Seldom Heard Voices Toolkit





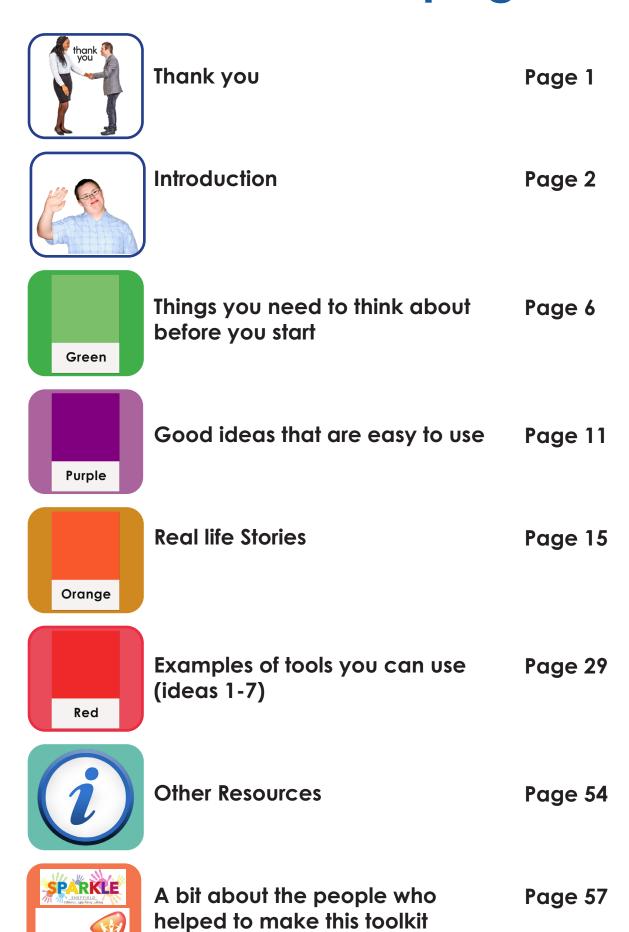






This easy read toolkit has been co-produced by children, young people and adults with learning disabilities and autism to make sure everyone's voice is heard and included.

Contents page



Speakup

Welcome and Thank you



This toolkit has been co-produced by children, young people and adults who are seldom heard. We would like to say a special thank you to Sparkle, Sheffield Voices and Speakup Self Advocacy.



The ideas are easy to do and will transform many people's lives. Some ideas need a budget but others will only need a visit to the art shop either online or on the high street.



Along with these ideas there are also lots of other things that can be done to support inclusion.



There are new phone apps coming out everyday that can support communication together with things like communication boards.



Think about the ideas in this toolkit and you may be able to think of lots more.

It's important to include everyone, inclusion is better than exclusion. So let's support health services that include all.



Everyone has the right to be treated equally and with respect, and their voices should be included in everything.



"There should be nothing about us without us"



We know that sometimes it is difficult to do this because everybody communicates in different ways.



Often people who do not communicate in the ways people expect are excluded and seldom heard.



This toolkit will help to make sure people who are seldom heard are included and it gives you ideas on how to do this.



The law says it is important to include all voices and if all services do this then it will make services better for everyone.



The law also says it's important to include, listen and engage children, young people and adults when talking about their health. In an honest and open way.



Health is really important in order to live a long and healthy life.



This toolkit will also give you ideas of things you can use when you need to act in a person's best interest.



 Examples of how to gain consent from children, young people and adults with seldom heard voices.



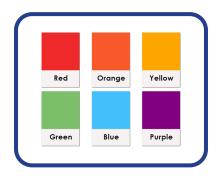
 How to think about reasonable adjustments to make sure that everyone is included.



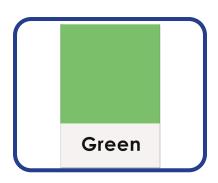
• Examples of how the environment is important.



So, let's turn the page and find some super ideas and solutions to working with people who are seldom heard.

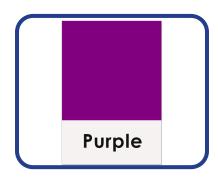


The toolkit is colour coded so you can find ideas easily:



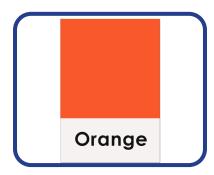
 Green Section - Things you need to think about before you start to work with a person who is seldom heard.

