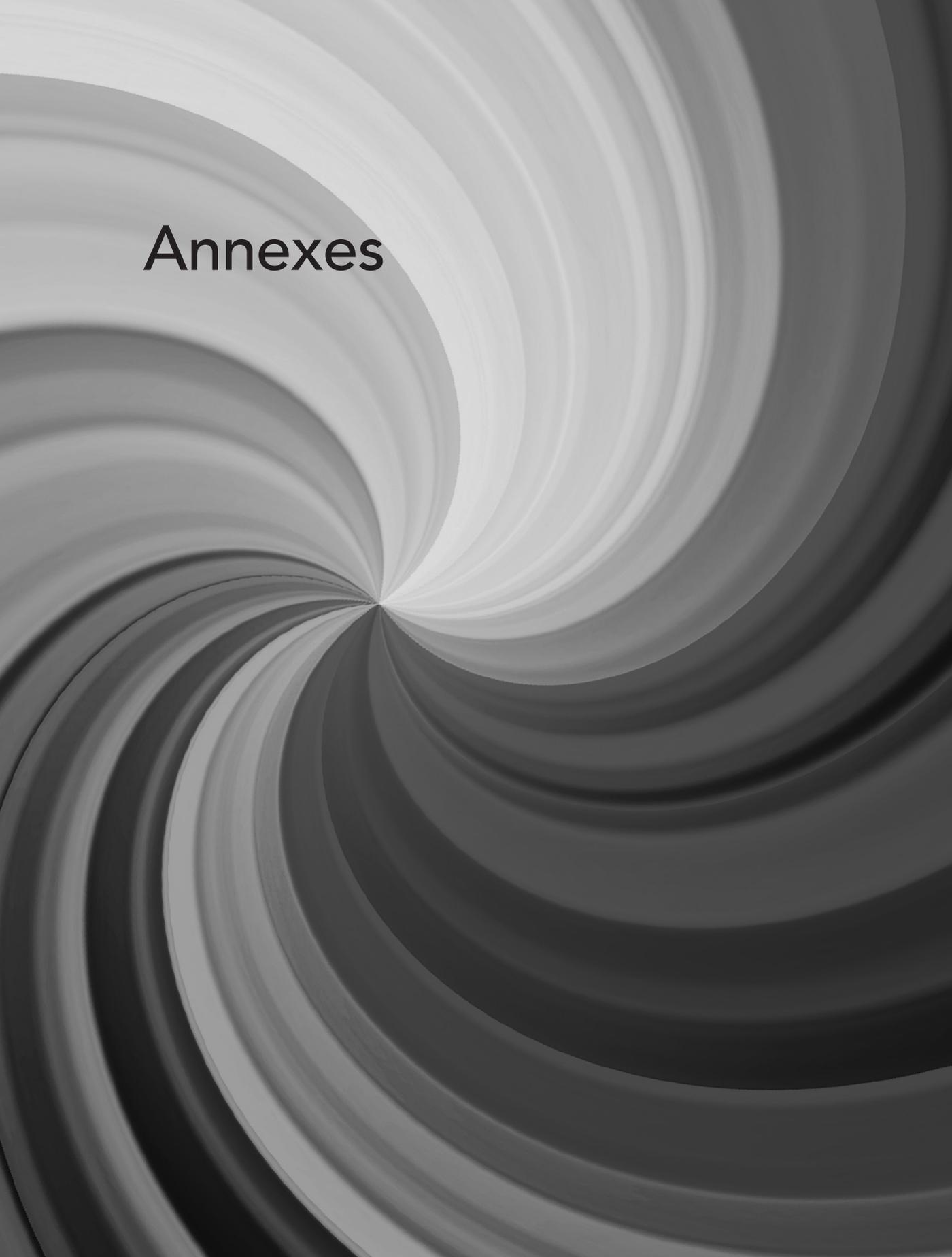


# Annexes

The background of the page is an abstract, grayscale pattern of concentric, swirling lines that create a sense of motion and depth, resembling a stylized vortex or a series of overlapping, curved bands.

# Annex 1: Understanding autism quiz

1. Autism affects more males than females	YES	NO	MAYBE
2. Autism is caused by the MMR vaccine.	YES	NO	MAYBE
3. Most people on the autism spectrum are of average or above average IQ.	YES	NO	MAYBE
4. Reported prevalence rate of autism in the UK is approximately.	1 IN 60	1 IN 100	1 IN 200
5. If a family has one autistic child the other children will also be on the autism spectrum.	YES	NO	MAYBE
6. The number of people on the autism spectrum are entering higher education (university) is on the increase.	YES	NO	MAYBE
7. The proportion of autistic people who have at least one co-occurring condition is:	20%	50%	70%
8. Autistic individuals are more likely to come into contact with the law.	YES	NO	MAYBE
9. Autistic individuals all have sensory sensitivities and/or difficulties or differences in sensory processing.	YES	NO	MAYBE
10. The proportion of autistic individuals who show exceptional skills (e.g. in music, drawing, maths) is:	10%	25%	50%
11. Autistic individuals are generally better at understanding the bigger picture (e.g. the wider context, the gist of a message) than understanding details.	YES	NO	MAYBE
12. Difficulties with executive functioning (e.g. planning and organising, processing sequences, inhibiting inappropriate behaviour) are unique to autistic individuals.	YES	NO	MAYBE
13. The number of children and adults reported as on the autism spectrum is pretty much the same the world over.	YES	NO	MAYBE
14. Autistic individuals experience higher levels of stress and anxiety than those without autism.	YES	NO	MAYBE

