



Learning Module

Welcome to this interactive learning module

This module was created using information gathered from women with autism (which we use to cover all autism spectrum conditions, including Asperger syndrome) who took part in the Autism in Pink project. The women participants completed questionnaires, underwent interviews and joined workshops to share information about their lives and the challenges they face. Their personal experiences were divided into 8 areas, determined by the domains of the 'Personal Wellbeing Index':

1. Standard of living
2. Personal Health
3. Achievements in Life
4. Personal relationship
5. Personal Safety
6. Community Connectedness
7. Future Security
8. Spirituality / Religion

Participants demonstrated or discussed what each area meant to them, and showed or described the obstacles and issues that arise for them in each area. They also shared strategies that they use to overcome some of the obstacles and issues. Some of these are not specific to autism; they may arise in relation to anybody, but seemed particularly relevant to some of our participants.

We used this information to devise this learning module, which consists of 8 mini-modules structured as follows:

- Issues / Obstacles
- Learning Goals
- Learning Strategies
- Stories to illustrate



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There are many other experiences, strategies and approaches to areas of difficulty described in the general literature on autism. The Learning module that follows is a unique document fed exclusively by the information given by the women participants of Autism in Pink during the project.

Using the learning module

The issues, obstacles and learning strategies described are *specific to individual participants of the project*. Some found that they had similar experiences, others had different ones; some strategies were relevant and useful for some of the women, while for others these strategies were not suitable.

Some participants were able to talk and to be fairly independent, while others were non-verbal and require support in most areas of their lives, and there are all combinations and levels of ability between. There is also a wide range of backgrounds, societal and cultural influences amongst the participants.

Individual women with autism vary tremendously, so it is extremely important to remember this when using the learning module. In reality, you may not experience some obstacles and issues described, or you may experience some not described. Similarly, some learning goals and strategies may suit the obstacles and issues that challenge you or the woman you are supporting, others may not. However, we hope that by using this information, you will be able to adapt the strategies described and that this will help you to challenge and overcome issues that are particular to you and achieve a positive outcome appropriate to your needs.

At times, our participants did not describe strategies to address some particular issues, but we hope that their description of these issues will help you to clarify and understand some of the issues and obstacles that you experience yourselves, and perhaps to come up with ideas for strategies of your own.

There are many useful and relevant strategies described on the National Autistic Society website: Please see the link below to find them-

www.autism.org.uk/a-z

Domain: Standard of living

Some potential issues or obstacles which can affect standard of living

Money / finances:

- Being unemployed or having a job that does not match with your potential can have financial implications on standard of living. (See also future security.)
- Some women with autism depend on their families to handle finances, especially if they need to carry out further study and/or struggle to get or maintain employment.
- Money is abstract so can be difficult to understand. Financial tasks such as budgeting and paying bills often do not involve real money. Financial factors are changeable and at times confusing.
- Dealing with banks and financial products, understanding information, understanding intentions of people who have their own agenda, and working out that buying their product might not be in their best interests.
- Organising information to do with finances, making sense of quantities of information, especially verbal information when already trying to work out social information as well.
- Money can be lost due to avoiding social contact. For example, not returning after being overcharged or short-changed, or if goods are faulty.
- Food can affect finances. Shopping for ingredients, food preparation and cooking may be difficult due to sensory issues and the need for multi-tasking. Pre-prepared food is easier but more expensive. Food choices can also be restricted by autism-related factors such as sensory differences and decision making processes. This may affect finances and health (see also personal health).

Accommodation:

- Sharing can be difficult especially with other adults who may have different expectations about rules and routines. They might also not understand the need for the home to be a place where escaping from social pressures is possible.
- Making accommodation autism-friendly to suit individuals' specific needs in relation to space and sensory aspects such as noise, lighting and smells can make it difficult to share. It also often requires planning and permission, and sometimes is simply not feasible – all of this has implications on finances and standard of living.
- In social housing it can be difficult to get social services to recognise autism-related problems. Getting information and understanding what housing procedures need to be followed can be difficult and confusing.

- Maintenance of accommodation involves communication either with a landlord, management company or with workmen directly. (See also personal relationships.)
- Maintaining and keeping the home clean and carrying out physical tasks can be slow and hard due to sensory and multi tasking issues.
- In an institutional setting, residences are often not specific to people with autism. Space and privacy may be limited, and there are often communal expectations to do the same things at the same time as others living in the same residence. There is often no choice regarding maintenance and decoration, and individual preferences may not be taken into account.

Possessions, and special interests:

- People are unpredictable and intangible, whereas possessions are solid and predictable. So possessions may accumulate for comfort reasons or because they might help some women with autism to define themselves, to know who they are. However attachment to some possessions can create anxiety that they might break, get lost or stop functioning.
- Possessions may also accumulate because some may avoid throwing things out. This could be due to specific interests, difficulty with change, or worries that things might be needed at a later date.
- Some possessions can be helpful; technology such as computers and phones can assist socially and organisationally, weighted blankets and headphones can help with some sensory differences. But these things can be very expensive, they may be unaffordable for some people, or might leave less money for other things.
- Special interests can become obsessive, and can involve buying excessive or unnecessary objects. This may lead to a shortage of money, time and space, thereby getting in the way of other things that women with autism would like to do, and also sometimes affecting relationships negatively.
- Financial worries may lead to buying bargains or extra stuff when it is on sale, and storing for later use. This could lead to losing track and spending more money on things that are already stored.
- Difficulty with change may mean that some have to keep buying the same brand of product, even though another brand might be on sale, and money would be saved if it were possible to use a different product.

Travel, pass-times, leisure activities:

- Some may not be able to go anywhere unaccompanied. This has financial implications both for travel and cost, and can also be limiting due to needing to fit in with the accompanying person.
- Travel difficulties can be restrictive. For some, driving is not possible, so travel on public transport is their main way of getting around. Living in a city can make this easier, but the cost of accommodation in these areas is often

high. Also, public transport can be extremely stressful; this stress might result in not going somewhere, having to pay for expensive taxis, or relying on someone else for company or to provide transport.

- Some activities that some women with autism might want to do might have to be avoided due to social aspects (see also personal relationships and community connectedness), cost and sensory aspects such as noise, touch and lots of people.

Learning Goal

To adjust your own goals to improve your standard of living in society

Learning Strategies

Money / finances:

- Make money make sense by linking it to your personal interests. Eg £5 equals one music cd
- Try to get neutral information regarding financial products, from the internet or an uninterested party
- Ask for any written letters to be autism-friendly, and explain what this means to you if necessary
- See money management as a logical numbers-based task
- Write things down and use money charts or a budgeting system.
NAS money managing web site:
www.autism.org.uk/living-with-autism/at-home/managing-money.aspx
Also: www.moneysavingexpert.com
- Use a phone app to work out the cheapest deals
- Get someone who understands autism to help you, learn from what they are doing so you become more able to do it yourself. This might include taking a rational approach, reading the small print in documents, and weighing things up.
- Listings of social situations it is suitable to carry out certain expenses rates and more frequent.

Accommodation:

- Get someone who understands autism to help you to achieve the right accommodation for you. (See also personal health and relationships for more about mentors)
- If accommodation is shared, use social stories, schedules, calendars and rules of courtesy to deal with common situations that might arise

Possessions, obsessions and interests:

- Collect things that don't cost money
- Use logic to assess emotional attachment and get rid of stuff if possible (some find this easy as they feel emotional attachment is not formed that readily anyway).
- Take out insurance to alleviate anxieties about treasured possessions
- Establish lists to help you assess which objects can be kept and for how long.

Pass-times, leisure activities, travel:

- Seek price reductions for people accompanying you on the basis that equal opportunities can only be upheld if you are able to join the activity accompanied, otherwise you cannot join the activity at all.

Personal Stories to illustrate

Emma uses the strategy of withdrawing the total amount of money per week that she knows she has available. She can then allocate specific amounts within this total to be used for specific things, breaking it down to how much she can spend per day. She can then just carry that amount of money allocated per day.

Ana and Barbara get some pocket money from playing in a band. They write down two different lists: 1. what they would like to buy and 2. what they really need to buy. They buy the things they need first so they don't end up just buying all the things they like, leaving no money for the things they need.

