Supporting people living with autism spectrum disorder and mental health problems

A guide for practitioners and providers

October 2015

We're Mind, the mental health charity.

We believe no one should have to face a mental health problem alone. We're here for you. Today. Now. We're on your doorstep, on the end of a phone or online. Whether you're stressed, depressed or in crisis. We'll listen, give you support and advice, and fight your corner. And we'll push for a better deal and respect for everyone experiencing a mental health problem.

mind.org.uk/equality

There are many terms that are used to describe the range of conditions that fall on the autism spectrum but for the purposes of this document we have chosen to use ASD (autism spectrum disorder) to include diagnosis and terms like autism, Asperger syndrome, atypical autism, pervasive developmental disorder not otherwise specified, and autism spectrum disorder.[1]

Lucy's story

"I think a lot of care is needed to make sure the needs of people with ASD who are not able to communicate their views such as nonverbal people are not lost. I have experienced services that treat mental health and ASD as completely separate issues and both services seem fearful of people with the other condition.

"I am just me – a whole person with my own unique personality, rather than a set of symptoms which can be easily recognised to one of my 'conditions'.

"The reliance on carers and professional views about my unmet needs, makes me want to shout "that's not what it's like" when they describe or interpret what they think I am thinking and feeling. It also seems that the attention is only on children with ASD like if one could 'grow out' of autism as you become older. As a result most services and interventions are designed for children, when obviously what is appropriate for a child at school can be very different for an adult like me."

Lucy lives with Asperger's syndrome and borderline personality disorder.

We are grateful to Mind for putting together this toolkit for mental health services to help support people on the autism spectrum. Although autism is not a mental health condition, people on the autism spectrum are more vulnerable to mental health problems. Research indicates that 70 per cent of children with autism develop mental health problems, while 16–35 per cent of autistic adults have a comorbid psychiatric disorder. It is vital that, when mental health problems arise, mental health professionals and providers are able to give high quality support that works for people on the autism spectrum. We hope this toolkit gives those professionals some of the guidance they need to make this happen.

Sarah Lambert,
Head of Policy
National Autistic Society

We are pleased that Mind is focussing on mental health difficulties in autism. When Autistica recently consulted with 1000 individuals and families, they identified support with mental health as their top priority, so this tool is clearly responding to the community's needs. It is reassuring that the tool was developed with those on the autism spectrum, and acknowledges that everyone is different so benefits from individualised support. We look forward to working with Mind, other autism and mental health charities, and the government to ensure effective, joined-up support gives individuals with autism the best possible opportunities in life.

James Cusack,
Research Director
Autistica

It was a pleasure reviewing this comprehensive document. Wirral autistic society is always keen to promote partnerships that improve outcomes for people with autism. We hope this toolkit will improve the quality of mental health services by putting autism specific strategies and approaches at the forefront of discussions on co morbidity.

Robin Bush, CEO
Yvonne Crowhurst,
Head of Autism Practice
Wirral Autistic Society

Contents

It's been great having somewhere to go where you're not the weird one; somewhere you can drop the cloak of pretence when you walk in the door. The group is somewhere I can go and talk about how I experience the world and know that others, even if their experiences are not exactly the same, will not judge me. In a world designed for people who are not like me, having a small space carved out in the week for people who are, feels a bit like coming home.

Section 1: About this guide

Over the past few years awareness around Autistic Spectrum Disorders (ASD) has been raised and both the[2] UK and Welsh Governments[3] have written strategies to enable this group to get the help and support needed to live successful and happy lives.

With expectations being raised and diagnosis becoming easier to access there are more people who have come to realise they have this condition, and whilst both governments have strategies in place to support people, in reality often services are either not up and running or they are inadequate.

Further to this the slogan "Nothing about us without us,"[4] did not appear to be applied to this group and many decisions have been made using one or two individuals on the spectrum. One of the most significant comments from over 120 people we consulted with is "no one consulted with me about my needs", and "why is it always professionals and carers who are asked how my condition affects me" It became apparent that because this condition is a social and communication disability, the people affected were and still are not being involved in service design and delivery.

Why we're involved

Evidence from our two year project highlighted that people with Autistic Spectrum Disorders (ASD) are particularly vulnerable to developing mental health problems. We also found out that existing services tend to treat people either for their ASD *or* for their mental health problems, failing to recognise the complex dynamic between the two.

A key message we are trying to promote is that mental health problems faced by people with ASD may not be directly linked to their diagnosis. Service providers must be aware of the implications in terms of how the person will interact with the physical environment as well as with other people.

Our research highlighted that about 70 per cent of people with ASD are at risk of suffering from depression and severe anxiety. Our consultations with over 120 people on the spectrum confirmed that though the diagnosis helps to make sense of things and understand their situation, specific support is still lacking and information already available is not easily accessible to people with ASD.

With few mental health services providing specialist support for adults with ASD in the UK, there is a great need to develop mental health services able to meet the needs of this particular client group in an appropriate and respectful way.

The purpose of this guide

This guide was developed in partnership with local Minds and communities in Aberystwyth, Leeds and Plymouth.

Autism spectrum disorders are obvious to those who know about them and hidden to those that don't, but they should not be ignored.

The main aim of this guide is to equip mental health providers and professionals with tools that will enable them to offer a service that is inclusive and able to cater for the needs of adults with both ASD and a mental health problem.

This guide sets outs a series of ways on how improvements to service provision might be achieved.

Future plans and development

Based on the response from wider public consultation, there is a clear need for further training and to make more information available to ensure both individuals on the spectrum and services who care for them are equipped to support their wellbeing.