See page 6



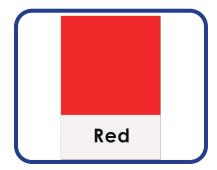
 Purple Section - Good Ideas and solutions that are easy to do and use.

See page 11



 Orange Section - Hear people's stories on how their seldom heard voice has been heard.

See page 15



 Red Section - Examples of good tools you can use to help communication.

See page 26



In this section you will find top tips to think about before you start to work with people who are seldom heard.

Consent



 Before you start your work you need to make sure that children, young people and adults who are involved in your work have all of the right information so that they can consent to taking part.



 You could use some of the ideas in the toolkit to help you to do this. This is called a reasonable adjustment.



 The law says that everyone should be fully involved in decisions about their own care even when they are not able to make decisions on their own. Some of the ideas in this toolkit can also be used to help make best interest decisions.

Making Adaptations and the Environment



 Before you work with children, young people and adults who are seldom heard you need to think about the environment you will be working in.



 It's a good idea to contact people before you work with them to talk about their needs and what changes may need to happen to make the person feel as comfortable as can be.



These changes might include:

A waiting place that is quiet.



 Providing toys or comfort items or agreeing that these can be brought in.
 These can be toys for sensory needs.

Making Adaptations and the Environment



 Having a space for someone to withdraw to when feeling overwhelmed.



 A sensory space where someone can relax when someone is feeling anxious.



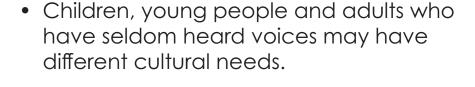
 A communication app if a person needs one, or a sign language interpreter.



 Music, a drink and a trusted person to talk to if they need a breakout space.



Awareness of a person's cultural needs





 It's a good idea before the meeting or appointment to talk with the person, their family, their support circle or using their profile on the Universal Alert. To help understand their needs.



 Reasonable adjustment could be as simple, as agreeing an appointment time. But it's a good idea to check what reasonable adjustments are needed before meeting the person.



 Learning about other cultures is a good idea because it will help ease anxiety, build a trust and help everyone involved think through the reasonable adjustments that may need to be made.

Looking at Records



Children, young people and adults with capacity have the right to access their own health records.



But they may be stopped from getting these if by getting the records, it would cause them to feel very upset.



Or if there is any information about another person without asking the other person first. The law should be followed when looking at these types of records.



If a person wants to have an advocate, friend, other supporter or family member to attend a Health appointment with them, this should be supported.



Everyone is different and children, young people and adults who struggle with communication may need lots of different tools to help them be understood.



 Some people will be able to use communication boards



Communication Flash Cards



Photographs to show what a person needs



Art and drama to help a person make decisions



• Videos to show a person daily life



Graphic design to show what a person likes



 One page profiles to give health and social care workers a pen picture of the person



 Drama to show how children, young people and adults feel



 Phone apps such as text to speech apps that allow a person to have more independence and have a voice.



Circles of support that include friendship circles



Jam Boards



 Easy read resources to help a person understand information in a way that they understand.



 All these ideas could be used by health services to make sure that children, young people and adults with seldom heard voices are included or asked about their health and wellbeing and what is important to them in their life.



 These tools can be used easily in lots of different places like GP surgeries, Dentists, Opthalmologists, Physiotherapists or hospitals.

Real life stories - Derek's Story



Derek and his partner Sandra are Experts by Experience and have volunteered and worked at Speakup since 2008.



Derek was an active voice for our organisation and very involved in fundraising, and supporting our colleagues in learning how to cook. He would give people good ideas about what to cook at home.



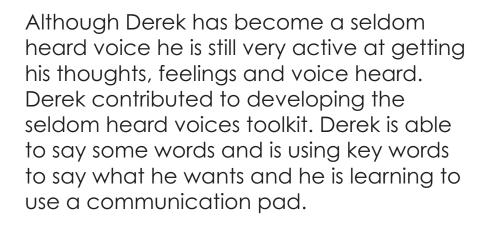
Derek was a very good friend to everyone and a very good listener. He would often support our self-advocates when they were feeling down. Helping them to build their confidence.



Very sadly in October 2020, Derek had a very bad stroke. This stroke has left him unable to speak and unable to walk.

Real life stories - Derek's Story







Derek also has his partner and a circle of support around him. These include his friends and family and all his colleagues at Speakup who have used zoom to connect with him almost every day.



