking about emotions and relationships, it's better to use photos rather than schematic symbols

#### 3.4. Prevention of violence

Children and adolescents with special needs are at higher risk of suffering sexual abuse -- a child with autism may not understand what is going on, may not know how to ask help and may not be able to cry for help. If a child is socially isolated (for example, studying at home), there may be very few adults around to whom they could turn for help. The level of risk is raised because of an inappropriate perception about touching, privacy, and one's body (for example, if a teenage girl is accustomed to her diapers being changed by a social care centre employee in the presence of others, this teenage girl will find it very difficult to understand that the intimate parts of the body are not to be seen or touched by others).

It is always easier to teach personal safety rules with a verbally able teenager. A non-verbally able teenager will largely rely on the behaviour he has been specifically taught before puberty.

Skills and habits that protect a child:

Understanding what a private body part is;

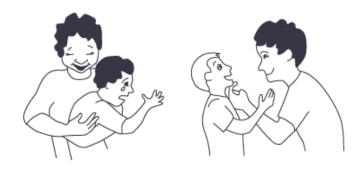
The habit of doing private activities only in private places (it creates the perception that nobody should watch or inappropriately touch your private body parts);

The habit of sleeping alone (if a teenager with severe developmental problems is accustomed to sleeping with an adult, he is at a higher risk because he will not protest if a violent person climbs into his bed);

The right to say 'no' if you do not like what another person does to you;

The experience of others respecting you when you say 'no'; Understanding suitable and inappropriate touch (you can talk about it with a verbal child; a non-verbal child will mainly learn it from the behaviour of the people surrounding him/her); Experience of social relationships (even for a teenager with severe communication / learning difficulties, it is very important to have an opportunity to meet other people, experience good relationships and to be in touch with people who can help if necessary).

#### The right to say 'no' if you do not want to be touched



The right and the ability to say 'no' are some of the most important security rules / responsibilities of a child's carer to teach us. It is easy for children to believe that there are 'good' and 'bad' activities, for example, an adult can easily convince a child that tickling or caressing are always good, and hitting is always bad. However, children need to learn that tickling is a good game only when both people enjoy it. Also, caressing, hugging or having someone sit on your lap are only 'good' if both people enjoy it.

As soon as at least one is no longer enjoying an activity, she or he has the right to say 'no' or 'stop', and the other person must stop immediately.

This should be an inviolable law, both at school and in the family, and should apply equally to both children and adults.

If a grandmother wants to kiss the child, but the child takes a step back, grandmother must stop the kissing. If a child crawls in her mother's lap in a way that is unpleasant for her, the mother has the right to say 'no' and the child must let go of his/ her mother. This applies both to playing with siblings, classmates, and the wishes of visiting relatives to snuggle children. If someone says 'no' to a specific touch, then the other does not touch. (Exceptions can include when receiving medical assistance – this should also be explained to the child as one of the very few exceptions to the law).

Parents may feel an emotional pressure from relatives, but this time the desire of relatives to stroke a child's head or to embrace the child are less important than the need to teach the child the skills that can protect him from sexual abuse in the future.

Later, when the young person has grown to an age when the opposite sex becomes interesting, you will discuss this law in relation to the opposite sex: he/ she may touch, hold a person's hand and embracing him/ her only if the other person likes it. If the other says 'no', that means 'no', and you must stop doing it. (If this law is acquired at the age of six, it is much easier to follow it at age 16).

#### Rules at home

For the child to be able to observe safe communication rules outside their home, the rules must be established and strengthened at home in the first place. The child can be protected from sexual exploitation only by clear and unequivocal laws that each person has private body zones, each person has the right to protest if he is harassed in an inappropriate way, and that every person has the right to say no. It applies equally to both children and adults. Examples of safe home rules:

No member of the family walks around naked;

- Washing and changing diapers or nappies takes place in the bathroom or the toilet, and it NEVER HAPPENS PUBLICLY;
- All family members close the door when in the bathroom or in the toilet;
- Everyone sleeps in his or her bed;
- Everyone has the right to say 'no' if they are touched in the wrong way, and they have the right to be heard;
- Even a non-verbal child can be taught to knock at the door. A STOP sign at the door would also do;
- Even a non-verbal child should be taught to understand the words 'no' and 'stop';
- No matter how sweet a child is, he cannot be allowed to embrace everyone.

It should be noted that people with autism tend to develop rigid habits that are very difficult to change. Therefore, it may be easier to teach the child certain habits right from the start (for example, to sleep in their own bed or change diapers only in the toilet), rather than to try to change habits that have already been established.

<u>Clear information for high-functioning young people</u> For young people with good intelligence, but with autistic spectrum disorders, it may be difficult to understand which situations safe and which ones pose a potential risk.