Eva has created a list of low cost gifts that may be suitable to give to friends when it is their birthday.

With use of extensive two-way supported communication such as social stories and symbols, Clarissa lives happily in her residential accommodation.

Domain: Personal Health

Some potential issues or obstacles that may affect physical and/or mental health

Physical / Mental / Feminine and Sexual Health

- Co-morbidity. Certain conditions seem to be more common, such as IBS and bowel problems, epilepsy / asperger epilepsy. Epilepsy and unexplained blackouts can be particularly stressful as they mean that constant supervision might be needed, threatening independence and putting relationships under strain
- Mental health issues such as stress, anxiety, depression, social phobia, are common often due problems around interaction with other people (see also personal relationships) and 'masking' or covering up difficulties and traits associated with autism
- Vulnerability to abuse in terms of emotional and sexual relationships, which can also seriously affect mental health
- The above points mean that women with autism may need more input from health and medical professionals, but making appointments and communicating with professionals can be very difficult , leading to greater stress, and sometimes to avoidance of appointments because the experience is just too unpleasant due to general lack of understanding of autism by receptionists and professionals
- Difficulty realising, identifying and articulating symptoms – many feel that something is amiss when they are unwell or getting unwell, but struggle with recognising the exact nature of the feeling, whether it is physical or mental, where it is, whether it is serious and merits going to a doctor or not etc. Symptoms and feelings can also be mixed up.
- Medication
 - side effects can be difficult to manage, and can make some women with autism feel that they are not able to be themselves
 - some find it difficult to manage medication, to ensure that they always take what they should at the right times, and that they have adequate supplies, repeat prescriptions etc.
- Areas of feminine health can present with difficulties, eg menstrual cycles can create sensory, pain and mood problems; changing hormones can be very difficult in terms of trying to understand mood changes and feelings; gynaecological visits and smear tests can be difficult in many different ways.
- Energy levels can be extremely low in women with autism, partly due to the effort that they are having to make constantly (see personal relationships and future security), and perhaps also partly due to factors such as Chronic Fatigue Syndrome, depression and stress.
 - taking rests and breaks can be a problem for women with autism, who often have difficulty stopping something if it is not complete, or changing

from one activity to another. Some see the activity as more enjoyable than the break.

- sleep can be an issue
- Keeping fit can be difficult for some women with autism
 - energy levels can be low as mentioned above
 - finding a form of exercise that suits them can be difficult. They may find that exercise classes and team sports do not suit them because of the social aspect, but exercise as an individual can be problematic due to the lack of natural structure in exercising alone.
 - co-ordination, hypermobility and lack of core strength can be difficulties for some.

Sensory differences (see also personal safety) - sensitivity to noise, smell, bright light, other visual stimulus, touch, too many people etc can cause problems in hospitals and surgeries etc, and during treatment.

- Lights can be bright, smells can be strong, waiting rooms can be crowded and noisy
- Sensitivity to touch can make physical treatments and procedures excruciating for some
- Hypo sensitivity:
 - Having a high pain threshold can mean that they don't always notice when they are ill.
 - May lead to self-harm due to seeking stimulation.
 - May enjoy something that could be damaging, because it provides some stimulation
- Hyper sensitivity
 - May dislike having anything on hands or feet, or body in general.
 - May lead to difficulties brushing and washing hair because the head is sensitive.
 - May only like certain types of clothing or textures.
- Sensory differences can lead to difficulty around eating knowing when they are hungry, thirsty or full, and this can lead to not eating, forgetting to eat or overeating
- Sensory differences can lead to craving of certain foods or limited intake of a variety of food, possibly leading to nutritional insufficiency

Other possibilities related to eating and keeping fit

- There can be conflict with other people regarding specific diets that they think women with autism should be following

- Having a food-related special interest such as counting of calories, can lead to development of eating disorder
- Certain food may be given by parents and carers to avoid difficult behaviour or tantrums.
- Difficulty around making food choices can lead to a limited range being consumed
- Women with autism may experience difficulties with certain fitness activities (see also standard of living and community connectedness)

Personal Hygiene, Grooming and appearance

- Some women with autism feel that they often do not know what is expected regarding their appearance; motivation can be low as they feel that they might not get it right anyway
- Some feel that even if they make an effort, they don't feel any different, again lowering motivation
- Low self esteem can make things worse, some find it very difficult to see when they might look good
- Some are not able to physically achieve the co-ordination that is required for doing hair, make-up etc. This may lead to an inability to affect their appearance independently
- Some consider that their physical appearance should be neat and can be compulsive, having a need to wash concomitant with obsessive compulsive disorder, derived from the belief that any contact with dirt can carry pollution or illness.

Learning Goals

To reduce the stress involved in all areas of health, and develop ways to maintain good health and fitness, both mentally and physically

To learn about sexual or emotional clues to reduce the possibility of from abuse or manipulation, and consequent effects on mental health

To learn to feel comfortable with yourself in all situations.

Acquire suitable hygiene habits.

Potential Learning Strategies

Regarding stress, good health and fitness:

- Training and checklists for professionals, professionals who specialise in autism
- Training for women with autism to help build confidence when communicating

with health professionals. Learn to be direct and express your needs from the start.

- Learn and use biological and medical terminology to help explain your symptoms and problems to health professionals, and to help your understanding when they explain things to you
- Take a mentor to appointments with you. A mentor needs to:
 - have good understanding of autism
 - be able to build a good understanding of you as an individual
 - be able to support you in a way that is appropriate to you
 - help you to learn how to do things yourself rather than do them for you, in order to become more independent in the future.
- Get someone who knows you well to help you identify what might be the problem when you feel that something is amiss, to ask you the right questions, observe your behaviour and mood etc, and support you in deciding what to do.
- Awareness of self, body and mood
 - Study your own baseline state over time; when you are calm, when you are in good health and feel like nothing is amiss, when your routine is as normal
 - Take detailed notes of how you feel, how your body feels and looks, for example pulse, heart rate, temperature, motor skills, colouring, eyes, when you last ate or drank – as much information as you can put together.
 - When you are feeling less calm or less well, when you feel that something is amiss or when your routine has not gone as normal, you can compare how your body feels and looks with your baseline state. You can gradually build up a picture of how your body functions and responds to things, and how it feels under certain circumstances. In this way, over time, you can learn what certain signs and signals mean to you, so that you can respond appropriately earlier.
- Find out basic information about what to do about certain symptoms, use resources like NHS Direct.
- Find out if alternatives and different treatment options are available if suggested procedures seem inappropriate to you
- Ask medical professionals to talk through exactly what is happening in a treatment or procedure
- Pre-plan a strategy to communicate to medical professionals if you want to stop during a procedure, and for them to communicate to you if this is medically possible or not.
- Use coping strategies to deal with stressful appointments and procedures, such as headphones, music, stress ball, counting down to insertion of needle

- Understand your rights and legalities such as access to your medical notes, GPs recommendations of fitness for working, driving etc
- Use strategies for taking breaks and changing activities to help with exhaustion, low energy levels, eating at suitable times:
 - Create timetables to plan breaks / changes of activity (make sure you try to build in a little flexibility, to avoid anxiousness if external factors prevent things from going to plan
 - Use outside cues to trigger when breaks should be taken or an activity should be changed eg timers as a plug timer to switch something off when it's time to take a break or change an activity; other people taking breaks; if working to music create playlist of appropriate length to take break or change activity when finished, or plan to take break or change activity at specific song or piece
 - Create structure within the breaks – plan doing something you enjoy during the break
- Find motivation specific to yourself to learn about staying fit and healthy, and carry out exercise that you enjoy, such as something with concrete goals eg martial arts which involves working towards different coloured belts, or trapeze which involves designing a routine to complete or show to others.
- Ensure that activity leaders know that when learning something new that requires physical motion, eg ballet or martial arts, you might need to have the different positions that comprise the overall motion described in detail, or to have your body actually put into these positions so that you can experience them.
- Find ways of relaxing that work for you eg yoga, breathing exercises, music
- Professionals dealing with eating disorders need to understand autism; source of an eating disorder might not be the same for a women with autism as for neurotypical women, where more typical causes are body image and comfort eating
- Practice moderation. Don't over-consume any one food or type of food. Instead, try to vary your diet so that you eat a little bit of everything in a moderate amount.
- Establish the quantity and time that you are going to eat before sitting at table and check your plan