To meet this demand, Mind's Equality Improvement team in partnership with key local Minds intend to act on four levels:

• Awareness raising to influence local service improvement.

• Training for other agencies (wider benefit locally).

• Awareness raising targeting both professionals (for example, GPs) and individuals.

• Political level, to influence positive change (for example, new Welsh Autism strategy).

We will act on the first three levels by developing specific resources that are meaningful, accessible and practical (including communication skills and employment support courses tailored specifically for people with ASD).

Consulting with people with ASD

Quite often both mental health providers and professionals tell us they are keen to increase access to mental health support for adults with ASD but need more understanding of their condition and support needs. Consultation with adults with ASD is one of the most effective ways of increasing awareness of ASD and person centred support.

You can find out about our 'world café' approach to consulting people with ASD and the carers in Appendix 1.

For details about training offered by Mind to support you please contact our Equality Improvement team at equality@mind.org.uk

Key features

This guide offers practical information to improve key aspects of mental health service provision, including handy tips to:

- help providers consult effectively with users and carers

- meet sensory needs of people with ASD

- enhance social and employment skills.

A unique feature of this guide is based on its development in consultation with people on the spectrum to ensure its representative of their needs. This also led to the decision of focusing on social skills and employment in particular, as these topics were the most popular amongst people we consulted. Practical guidance and tools around these two areas are contained in section two and section three of this guide.

Research revealed that most of the consultations about this group of people was undertaken with carers or professionals and not with people with ASD. This has caused mistrust and frustration for people with ASD as the solutions and services tended to meet the needs of carers and professionals rather than those who need services. That's why we felt it was particularly important for providers to hear the voices of people with ASD themselves.

The hardest thing about living with autism and bipolar is that most people remember me by my meltdowns rather than what I'm good at. It upsets me because I'm more than a person with problems and I wish people will just see that.

Section 2: Developing the social skills of people with ASD

Often people with ASD are defined by society as people who prefer to withdraw from society and not in need of friends. Most people with ASD who have been consulted with have shared that this is not the case. Our consultation demonstrated that having a social and communication difficulty made it harder for people on the spectrum to socialise but this did not mean they did not want to socialise.

It is important to recognise that we tend to focus on the challenges of ASD rather than its strengths. Many people on the spectrum told us they would like support to be offered in a way that enables them to use their strengths to develop positive social interactions.

1. Set the scene

When you're meeting with people with ASD, it's useful to have certain things in place.

Operate on "ASD time"

Some people with ASD take longer to process information and answer questions: you will need to leave enough time to allow them to respond. This might mean leaving extra time for consultation – especially for topics that might require a more lengthy discussion (providing accessible written information and allowing for written answers might be good practice. Find out what time works best for them. It's really important to get their input on timescales.

Have a regular venue, time and date

Having a regular venue time and date is important as most people with ASD like and need routine. Life does get in the way sometimes, but this needs to be clearly explained to the group members with as much warning as possible. The group members will have different communication needs so informing them of changes is also important.

Create supportive social environment that meet their sensory needs

Noise, lighting and constant change to physical space can increase anxiety for people with ASD. It's important to be mindful of their sensory needs and how the environment may impact that.

Lighting

Try to find and hold a social group or 1:1 meetings in a room/space with low lighting or ideally no fluorescent lighting, with a private area for quiet withdrawal. We understand, venue is not always easy to control but if there are fluorescent lights try not to switch all of them on. Lamps can sometimes be better than overhead lighting. To manage changes to the environment, we encourage you to schedule consistency and inform them of changes in advance.

Have dedicated staff/volunteers for general support or help with emergencies

People with ASD exhibit a variety of behaviours. Learning about ASD and how it specifically affects someone on the spectrum will help you effectively manage these behaviours. Ensure staff or volunteers/helpers are trained in basic awareness of ASD, for example – no touching of people, know when to leave someone alone, clear communication, but also fun to be with.

Be generous with praise

Find opportunities to tell smeone with ASD what they did right. Compliment both successes and worthy attempts at success. Be specific with your

words so that they know why you are providing praise.

Create a balanced agenda

Consider co-creating a visual schedule that includes daily activities for people with ASD. Monitor and restructure the schedule together as and when needed.

Share the agenda

People with ASD can have difficulty distinguishing between information that is essential and information that is not. In addition, remembering information acquired from past experiences can be harder than for people without ASD. Thus, it is important to state the obvious and 'live out loud'. This can help clients with ASD understand the meaning behind your actions. You could share the meeting agenda with carers and other support staff which will help with meeting preparations

Manage change of plans

People with ASD understands that sometimes planned activities can be changed, cancelled, or rescheduled. Have backup plans and share them with group members in advance. Prepare them for change whenever possible. Inform them and their carer's about staff holidays, staff changes and endings. These changes to the schedule may cause anxiety, if they are not properly informed.

Simplify your language

Keep your language clear and concise, and speak at a deliberate pace. People with ASD have difficulty "reading between the lines," understanding abstract concepts like sarcasm, or interpreting facial expressions. Be clear and specific when providing instruction in a respectful

way. An ASD specific advocacy can be useful in some situations but only as a last resort. A note taker could be considered in the event information might be misinterpreted. Having someone to discuss and clarify what happened can be useful

2. Communication

During our consultation, adults with ASD told us they had difficulties interpreting written information by post and email. This included event posters and appointment letters from local GP and services. Many struggle to pick out important information and as a result can overlook them. It's good practice to find out from clients the best way of communicating key information to them. Since many think in pictures, we also encourage you to present service information in a visual way. You don't have to reinvent things, just build on the resources you have by:

- enlarging text or changing colour text for meeting and rest room signs

- adding more pictures to posters on notice boards

- adding staff pictures on appointment letters or service information

- adding a venue map to group activity posters for group activities.