If the child becomes independent (goes to school, has hobbies, attends workout sessions, goes to shop, visit friends and goes on school field trips, etc.), it is important to repeat to him or her the standard safety rules again and again: do not go with strangers, do not get into a stranger's car, do not talk with strangers. You must remember that a child with an autism spectrum disorder is more socially naive than his typically developed peers. He can even believe gross lies ('Your mum suddenly got sick and asked me to tell you to come along with me after school') and may be easier to lure using his or her special interests. There is a very clear need to discuss the fact that there are malicious people in the world and they tend to lie to children.

For many children, films and video games may teach the idea that 'evil' can be recognised by someone's appearance: they must be ugly, bearded, have scarves on their face, etc. For a child with Asperger's Syndrome, such misconceptions may be even more common. It must be clearly stated that the 'bad guys' cannot be recognised by their appearance. It must be said that the bad guys can be either a man or a woman and that he or she may also pretend to be 'particularly good', that is, offer candy, games on the phone, be very kind and so on.

It must be regularly repeated what the child should do in such situations (say 'no', run away, call your mother right away / tell the teacher, etc.) and draw up an adult list that the child can turn to for help.

For young adults with Asperger's Syndrome who start college, live in dormitories or simply start activities such as going to concerts or going on trips on their own, etc., they may require very accurate information about 'what is what' in the sphere of relationships.

In <u>Sexual Health and Relationship Skills. A Guide for Adolescents and</u> <u>Adults on the Autism Spectrum and Their Partners</u>, Jonna Oksanen gives young people with autism spectrum disorders a precise description of what are:

- Sexual activities (it is important also to explain 'implicit' activities, including taking naked selfies, watching a naked body or its private parts with the aim of sexual satisfaction, touching the private parts of your own or other people's bodies, etc.);
- Sexual violence (the author accurately describes a situation of violence, for example, someone who wants to take off your clothes without your permission, tries to lock you on in a room, wants to go to the shower or sauna together with you without your permission, watches pornographic movies with you, watches you when you're naked but you do not want it, etc.);

It should be considered that it may be difficult for a young adult with an autism spectrum condition to recognise the intentions of others. For direct language perception, it may be difficult to understand hints and jargon. It is recommended that you explain to young people the most typical ways in which people can offer sexual intercourse using indirect language. Some examples (from the 2013 book *The Aspie Girls Guide to Being Safe with Men'*, by Debi Brown):

A person you have not previously been acquainted with offers you a massage. He may mean having sex;

A person, who is interested in you, suggests sleeping in one bed. Sleeping in one bed makes you available for sexual intercourse if this person is planning it;

A person you date proposes to go to a more comfortable place, such as his/ her home (for a coffee, for example). This may mean not only a desire to spend time with you there, but this person may be thinking of having sex with you;

A person kisses you and uses his tongue in your mouth during the kiss (a 'French kiss'). Often this is an implicit offer to continue to intimate touches that lead on to sex.

It is wise to say 'no' to such suggestions unless you yourself want sexual contact with that person, feel safe and know how to use appropriate contraception. Resources for talks on security and violence:

In Latvia many useful resources and assistance are provided by the Centre against Abuse 'Dardedze'. The 'Jimba's School' programme <u>http://www.dzimba.lv/lv/</u> teaches children to distinguish between good, bad and 'secret' touching; teaching safety rules when dealing with strangers, and so on. This program is mainly for typically developed children, but experience has shown that children with Asperger's Syndrome understand it very well and gain a lot. On Dardedze's <u>http://centrsdardedze.lv/</u> you will also find suggestions and useful materials for talking with children about security and violence;

Very good resources for older teens and adolescents are available at www.wikihow.com. The section called 'Youth' https://www.wikihow.com/Category:Youth on this website provides social stories with easy-to-understand images for young people about building relationships. It also includes specific tips on what to do if you feel at risk during a romantic date, how to say 'no' to an unpleasant touch; when and how to report to the police if you need help and other personal security issues. One example of a social story is given in the appendix (https://www.wikihow. com/Tell-a-Boy-to-Stop-Touching-You).

Many recommendations on how to protect a child with severe autism are available in Kate E. Reynolds's book Sexuality and Severe Autism. A Practical Guide for Parents, Caregivers and Health Educators, from 2013.

Useful materials for high-functioning adolescents with Autism Spectrum Disorders can be found in Jonna Oksanen's <u>Sexual health and Relationship Skills: A Guide for Adole-</u> scents and Adults on the Autism Spectrum and Their Partners.

#### Appendices

#### **Recommended literature**

Anna Baka and Karls Grunevalds, Book about Care, Preses Nams, 1998.