Regarding mental health:

- Understand the limits between good practice and non-ethical practice in sexual and affectionate relationships:
- Learn that refusing to be touched is a right
- Learn that secrets about being touched are not OK
- Learn self-protection skills

- Who can/can't touch the individual and where on his/her body
- How and when to say "No"
- How to ask for assistance
- How to recall remote events and convey where an individual touched him/her

(American Academy of Pediatrics, 1996; Nehring, 2005; Roth & Morse, 1994; Volkmar & Wiesner, 2004)

Regarding hygiene habits:

- Learn to appreciate yourself as you are (see religion and spirituality, and achievements), but take into account social situations
- Learn what is appropriate for different situations with respect to hygiene, clothing and appearance
- Learn to care for your appearance
- If you want to use make-up and perfume, learn how to use it appropriately
- Ask a mentor or someone you feel comfortable with to help with the aspects of learning above (See also personal health and relationships for more about mentors)
- Study and analyse different stereotypes and social impact about clothing and body images, teach how to have a critical but social thinking about cultural aspects of appearance related with places and people.

Personal Stories to illustrate

Jenny craves food that has a negative effect on her appearance and energy levels. She really loves playing in a band; this helps to motivate her to eat food that is better for her as she wants to feel that she looks good when she is on stage, and has enough energy to perform.

Julie and Alice had no interest in doing any exercise. They each chose an activity that they liked the idea of, and created a timetable for completion. A recording sheet was established and they continue to exercise and improve their fitness levels.

Amy made an immense effort over time to learn about her personal baseline by exploring and testing her motor skills, her temperature etc. As a scientist, she had good knowledge of biological and medical terminology and anything that she did not know, she researched. She took down notes regarding many aspects of herself so that she can now describe her body and how it feels when she is well. Then, when things stray from this baseline, she is able to use this information and a checklist that she has made to remind her of the questions that she needs to ask herself. In this way she can pair up her own personal signs and symptoms to work out what is

wrong with her. Her knowledge of the correct terminology makes it easier for her to explain what is wrong to medical professionals.

Kelly is concerned that she looks very young, but she is not able to put on make-up, tie up her hair or do different things with it. She feels that this might affect respect that other people have for her in circumstances where she needs to look professional and efficient. She is very successful academically, and it is difficult for other people to understand that there might be discrepancies of this sort between her abilities.

Inga is very interested in learning makeup techniques and fashion design with a Gothic style, and uses this as a way to express her identity

Alexandra used to put plenty of make-up on, but the psychologist that she like very much convinced her to use make-up appropriately and helped her to apply it on herself.

Helena doesn't care for her appearance but the person in charge of the laundry where she works helps her to pick out clothes that match.

Domain: Achievements in Life

Achievements and how we feel about them are different for everyone, including for each person with autism. They are closely linked to our uniqueness and sense of self. Religion and Spirituality covers sense of self, so please also see this section for further information relevant to the area of Achievements.

Many achievements often have to involve some level of interaction, so they are also closely related to ability to communicate and interact socially. Since obstacles in these and other areas are different for individual women with autism, there is a huge variety of things that can be seen as achievements.

Some potential Issues or Obstacles that relate to achievement

Barriers

- Difficulties with communication and social aspects might affect ability to achieve goals. Eg interviews, auditions, networking, going to classes, using the right vocabulary to speak with other people, and using alternative ways to communicate
- Any person with autism will have things that they want to achieve, but difficulties with communication may lead to difficulty in expressing what they see as an achievement, so there may be achievements that they are striving for or want to strive for that no-one is aware of. In this case, appropriate support cannot be given.
- Difficulties with physical co-ordination, hypermobility and core strength can prevent achievement in some areas, particularly in areas where exercise and even walking is involved, in certain cases.
- Teaching methods and text books are not necessarily geared towards needs of women with autism, and material may not be presented in a way that they are able to understand or learn from. For example, when doing assignments and exam questions, phrasing is often not straight forward and does not test real knowledge and ability; questions may be misunderstood, or valuable time wasted trying to work out what they mean.
- Organising information, making sense of quantities of information, and bringing related areas together to form an overall understanding can be very difficult.
- Prioritising and putting tasks in an order that might optimise the outcome can be difficult. There may be a tendency to focus on some areas at the expense of others, thus affecting overall achievement.
- Women with autism may be working extra hard to hide or overcome autism-related obstacles. This might mean that there is little energy left for other things, including potential achievements
- Strong focus and perseverance can help towards achieving goals, but can

also be a hindrance in knowing when to stop, and when to take breaks. This can cause burnout and have a negative effect on mental health.

- Even if a woman with autism learns when to stop, she may then have to cope with the disappointment of not having achieved what she felt she was capable of.

Misunderstanding of achievements and difficulties

- Some achievements and abilities of some women with autism may mislead other people into thinking that there are no difficulties, therefore leading to problems and a lack of understanding when support is needed.
- Achievements of some may also lead other people to generalise and think that all women with autism are capable of the same accomplishments.

Non-recognition of achievements

- Autism-related difficulties may mislead people into thinking that some women have not achieved anything, and have no potential for achievement. So expectations can be low which in turn can lower self esteem.
- Some women with autism might have to work hard to achieve something that would not generally be considered in society as an achievement, but for them the obstacles may have been immense, and the achievement very much deserves recognition. Recognition by the woman herself might not take place because she may not see it as an achievement if society does not.

Learning Goals

To see your achievements as part of your whole self, taking into account all aspects of yourself, and not comparing with society.

To recognise the accomplishment of your goals

Learn that nothing is perfect, and that happiness and satisfaction comes from within you.

Potential Learning Strategies

- Try to balance perseverance against learning when to stop and take breaks. Try to take the breaks that you need and use perseverance to allow yourself to take the time that you need. Try to acknowledge that if you push yourself to a place where your mental health suffers, you may not achieve the goal anyway. See also Personal health for strategies to assist in taking breaks.
- Break things down into small structured steps. Eg Separate tasks into small tasks and define goals for each task.
- Write down all of your small accomplishments, however small you think they are

- It is important for people who don't have autism to try to see achievements from the viewpoint of the individual with autism herself, so that support can be given in the areas that she would like, and recognition and celebration can take place for things that she sees as an achievement.
- See strategies for religion and spirituality, and strategies regarding taking breaks in the personal health section
- Other strategies may also be relevant, eg if difficulties in communication and social interaction are preventing achievement, then strategies in the personal relationships and community connectedness sections might be of use.

Personal Stories to illustrate

Ellie achieved her A Levels and a University degree, graduating with honours despite having dyslexia and other struggles including co-ordinating tasks when learning. She continued to persevere through various setbacks, pushing herself outside of her comfort zone until she defied expectations and overtook other people in her mastery of areas that she struggles with.

Sofia also completed her university degree, despite many obstacles. She did not have a diagnosis of autism at that time, and therefore had little insight into what her difficulties were about. For her, it was a great achievement to obtain a diagnosis, and it provided her with the clues that she needed to start understanding herself and to continue to move forward in her life. She had wanted to train as an art therapist, but now feels that this is not appropriate for her. She knows that some of her autism-related difficulties mean that she might not be in the best position to respond appropriately to other people's difficulties. But instead of allowing herself to feel that she cannot achieve her goal of being an art therapist, she has looked at herself as a whole, trying to reconsider her career focus and re-set her goals. She does not see this as lowering her goals, but as adapting them suit to her improved knowledge of herself. In this way she remains positive and realistic at the same time.

Maria separates her tasks for the day and puts a mark for each achievement she completes. This has two advantages; she recognizes her achievements, and is also able to show them to others, as small as they may be.

Paloma feels achievements in her life are related to the time that she is able to spend with her family. Achievements can be related to external motivations.

Julie's obsessions and co-morbidities have a real impact on the achievement of her goals as well as on her employment and on the community activities that she can take part in.