Visual waiting cards

Some adults with ASD can have difficulties when having to wait, especially those with severe anxiety. These waiting cards are great visual aids for those that arrive early for their appointments and have trouble waiting. Its also useful for those without an appointment and have trouble waiting for you to finish talking to another client or colleague(s).

Having something to do while they wait can also reduce their anxiety. This could include reading information about today's appointment (in which case ensure its presented in a visual way) or completing a sessional form. You can also get a volunteer to help them complete these forms or keep them company while they wait.

Here are two examples.
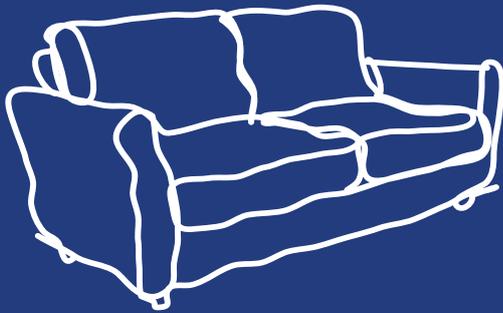
Thank you for arriving on time

Please take a seat in the waiting area and the relevant staff member will be with you between 5 and 10 minutes

I'm with a client at the moment

Please take a seat in the waiting area. I'll be with you between 5 and 10 minutes.

Staff name: _____

We have been very mindful to not set specific times as this can cause anxiety and challenging behaviour especially if you're late.

Letter Templates

Every adult with ASD is different and depending on their sensory needs, some may like bright colours while others may not.

Here's an example:

Important information for you:

Please bring along any information you feel will add value to our meeting

Any problems please call us on _____

Office Map overleaf
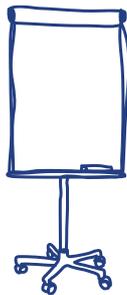
Learning by understanding tool

Learning by understanding cards explore the strengths of people with ASD and increase awareness around their support needs. Every adult with ASD is different and for this reason please feel free to tweak and personalise these cards according to their individual needs.

It helps client to understand what they and other people want from a social situation and considers how they can respond in a way that matches both expectations.

We discussed this in relation to the course sessions. The tutors want to deliver the course so that the students have a rich learning experience. The students want to learn from us and each other. Think about a challenging social situation and use these cards to help you explore your strengths and needs. You can also use some of the examples highlighted in how to start a conversation.

Learning by understanding card

What do I need in this situation?

Learning by understanding card

What do others want in this situation?
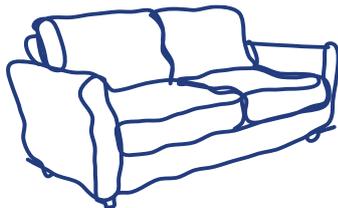
Learning by understanding card

In what way can I use this knowledge to guide my actions in this situation so both needs are met?
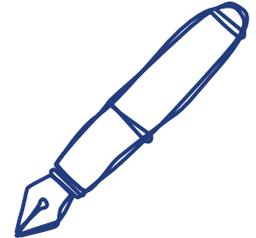
Learning by understanding card

How would I know when these needs are met?

Who can I ask for help when needed?

Strengths – what does ASD enable me to do?

e.g. Amazing memory

How can I use it to interact in a positive way

Help me remember name, places and appointments.

As the saying goes, "once you've met a person with autism, you've only met one person with autism".

We recognise that people with ASD are individuals with different needs. For some these question may need to be more direct to avoid feelings of anxiety. While others may find it more suitable to draw the picture cards themselves in a way that best matches their individual needs. Either way, it's worth finding out what works for them.
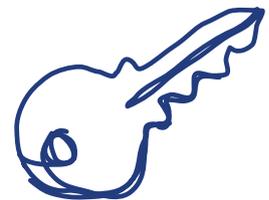
Let's start with Hello

Starting a conversation may cause overwhelming anxiety for some adults with ASD. Understanding what is an appropriate thing to say and what isn't during a conversation can also be challenging. Those we consulted with expressed difficulty interpreting facial expression, and responding to the feelings and intentions of others, especially when they are being sarcastic or cynical. Some told us it can even stop them from joining group discussions, going to appointments or even talking to their GPs, support workers and employers. Others find it so overwhelming that they struggle to communicate what they need and often avoid asking for help.

Here are some things to help someone with ASD:

• How well we know the person

• The circumstances of the other person

• Our circumstances

• Whether we are prepared to spend some time in conversation with that person

• Whether we or the other person is alone or with someone

Looking at the examples below, think about whether these comments are appropriate or inappropriate in each example. (Individually or as a group)

Who	Conversation introductions	Appropriate because:	Inappropriate because:	Examples of when it's appropriate
Stranger	"Hi how's it going, fancy a coffee?			
GP	Good morning, how are you today			
Support worker	"Fancy seeing you of all people here!"			
	What are you up to?			
New colleague	Gosh you look rough what's up?			
Friend	Hello, hope you're OK			

Another important step to take is exploring 5 key areas that influence their emotional responses during social situations.

Social environmental triggers

Interpretation

Behaviours

Support

For example you can understand their emotional responses through this:

- Triggers – Someone is shouting.

- Interpretation – What have I done? How dare you shout, it made me jump!

- Uncontrollable physical cues – shaking, sweating and rapid heart rate

- Behaviour – covering ears because it's too loud or rocks forward and backwards as a way of coping with it.