## Annex 2: Answers to quiz

Answers
1. YES: but the numbers of females are thought to be under reported as autism is not thought to be as common, and therefore the possibility is ignored by doctors. It is also said that the tools used to diagnose autism were standardised on boys and that girls develop more 'socially' than boys but there is little hard evidence of the latter. Girls often appear for the first time in adolescence and adulthood with other mental health problems.
2. NO. There is no evidence that autism is caused by the MMR. Autism is not a single condition or disorder and it is likely that there are many causes. Some people do not like the term disorder and prefer 'difference', as to use the term 'disorder' is to stigmatise an individual.
3. MAYBE: findings from research have varied in terms of the rate of co-occurring intellectual disability (which is noted by an IQ of below 70) – rates have varied from 41% to 80%. It is likely that the balance is more towards the majority having average or above average IQ as the tests that have been used do not accurately assess the spiky profile associated with autism.
4. The reported rate of autism in the UK is 116 per 1000 for children (Baird <i>et al</i> , 2006) and 1 per 100 in adults (Brugha <i>et al</i> , 2009). As such we usually say that there is approximately 1 in 100 people on the autism spectrum.
5. MAYBE: there is an increased likelihood, but the reasons are complex and it should not be assumed. Genetic factors are important but are only one part of the story. Advice must always be given by competent and experienced counsellors.
6. YES: figures from the National Audit Office 2008 show an increase.
7. Research has found that approximately 70% of autistic individuals have at least one co-morbid condition (e.g. a learning disability, ADHD, a mental health condition, epilepsy, gut or intestinal conditions, allergies etc). 40% are reported to have two or more.
8. YES: it is said that the number coming in to contact with the criminal justice system is four times higher than average but this includes as victims and as witnesses. Sometimes all people can be victims, witnesses and offenders.
9. YES (well almost all...): sensory sensitivities and sensory processing difficulties/ differences is now part of the diagnostic criteria for autism spectrum disorder under DSM-V. Research such as that by Leekam <i>et al</i> (2007) found that almost 93% of people showed sensory processing issues or sensory sensitivities.
10. People with autism usually have a spikey profile of strengths and weaknesses but only approximately 10% have those exceptional skills that used to have people classed as an 'idiot savant'.
11. NO: autistic people are usually much better at working with detail than with the bigger picture – this is usually referred to as weak central coherence.

12. NO: many groups can show difficulties with executive functioning including those with ADHD, dyspraxia, those who have had an injury to their frontal lobe (front part of the brain), etc.

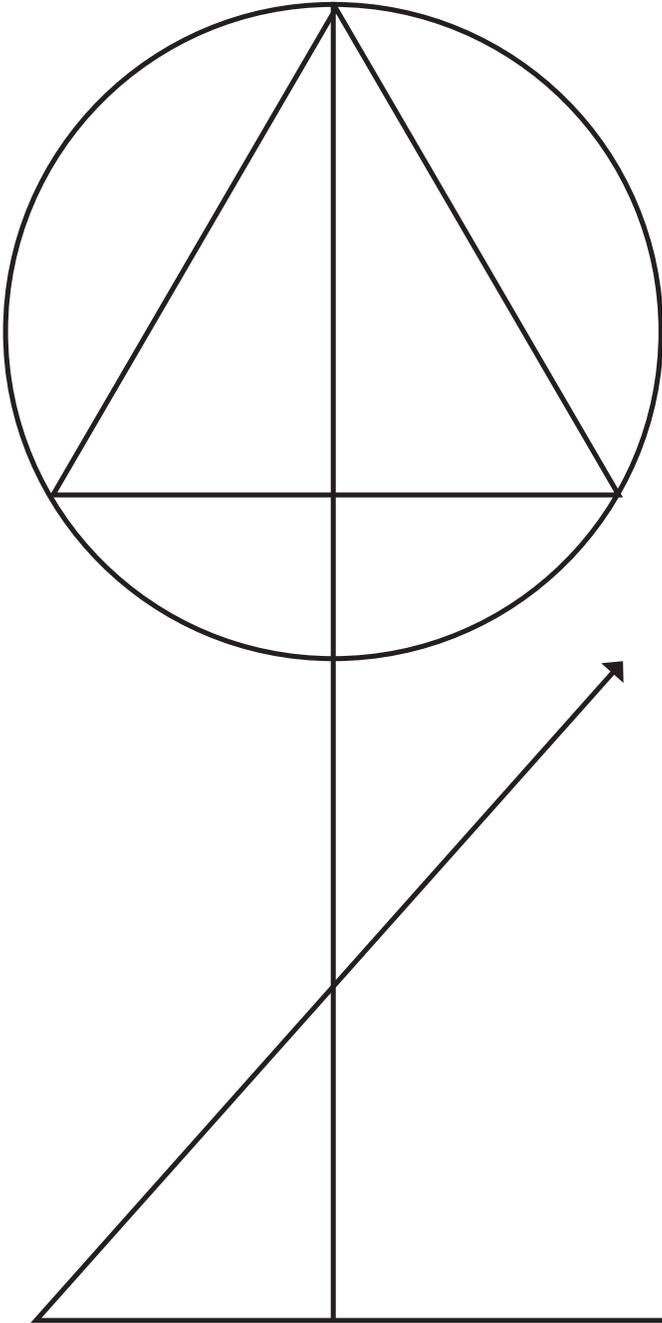
13. NO: the reported number of people with autism varies across the world – depending on awareness of autism, the availability of diagnostic services, diagnostic systems and tools used, and even how the culture perceives difference.