Domain: Personal relationship

Personal relationships are all types of interactions and relationships with other people in all areas including family members, partners, friends, colleagues, members of the public, teachers, health professionals, employers and anyone else.

Some potential issues or obstacles which can affect personal relationships

Lack of understanding of autism by other people in general

- Lack of interest in learning about autism, or taking on board realities of autism can be frustrating, and strongly affect relationships.
- Because of the invisibility of autism sometimes, there is often little pre-emptive support and other people tend to forget until some kind of mishap occurs to remind them.
- People can have a very mistaken negative perception of women with autism, due to such things as interpreting directness and/or reluctance to socialise as rudeness, or mistaking quietness and/or confusion for ignorance.
- Being treated like a child, not trusted to make their own decisions, overprotected – these things have a negative impact on self-esteem, independence and ability to become more independent.
- Expectations of other people because of being female – such as expectations about appearing feminine and caring, and wanting to talk about having boyfriends and children.

Misunderstanding by women with autism

- Misinterpretation and making mistakes at times can lead to constant uncertainty and anxiety about being conspicuous and/or not fully understanding what's going on. It can also lead to over-analysing situations, trying to spot ulterior motives or hidden agendas when they're not always there.
- Lies and untruths by trusted people can result in difficulties with trust, including self-trust because of being aware of struggling to ascertain what is true and what is false. Untruths can also lead to confusion when a woman with autism believes something that others would not expect them to believe. And this in turn can lead back to misunderstandings by other people, who may then assume that they are unintelligent, or that they are being deliberately obtuse.
- Women with autism may hold myths and about people who do not have autism; their experiences may have led to negative thoughts which are likely to affect their relationships. Some women with autism have described the world of social relations between women as prototypically more complex and less attractive than relationships with men.
- Can they trust anyone but the run out to meet and have difficulty separating the intimate space of the public (The women with ASD have a tendency to trust anyone the same way. This leads to a difficulty to separate the relationship with friends from the relationship with public in general acting the same way with both populations)?

Building relationships and deepening relationships can be immensely difficult

- There is a tendency to rely on other people to take initiative in a relationship. This can mean ending up with the wrong types of people, but perhaps not realising this.
- Not noticing cues given out by other people can lead to a tendency to assume that other people don't want to make friends. This can lead to fear of rejection, lack of confidence, and not knowing when to initiate (therefore leading back to relying on others to initiate).
- Even if an initial contact is made, women with autism note a tendency to continue to need other people to initiate conversation. Other people may get frustrated with this, or start feeling that the relationship is very one-sided.
- Phone-calls can be difficult because of the lack of any other activity aside of just talking, and as phone calls are often unexpected, some find this aspect of social contact difficult to handle. Having difficulty talking on the phone can lead to relationships fizzling out because contact is not easily maintained between occasions of seeing each other.
- A lack of contact with extended family and other people in general, due to not being sociable, can lead to a feeling of social isolation.
- Women with autism can experience a huge internal conflict between contradictory aspects of themselves; one side of some is inadvertently rude or hurts people's feelings, but the compassionate side does not want to do this. The side that strives for justice struggles with people having a mistaken impression of their intentions and personality, and the side that strives to fulfil potential realises that upsetting people affects one's prospects. So they may have to work really hard to overcome the side of them that might make social blunders, but this is very exhausting and might mean not being free to truly be oneself.
- Having anxiety about speaking up, having something to say, or saying the right thing can have the effect of having less to say, leading to worries about being boring.
- Having conversations about personal matters involving complex emotions can be difficult because of not always knowing how to respond, advise or show caring and interest. This is not the same as actually not caring or being interested.
- Women with autism often manifest a better connection with other people with autism.

Relationships with partners or potential partners

- Women with autism may not notice cues when other people are interested in them. This can result in opportunities being missed with nothing getting started when perhaps it could have. Alternatively, it could mean that they get into a friendly, innocent conversation but give the other person the impression that they want a relationship when they might not. Women with autism note that they struggle to deal with unwanted attention.
- A partner or potential partner may think that they are being stand-offish when it is more likely that they just need some space, or time to process things.
- Some feel that they maybe do not experience attraction or desire in the same way

that other people do

- All of the above can create lack of motivation and a general lack of wanting to be with other people because it just isn't enjoyable.
- Loving relationships are interpreted as a kind of romantic salvation, or a disney movie by some women with autism, generating a lot of stress and difficulty in achieving and maintaining a realistic romantic involvement, or putting them off this type of relationship altogether.
- Some women have difficulties related to gender and sexual identity, which may lead to additional struggles in forming intimate relationships, and in understanding what they really want regarding having their own children.

Learning Goal

To improve two-way understanding between yourself and other people

To enjoy yourself and your relationships, and to feel more comfortable in them (not any / every relationship – just those relationships that you want)

Learn the signs of a healthy relationship, as well as warning signs of inappropriate or abusive relationships.

Potential Learning Strategies

Regarding a two-way understanding:

- Don't wait for other people to take pre-emptive action, take pre-emptive action yourself; try to figure out what your needs are and tell others what they are.
- Speak to people who you sense have a more natural understanding of the autism spectrum.
- Don't be afraid to talk about your autism
- Express what you're thinking; try not to over-analyse, assume or jump to conclusions. Ask, give the other person the opportunity understand where your confusion, frustration or anger might lie and to clear up any uncertainty.
- Have a mentor, a trusted female who does not have autism who can help you to learn social skills and discern when to take things at face value, and when another person might have a hidden agenda. (See also personal health for more about mentors)
- A mentor can also help explain possible cues and body language that you might be missing.
- A mentor can also help you to learn from difficulties, and use them to improve your understanding
- A mentor might also be able to increase understanding of the people around you.
- Take a step back and try to take a different perspective from your own – this will give you a wider view of what might be going on. Put lies / untruths into a more general perspective, and speak to a mentor about why they might have been told.

- Visual / Written Support to help with communication
 - Lists, written instructions
 - Timetables
 - Picture cards, symbols
 - An example is at a gathering of people with autism, everyone wears a traffic light badge – red, orange or green. Wearing the red badge means ‘I do not want anyone to approach or talk to me’. Wearing the orange badge means ‘I may not want to speak to anyone – please check with me first’. Wearing the green badge means ‘I am happy to be approached and willing to interact, but I may get it a bit wrong!’

Regarding a healthy relationship:

- Learn to appreciate shared history and experiences of families, unspoken acceptance and closeness
- Have fun, do activities with the other people that you genuinely enjoy.
- Try new things and seek out a range of opportunities for meeting people; this can lead to you learning more about yourself – you could treat this as a science project. Don't say no because you might be scared of something, or because it is unfamiliar – you might never find out the things that you enjoy and/or are good at if you don't try.
- See differences of opinion as exciting, push boundaries and enjoy having your boundaries pushed.
- When trying something new or out of your comfort zone, always have an escape plan. This makes it less scary because you know that you are able to leave the situation if you need to, and you can maintain control on your own terms.
- Be more forward if you're interested in someone, and don't assume they're not interested. Express what you want as it may lead to something, but try not to be put off or take it too personally if it doesn't.
- Learn when to move on if you don't want a relationship with someone, or you are not getting on with someone, or it is not going anywhere
- Plan things in advance, for example make appointments for phone calls, and make lists of things that you want to talk about and things that you want to ask.
- Make connections with people who are strong socially, as this helps lead the conversation
- It can be worth trying friendships with people on the spectrum as they can be more understanding
- Use technology, for example facebook often provides good starting points for conversation - something to comment on rather than initiating something out of what might seem like nothing. Photos can also be useful in a similar way.
- Find shared interests and genuine reasons for keeping in contact.
- Accept your own feelings, don't be distracted by what society tends to dictate. If you are happy without partner, then that is the most important thing.