- After effects and others' perception – start to shut down and ignore everything around them. social anxiety around people's negative reaction to their coping strategy – e.g. fear of people staring or laughing at them.

To reduce social anxiety, we also encourage you to use our emotional regulation tool. It's a good way of increasing their confidence and helping them feel in control.

3. Emotional regulation

Emotional regulation skills help us to understand and manage how our feelings influence our thoughts and behaviours.

People with ASD find it difficult to understand and manage their feelings. Their hyper and hypo sensitivity to the physical space and social situations mean that very often they can go from being ok to being overwhelmed by their emotions. This tool supports them to identify and understand their emotions rather than ignoring and blanking them out.

How are you feeling?

Encourages them to recognise and talk about their feelings. Our Mindful Mood wheel offers them a visual way of communicating their feelings. Staff can then use the table below to explore their feelings and behaviors

Alternative versions of this mood wheel can be found in Appendix 2

Record clients' experiences and what they do and how often here.

Emotion	How it makes me feel	What do I do as a result	How often
Anger	Irritable, grumpy	Rocking forward and backwards	Every day
Calm			
Happy	Energised, excited	Talk to others	Occasionally
Sad			
Courage			
Fear			
Shame			
Guilt			
Boredom			

When thinking about the emotional regulation tool, we also considered how feelings, for some individuals, can be difficult concepts to identify due to their abstract nature. We therefore, recommend an introductory stage to emotional regulation. This could be called emotional identification stage to help individuals become more aware of different emotions and what they look like. This can help them know when they are feeling excited or worried for example. During this stage, we also recommend use of emote-flash cards, examples of some are below. These illustrative cards are also useful in helping them to fully participate during these discussions. Exploring emotions as physical and psychological states can also be helpful.

SAD

IN CONTROL PLEASE CIRCLE A DOT OUT OF CONTROL

HAPPY

IN CONTROL PLEASE CIRCLE A DOT OUT OF CONTROL

I DON'T KNOW

IN CONTROL PLEASE CIRCLE A DOT OUT OF CONTROL

FRUSTRATED

IN CONTROL PLEASE CIRCLE A DOT OUT OF CONTROL

For more information about acquiring and using these cards, email equality@mind.org.uk

Recognising my triggers

This part helps to increase awareness of client's social and environmental triggers.

For non-verbal people with ASD, we encourage you to explore some of the examples from the anger and frustration guideline. Tools and guidance for this part are below.

My triggers

Step 1 – Recognising my triggers

These are the things that trigger me:

- _____
- _____
- _____

Q: What does that suggest you want or need?

A: _____

Step 2 – Recognising early signs of my sensory overload

These helps me notice when my thoughts, feelings and behaviour start to change:

- _____
- _____
- _____

A: This is how I think, behave and feel when situation becomes uncomfortable

Step 3 – Co-producing tailored support

These are what I can do when I'm triggered

- _____
- _____
- _____

A: This is what others can help me to do to prevent things getting worse?

Frustration and anger guidelines

Frustration and anger are normal emotions and can range in intensity from mild irritation to feelings of rage. We recognise that clients with both ASD and mental health problems can exhibit a variety of behaviours especially when experiencing these emotions. As well as not touching or overcrowding them, knowing when to offer support is also important.

Step 1
Identify intensity of emotions

Step 2
Explore what's triggering frustration and anger

Step 3
Identify what these emotions suggest they want or need

Frustration and anger – traffic light tool

People who are hypersensitive or sensory defensive can be highly anxious, have difficulty focusing, or become easily overwhelmed or withdrawn.

The traffic light tool increases client's awareness of when they are becoming angry and frustrated. It helps people to recognise through physical cues when this is happening and informs staff how to respond appropriately

The red, yellow and green indicate intensity of these emotions and the potential risk of harm to themselves and others.

Red light

Indicates that I am angry my voice is loud. My body is sending me signals:

- heartbeat is racing
- clenched fists, pointing my fingers
- dry mouth, pacing up and down
- banging things on the table
- tapping my fingers

Yellow light

Indicates that I'm frustrated:

- Very irritable
- My voice is becoming louder
- I can feel my body beginning to tense up

Green light

Indicates that I am calm:

- I am speaking in a low tone
- My muscles are relaxed
- My heart rate and breathing are normal

Tips to move away from the Red light zone

- No touching or crowding. offer a restroom for quiet withdrawal
- Use Emotional regulation tool described above to explore feelings
- Use learning by understanding tool to identify needs in that situation and support them to understand others need

- Review their stay well support plan, or speak to occupational therapist, ASD support worker or carer

- If symptoms gets worse call ambulance

Tips to move away from the Yellow light zone

- Offer a rest room for quiet withdrawal

- Explore feelings with Emotional regulation tool

- Speak to occupational therapist or ASD support worker

Tips to stay in the green light zone

- Use Stay well support plan (see next section)

Stay well support plan

The plan draws from client's experiences exploring what works for them and building support around that. This will also give staff an idea of the strengths and challenges relating to their ASD. The things they can do alone and those needing others support.

In the event client is overwhelmed by emotions and showing early signs of melt down, the traffic light tool presented above is also a fantastic resource to identify and minimise potential risk.

Stay well support plan

These are the things that help me stay well:

- _____
- _____
- _____
- _____
- _____

This is the staff support I value and need:

These help me notice when my thoughts, feelings and behaviour start to change:

- _____
- _____
- _____
- _____
- _____

These are some new things I would like to try to stay well:

- _____
- _____
- _____
- _____
- _____

Complementary stay well tips

- Get as much sleep as you can by turning off TV or any stimulating thing in your room.