14. YES: people with autism not only report high levels of stress and anxiety but research has found that they have higher levels of cortisol (our stress hormone), which remain higher for longer than non-autistic people.

## Annex 3: Our reflections on 'A is for Autism' video

1. If you have been able to listen to the video really loud, you will probably have found that you were very tempted to turn it down as it would quickly have left you feeling over stimulated. Even visually, many people find it difficult to watch the video because there is so much happening and it is consultant changing, moving etc. There are lots of spinning and repetitive noises and images. This was done on purpose by the autistic people who created the video – they wanted to give those watching it a small experience of what it is like to be affected by sensory sensitivities.
2. Some of the key points you might have noted:
  - a. How do people speak: you might have noticed that there was quite a lot of variety in how people spoke during the video. Some people spoke with very monotone voices; others had intonation but it was in the wrong place; some had unusual production of speech in terms of speech being very 'broken' and halting, like the young man who was talking about his drawings.
  - b. Activities and interests: things like trains, Shell tins, numbers, repetitive activities – turning taps on and off, switching light switches on and off, ripping paper, spinning things, flapping, repetitive questioning, the new TV channel.
  - c. Sensory sensitivities: noise (including speech), being touched.
  - d. Processing difficulties: the young man who talked about his perception being distorted and difficulties processing verbal information – small shops seeming only one metre squared, and the words said by the teacher (or written on the blackboard) merging and becoming undistinguishable – notice the impact of this for him – being late for class.
  - e. Skills: drawing; accuracy and precision; numbers; tenacity to complete something that you and I might find boring.
  - f. Social difficulties: being seen as different, being bullied etc.
  - g. You may also have noted examples of the need/preference for sameness, predictability, consistency. Think about why trains are so popular, in particular with boys with autism? Did you notice how the man talking about the Shell tin talked about taking it with him everywhere?

# Annex 4: Diagram for exercise 4



# Annex 5:

## Responses to exercise 5: Getting the message

### Part 1

**Imagine you are running a meeting and a secretary comes in to give you a message that one of your colleagues has phoned. The message they have received is as follows:**

*'There has been an enormous accident on the road up ahead. There are five or six cars all badly damaged. There is a red Volkswagen upside down and a yellow Skoda has crossed the central reservation. I can see three fire engines and there are four ambulances at the minute. Lots of police cars and I can hear the air ambulance arriving. I don't know how long it is going to take to clear but am not going anywhere at the minute.'*

**What information is your secretary mostly likely to give you?**

If your secretary doesn't have autism then she is likely to just tell you that your colleague is going to be late due to an accident en route.

If your secretary had difficulties with weak central coherence then you are likely to hear all about the different cars and the number of ambulances etc.

### Part 2

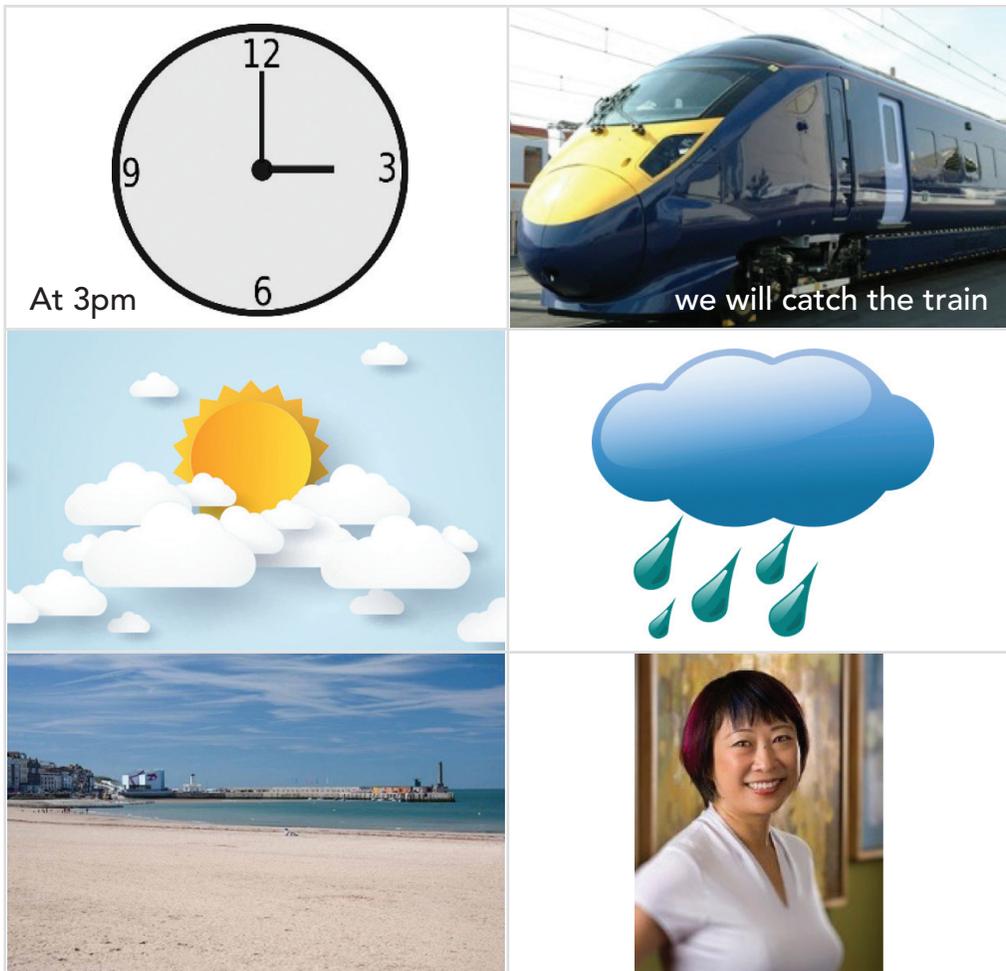
**For the following paragraph, try to rewrite it with just the most important information that the person being spoken to needs to have in order to understand what is going to happen during the rest of the day? Which elements might be more difficult to translate for someone who is on the autism spectrum and doesn't process verbal information so easily? Can you think of how you might make this easier for the person?**