- When building a relationship with a partner (if you want to), take advantage of the fact that the development of this type of relationship can be more tangible, more structured.
- If hoping for a relationship with a man, you can also take advantage of the fact it generally tends to be expected that men will approach women, so feel comfortable in yourself in allowing the man to take the lead, and respond to what you feel genuinely happy with.
- Don't be afraid to try relationship counselling with your partner, using a counsellor who has specific understanding of autism (and in particular focusing on when it is a woman with autism in the relationship)
- Working the circle and explain relational activities and conversations levels of intimacy and adaptation to the context

Personal Stories to illustrate

Louisa has built good relationships with her extended family, especially the children. She takes them on activities, they stay with her overnight. They have been able to have lots of fun and deepen their relationships.

Hannah has used the more tangible structure of a partner relationship with a man as a tool to help her develop a deeper friendship and companionship with her partner. He has recently become her husband.

One of the Spanish participants shared their personal data, and gives information about his own diagnosis of others indiscriminately aspects that can make this does not always help, but also a fact that can be exploited by others.

Frederica and Matilde, who play in a band, began to speak freely with everybody after going out to play music with them. This shows how more much comfortable they can feel in an environment where they feel they fit, and where they have an inherent interest in the activity that is taking place.

Tanya has developed unrealistic ideas about romantic relationships and has a specific aversion to sexuality, indeed to her own needs in this area.

Domain: Personal Safety

Women can be particularly naive and vulnerable socially, which can lead to a range of possible safety issues. Sensory differences can also lead to potentially dangerous situations.

Potential issues and obstacles related to keeping safe physically, mentally and socially

Uncertainty regarding reading situations and intentions, and knowing how to react suitably or act in a way that does not provoke other people:

- Women with autism may feel unsafe when using public transport – the atmosphere can be quite intimidating especially if there are groups of people travelling together, and picking up cues is difficult so it is hard to know what to expect
- Some are not always aware of what cues they are giving out so might look like they're staring at someone or catch someone's eye, or they might look sullen or stand-offish, inadvertently causing someone else to become negative or confrontational.
- Some may sense the difficulties and hostilities of people around, especially family. They may feel unsafe but find it difficult to express or handle. They may also think they do not have enough strategies to manage any hostility.
- Awareness of problems and vulnerability means that some women rely heavily on other people for their safety. This can be frustrating and also limiting in that some may not be able to go out alone.
- Feeling unsafe if anyone approaches them
 - men might be trying to make advances, comments, giving unwanted attention. They may not know how to deal with this, and may also be more deeply affected, feel like a sexual object and not be able to brush the whole incident off
 - some people (particularly neurotypical women) can be unpleasant especially in a group; they may target women with autism because they somehow look vulnerable.
 - someone might say something to that they might feel unsure how to react to. Any reaction, even no reaction, might be the wrong thing and might turn a situation into something negative.
 - They can feel very vulnerable, not knowing how to react when approached in the street by charity workers, beggars, etc
- Vicious circles can be created:
 - the more anxious they become, the more they feel unable to deal with other people, and the more unsafe they feel. Then the more unsafe they feel, the more anxious they become.
 - the more stressed and anxious they may become, the more that other people may pick up on and exploit their vulnerability
 - if a women with autism acts in a way which is received negatively, she

may become more nervous and anxious, and therefore more likely to act in a way that elicits even more negativity from the other person or people.

- Cash points can be a particular worry, they can be very uncertain and nervous regarding the possible intentions of people waiting while they take money out.
- They may have difficulty knowing the difference between real and perceived threat / danger. Also difficulty in reading the environment, knowing if the environment itself (rather than the people in it) might present danger.

Bullying and exploitation of naivety

- Some women with autism find interacting with men less difficult than with women, but this can lead to misinterpretation by men, possible misreading of their friendliness or sociableness, thereby eliciting unwanted sexual behaviour.
- Naivety might lead to misreading of situation or man's intentions, leading to awkward and potentially dangerous situations. Also difficulty in identifying one-night stand (at any stage).
- Some are not always aware what body language means, so might inadvertently give out misleading body language simply because a certain stance might be more comfortable. Some are aware that they might give out the wrong signs, which then might make them more anxious or awkward, at times being afraid to do such things as be friendly or give a hug, in case of misinterpretation by others.
- Some women may have a tendency towards obsessiveness around sexual relationships making them vulnerable to hurt from rejection, or exploitation.
- Bullying can happen anywhere simply because of women with autism sometimes not fitting in, visually or otherwise. They can also be bullied or exploited because of naivety.
- Bullying in the school playground is frequent, especially in secondary school. This can be a very hard situation and can lead to continual stress.
- Women with autism may be particularly vulnerable to abuse within a 'partner' relationship for many reasons; they may not identify that they are being subject to abusive behaviour, they may not have peers to talk to about it, so might not get the help that they would need to identify it, they might have low self-esteem so see it as their fault, they might stay in the relationship because they feel that they have nobody else to turn to for company, or that they will not find another partner, or that they have nobody to support them through a break-up of their relationship.
- Awareness of vulnerability might lead to feeling insecure at the prospect of sharing a flat, meeting someone new, travelling or living out of town and starting any new leisure activity or academic study because of the worry of misunderstanding or being harassed

They may think they do not have enough strategies to manage hostility.

- Trusting a person might lead to assessing a situation as completely safe, but both the trust and the safety aspect could be misjudgements caused by naivety

Sensory differences – tendency to focus on one sensory input at a time, sensitivity to stimuli such as noise, smell, bright light, other visual stimulus, touch, too many people, no space, etc.

Difficulty with multi-tasking or needing to think about several things at once.

These areas can lead to danger:

- Sensitivity to sensory stimuli can cause overload and sometimes meltdown, where a woman with autism may find it difficult or be unable to take any action to help herself out of a situation
- Losing or forgetting keys / bags etc, leaving front door or car unlocked, bag unzipped
- Not being able to find the right train, bus etc, getting disorientated or lost

Other people not playing by the rules can lead to escalating and potentially dangerous situations. For example, people breaking rules when driving can make women with autism who are also driving cross and frustrated. They need to prevent escalation, and still be able to drive safely when cross, or to stop in such a way whereby safety is not compromised.

Unexpected situations and incidents that need to be reported to authorities, police and / or medical professionals

- Thinking and worrying about steps ahead may lead to not being in the moment, being less responsive and receptive to stuff going on around. This may mean that professionals might misinterpret their behaviour.

Behaviour might be perceived as strange and suspicious, communication, body language and emotion might not match
- Women with autism might become completely overwhelmed with emotion, not be able to cope, freeze up or and not be able to stay calm, so not be able to get help if someone else needs it

Self-imposed danger, such as self harm, suicidal thoughts, anger directed inwards.

Learning Goals

To be able to go out when you want to, and to be safe and feel comfortable when doing so.

To be able to manage emotions of frustration and develop strategies to identify and evaluate situations where you may be unsafe.

Potential Learning Strategies

Regarding confidence and emotions of frustration:

- Go out with someone who is more confident and better at reading the situations around them.
- Wear headphones, listen to music, read a book, or close your eyes avoiding eye contact and looking at other people. These things can also help avoid meltdown due to overload by numerous stimuli (but remain alert and aware of what is going on around – don't allow yourself to get too immersed in the music / book etc).
- Learn how to recognise and respond to cues, as well as how your behaviour can be perceived by others, and what to do that would be suitable to the particular situation. A mentor can be very helpful with this.
- If giving no reaction is making the situation worse, try reacting in a measured, logical non-aggressive way.
- Some women with autism find that thinking about a worst case scenario can be calming because it does not happen (or happens very rarely). But others find this provokes further anxiety.
- Work on your own potential anger and angry reactions outside of this type of situation – in counselling, with a mentor, using role play.
- If someone's sexual approaches are unwanted be clear and direct, but remain polite.
- If you are not comfortable with a situation whilst using public transport you could change seats, change carriages, or get off the bus / train.
- Remain aware of your belongings.
- Put routines in place to ensure safety such as checking your door is locked, and your bag is closed. Have checklists in suitable places and make sure that you have a mobile phone with you.
- Plan ahead, for example plan your route if you are using public transport and have back-up plans in case changes need to be made.
- Have lots of keys cut and leave them in different places around your house. Tie them into your bags with long string or ribbon.
- Sometimes travelling where you might meet people that you know, or who have bullied you in the past can make you very anxious, so try building up general confidence on public transport by travelling somewhere unknown
- Use logic to deal with the situation – get on with what needs to be done, putting emotion aside.
- If police are involved, request assistance from a friend or advocate who has understanding of you and your autism (you are legally entitled to this in the UK).

