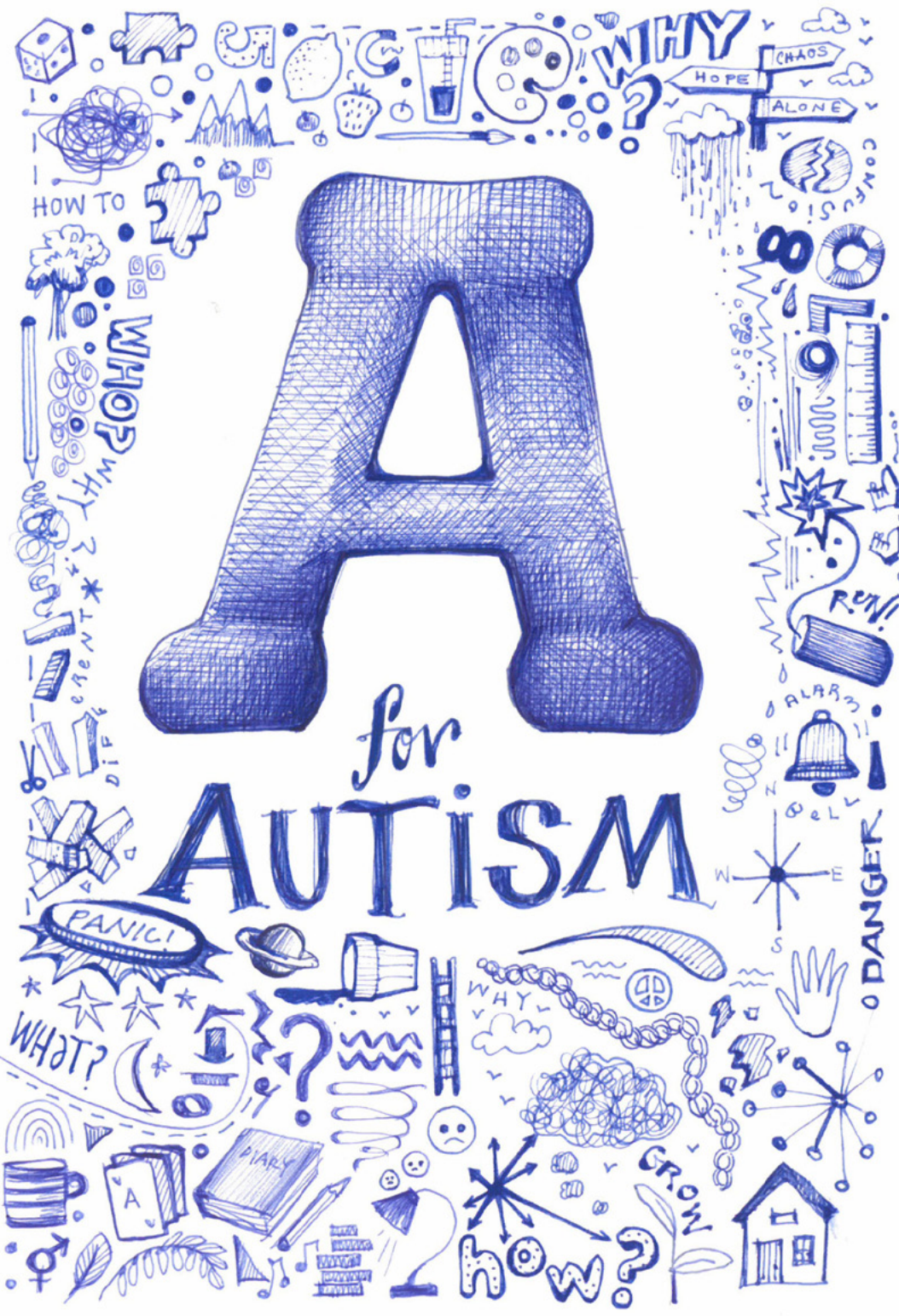


A

for
AUTISM



WHY?

CHAOS
HOPE
ALONE

HOW TO

WHOM?

80

LO

RUN!

ALARM



BELL

DANGER

PANIC!

WHAT?

WHY?

how?

GROW



A for Autism

A Guide for Practitioners,
Parents & People who Care

Written by Mark Wallis

Illustrations by Andrea Joseph

In my experience therapy can be difficult for autistic people, however, especially with Cognitive Behavioural Therapy, you can adapt it by focussing on the behavioural aspect. I have personally found resources helpful including the publication 'Exploring Depression and Beating The Blues' by Tony Attwood.

The trigger for Post-Traumatic Stress Disorder for autistic people may be considered smaller when compared to non-autistic people.

Active listening tools like paraphrasing can help autistic people to feel heard, and being heard is a benefit to all humans.