Debi Brown, The Aspie Girls' Guide to Being Safe with Men, 2013.

*Latvian Autism Association,* Daily Skills and Activities for People with Autism Spectrum Disorders, 2014. (The book is available electronically on the webpage <u>www.autisms.lv</u>).

*Eve Fleming and Lorraine MacAlister,* Toilet Training and the Autism Spectrum: A Guide for Professionals, *2016. Carol Gray,* The New Social Story Book: Revised and Expanded 10th Anniversary Edition:

Over 150 Social Stories that Teach Everyday Social Skills to Children with Autism or Asperger's Syndrome, and their Peers, *2017*.

Alex Kelly, Talkabout: A Social Communication Skills Package, 2016 (Ready-made group lesson with handouts and lesson descriptions. Materials are also available on the internet at <u>www.speechmark.net</u>).

Jonna Oksanen, Sexual health and Relationship Skills: A Guide for Adolescents and Adults on the Autism Spectrum and Their Partners, 2013 – 2015, Autism Foundation in Finland.

*Kate E. Reynolds,* Sexuality and Severe Autism. A Practical Guide for Parents, Caregivers and Health Educators, 2013. <u>www.autisms.lv</u> (social stories and pictograms about self-care) <u>www.autismsberniem.lv</u>

<u>www.dzimba.lv</u> (materials for security in dealing with strangers, prevention of violence)

<u>www.autismawarenesscentre.com/prepare-girl-autism-menstru-</u> <u>ation</u>

<u>www.do2learn.com</u> (pictures of puberty, masturbation, self-care) <u>www.embracingimperfect.com/.../autism-and-menstruation</u> <u>http://www.visualaidsforlearning.com</u> (pictures of puberty, masturbation, self-care)

www.wikihow.com/Tell-a-Boy-to-Stop-Touching-You (In the section on 'Youth', there is a lot of good material about relationships).

### Chapter 6.

### Suggested reading and Internet sources

#### In Polish:

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- Attwood T.: Zespół Aspergera. Kompletny przewodnik. Wydawnictwo Harmonia Universalis, Gdańsk 2013. (M2)
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- Frith U.: Autyzm. Wyjaśnienie Tajemnicy. 2008, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2008. (M1 i M2)
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Henault I.: Zespół Aspergera a seksualność. Wydawnictwo Harmonia Universalis, Gdańsk 2015. (M2)

Hendrickx S.: Kobiety i dziewczyny ze spektrum autyzmu. Od wczesnego dzieciństwa do późnej starości. Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2018. (M2)

Higashida N.: Dlaczego podskakuję. Wydawnictwo <u>W. A.B.</u>, Warszawa 2016. (M1 i M3)

Jackson L.: Seks, prochy i zespół Aspergera. Przewodnik po dorosłości dla osób z zespołem Aspergera. Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2018. (M1 i M2)

Kaczmarek B., Wojciechowska A. (eds.):Autyzm i AAC . Oficyna Wydawnicza Impuls, Kraków 2015

Łaguna M., Fortuna P., Przygotowanie szkolenia, czyli jak dobry początek prowadzi do sukcesu. Gdańsk GWP 2009. (M1)

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### Summary

We hope that the modules, lectures and activities put forward herein will inspire the readers to create courses that consider the specific environment of their workplace and their specific needs. When preparing our modules, we took great inspiration from the idea of experiencing. That is why so many activities incorporate the role of a person with an autism spectrum disorder. We strongly believe that this is absolutely necessary to better understand difficulties that adults with ASDs must face.

Every module course book features the module's aims, expected results, lesson plans containing the scope of material of every lecture, and descriptions of workshop activities. However, please note that the instructor's experience, knowledge and competence always remain the focal point of our courses. We know that to properly conduct a course one needs facilitators that, through their attitude and knowledge, can help the participants establish an interpersonal relationship with a person with an ASD, that is characterised by empathy. A diligent instructor (who is self-aware) with great communication skills and experience in working with adult people with autism spectrum disorders can create an environment in which one can effectively gain knowledge and develop practical skills. A facilitator with an open, accepting attitude, that is full of respect, gives an opportunity for positive impressions and relationships. Such a facilitator helps with the building of good relationships between staff and people with ASDs, and will understand the subjectivity of his or her own experiences.

One of the strong points of the course is the opportunity to work in a team, to support each other, to prepare a joint project and build on the rich experience of SYNAPSIS facilitators. We thank you. We would not exist without you. We share our knowledge and experience in this course book, bearing in mind that it is no one other than the adults with autistic spectrum disorders who were and still are our best and most important teachers.

> The trainers from the organisations: SYNAPSIS Foundation AS Mentoring Ltd. Latvijas Autisma apvienība