Derek is also having support from a speech therapist who has loaned him a communication pad and worked with him and Speakup on a communication passport and a communication grab sheet.



You can see how Derek is feeling on page xxx when we supported Derek to complete a Jam board when he first returned back home.

Real life stories - Alfie by Theresa (mum) circles of support



Alfie is 34 years old now, but during my pregnancy I had a big bleed. At the time I wondered if something was wrong.



I remember the midwife saying he could have Downs Syndrome, but the scans showed that he didn't.



Alfie was born and he looked beautiful! Long limbs, wonderful sparkly eyes and healthy, but we noticed that he wouldn't feed from the bottle or breastfeed.



When he did get milk down him he would projectile vomit, and struggled to breathe through his nose and his mouth.

Real life stories - Alfie by Theresa (mum) circles of support



We took him to hospital and specialists told us that he wouldn't have a good quality of life.



I was determined he would, Alfie was so beautiful but very frail and didn't meet any of his milestones.



We went through lots of tests for 3 or 4 years. On his very last test we got a diagnosis of depletion of Chromosome number 5. This is a very rare condition.



It is the most distal region of the short arm of Chromosome number 5, which does mean that even though he has this condition, he does have a good chance to have a good life.

Real life stories - Alfie by Theresa (mum) circles of support



We didn't give up. I was told he would never walk, his co-ordination was really bad, his hands would shake uncontrollably, he couldn't go to the toilet.



We taught Alfie to use his hands by giving him some Lego; he was 3 years old before he could walk. He went to primary school and the head teacher supported him to learn to swim, read key words and understand them.



We have continued to fight for Alfie all his life, I never said to Alfie he couldn't do anything. He went to a mainstream primary school until he was 11, but unfortunately only managed one year in secondary school because the lack of support.

Real life stories - Alfie by Theresa (mum) circles of support



Alfie has always struggled to speak but there was one instance where he showed understanding and fun when I was telling him off "you're a pain in the bum Alfie" and he replied saying "me no pain in the bum, mummy pain in the bum".



He needs real encouragement to speak at all but he does sometimes say sentences and odd words with emotion.

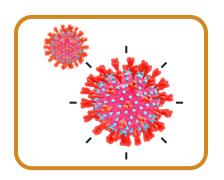


Alfie completed courses at college with support doing brick laying, gained cooking qualifications, gardening, and drama.



He still leads a full life with support and is now living in supported living, he has personal assistants and enjoys lots of activities such as crazy golf, gardening and baking.

Real life stories - Alfie by Theresa (mum) circles of support



During the Coronavirus pandemic he has been more limited in what he can do and who he can see. This has meant his movements are more laboured.



Alfie seems to be struggling with his speech and the speech therapist has suggested using Makaton to encourage speech.



We will be exploring this with his Circle of Support and hope that when everyone uses this method with him, it will help his communication.



Alfie has a seldom heard voice and he has a great sense of humour, loves to dance and will often laugh when people may have been acting silly. He loves Mr Bean, and other comedies.

Real life stories - Alfie by Theresa (mum) circles of support



Alfie has a good life because I have never accepted the word 'No'. We had to fight for Alfie to give him the best chance in life, that he deserves.



This true life story demonstrates how someone with limited speech, needs a Circle of Support to enable them to be fully included and to find out what their wants and needs are.



Together with his family, the home where he now lives and Speakup, he has a strong Circle of Support.



The Circle of Support enables Alfie to have that inclusion in his life through the people who know him best and understand his communication needs well.

Real life stories -Clinton written by his mum



I was told by Specialist Doctors, that my son, Clinton, had 'severe Autism' when he was 2 ½ years old and that he also has a 'severe Learning Disability'.



My son was given a Special Needs Statement of Educational needs when he was 2 ½. He went to nursery and then onto a Special Primary School.



The draft Education Health Care Plan for my son, that the Council did in Year 6, was nothing like my son and did not show his needs.



We had to fight to get him into an independent special school, because no other school could meet his needs.

Real life stories -Clinton written by his mum



Since then, my son has gone to the school we chose.



But he does not have any proper Speech and Language or cultural support in that school even though that was in his Education, Health and Care Plan.