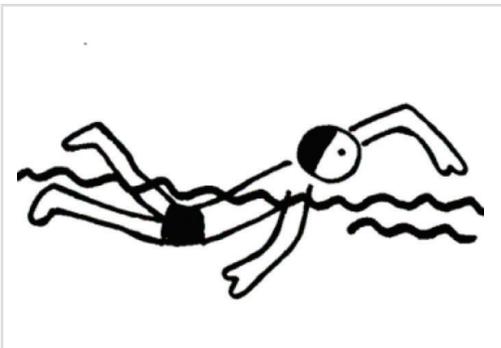
*'At 3pm we will catch the train to Margate. We will go for a swim, build sand castles and then have fish and chips. If the weather is bad we might go see your aunt or we will go to the museum and eat in the cafe.'*

The exact information needed will depend on the person and what is important to them and how they process information. In general, the fewer ideas the better –

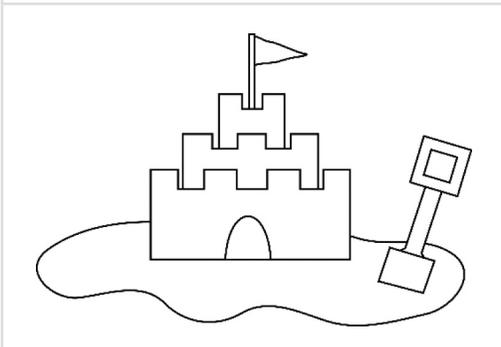
just enough of the right information, accompanied by images of whatever form is most helpful for the person. Working out how to deal with uncertainty e.g. due to weather is something we often have to think about. Whether you need to indicate the time that you will leave, will depend on how important this is for the person and whether they understand time. Here I have chosen a picture of the high speed service as this is one of the trains that go to Margate. If using photos it is best to use photos that represent the real object or place, otherwise it is often better to use line drawings or symbols.

Under the raining option, it would be better to find out whether their aunt is going to be there and available before presenting the visual schedule. For many people – more than two possibilities would be too many.





Or...



## Annex 6: Further information on person-centred approaches

As mentioned in the section on positive approaches and expectations, those providing support often need to have a range of practical skills in order to provide the person with both opportunities and the support to make the most of those opportunities to develop and to experience a better quality of life. Just having empathy and understanding the importance of facilitating people to have a better quality of life is often not enough, especially if people have complex needs – for example a co-morbid intellectual disability or severe communication difficulties. This is also true if people have already developed behaviour that is considered challenging.

There are a number of other approaches that support the implementation of the SPELL framework. In this section, we will briefly outline the following:

- Person-centred active support.
- Positive behaviour support.
- Alternative and augmentative communication.

### Person-centred active support

Person-centred active support is a way of supporting people with disabilities to participate in a range of activities and relationships at home, in the community, at work etc. Like the SPELL framework, person-centred active support reflects what we know works for everyone, and brings together elements of applied behaviour analysis, learning theory, occupational therapy, physiotherapy and speech and language therapy.

Person-centred active support is about providing just enough of the right support for people to engage in a range of meaningful activities and relationships so that people can experience real choice and control, grow in independence and skills and become a valued member of their community. It applies irrespective of the severity of disability or the presence of additional difficulties and conditions.

It is about supporting people to be involved in everyday activities that are about looking after themselves and their home (e.g. shopping, cleaning, cooking, gardening), leisure activities, work-based activities (paid or voluntary), social activities and also less common or special activities (such as holidays, horse-riding, abseiling down the Grand Canyon etc).

It starts from what is already known about the individual – their likes and dislikes, their skills and interests – and gradually encourages and supports people to try new things. Although originally developed to support people with severe intellectual disabilities, person-centred active support provides a really useful framework for supporting people with autism. The approach is now also being used with children and adults with mental health conditions, acquired brain injury, traumatic histories etc.

There are four core elements:

- Every moment has potential.
- Little and often.
- Graded assistance to ensure success.
- Maximising choice and control.