- You can also disconnect and relax with a lovely cup of herbal tea or hot chocolate drink before bed

- Make a daily routine even if you don't enjoy what you do, recognise the effort it has taken

- Take part in art or music therapy group

- Take plenty of breaks & practice breathing exercises in rest room

- Go for a walk or exercise at your local gym

- Attend courses about something that interests you and may teach you new skills

- Remember what you are good at and start doing it again

- Make small achievable goals

- Re-engage with friends

- Join a social activity about your specific subject of interest

- Think about the good things in your life now or from the past

- Notice your emotions and imagine they are the sea coming into the shore and going out again

- Explore some of these conversation starters with people:

- Rely on core strengths relating to ASD to encourage conversations, for example: use good memory of people and places to share interesting facts about someone's name or place of interest

- Talk about common experiences and interest such as pets

- Offer to help such as I am making a cup of tea would you like some? Or do you need a hand with these boxes

- Compliment someone

For more complimentary tips, please visit mind.org.uk

We feel it is important to reiterate the fact that all these exercises and activities were co-designed with a group of ASD individuals. You can use all or some of these tools to deliver a social skills course in an ASD friendly way.

Here are some additional helpful guidelines in order to do this effectively:

There is certainly need to raise awareness in the community and offer training to services getting in contact with the client group (e.g. housing, DWP, police). It would be good to have an Autism Champion in each service as well as a need for ASD specific advocacy.
Participant in consultation event, 2014

I am just me – a whole person with my own unique personality, rather than a set of symptoms which can be easily recognised to one of my 'conditions'.
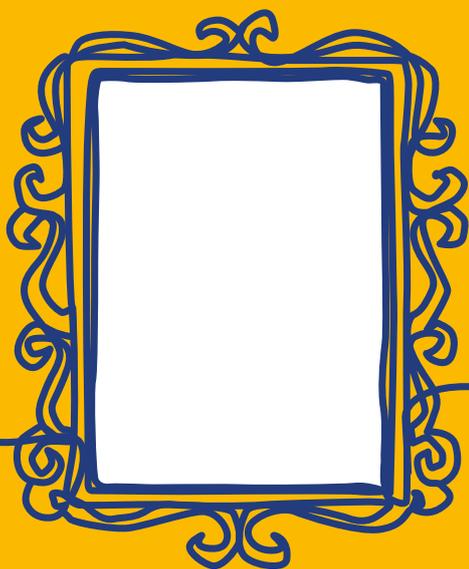
Section 3: Being well at work

We believe that maintaining work is not just a means of earning a living, but also plays an important part in our wellbeing. Work can bring meaning and structure into our lives as well as the opportunity to achieve personal goals – and for some people with ASD, just being in employment may be the goal.

We recognise that although work is an important part of wellness, it can also bring difficult situations and numerous personal stressors that can compromise our mental health and wellbeing.

Due to the problems adults with ASD experience with communication and social environment at work, we consulted with local autistic services to look closely at these issues. Over a period of time and through various consultations and feedback from a range of clients, services and employers the Being Well at Work course was developed. The course offers a peer support approach to explore techniques and ideas for dealing with work related issues in a positive and effective way. We identified through our consultations, that peer support has the potential to put people with ASD in a better position to confidently interact with their colleagues and employers.

Our peer support model is based on the idea that the resources and solutions that are needed for healing and wellbeing come from within, and that people are experts in their own emotional and mental health. Everyone within the Peer Support model has experienced some kind of difficulty with their mental health, and we all value the shared experience and empathy that this creates.

Delivering this approach through a course setting also increases commitment and reassures them they will get something out of it, whether that's through skills or shared learning. We ensure group setting mimic a professional working environment with the twist of conducting all group work in a creative and laid back setting.

The course Leeds Mind is offering runs for two hours each week where these structured headings are explored.

Employment support course

This type of course would be typically structured following these themes:

1. Introduction & positive thinking

2. Confidence and self-esteem

3. Assertiveness / Communication skills

4. Dealing with conflict

5. Managing crisis and reasonable adjustments

6. Food, relaxation & exercise

7. Time management

8. What next?

In Session 1 it is deemed good practice for someone who has accessed a previous course to come and talk about their experiences.

If an ex-participant can become a facilitator (trained, skilled and has the desire to facilitate) this will create a true peer support model. Therefore giving people the potential opportunity that they themselves can become facilitators of future courses ensures that the skills, knowledge and information is not just located to a couple of facilitators. This ensures a continuation of facilitators for the foreseeable future.

Throughout the course, participants are expected to create their own "Wellness Pack" of resources, coping strategies for them to use at work and possibly in other areas of their life.

Below is an example of how a session can be run. This case refers to Session Two – Confidence and Self-esteem:

Session Two – confidence and self-esteem

7.00–7.10	Welcome – Reflecting back and dip into pack
7.10–7.25	Ice-Breaker – Bingo
7.25–7.30	What do we perceive confidence to be? Group Discussion
7.30–7.40	Where is your confidence? Group Floor Exercise
7.40–7.50	What is the difference between being confident and lacking confidence?
	Card game – small groups
7.50–8.00	What gets in the way of confidence?
	Flip chart paper – work in pairs
	Feedback
	Which of these are internal/external influences?
	Tutor/Group discussion
	As you can see from these examples, low self-confidence can be self-destructive, and it often manifests itself as negativity. So we need to look at ourselves and realise that a lot of the issues mentioned link into self-esteem as well as being a confidence issue.
8.00–8.10	Break
8.10–8.15	So what do we think self-esteem is?
	Group brainstorm – flip chart definition
8.15–8.30	Break into two groups:
	• Characteristics of high self-esteem
	• Characteristics of low self-esteem
	Feedback
8.30–8.35	How can we help ourselves? Different pairs
	Group feedback – flip chart
8.35–8.55	How can we help ourselves continued – some ideas we have
	Positive thought – go round in a circle
	Gratitude attitude – individual/group feedback
	Eating and balanced diet
	Thought diary
	Achievable goals – courses
	Creating your own affirmation
	External help – confidence course, talking therapies
8.55–9.00	Bring to a close – ripple effect. Next week