We are moving him to another College now he is 16 years old, which will meet his needs better

Real life stories -Clinton Written by his mum



From this life story you can see that services failed Clinton and his family, who had to fight to get the support they need. Clinton needs a Circle of Support that includes therapists such as speech and language therapists.



For Clinton to be someone who is heard and not forgotten he needs a big support team around him including family members who can advocate for him so that he can have the best life possible.

Real life stories - Freddie likes and dislikes



We asked Freddie what was working well for him this is what he said.

"Going good for me, got my new dinosqurs"



"Got to do my work"



"Playing outside"



"See the doctor. He's helping me get tall"

Real life stories - Freddie likes and dislikes



"In a tag rugby team. Now on Teams"



Freddie was asked whether he is happy. He said "Happy lots, sad sometimes".



Things that make Freddie happy, he said "House and Home"

Family

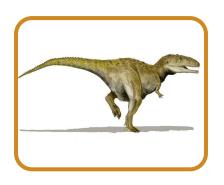


School

Real life stories - Freddie likes and dislikes



Rugby



Dinosaurs



Freddie was asked what makes him sad:

"Image of tall boy" and he then finds an image of a small boy and points to the small boy and then to him



He selects an image of friends and turns it over and says "them not friends to me"

Examples of tools you can use



In this section you will find different tools you can use to help children, young people and adults to have their say.



We will start with a really easy idea that all services could use. It wouldn't cost a lot of money and could be available everywhere.



Idea 1 - Happy, Ok, Sad Face

This idea uses:



A happy face



An ok face



And a sad face



All services could use this for children, young people and adults with seldom heard voices. To ask them simple questions or find out how people are feeling.

For example how are you feeling today?



Are you happy?



Are you ok?



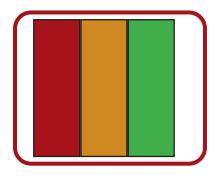
Are you feeling fed up?



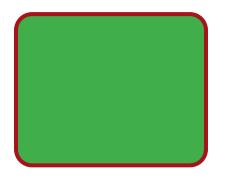
Ask the person to scribble OR point on the face that best describes their feelings.

You can use lanyards with a happy, sad, or unhappy face. This may give an immediate understanding of how a child, young person or adult is feeling when they meet anyone.

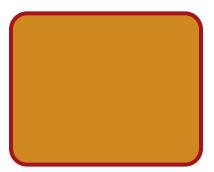




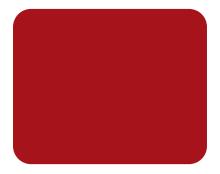
Using colour is another easy way of working out if someone is feeling ok or not, or working out whether someone agrees or disagrees with a decision.



Green could be used for people to say whether they agree with something or they are feeling ok.



Amber or Yellow for people who are not sure about something.



Red for people who do not agree or are not feeling ok about something. These colours could widely be available when going for health appointments to help people make decisions.



Idea 3 One Page Profiles



One page profiles could work with both idea 1 and 2 because the person with a seldom heard voice and their family carers could use their profile to say what they think about each service see example on page xxx.



Health services could then look at these and using the scribble boards or colour charts adapt their health questions for their individual health services.



See example of this on page xx



Communication for children, young people and adults changes everyday depending on the persons mood, or what is happening to their routine that day. So its important to always adapt your practice to suit the person's needs.

One page profiles in health settings

My One Page Profile for the Dentist



What do the dentist need to know about

I have a learning disability and a speech problem, I sometimes slur my words, I do not take medication.

I take a bit of time to get my words out, this can be made worse when I am feeling anxious.

I do get scared of the dentist it makes me nervous when I see the equipment and hear the noises I feel like my personal space is invaded.

I am scared of needles but I know that a needle stops me from being in pain.

How can you best support me?

I need a longer appointment so more time can be taken to reassure me.

I need you to talk to me in a calm way and check my understanding so that I don't get anxious.

Please tell me what you are doing while you are doing and let me know when there maybe noises so I know what to expect.

If I have to have a filling and need a needle, please explain exactly what is going to happen and reassure me this will only take a few minutes, and my mouth may be numb for a few hours after.



One page profiles are simple to do and can be changed to any health service. Here are two examples of how a one page profile can support children, young people or adults when they go for healthcare appointments.



One page profiles could become part of a service so that families, or support circles could help a child, young person, or adult with a seldom heard voice to prepare for the appointment and think about what they need to tell the healthcare workers.