Beadle-Brown *et al* (2017) demonstrate how active support and the SPELL framework are not just useful companion approaches but are intrinsically linked.

You can find out more about person-centred active support in the following resources:

1. Mansell and Beadle-Brown J (2012) *Active Support: Enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley Publishers.
2. Beadle-Brown J, Murphy B & Jill Bradshaw (2017) *The Person-Centred Active Support Training Pack (2nd edition)*: <https://www.pavpub.com/person-centred-active-support-2nd/> and *The Person-Centred Active Support Self-study Guide (2nd edition)*: <https://www.pavpub.com/person-centred-active-support-selfstudy-guide/>
3. Ashman B & Beadle-Brown J (2015) *An Introduction to Active Support* booklet: <https://www.pavpub.com/an-introduction-to-active-support/>
4. The person-centred support You Tube channel: <https://www.youtube.com/channel/UCeeTvLnOkjRj5M6715orqdg>
5. United Response's guide on active support: <https://www.unitedresponse.org.uk/active-support-guide>
6. Tizard Centre and United Response DVD: <http://www.unitedresponse.org.uk/Shop/person-centred-support-dvd>

## Positive behaviour support (PBS)

Positive behaviour support (Koegel *et al*, 1996; Carr *et al*, 1999) is a way of working with people who present challenging behaviour that doesn't focus narrowly on the challenging behaviour and trying to reduce it, but which focuses on preventative and educational approaches. It involves careful assessment of the function of the challenging behaviour and the development of a behaviour support plan that sets out any reactive strategies that might be needed as a last resort but with an emphasis on proactive approaches to prevent challenging behaviour in the first place. Proactive approaches might include changing the situation so that triggering events are removed, teaching new skills that replace challenging behaviour, minimising natural rewards for challenging behaviour and emphasising on improving overall lifestyle quality.

Like person-centred active support, PBS and the SPELL framework are intrinsically linked. If you are supporting someone who shows behaviour described as challenging then just understanding how they are affected by their autism and supporting them to be engaged in meaningful activities and relationships may not be enough. In this case, you may need to be able to draw on the mechanisms and concepts inherent in PBS in order to help people have a good quality of life. However, the two approaches are linked in another way – you cannot really implement positive behaviour support, in particular you cannot do a functional assessment of behaviour without understanding how someone is affected by their autism – for example, their sensory sensitivities, their difficulties with processing information etc.

You can find out more information about positive behaviour support in the following resources:

1. United Response's website and PBS guide: <https://www.unitedresponse.org.uk/positive-behaviour-support>
2. The PBS Academy <http://pbsacademy.org.uk/>
3. BILD PBS video <https://www.youtube.com/watch?v=epjud2Of610>

## Alternative and augmentative communication (ACC)

A key principle that we mentioned under empathy and low arousal is the need to reduce verbal communication and give people ways of communicating that don't rely solely on verbal means. There are many approaches to supporting communication – both formal and informal.

One example of an approach to supporting communication is ‘total communication’ (Bodner-Johnson, 1996; Jones, 2000), which involves the complementary use of signs, symbols, pictures, photographs and objects, as well as speech, to improve understanding, expression and literacy or other forms of verbal communication such as vocalisations or humming. It involves ensuring that everyone providing support uses the same methods and that all means of communication are valued and responded to. The person would usually have a communication passport that could then be used to facilitate communication in settings outside of the home or normal day centre – for example in local shops, hospitals, churches etc.

Much can be done to support communication through the implementation of person-centred active support. Communication is an activity/interaction and the four principles can be applied in the same way as supporting any other activity or task. Finding ways to communicate effectively with people and to support their communication is also key to reducing behaviour considered as challenging. While a lot can be done as part of day-to-day support, sometimes this is not enough, or people can be supported to be more independent in the communication with the use of more formal devices and technologies.

There are many AAC devices and technologies that can be used and it is important that a thorough assessment is done (usually by a speech and language therapist) to find out which device or approach will work best for each individual. Such devices or approaches include sign language (for example British Sign Language, American Sign Language, Makaton etc), communication books, interactive communication boards, voice output communication aids, apps for tablets and smart phones (e.g. My Choice Board, Proloquo2Go, Blue Assist to name just a few of the hundreds available). One of the most well studied and researched methodologies is the picture exchange communication system (PECS).

PECS is one of the approaches that is used most often, especially with children with autistic spectrum conditions. It was originally developed and used by Bondy and Frost as part of the Delaware Autistic Programme (Bondy & Frost, 1994; 2001). You will see PECS being used in some of the photos and films in this resource but in other examples you will see people using different methods of communication. Essentially, children learn to use a picture (usually with the word written underneath) to communicate their wants and needs initially and then later to communicate more complex expressions. The symbols are usually accompanied by the spoken word, modelled by the adults initially and then encouraged from the children. Children have to be trained to use the system, initially using preferred food and toys but gradually they learn to use PECS much more independently. PECS is used initially to facilitate interactions and

then is often faded out when people are communicating verbally or through other means (for example pointing). Research Autism has identified and evaluated the research on the use of PECS and some further information can be found on their website (<https://www.researchautism.net/interventions/36/picture-exchange-communication-system-and-autism>).