- Know your own signs and signals when you are becoming overloaded, or a situation is becoming too much. Have coping strategies such as taking yourself somewhere quiet, listening to music and try to be able to use these coping strategies in response to your signs and signals, before the situation worsens.
- Be aware that Facebook and other social media are not completely private or secure. Use different usernames, false names on line.
- Have a list of clues about how to recognise potentially dangerous, exploitative and untrustworthy behaviour, and how to act to protect yourself and how to respond to cheating, bullying or mobbing
- Explain your needings of help with manage jokes, double senses or critics to an specific natural support in all the environments that you will be involve
- Practice of sports, judo or another form martial art could make you strong
- Never show that you are afraid of the other people in the street or elsewhere
- Make believe you are stronger than the people who might bully you in school

Personal Stories to illustrate

Leah found that she kept being approached by men with sexual intentions when she was waiting at bus stops. She eventually discovered, after much in depth conversation with her advocate, that she was attracting these advances because she was unwittingly standing in a 'sexy' way. She had no idea of this, she simply found that the way that she was standing was comfortable. Now that she is aware that the particular posture she often used was the cause of the problem, she stands in a different way and men no longer make unwanted sexual approaches.

Lucia invited any person that looked kind or gentle in a conversation with her to her home. She didn't get involved in any problematic relations, but she now realises that this kind of behaviour has many risk factors.

Monica was bullied by boys in her school. She went to Judo classes and is very sporty and strong. When a fellow pupil began bullying her, she applied a Judo trick in self-defence. This meant that she deterred potential bullies and they admired her and her courage.

Domain: Community Connectedness

Some potential issues or obstacles experienced around being in the community

Being out, using facilities and services, participating in groups

- Using facilities such as banks, libraries and shops can be difficult if women with autism need to ask for something; some might go out of their way to use the same facility each time so that they know where everything is, others might go out of their way to use different ones so that staff do not start to become familiar and do not feel they should start to build up a relationship with them. At times some women with autism might avoid using facilities altogether, or leave without having achieved what they wanted to because of the need to interact in order to find something or understand something.
- Being out in the community incurs the risk of meeting people that you know or are acquainted with
 - Women with autism may struggle with recognising people out of the context (prosopagnosia) in which they met them. This may mean that opportunities for further socialisation are missed (if they are desired), or that they are mistakenly judged as being rude or stand-offish
 - small talk may be required or expected, which makes women with autism feel uncomfortable
- Attending groups, classes, activities where other people have to be involved:
 - lack of structure and organisation of some groups can put women with autism off going
 - women with autism believe that neurotypical people tend to socialise and make small talk during breaks and unstructured time; tending to develop friendships fast and easily. This can leave women with autism feeling left out and isolated
 - they attend groups because they are interested in and want to focus on the activity, whereas other people seem to be equally interested in the social aspect. Cliques can emerge, sometimes other people start to socialise outside of the group as well. Again this may leave the woman with autism feeling unaccepted and not part of the group, as well as frustrated by the lack of focus on the desired activity
 - they might not initiate any social contact for fear of being rejected by others, others may misunderstand and misinterpret fears as not being interested in social interaction, which may not be the case
 - they can struggle to speak up in a group, especially in a large group
 - they might feel uncomfortable because on the one hand they may not actually want to make friends; but on the other hand they feel stigmatised and isolated by not doing so
 - autism or disability specific groups can also be a problem due to

stereotyping. Also, these groups are perhaps less likely to be carrying out specialised activities that women with autism might have as particular interests

Because of past experiences of harassment or isolation, some women with autism may have negative attitudes towards people who do not have autism. They may have fears and more radical positions in defence of the culture of autism as a culture some consider to be morally superior. This could further increase their isolation within the community.

Some women with autism who require support on a day-to-day basis perceive that participation in the community is limited by the lack of professionals who have the understanding to help.

Feeling useful and having a role in the community can be a positive thing for women with autism, but there may be some difficulties:

- Uncertainty with indefinite, vague unstructured roles
- Lack of understanding of management or leaders; sometimes they don't know how to make suitable adjustments for those on the spectrum who may lack the confidence to discuss the adjustments that they need
- Some women with autism already involved in the community recognise the positive contribution they can make to the community, and their ability to be agents of change in their environment. But that important contribution to raise awareness in autism is not always recognised in all European societies.

Neighbours

- May not be able to deal with difficult neighbours – shy away from possible conflict
- May be comfortable to say hello, but anything further may be difficult because unstructured, without clear purpose or joint goal
- Women with autism may feel that it is important to be able to ask for help in emergency (more than just getting on with neighbours), but also feel that in practice this may not be possible

Using online community facilities eg messageboards, forums, social networking

- Women with autism often use these tools to replace face to face interaction that they find difficult or impossible to access, especially finding people with who they can share less typical common interests. This can lead to further isolation and lack of opportunity to learn practice social skills.
- May be unaware of online vulnerabilities

Learning Goal

To gain confidence and self esteem so as not to feel that other people always seem to have the upper hand

Do activities that you enjoy, talk about things that you enjoy – make this your focus, and you may feel more connected to others as a result

Regarding confidence and self esteem:

- Internet options can be more attractive and accessible for the development of relations. Online activity enables you to cut out the 'small talk' and opens doors for interactions you wouldn't otherwise; this can boost confidence and then perhaps you can move on to more face to face contact with other people.

Sometimes it can be dangerous because of their naïveté

- Create an initial bond that you can cope with eg Xmas cards for neighbours, or maybe offer them some stuff that you have in surplus or something you've grown; this is a fixed type of communication which may open doors for further communication. But even if it doesn't, neighbours may be better disposed towards you, and you may feel more able to ask for help in an emergency.
- Spend time with older people, they tend to be more open to difference, more likely to value you for your individuality
- Take tiny steps when less stressed – set yourself individual tasks involving interaction with less familiar people, to do alone, when feeling relatively unstressed. Eg. ask a stranger or neighbour a structured question like “what time is it?”, even if you don't need to know the time. Build this up, gradually setting goals to do it more frequently. This can lead to overall self esteem and increased confidence in approaching strangers and interacting with people. Try to develop this when motivated for specific outcome
- Talk about areas of specific interest, repeat them with different people; this can lead to increased overall confidence and widen circles of people who you speak to. By the time people are fed up with hearing you say the same thing the ice is broken, people are more comfortable, you might naturally have other things to say if you're feeling less shy talking to them.
- Pre-plan list of topics to ask other people and talk about, so that conversation is more flowing
- Give yourself a role, a speciality, embrace your differences, turn them into positives.
- Copying, mirroring, learning from neurotypical people
- Use a buddying or mentoring service re social skills (see also personal relationships)
- Volunteering somewhere can be a good way to boost confidence and socialise.
- It is important to learn about body language so you understand how to present yourself to others
- Be open about sharing your diagnosis with others – some feel it works best if you get to know other people a bit first, then share your diagnosis so it can help them to understand you better

Regarding activities:

- Have fun, do activities with other people that you genuinely enjoy.
- Finding people / groups with shared interests is the key, try to use the common interests to help build relationships

- Develop a list of exciting activities or hobbies that can include you in your interest groups (such as reading clubs, photography workshops, art ...)
- Try to change your attitude to challenges, see them as 'adventure', a positive not a negative challenge
- Flip things to positive eg anxiety to excitement, obstacle to enjoyable challenge
- See personal relationships
- Consider going out to shows, concerts, games, sports, according to your interests. It is a motivation to go out and interact with other people (see also personal relationships)
- Use sources such as the internet, libraries, community centres and local colleges to find out possibilities regarding involvement and participation in community activities.

Personal Stories to illustrate

Diana feels a part of many groups in her community and has an active role as a volunteer in one of them. But this can be problematic because her role can be to go around and chat to people. She would prefer a more structured role eg working on the till, where chatting is secondary and more natural. The people around her say that they are accepting and understanding of her autism, but she feels that if they really were, they would not put her in this kind of position and support her in a role in which she feels more comfortable.