One page profiles in health settings

My One Page Profile for the Optician



What do the optician need to know about me?

I am a young person who is autistic so please explain things very clearly to me.

My mum is here can you talk to both me and my mum so that if I don't understand things she can also support me.

Please will you explain why it's very important to have an eye test.

I sometimes get the alphabet muddled up is there another type of eye test in case I aet stuck.

Please tell me what happening one step at a time and don't tell me lots of information as I feel overwhelmed by this and I start to feel anxious.





How can you best support me?

I need a longer appointment so more time can be taken to reassure me and also talk to my mum.

I need you to tell me in a calm way and check my understanding so that I don't get anxious.

I need you to find other types of eye test rather than just the alphabet; I am quite good with pictures and photos.

As we are going through the eye test can you explain one step at a time. You might need photos to help you do this. If you think I am not understanding ask my mum also to support me.



This is an example of a person's one page profile for the optician.



As you can see these are very easy to adapt the one page profile for each service.

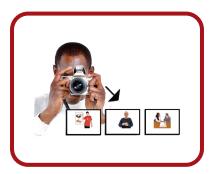




Communication Flash Cards with key messages or questions are another easy way of helping people communicate in health settings.



They are available to buy online and do not cost lots of money. So GP surgeries, community nurses, dentists, and other health workers could have these adapted to their service, in surgeries, and onwards.



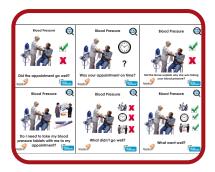
There are also photo action cards that can help people tell a health worker what they need. This makes things more visual and helps conversation.



You could make these yourself, they are pretty easy to do and would be personal to the healthcare setting.



Flash cards are inexpensive and health services could make their own to suit their service quite quickly and easily.



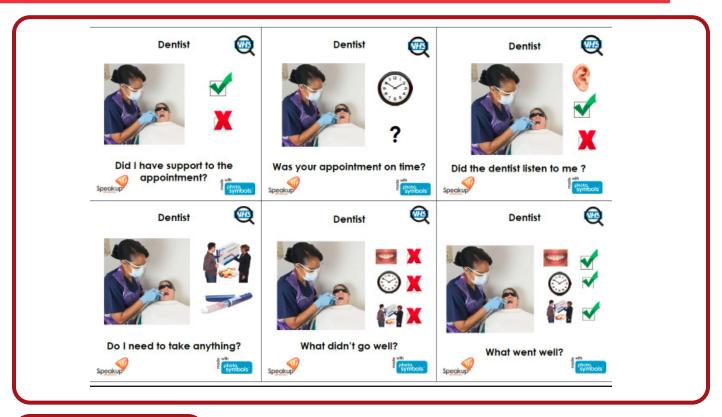
The next few pages show you examples of flash cards, these ask people if their health appointment has gone ok. These flash cards were made in co-production with people who have learning disabilities to show services what to do to support decision making and to improve quality of services.



They ask about the time it took, if they were listened to and if the health care worker was ok.



They ask about what went well and what didn't go well. We tested these out with our people with Seldom Heard Voices and they worked well.