For some further ideas about some of the ways you can adapt communication on a day-to-day basis, please see the communication booklet written by Jill Bradshaw for United Response: <https://www.unitedresponse.org.uk/Handlers/Download.ashx?IDMF=4b339200-3368-42c0-81d7-7f71b5c8c6b7>

You can also find out more about communication passports here: <http://www.communicationpassports.org.uk/Home/>

The National Autistic Society has some useful pages on their website on communication and visual support. See <http://www.autism.org.uk/about/communication/communicating.aspx> and <http://www.autism.org.uk/visualsupports>

## Annex 7: Sensory processing and sensitivity

There is growing evidence of the role played by differences in sensory processing. All sensory modalities are affected: touch; hearing; sight; taste; smell; and the internal senses affecting the proprioceptive (muscles and joints) and the vestibular system (balance). There is a growing body of research, notably by Dunn (1999), that individuals with autism differ significantly from the general population in terms of their sensory profile. This has very significant implications for the way that we work with children and adults.

The best established measure for assessing sensory sensitivities and processing difficulties is the Sensory Profile, originally developed by Dunn in 1999. There are two versions, one for children and one for adolescents/adults, and it is available commercially (currently through Pearson <http://www.pearsonassessments.com/HAIWEB/Cultures/en-us/Productdetail.htm?Pid=076-1638-008>). The Sensory Profile helps you to:

- understand the complexities of the person's sensory processing
- gather critical sensory information related to home, school and work
- design strategies for managing daily life.

There is also a short version, which has been used in research to establish the prevalence of sensory processing difficulties.

Tomchek and Dunn (2007) found that 95% of children with autism spectrum conditions showed some degree of sensory processing dysfunction. Kern *et al* (2006) also found that 95% of children showed sensory sensitivities or processing difficulties using the Sensory Profile.

Leekam *et al* (2007) used the DISCO to assess the sensory profile of children and adults on the autism spectrum and found that 90% of children showed sensory difficulties across different domains. In comparison to children without autism, but with other clinical conditions, children with autism showed more symptoms overall and in particular in the domain of smell, taste and vision. They found that sensory differences occurred across age groups and level of ability although age and IQ did affect some types of sensory symptoms.

For further reading on how sensory processing issues affect people with autism, see Stephen Shore's (2003) book *Beyond the Wall*.

## Annex 8: Example of a person-centred plan

### My introduction – great things about me

What do people like and admire about me?  
What are the good things they say about me?  
How would I like to be introduced?

'Friendly'

'Wicked'

'Great sense of humour – loves slapstick'

'Very fit – a very fast runner'

'Polite'

'Lots of energy'

'Lovely eyes'

'Great cheeky smile'

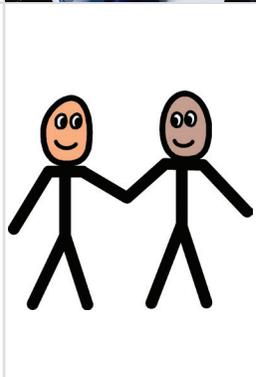
'Handsome'

'Has lovely relationships with people'

'Easy going'

# What is important to me?

What do I want other people to know about the things that are important to me?  
Who are the people who are most important to me? What do I do with them? What are the things that I do (and things I need to have) if I am going to be happy?

	<p>Keeping good contact with his family. They visit really often and R speaks to them on the phone.</p>		<p>Listening to music. R likes pop singers like Kylie Minogue.</p> <p>Image courtesy of Darenote Ltd (2010)</p>
	<p>Going to watch football matches. R likes to support Chelsea Football Club and loves to watch them play on telly.</p>		<p>R needs to have a lot of company. He loves to chat with people. R likes people who have a good sense of humour.</p>
	<p>Opportunities to burn off some energy. R loves the outdoors, long walks on the beach, swimming, riding bikes.</p>		<p>R really likes to go for a ride in the car or bus.</p>

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Going to the pub for a pint of Guinness.



Living somewhere that has a lot of space. R's parents are happy that he has settled well in Neath.

## What is important for me? What do other people need to know or do to help me stay healthy and safe?

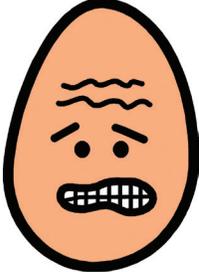
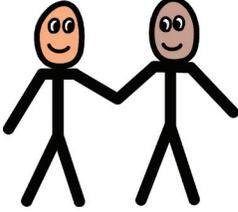
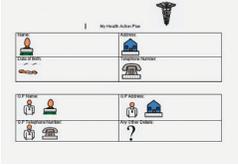
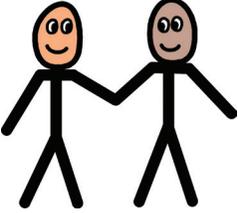
Do I have medical conditions that other people should know about? Are there times when I need help in managing my health and safety?



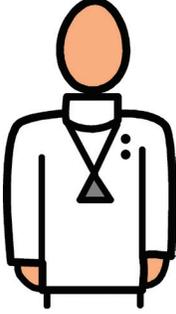
R needs to be supervised **AT ALL TIMES** when eating and drinking. He needs staff to cut up his food into small pieces before serving it. R can choke if this is not done. Staff need to know R's eating and drinking recommendations from his service file.



R is on a dairy- and gluten-free diet. He should never be given pickled onions or processed tomatoes.