Flavia also volunteers and feels that it has helped her to meet other people, and to have a role in her community.

Anastasiya feels that she has good connections with her community – she is on several committees and leads a consort group. She gains respect from others in her groups because her strengths and talents speak for themselves. She feels that she would be comfortable enough to ask for assistance if she needed it from some members of these groups – this could help her build wider circles of support around her so that she can gradually become less reliant on her parents in the future, so has a positive effect on her future security.

Anna is following a process of person-centred planning, in which family and others close to her are agents of connection with the wider Community

Isabella can't hear but likes going out to shows, restaurants, concerts and spectacles very much. She quite enjoys movement: of people and of things. Her mother takes her everywhere. Her interest is being supported on her own terms.

Lucia helps in a kindergarten and as she enjoys being with children. To do this she fights her own fear of going out to meet people, thus gradually building her confidence.

Domain: Future Security

Some potential issues or obstacles that relate to the future

Thinking about the future is difficult as it is generally abstract

- This can lead to difficulty in planning for the future. Without planning, coping with what the future brings might be problematic
- This can also lead to enormous concerns and anxiety about the future

Additional practical, emotional and financial support in the future

- Worries about where additional support will come from, especially when parents become elderly and die. A lack of contact with extended family and friends due to social difficulties, and / or struggling to deepen friendships (as mentioned in personal relationships) can decrease the potential number of people around them who can offer support (later referred to as circle of support), sometimes increasing reliance on parents.
- Autistic women who live in residential homes have poor expectations in the future especially if parents are not around; there may be no possibility of a future independent job, so they remain in the residential home, sometimes with families or friends who help them.
- It can be difficult to get appropriate formal support from outside as an alternative to support from parents and family:
 - Some women with autism are thought to be ineligible for support from social services as it is not understood that they can appear to be so able and articulate, but still need support with some practical things like banking, finances, going shopping, looking after themselves. Some need to fight hard to get others to understand, and are often passed from department to department, with phone calls and emails not being responded to. The whole fight can be more than they or their families are able to take on in lives that are already busy and/or stressed.
 - Some women with autism feel that support from outside of their family would not work for them. Trying to connect with a stranger and communicating what needs to be done to give the appropriate support would be difficult and/or increase stress levels.
 - Some do get some support but it is not always appropriate – as mentioned above it can increase stress levels, especially if the person who is supposed to be supporting them has difficulty in understanding their needs.
 - They might need to be supported in different ways for different things. For example, they may need advice for some things and practical support for others. Sometimes they may need something done for them, but other times the best support is to teach and explain how to carry out certain tasks or solve certain problems independently, in their own way. A single support role often cannot cover these different needs, so this may mean

more fighting for appropriate support.

- It is important to strive to become more independent so that less/no additional support will be needed in the future and when change occurs. The right support is needed now for skills towards independence to be developed. Formal support can be difficult as described above, but also informal support from parents and family can incur difficulties:
 - Parents and family can be over-protective and treat women with autism like children unable to fight their own battles and make their own decisions. Sometimes an understanding of autism is lacking. Autistic women can feel claustrophobic living with parents, but not be able to live independently at the moment.
 - It can be very difficult to get the right balance between being supported and becoming more independent, developing more skills so that they can be more self-reliant in the future.
 - Some have to deal with the emotional impact of needing support, relying on others, feeling a burden on other people now and into the future, and not being able to support others as much as they would like to. Some feel guilty and anxious about this, thus increasing stress levels that are already high.
- Owning own property / accommodation is important to avoid being subject to property owners and landlords deciding to make changes for their own reasons. But buying a property / getting a mortgage can be difficult and expensive, especially with problems regarding employment.

Employment

Like most people, women with autism want to earn their own money so that they don't need additional financial support in the future, not only in relation to providing for themselves, but also very much in relation to wanting to be able to support others such as children and parents.

- It is often difficult for them to get paid jobs that are in line with abilities and qualifications.
- Most employment has a social aspect, and the better paid the job, the more likely it will involve an element of management and therefore quite complex social aspect to it, increasing stress levels.
- People change jobs more now than they used to, and are less focussed on progressing in a chosen lifetime career. This societal trend is a worry for some women with autism, who know that change in the workplace can be a great challenge for them.
- For some, employment may not be an option for them at this time. Possible changes to benefits in the future are a concern, especially regarding lack of understanding of authorities around why women with autism might not be able to meet certain requirements.

Learning Goals

Increase the circle of support around you, and achieve empowerment regarding autonomy in your daily life.

Work actively now (with support if necessary) towards more future independence practically or emotionally, in whatever ways suit you as an individual.

Potential Learning Strategies

- Get appropriate formal support, both practical and emotional with strong understanding of autism; seek this support via medical professionals, social services, local charities, groups, workplace, educational settings, and advocacy services. Get someone to help you to fight for this support.
- Learn explicitly about existing community resources and autonomy skills or resources to seek and obtain help
- A mentor, counselling, an advocate or a support worker are some of the possibilities that might be appropriate, depending on your needs. (See also personal health and relationships for more about mentors)
- Get someone who can explain and teach rather than do things for you.
- Try to develop friendships (could be one or two – doesn't have to be many) with trusted persons who could check on you regularly. Keep parents or a trusted friend updated about who your friends currently are.
- Be aware that sometimes parents and family have their own issues and worries, which can affect their actions around you.
- Look into turning hobbies and talents into a job.
- Broaden your horizons when thinking about jobs that you might be able to do.
- Do volunteer work to improve your job prospects and experience.
- Get assistance from careers advice services specifically trained in autism.
- Develop interview skills and job skills, through training or assistance from a mentor
- Look into benefits available as it can be possible to get a personal budget to help with specific autism-related needs.
- Use logic as a strategy to decrease worry over things that you can't control.
- Off-load worries using a strategy that suits you – eg. painting, music, writing a diary, talking to someone who understands.
- See also Standard of Living for strategies related to finance and budgeting.
- Look into whether there is a support helpline available which you could contact whenever you needed to.
- Creating a forum or web site with strategies and resources for independent living, video modelling, training and histories, social stories

- Participation in environmental planning models (person centered plan) to help set short and long term to strengthen security in the future
- Importance of creating specific Autism support such as housing services, residence, personal assistants supports housing, following good practice such as the TEACCH model and visual or written supports such as lists, written instructions, timetables, picture cards and symbols.
- Communicate with employers before you go for an interview and once in employment, give them information about autism, and offer suggestions for reasonable adjustments that they could use to support you to carry out your job in the best possible way.
- Reasonable adjustments / reasonable accommodation according to UN convention:

In the UK, if a disability is disclosed eg in the workplace, then 'reasonable adjustments' must be considered, to take into account difficulties that the person with a disability might encounter. It is worth looking into the legalities of this, according to the individual situation. It is a good idea to request adjustments pre-emptively based on your individual needs, rather than waiting for difficulties to arise.

In Portugal the laws are in favour of employment for persons with a disability and “reasonable adjustments” must be considered. There are financial prizes for those who employ these persons. However employers favour employees with physical impairments instead of intellectual disabilities like autism. In certain cases people with autism are cherished and adjustments come naturally. Requesting adjustments as soon as possible is also a good idea.

Personal Stories to illustrate

Rosie lives independently but feels her mother often treats her like a child – trying to influence her choices, buying clothes for her and not involving her in family tasks and decisions. She feels patronised and undermined, and family relationships are strained. She was advised to try not to take her family's behaviour too personally, and to try not to read too negatively into some of the things that they do. She was reminded that family members might have issues of their own for example wanting to feel that they are still needed as they become more elderly. Also that they may be trying to relieve financial pressure that they think she is experiencing; they might be choosing the wrong ways of going about trying to be supportive of her.