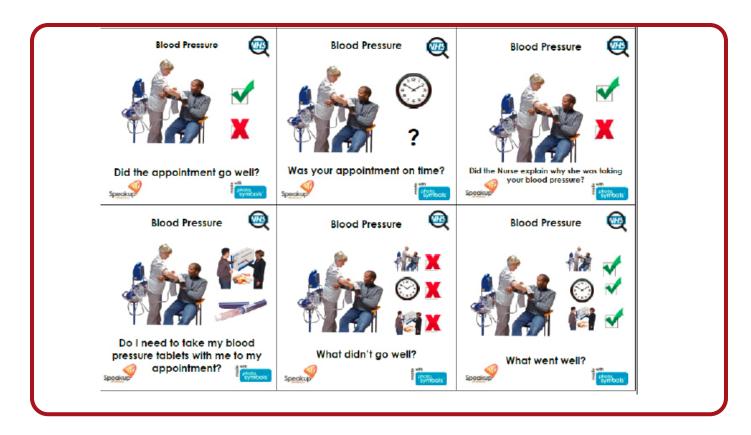


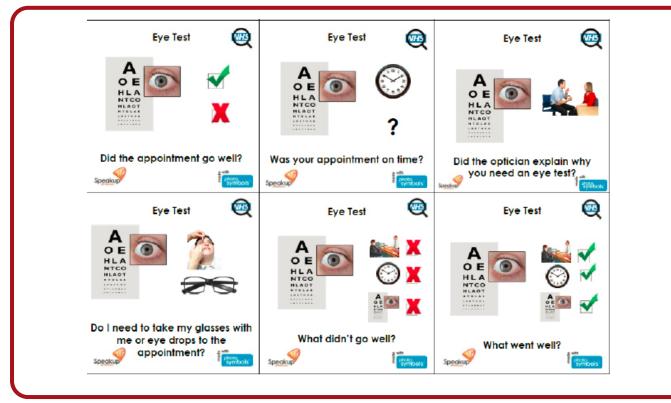


Here is an example of a dentist appointment flash card. Flash cards can be made in groups of six like this using photo symbols and can be laminated and cut up.



A dry marker can be used to circle round the ticks and crosses so that the health worker knows how well they have done before the person leaves the appointment.







As you can see these are further examples how you can use flash cards in different health settings.



Time is very important for everyone. These flash cards can help services work out if they are keeping to time, or if they need extra time for example when someone with learning disabilities or a person who is autistic visits.



People complain about not being listened to or things not being explained to them.



Flash cards like these could clearly tell a service whether they are getting some of the basic things right and encourage inclusion for people who need a voice.

Idea 5 Jam Boards



If a health appointment is planned, the health worker and the person together with their family, personal assistant or supporter could work together on a jam board.



The doctor, nurse, dentist, optician, or other health worker could go online and bring up a jam board. Then ask questions and put pictures and sticky notes down on the board ready for the appointment.



It helps a child, young person, or adult with a Seldom Heard Voice to be heard. The person will feel included in the meeting and their thoughts and feelings can be talked about even if they can't verbally tell you how they feel.



Google apps have a Jam board that you can download online but you must download google chrome before you do this. There are lots of other apps too that you could use.



Derek's Jam Board

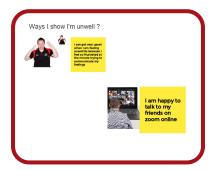
Derek answered some mental health questions using a jam board with the help of his circle of support.



We have told Derek story on page xxx. He has had a bad stroke and lost his speech he worked out the answers with his partner and support circle.



We asked him yes or no answers to the questions by making them personal to him.



This Jam board clearly shows what's working well and what needs more work.



What is working well?



I am happy to be at home with my partner and my cat Sox

I am happy to

talk to my

friends on

zoom online

I am happy my partner Emma has a

supporter who is

also know her very



for you?

Sometimes my care at home is not good. I feel like they don't understand me and my partners learning disabilities and autism

What is not working well

and what makes life hard



I feel like I have lost my independence since having a stroke. I used to do a lot of things for myself now I am confined to my bed and can no longer drive and find it difficult to speak



I used to be a very strong self-advocate and was one of my charities fundraisers. I feel sad I can't do this anymore, I also used to cook for the events and cooking for independence group. Ways I show I'm unwell?



I can get very upset when I am feeling unwell its because I feel so frustrated at the minute trying to communicate my feelings

How I would show I'm well?



If I am well I will laugh, feel happy and shout HAHA

Do people understand my mental health needs and are they planned for

No



We had to think of questions that we know that Derek is interested in such as food for e.g. "are you happy with Sandra's supporter cooking food?" Derek was able to answer yes to this and smile.

"Do you feel frustrated about lying in bed all day?" Derek was able to answer yes and point outside to the window at home to his car, as he was able to drive before having a stroke. Derek really loved going for a drive on his own, with his music playing, it was his way to feel calm if he was feeling worried.



Tony's Jam Board

Tony is a young man with learning disabilities. Although he is able to talk, he struggles to understand and communicate his feelings or thoughts.



We did a Jam board to ask Tony some questions about how he keeps healthy and his mental health good.

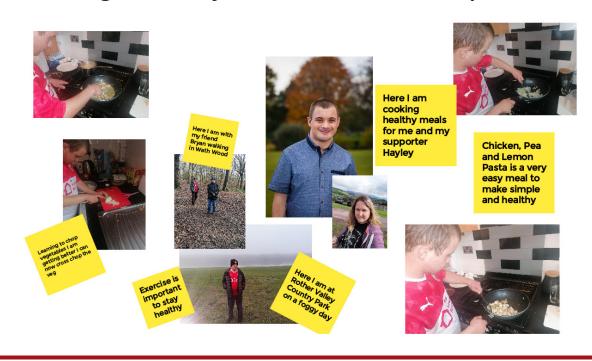


Showing Tony photos of the things he has done with his supporter, triggered Tony's memory and he picked the photos he liked best.