For more information about this course and further details Mind's training offer please contact our Equality Improvement team at equality@mind.org.uk

Valuing different kinds of Minds

One dimension that we found very useful to explore in this context was relating to how different people learn and absorb information. Awareness of this can be crucial to enable people with ASD to identify adjustments to operate effectively in the workplace. The following tools can be used to have a conversation on this topic.

We don't all think the same which can be a good thing as we can all learn from each other. With that being said, it's important not to paint adults on the spectrum with one brush. This is a great tool to understand and meet their learning needs during our course. However we encourage you to use this at 1:1 meetings and group activities. Speak to clients before these meetings or activities and ask them to identify their learning style and how they would like to be supported.

	1: Describe	2: Ask	3: Support
Visual	I need to see what's happening	Do you mind if I sit/stand closer to you so I can watch	Use illustrative cards for group ice breakers, consultations and workshops
Tactile	I have trouble translating what I see into making my fingers move	Would you mind taking my hand and doing the action	Use peer support or co-facilitate session with someone on the spectrum who can demonstrate actions
Experimental	I need some time to internalise what you're saying	Can I work on my own for a few minutes and I'll let you know if I have questions	Provide pen and paper to write down their questions for later
Holistic	I have to understand all of the steps before I start	I'm going to watch you do the whole thing and then try it on my own	Provide flowcharts to illustrate steps or draw them on flipchart paper
Auditory	I learn best hearing about what you're doing	Can you describe aloud every step you're doing as you go	They take a literal approach to what's said – so be specific or provide peer support
Technical	I need to get every detail of the technique	After you've finished your demonstration, do you mind if I ask some more detailed questions	Provide pen and paper to write down their questions as well as peer support

Section 4: Conclusion

Everyone on the spectrum is different. We believe by encouraging independence and creating an environment where the individual can make the majority of the decisions will be beneficial. That's why we think it is essential that mental health service providers listen to the people they serve and design services that incorporate the lived experiences of people on the spectrum. Above all, we hope this guide will act as a further drive to:

- support people who are at risk of developing mental health problems, to stay well. Making sure that they are at the heart of decisions made about their care

- improve services and support. We want to make sure people get the right services and support at the right time to help their recovery and enable them to live with their mental health problem

- remove inequality of opportunity. We want to gain equality of treatment for people who are at risk of experiencing both a mental health and other forms of discrimination because of protected characteristics including developmental disabilities such as Autism/ASD/Asperger's Syndrome.

This guide is by no means an attempt to establish Mind as an "expert" on ASD. We believe people receive the best support when services are joined up and able to work together across sectors. We therefore actively encourage partnerships between mental health providers, ASD providers as well as community groups to increase awareness and knowledge to support the mental wellbeing of people on the autistic spectrum.

We hope this resource will help you champion this work within your services and start a positive change towards ensuring people with ASD get access to the right care and support when they experience a mental health problem.

This resource has been developed in collaboration with Aberystwyth Mind, Leeds Mind and Plymouth & District Mind as part of a National Equality Improvement Programme supported and coordinated by Mind.

For more information and to provide feedback to help with further development of the guide please visit website mind.org.uk/equality or contact us at equality@mind.org.uk or call 020 8215 2372.

Appendices

Appendix 1: World café approach to consulting people with ASD

The best ideas by both people with ASD and their carers are formed in a creative, laid back setting where both feel at ease and valued. World café events are a great way to achieve these outcomes. We had previously used a 'world café' format to consult with other groups and felt that with a few adjustments this would be a suitable method to use for consultation.

Mind's Equality Improvement team and its partners held a total of five world cafe events during our project exploring how to best support the wellbeing of people with ASD. We had tables where people could write/draw on table cloths as a way of recording the discussions. We found it gave them confidence to speak their mind and fully participate throughout the event.

World Café Guidelines

- Contribute your thinking

- Speak your mind and heart

- Listen to understand

- Link and connect ideas

- Listen together for insights and deeper questions

- Play, doodle, draw – write on the tablecloths!

- Have fun!

During our world cafes, the following setting worked very well.

Five tables with a facilitator on each table and the following headings:

1. What do we need?

2. What are the barriers to accessing support and services?

3. What helps staying well?

4. Social Groups: which ones you find most effective?

5 Carer's Input

Have a separate table for carers. We often find that carers have valuable input but sometimes their voices drown those of service users. By having a separate table for their input demonstrates that you value their input but also gives those with ASD the space, confidence and a chance to voice their own opinions. We learnt this approach works really well in increasing trust and participation from both.

The benefits of using the world café format for people with ASD was that it creates a relaxed space for discussions, somebody could write down their opinion without voicing it or could doodle. This approach will also reduce anxiety.

We found that offering facilitators 'Suggested Questions' matched with each topic didn't work as well as we hoped. Some of our facilitators became fixated with what the answers to those questions should be rather than use them as a springboard for discussion. We recommend briefing facilitators on each table with prompt questions to stimulate discussions. This will eliminate the need for 'Suggested Questions'.