	<p>R needs to have his tea quite cool because he may rush it and burn his mouth.</p>		<p>R needs stability to avoid things that may make him stressed or anxious. He needs support with this.</p>
	<p>R needs to have dental check ups twice a year to make sure that his fillings are not becoming loose.</p>		<p>R needs one-to-one staff support in the community. He has little sense of danger.</p>
	<p>Staff need to know when R may need medication to lessen his anxiety. Staff need to know R's PRN guidelines.</p>		<p>R's keyworker needs to help him stay healthy by monitoring using the health action plan.</p>
	<p>R needs lots of company. He seems to prefer male staff who like a chat but doesn't mind chatty females.</p>		<p>When R has a lot of energy, he needs opportunities to burn it off.</p>

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	R needs to buy a new bike. He needs to ride his bike in quiet areas away from traffic.		R needs support from staff when he needs medical or psychiatric input to lessen his anxiety.
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## What do others need to know or do to support me?

If I am going to have the things that are important to me, and stay healthy and safe, what do people need to know about me? What do they need to do? How do I need to be supported at home, at work, and when I am out in the community?

- R needs to have a member of staff with him most of the time to chat with him and support him. R gets anxious if this doesn't happen.
- R responds well to praise, encouragement and humour.
- Staff need to be clear and direct when instructing him. Don't use too many words. Always use positive language, ie. don't say 'Don't walk on the grass'. Instead say 'Walk on the path'.
- R ALWAYS needs to be supervised when eating and drinking. His food needs to be cut into bite-sized pieces.
- R likes to spend a lot of time outside. He likes to be active.
- R likes to have a shower in the morning. He is only to use Simple and Dove products.
- R needs to be reminded to use the toilet regularly.

## What are the characteristics of people who support me best?

If I were to pick a new person to work with me (for example care manager, support staff) what would I look for? What do the people that I like to work with have in common? Have there been people that I couldn't work with? What do they have in common?

- R seems to prefer male staff with a good sense of humour but doesn't mind female support. R likes people of any age.
- Calm, patient people.
- Easy-going people with a low arousal approach (not bossy!)
- People who like to chat a lot.
- People who like to be active.
- People who give R lots of attention.

## How do I communicate?

What I say or do	What it could mean	What you should do
R likes to chat with staff. He usually repeats phrases or things he hears.	R wants a chat.	Chat with R. If he is very repetitive, introduce a new topic. Ask R questions (about his family etc).
'Have a big wee now'	R may want to use the toilet.	Say 'Go to the toilet R'. Show him where the toilet is.
R's facial expressions can tell you how he feels.		If R is happy, have a chat and a joke with him. If R is anxious, try to help him to relax.
R can answer 'yes' or 'no' but finds it difficult to ask for things he wants.	R needs staff to offer choices.	Ask R regularly if he would like drinks etc. Try to offer R choices by showing him what you are offering.

## Annex 9: Scenarios and answers

### Scenario 1

Harry, Jim and John all attend the day centre in the local town three days a week. They all travel together and when they come in from the day centre, staff show them their visual timetable for the evening, which consists of the same activities for all three – snack, TV, craft activity, eating dinner, making a hot drink, TV, bath or shower and bed.

**This is a misunderstanding of the principle of structure – the three men have a visual timetable but it is not personalised and therefore is likely to be reflecting the agenda of staff, rather than that of each individual.**

### Scenario 2

Mary has always loved watching show jumping on TV and loves looking at pictures of horses. Staff at the day centre start to explore the possibilities for Mary to try riding.

First, however, they have to see whether she actually likes horses ‘in the flesh’. They arrange for her to go to local riding stables, initially to look at the horses from a distance. Mary seems keen to get closer so they arrange for someone to bring a horse close to the other side of a fence from where Mary is standing. Staff show her how to touch and stroke the horse’s nose. Over a three-week period they visit the horses twice a week. It is clear that Mary loves the horses and having watched others riding, she emerges one day from the stable tack room with a riding hat on. Mary had her first riding lesson that week and continues to enjoy it. She is now supported to groom some of the horses and even does some mucking out.

**This is an example of good practice in positive approaches and expectations. Staff identify something that Mary shows some interest in, which gives them a place to start in trying to expand Mary’s repertoire of behaviours and increase her quality of life. Staff then gradually expose Mary to the new activity and support her, first of all to approach the real horses and later to ride and work with the horses. This allows Mary to build her confidence and to experience something new and potentially quite anxiety provoking in small batches. It is also good practice because it doesn’t end with riding. When staff realise that she really enjoys the horses and riding they support her to continue to develop her skills and experience by working at the stables looking after the horses.**

### Scenario 3

Staff working with Joshua are convinced that he is over-sensitive to something in the environment but they don't know how to go about finding out what it is. They ask the local clinical psychologist for help but are told not to worry – it is just the autism that is making him difficult and they should just keep giving him his medication.

This is a violation of the principle of empathy by the psychologist, although initially good practice is demonstrated by staff who try to find out what Joshua is sensitive to. It is also a case of diagnostic overshadowing by the psychologist, who is attributing everything experienced by the individual to the autism as an internal state rather than as something that might be caused or made worse by the environment. The clinical psychologist should have helped the staff to do a sensory profile for the individual.