It allowed Tony to engage more in conversation and express his feelings. This also shows that flash cards in health settings would support Tony to make decisions.

Two things I really like to do that keep me healthy





Jam Boards, Photos, or Visual aids really help Tony to express his feelings and he did this with his new social worker. When she first met him photos were used to show her what interested him and clearly showed his positive reactions.



This meant he was included in decision making, and led him to getting more support hours to engage in community life and keep his mental health good. Asking the person or family members of carers to bring photos to a health appointment and also using flash card or jam boards at the appointment will encourage lots of interaction.

Keavey's Art







Some people express their feelings through art and this is a way of working out whether someone is happy, ok, or sad.

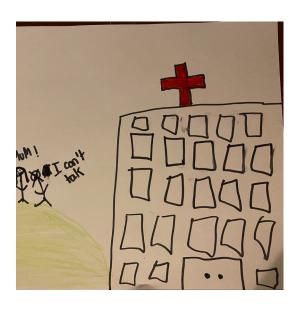
As you can see from these colourful pebbles Keavy is expressing her happiness. Keavy says:



"When I am doing my art I feel really happy, calm and the anxieties disappear. I also use wax crayons because the paint and the crayons help the emotions get less and leave my body".

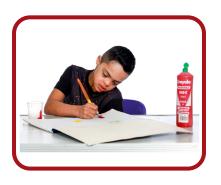
Having some artwork in health settings might support people like Keavy in health appointments to express how they are feeling.



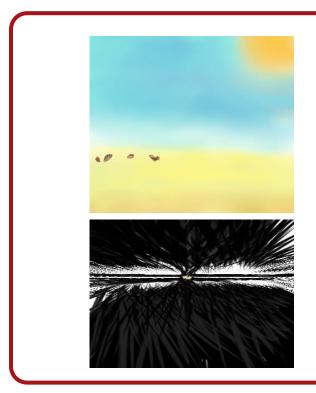


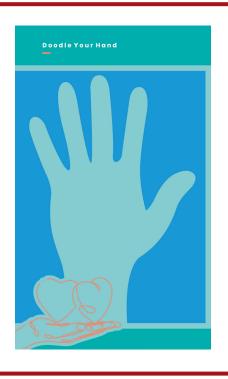


These pictures from Lee and Shanice show how art can help people make decisions or think about feelings. Here Lee is thinking about his place in the world, and Shanice is thinking about going to hospital with her mum.



As a possible solution if there was some drawing or art equipment in health departments then this would help people express their feelings.







Stephanie is 12 years old and uses colour to express how she is feeling. As you can see Stephanie has used bright colours and dark colours to reflect her mood on different days. It also helps her to concentrate and release stress.



Doodle your hand - Doodling is a really relaxing way of drawing so people can use pens to express how they may be feeling. It is something that doesn't cost any money, you just need to encourage the person to do this.

In Melt Down Mode

Like a firework, my head goes pop
It all goes blurred
I go into fright and flight
Run away! My insides shout!
My Brain says 'calm down'
While my legs are running away
Running in front of cars, I escape from the crowds
Head is not thinking, looking for protection
My heart is pounding, and my throat is choking
Can't stay there, it's suffocating me

Poem by QiQi aged 15- Diagnosed with Autism.



This poem by QiQi clearly shows how she is feeling when she is very overwhelmed with her thoughts.



Poetry can help in health and social care settings to help people express their thoughts. It can give a person a sense of release and helps people who are supporting know how the person is thinking about the situation they are in.





Films can support people to understand health and social care issues. They can help children, young people and adults to learn something new, gain knowledge, learn about rights and responsibilities and help people keep safe.



They can tell you what to expect when going for things like health appointments. They can also teach you that its ok to make a mistake or an unwise decision and learn from this.



Speakup have also done some easy read showing people exactly what to expect when you have a vaccination.









Films can be fun to watch and also give people the information they need to lessen anxiety and think about reasonable adjustments.