Sophie has a well-paid job as a teacher, and head of her department. She is good at her job, has high aspirations and wants to achieve what she knows she is intellectually capable of. Stress levels are very high for her due to sensory sensitivities and the social demands of her job; she is able to meet these social demands with continual effort. She needs to be able to truly relax and be herself at home, but this is often not possible because of further work demands (amongst other things). She is left feeling continually drained, and sometimes unable to do other things that she would like to do with her spare time. She feels that she has to make a choice between her financial security and her mental well-being, knowing that she would be less stressed if she had a less demanding job, but at the same time would have less money and would have to decrease her standard of living, as well as lower her

aspirations and perhaps feel less fulfilled. She would also like to have her own family, but she thinks that she would not be able to manage this and a full-time job at the same time, which again would affect future financial security. She is working on trying to set up her own business, but this of course comes with its own stresses.

Marcia and Claudia continue to live with their families. They have difficulty dealing with some aspects of everyday life such as shopping, choosing and making food. Investing large amounts of time in getting or keeping a job is likely to have a negative overall effect for them, as there would be little time left to work on these areas and to continue striving towards independence in their daily lives.

Amelia has studied at college and lived abroad. She currently has a temporary job. She paid for her studies with financial support from her family. She perceives that her future security depends mostly on her emotional state, having a job, and developing skills to deal with the deception of others.

Alicia is an orphan and lives in a residential home funded by a charity, but it is not a residential home specifically for persons with autism. She goes every day to a Day Centre for persons with autism. She is nice, plays drums in a music band and has a circle of friends among the staff. They invite her to lunch at weekends. She has not had the possibility of being adopted because of her age, but works in the laundry in the Day Centre. It is not possible for her to live an independent life but she is happy with her life and doesn't seem to worry much about her future security.

Domain: Spirituality / Religion

As with anyone, religion in itself may or may not be relevant to women with autism. Religion is mentioned here at times, but the more universally relevant aspect of the topic of spirituality is that of sense of self, which many women with autism feel that they struggle with.

Some potential issues or obstacles which may relate to religion or spirituality

Sense of self, achievement and self-fulfilment

- Many women with autism feel that their sense of achievement, fulfilment, joy and satisfaction is closely linked to personal connections with other people. Since personal relationships can be difficult, these things can be affected negatively.
- Sense of self is affected by society, and what is generally thought to be the norm, such as marriage, children, a job. Because women with autism sometimes don't conform to the norm, they may feel that their achievements are less valuable, and that they are a failure, especially in the eyes of society.
- Understanding of self and sense of self can be difficult due to lack of concrete nature. Sometimes, some women with autism have difficulty in clearly identifying their own physical and emotional feelings, so this can make it difficult to know themselves.

Strong sense of justice, truth and right and wrong, strong moral and ethical codes, and adherence to rules that make sense

- Speaking the truth can get some women with autism into trouble because sometimes the truth is negative, and other people might prefer not to hear it. The other person might be offended by the truth, or feel angry with them for voicing it, or they might see things from a different perspective, so not agree with the truth as they see it.
- Some are aware of this, so often have to make a conscious (as opposed to instinctive) decision regarding whether they tell the truth or not. If they decide to, they may have to face negative consequences from other people; if they decide not to, going against their nature can feel uncomfortable, and lead to further uncertainty regarding sense of self.
- Women with autism who are less able to see how their actions might affect others may be using a much more personal set of parameters regarding 'right and wrong.' For example, if they are hungry, it may be absolutely 'right' for them to try to take the food off someone else's plate, and absolutely 'wrong' for the other person not to allow this. This can lead to anger and conflict on both sides.
- Strong sense of justice, morals and adherence to rules can cause problems and frustration when other people behave in a way that could be seen as unjust or less moral. It can also be very frustrating for those who stick to the rules, but find that other people don't bother. This can lead to anger and

conflict if women with autism decide to voice their frustrations. It can also lead to a sense of superiority mentioned in community connectedness, which can lead to relationship difficulties.

Religion

- A negative opinion of religion may be formed due to seeing injustice and a lack of morality taking place in some religions. The negative opinion is not a problem in itself as we are all entitled to our views, but in some cases women with autism can end up feeling very angry, which can affect their personal wellbeing and sense of joy for life in general.
- Some have difficulty empathising and managing their beliefs when others do not share their abstract understanding of religion. It can be a controversial and emotional issue which is hard to handle and communicate.
- Some women with autism just find religion illogical, but have their own special sense of the world, nature, animals, science or art, which other people might struggle to understand.
- Some may be vulnerable to treachery or manipulation by coercive groups.

Birth and Death

- The birth of someone close in the family can be difficult for some women with autism to understand, especially if there is suddenly less time for them, and family members are giving them less attention.
- Bereavement can be a particular problem. Death is intangible therefore especially difficult to think about. Difficulty with thinking about the future may mean that women with autism find it more difficult to prepare themselves regarding the death of other people.

Learning Goal

To learn to see your own intrinsic value and have faith in yourself just as you are, without comparing yourself to the expectations of society.

To be able to defend your personal beliefs assertively but respectfully.

Potential Learning Strategies

Regarding value and faith:

- Think about your achievements and what you are doing on your own terms, don't compare with other people. Try to appreciate your uniqueness, see your own worth.
- Disconnect with expectations of society; your own expectations and ways of feeling fulfilled are far more important, as long as you're not hurting anyone else. Seek self-development in terms of your own joy and your own achievements.
- Use logic to help to see that something could be 'right' in a different sense. For example, taking the decision not to say a particular 'truth' might result in avoiding

someone being upset, thinking badly of you, or starting a fight.

- Use logic, research skills and scientific inclination to learn more about the world and life in general, for example on a sub-atomic level. This can open up your sense of awe and wonder about the world and yourself, and help you to understand that there are gaps in your knowledge and always will be. This in turn can help you to reconcile with not being in control at times, and not knowing all the answers in your own life.
- Explore your talents and express your inner self and sense of transcendence – this could be through music, art, photography, trapeze, martial arts etc. Doing things that you are good at can build confidence and self-esteem, and help you to have a stronger sense of self. Letting other people see or recognise the things that you are good at can also be very positive.
- Belong to a group -it could be religious or otherwise- but somewhere you are accepted as an individual.
- Find a role or responsibility that suits you, that could give you purpose in your life if this is lacking. This does not have to be employment - it could be the case of identifying something that you already do in this context.
- Be positive – discussing barriers is not necessarily negative, as sometimes other people see it. It can be a way of seeing the barriers as challenges, and finding solutions or working out the steps needed to overcome the challenges.
- Become aware of coercive groups that might appear as religious or progressive in areas of personal development, and learn to distinguish these.
- Religious services such as Sunday mass, marriages, funerals, christenings and other religious habits and customs can be useful in helping to provide a structure or something familiar. The predictability of things such as what is worn, what people sing, how people behave in certain religious ceremonies can help to create meaning for a woman with autism who might be struggling to understand what is going on around her, especially in relation to abstract concepts.

Personal Stories to illustrate

Karen is a member of her local church. She is accepted as a valuable member of the group and has several roles within her church – she leads choir practices, compiles songs and types out song sheets for the services. All of this gives her a solid role, a sense of responsibility and acceptance. She is also a fantastic singer, so this is a chance for her to express and enjoy her talent, and for it to be recognised by others too. There are areas in her life which are frustrating, and people sometimes do not see past her autism to her individual strengths and capabilities. So the sense of self that she gets from being a member of the church helps to build her confidence and self-esteem in a way that is very valuable for her life in general.

Emilia has a similar story - she sings very well, really enjoys it, and wants to be a singer. When she sings in the church choir she says she feels like she is soaring above the world. In this case religion is strictly linked to her spirituality and sense of joy.

Kelly has learned to accept that she's not really a spiritual type of person. Although formal spirituality/religion doesn't play much part in her life, she still has a sense of personal well-being and development." She also tries to think more about what she is managing to achieve and to recognise her achievements. She feels it is less necessary to compare herself to others, now she thinks more about what she is doing on her own terms.

In contrast, Gabriela's only interest is scientific knowledge, as things that you cannot prove are not real to her and do not convince her.

Monica feels she has a special connection with nature and is able to sense thoughts or events that are going to happen; she feels that this is about her special or different sense of the world and her perception of reality.

There are times when places are adapted and Joana can access to her objects of interest with freedom from trying to be different from who she really is. This can create particularly special moments, with extraordinary quality and connection to her sense of self.



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