### Scenario 4

When building the new hall at a school that had a unit providing support for 20 children on the autism spectrum, the head teacher insisted that it was essential to spend a little bit more money to use special bricks that had sound-proofing qualities to reduce the echo, lots of windows around the roof with blinds that could be used to adjust the level of light and a special floor that was quieter and 'softer' to run on.

This is an example of good practice in creating a lower-arousal environment so that all the autistic children could be included in gym activities and were more likely to be able to attend and enjoy assemblies etc. They used the opportunity of needing to build a new hall as a way of increasing the social inclusion of the autistic children in the school. There is no doubt it would also have improved life for many of the other children in the school too.



This is a sports hall at a school attended by autistic children. When the new hall was constructed the school invested in ensuring the hall was as low arousal as possible. The bricks used help to reduce echo and serve to dampen noise, the flooring also absorbs noise and vibrations and the use of large windows at the top means that the hall is usually



lit by natural light rather than any form of florescent lighting. Note how tidy the hall is – there are no big bins or loose equipment lying around.

## Scenario 5

Jamie requires a special diet to help to keep her weight down and to help control some food intolerances. The diet has been agreed between her parents and the specialist dietician. A copy of the diet is sent to the respite home and to the day centre.

Jamie usually takes a packed lunch to the day centre and during cookery sessions she is supported to make something nice from her list of allowed foods. At the respite centre, staff do not follow the diet most of the time as it usually requires that they prepare separate food for Jamie. They say that it is unfair that other people in the home should be allowed to eat nice things and that Jamie can't. They say that Jamie is an adult and should be allowed to choose what she eats even if that isn't always what is best for her health.

This example shows both good practice and violation of the principle of links. There is good communication between the parents and the services involved in Jamie's life. The day centre clearly acknowledges and respects the need to help Jamie keep her weight and dietary sensitivities under control – this is important for her physical health. They help her to be involved in activities involving food (positive approaches), while ensuring that her diet is maintained. In the respite centre, staff are using the argument that Jamie should be allowed to eat what she wants as she is an adult and it is unfair to deprive her of nice things. They have ignored the fact that Jamie needs a lot of help to manage her diet. They have also ignored the parents' wishes and the dietician's advice – all examples of violation of the principle of links.

## Annex 10: Diagnosis of autism

You will see reference to difference categories of autism and the systems used to define autism. It is important therefore that you understand what these are.

There are two main ways that autism is defined and categorised for diagnostic purposes. With thanks to WHO DSM and Autism Europe.

1. ***The Diagnostic and Statistical Manual of Mental Disorders (DSM) edited by the American Psychiatric Association and now on its 5th edition (DSM-5).***
2. ***World Health Organisation (WHO) International Classification of Diseases (ICD) now in its 11th Edition (ICD-11).***

Both are used internationally but in the UK the ICD criteria has been the favoured system.

### Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

The DSM is a classification of mental disorders that is used as a reference tool for diagnosis by many health professionals. Moreover, it is used for research purposes and for elaborating public health statistics. The changes introduced in the fifth edition of the DSM (DSM-5) reflect a significant departure from the diagnostic criteria that have been used in past decades to diagnose autism and related conditions. Initially classified under the label of ‘childhood schizophrenia’ in the first edition which was published in 1952, the diagnostic concept of autism has been subject to a new definition in each of the subsequent editions of the DSM. Each of these updates has been met with controversy, and the latest changes in diagnostic criteria, introduced in the fifth edition in May 2013, are no exception.

### Revised diagnostic criteria for autism spectrum disorder in the DSM-5

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:
  1. Deficits in social-emotional reciprocity.
  2. Deficits in nonverbal communicative behaviours used for social interaction.
  3. Deficits in developing, maintaining and understanding relationships.

- B. Restricted, repetitive patterns of behaviour, interests or activities as manifested by at least two of the following, currently or by history:
  1. Stereotyped or repetitive motor movements, use of objects, or speech.
  2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour.
  3. Highly restricted, fixated interests that are abnormal in intensity or focus.
  4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment.
- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder), or global developmental delay.

## International Classification of Diseases (ICD-11)

The ICD-11 criteria (2018) updates the diagnostic criteria for autism, and is now more in line the DSM-5. It also includes or subsumes Asperger's syndrome, childhood disintegrative disorder and certain other generalised developmental disorders, within the category of 'autism'.

With regards to the described characteristics of autism, the ICD-11 also includes the same two categories as the DSM-5: difficulties in interaction and social communication on the one hand, and restricted interests and repetitive behaviours on the other. It thus removes a third characteristic listed in the previous edition of the ICD, related to language problems. Both classifications also point to the importance of examining unusual sensory sensitivities, which is common among people on the autism spectrum.

However, the ICD-11 and the DSM-5 do vary in a number of ways. For example, the ICD-11's classification provides detailed guidelines for distinguishing between autism with and without an intellectual disability. The DSM-5, for its part, only states that autism and intellectual disability can occur simultaneously. The ICD-11 also includes the loss of previously acquired competences as a characteristic to be taken into account when making a diagnosis.

With regard to autism during childhood, the ICD-11 places less emphasis on the type of play that children partake in, since this may vary depending on the

country or culture. Instead, it focuses more on whether children follow or impose strict rules when they play, a behaviour that can be perceived in any culture and is often regarded as a common characteristic among autistic people.