Speakup produced the 2020 NHS Flu vaccination film. To try and encourage people with learning disabilities, autistic people, and family carers to have the flu vaccination.





This is an animation made by Sparkle Sheffield at the beginning of the project and was used to help children and young people engage in the project. The animation explains what the project is about and ask children and young people if they want to be involved.



Using animation is one of the ways you can speak to people who don't use words or are able to read to encourage engagement.





Widget symbols is a communication software aid that can be purchased by going to www.widgitonline.com



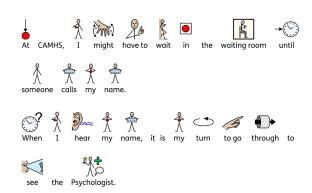
Some people prefer graphics to photographs it's up to individuals but this is a useful tool for developing easy read letters and preparing someone for an appointment.



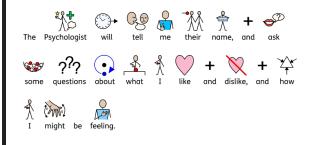
On the next page you can see an example from Sparkle Sheffield. Where they have created a social story using widget symbols to help a person understand what to expect when they are going to see a Psychologist.

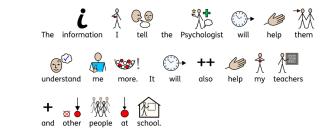
















Other resources



Sparkle - Sparkle understands what life is like and works to improve the lives of children, young people who are autistic and their families.

https://sparklesheffield.co.uk

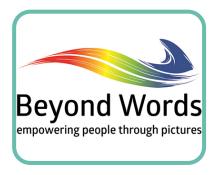


Speakup Self Advocacy - Has lots of film and easy read resources that support people to understand things and lead an independent life.

www.speakup.org.uk



Easyhealth - has lots of information about health conditions and health services in the form of easy read booklets, leaflets, and films. www.easyhealth.org.uk



Books beyond words - picture stories that are accessible to everyone whether you can or cannot read words.

https://booksbeyondwords.co.uk



With Widget online you can: Create documents using your voice with the speech input feature. Read documents out loud with the iPad's speech voice. Some of these resources you may have to pay for.

https://widgitonline.com/

Other resources





The Universal Alert is a free and safe way to support a child, young person or vulnerable adult with a hidden disability when they need it the most.



It shows professionals all the unknown information that only that vulnerable Disabled person or their parent or carer would know.

This helps them to be able to suport the person in the right ways.



This might mean their triggers, body language, when they are anxious like flapping or shouting and other things about the persons such as their background.



This can really help in an emergency, or when visiting a dentist or doctor's appointment, at nursery, school, college, university or where they are in residential care, a nursing care home, or if the police need it.



You can find out more about this at

www.universalalert.co.uk

Other Resources



Ask Listen Do supports organisations to learn from and improve the experiences of people with a learning disability, autism or both, their families and carers when giving feedback, raising a concern or making a complaint.



It also makes it easier for people, families and paid carers to give feedback, raise concerns and complain.



As an organisation, how are you getting comments, compliments or complaints from people who are seldom heard?



You can use this toolkit together with the things in 'Ask, Listen, Do' to make sure you help people with Seldom Heard Voices to give feedback, raise concerns and complain.

Find out more here:

www.england.nhs.uk/learning-disabilities/about/ask-listen-do/

A bit about Sparkle Sheffield



Sparkle Sheffield is an award winning charity that supports children, young people and young adults with autism, some children have other conditions too.



Sparkle Sheffield also supports families. The charity is run by people with autism, families and supporters. Sparkle provides independent advocacy services, children and young people's exclusive and inclusive activities and events.



Sparkle Sheffield also provides training and consultatation, family support and an expert by experience research service.



Sparkle Sheffield not only work in Sheffield but also works across the whole of the Uk and further a field too.

A bit about Speakup Self Advocacy



We are a unique and lively organisation run by and for people with learning disabilities, autism, and mental health issues. Supporting understanding, choice and control. We do this by working with local councils, CCG's, the NHS, schools, colleges, universities, TLAP (Think Local Act Personal) and the CQC.



We are passionate about employment and education. Supporting people with learning disabilities, autism and mental health issues to live independent lives, free from crisis and hardship.



All voices count. We encourage voices through lots of different project work so that everyones opinion matters.



Our training helps both people with learning disabilites, autism or both and skills health and social care professionals to better communicate together and support people to live more equal and full lives.