The creative items at each table were popular, especially the plasticine, all of which was used at each event. Depending on your service users, this can also be a great way to increase their participation.

We held two events in the day time and one in the evening to give people options. To ensure good attendance of these type of events we would recommend holding them in late afternoon

to enhance attendance from both people with ASD and carers.

Good practice tips for world café consultations

• **Leadership of people with ASD is key**
Include people in planning and organising. People on the spectrum do like to learn new skills and should be included to contribute to the development of their services and group activities.

• **Assigning specific roles**
Assign specific roles to those users who are particularly vocal, as it boosts confidence and participation from their peers. These roles can include promotion of and facilitation at the event. Buddying the less vocal members with most vocal also increases involvement. This enables them to input on the key themes to be explored at the event.

• **Make sure the physical environment is fit for purpose**
When sorting venue, consider the way physical space may impact their ability to engage. The locality of the venue in relation to accessibility is important. People on the spectrum respond well to buildings that are welcoming but not too busy with people, noise and lighting. Clear signs of where to go, where things are. Consider the size of the room and ensure there is space for people to withdraw if they need to.

• **Ensure food and refreshments are provided**
This is general good practice that anyone involved in an event will appreciate. Refreshments also help keeping the atmosphere informal.

• **Advertise in an accessible way**
Quite often, there are lots of great events held but many don't attend because information is not in a simple user friendly way. So whether it's through, email to contacts (both professionals and service users) local paper and via posters in services and local ASD community, ensure content is presented in a visual way – keep it simple by using less words and more pictures.

We recognise that world cafe styled events may not be suitable for everyone. For some people living with ASD it may increase social anxiety. A good way of involving everyone in this process is by offering support in stages. For example, through 1:1 support then into a small group environment or even offering more remote access such as through text, email or skype.

Appendix 2: Mood wheel templates

Here are more templates of our mood wheel to meet the needs of those hyper and hypotensive to colours.
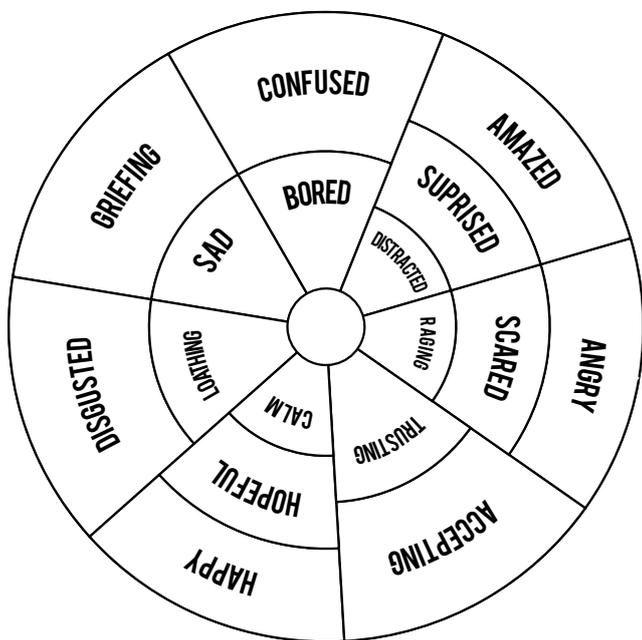
Appendix 3: Useful resources

Increase ASD Awareness

NAS & Autism Alert Cards

NAS is one of the leading organisations on autism. Their website offers a range of information to support people on the autistic spectrum. This includes ASD alert cards to support those involved with the criminal justice system as a consequence of their vulnerability or due to their social and communication difficulties. If somebody with ASD comes into contact with any emergency service, they can produce the credit card size ASD Attention Card which will not only inform the professional that they have ASD but also offer pointers on how to communicate with them more effectively.

The card also provides telephone numbers for emergency service personnel to call for further advice, support and information about ASD.

nas.org.uk

Visual support to increase social and

communication skills

Stickman communications cards

An amazing resource. This has an array of Language widgets to increase communication skills of people on the spectrum. These widgets also increase staff awareness of their support needs.

stickmancommunications.com

Enhancing capacity to meet the needs of people with ASD

Autism Alliance

Autism Alliance is a major UK network of specialist ASD charities.

Together, they support many thousands of people with ASD, including more than 2,000 adults in residential homes and thousands more through outreach services. They run schools for children with ASD and train their own staff as well as staff in the public and private sectors. They are on the Autism National Programme Board and are represented on the Advisory Group to the All-Party Parliamentary Group for Autism. Collectively, they have the largest concentration of practical autism expertise in the UK.

autism-alliance.org.uk

Latest Developments in ASD Research

Autistica is the UK's leading ASD research charity. They work closely with individuals and families with ASD to define their research strategy and ensure that the work that they fund makes a real difference to the lives of those affected. You can find out more about their current work in the areas of mental health in ASD, early intervention, early diagnosis and ageing with ASD at the Autistica website.

autistica.org.uk

Appendix 4: Terminology

Provided by Mind Aberystwyth in consultation with ASD steering group

ASD stands for Autistic Spectrum Disorder, but what about Asperger's? What's the difference? Are they different? Are they the same? What do they all mean?

The point is, it's a spectrum, and labels just serve as that. Labels: to pigeon hole. To fit us all into neat packages. Having said that, they can be helpful, particularly if you do need support and or services.

With ASD, just as with everything, there are different ends on the continuum of the spectrum, and, there's a middle ground. Some people function with help, some need more than others, some less, some with the right support are able to manage well. Whilst they feel different, they manage to integrate into society well

ASD can present all manner of challenges. However, it can also be accommodated with some understanding and, adaptations of predominantly neurotypical societal and cultural rules.

The need to define ourselves is inherent and if the definition is helpful, positive, enabling, then that definition is influential. If the definition creates labels, constraints, maybe even lack of expectations, or even worse social engagement then definitions are no longer a useful concept.

One individual told us:

"One thing I didn't put in the questionnaire but have been discussing recently is, it may be easier to explain the differences between high functioning autistics using fictional characters. Main examples I can think of to hand are Mr Spock, Data, Peter Capaldi as Dr Who and Sheldon from *The Big Bang Theory*. There

are probably others, someone suggested Captain Jack Harkness (*Dr Who/Torchwood*)."

Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social Interaction, verbal and nonverbal communication and repetitive behaviours.

ASD can be associated with difficulties in motor coordination and attention and physical health issues such as sleep and gastrointestinal disturbances. Some persons with ASD excel in visual skills, music, math and art.

Autism appears to have its roots in very early brain development. However, the most obvious signs of autism and symptoms of autism tend to emerge between two and three years of age.

To provide a comprehensive definition of Autism Spectrum Disorder, there are separate labels given to children with autism for different points on the Autism spectrum. At the least affected end, you may find labels such as "Asperger's Syndrome", "High Functioning Autism" and "Pervasive Developmental Disorder – Not Otherwise Specified" (PDDNOS).

At the other end of the spectrum you may find labels such as "Autism", "Classic Autism" and "Kanner Autism".

With the May 2013 publication of the DSM-5 diagnostic manual, all autism disorders were merged into one umbrella diagnosis of ASD. Previously, they were recognized as distinct subtypes, including autistic disorder, childhood disintegrative disorder, pervasive developmental disorder – not otherwise specified (PDD-NOS) and Asperger syndrome.

We have used the term ASD throughout in appreciation of the diversity[5] of the spectrum. We hope that this will promote inclusivity and recognition of the diverse needs of populations, irrespective of labels and typicality.

The definition of Autism and Autism Spectrum Disorder (ASD) is provided by the Diagnostic and Statistical manual of Mental Disorders (DSM-IV). Children with autism are less able to interact with the world as other children do. Typically they have difficulties in three key areas:

- Verbal and non-verbal Communication

- Social awareness and interactions

- Imaginative play (variable interests and behaviours).

NHS Direct defines ASD as:

"Autism spectrum disorder (ASD) is a condition that affects social interaction, communication, interests and behaviour. It includes Asperger syndrome and childhood autism. Some people also use the term autism spectrum condition or 'neurodiverse' (as opposed to people without autism being 'neurotypical'). The main features of ASD typically start to develop in childhood, although the impact of these may not be apparent until there is a significant change in the person's life, such as a change of school.

"In the UK, it's estimated that about one in every 100 people has ASD. There is no 'cure' for ASD, but a wide range of interventions – including Education and behaviour support – can help people with the condition."

You can read more about NAS interventions to support the co conditions of autism spectrum disorder at their website nas.org.uk

Signs and symptoms

ASD can cause a wide range of symptoms, which are often grouped into two main categories:

- Problems with social interaction and communication – including problems understanding and being aware of other people's emotions and feelings; it can also include delayed language development and an inability to start conversations or take part in them properly.

- Restricted and repetitive patterns of thought, interests and physical behaviours – including making repetitive physical movements, such as hand tapping or twisting, and becoming upset if these set routines are disrupted.

Children, young people and adults with ASD are often also affected by other mental health conditions such as attention deficit hyperactivity disorder (ADHD), anxiety or depression.

About half of those with ASD also have varying levels of learning difficulties. However, with appropriate support many people can be helped to become independent.

Children with more severe symptoms and learning difficulties are likely to need more additional care and assistance to live independently as adults, although there is no reason why they and their families cannot enjoy a good quality of life.

Getting a diagnosis

Autism features can often be recognised in children before the age of two or three years. However for many, the signs will often only become more noticeable as they get older.

See your GP or health practitioner if you notice any of the symptoms of ASD, or if you're a parent and concerned about your child's development. You can discuss your concerns together in depth before deciding whether your child should be referred for specialist assessment. It can also be helpful to discuss your concerns with your child's nursery or school.

Adults can also be diagnosed with ASD. See your GP[6] if you are concerned. They may use a screening tool to check if you have signs of ASD and they can refer you to appropriate services in your area.

You can read more about diagnosing autism spectrum disorder at autistica.org.uk[7].

What causes ASD?

The exact cause of ASD is unknown, but it is thought that several complex genetic and environmental factors are involved. In some cases, an underlying condition may contribute to ASD. In the past, some people believed that the MMR (mumps, measles and rubella) vaccine caused ASD, but this has been investigated extensively in a number of major studies around the world, involving millions of children, and researchers have found no evidence of a link between MMR and ASD.

You can read more about the causes of autism spectrum disorder at autistica.org.uk[8].

Autism in adults

Some people with ASD had features of the condition as a child, but enter adulthood without ever being diagnosed. However, getting a diagnosis as an adult can often help people with ASD and their families understand the condition and work out what kind of support they need.

You can read more about autism in adults at autistica.org.uk[9] and NICE guidelines on diagnosing autism for adults on the spectrum can be found at nice.org.uk[10]

A number of autism-specific services are available to help adults with ASD find advice and support, get involved in leisure activities and find somewhere they are comfortable.

Autism Alliance Autism connect is an online social network for people with autism and their families. This is the place for them to meet new people, make friends and find support within the autism community.autism-connect.org.uk

Endnotes

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6. Carole Buckley, C.B., (2014) Making the most of your visit to your GP available at rcgp.org.uk

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