Robyn Steward

Author, trainer, artist, musician
and autism activist

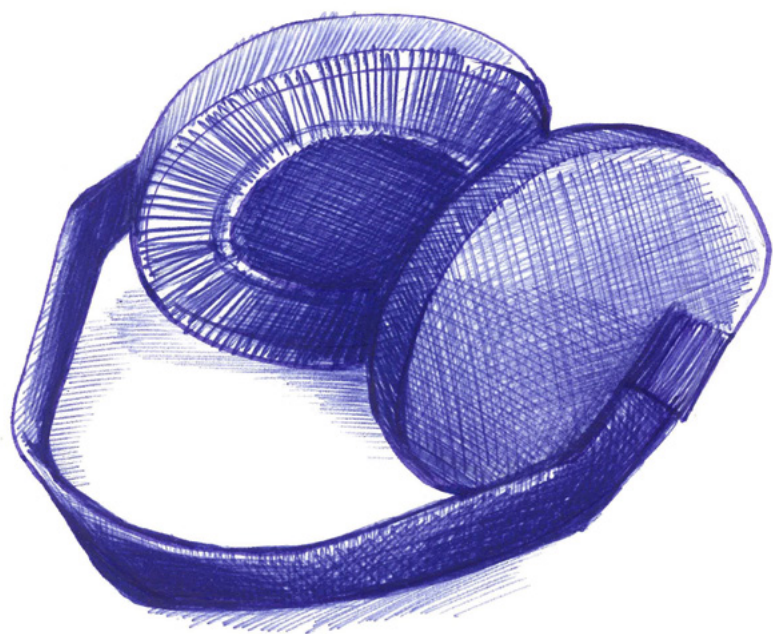


This handbook challenges the assumptions that may be held about autistic people by services. It advises on how best to support us, what support options are available, and how to ensure its accessibility.

As an autistic psychologist and the sibling and friend to quite a few autistic young adults, I hope readers will use this to shift their perspectives and create positive change in our services, environments, and lives.

Michael Arhin-Acquaah





Contents

Introduction	9
What are counselling and key-working?	13
Working in partnership with families	15
Feelings and emotions	18
Communication and processing information	23
Mental health	27
Behaviours that you may find challenging	28
Safeguarding and disclosure	33
Sensory and neurological processing	34
A person-centred environment	35
Materials included in this guide and how to use them	36
<i>Questions to ask yourself as a practitioner</i>	<i>37</i>
<i>Questions to think about with clients (and how to have them conversationally)</i>	<i>38</i>
<i>Questions to think about with parents and carers</i>	<i>40</i>
<i>Self assessment: The sensory needs</i>	<i>41</i>
Useful contacts and support networks	55
Autism resources	60



Introduction

Welcome to 'A for Autism – A Guide for Practitioners, Parents and People Who Care' in support of individuals with autism. In the opening pages, I thought it was important to establish the rationale and the background that led to the formation of this book.

Following research and evidence-gathering we identified the need for greater guidance for practitioners in positively supporting autistic clients. From this feedback, plus our experience of greater numbers of young people requiring support finding their way to our front door, our joint working group meetings, the production of multiple survey questionnaires with the aim of establishing the needs of families, clients and practitioners we find ourselves now in print, before you.

We have written this guide also as a result of the enormous number of conversations we have been having with young people, parents, carers and colleagues who were all looking for some better explanations of what was happening and most importantly, for some help to understand how to live better and respond better around autism and its many derivatives.

The information we have gathered here is designed for practitioners, parents and carers with the objective of offering a greater awareness that will enable and empower the amazing young people with autism and their relationships with the community, on all levels. All the material gathered in this guide has been taken from real life stories and lived experiences.

We know there is no perfect diagnosis, we dislike absolutes and we dislike boxing clients in so this guide is a testament to our shared, ongoing learning from and with each other. We sincerely hope our contribution helps to make a difference. Viewing autism as a culture and a need for individuals to be celebrated for the richness of our difference and uniqueness.

Our desire is for society to be more flexible around the needs of autistic people instead of expecting people with autism to slot into societal norms. The tools and guidance we offer here is intended to assist practitioners, parents and people who care to work together more effectively for the benefit of people with autism.

Thank you for joining us.

Mark Wallis

Note: for the purposes of this handbook, we refer to young people engaged in working with us as clients.

A parent was bringing their 17-year-old son to an appointment with a medical practitioner, they knocked on the door, opened it and hovered at the entrance. "Come in and take a chair" said the practitioner so the teenager entered the room, reached out to pick up one of the chairs and carried it back out the door into the reception area.



Practitioners are required to take ownership for their professional development in terms of remaining flexible in exploring new ways of learning about autism. A willingness to visit the autistic person's world, developing empathy and relatedness. Treating individual clients with autism non-judgementally, being aware of the 'self', ie. body language, facial expressions, tones of voice and remaining neutral. We expect our own Croydon Drop In practitioners to provide a person-centred service provision, centred around the needs and wishes of clients with autism.

Be mindful as a practitioner to pace your speech and tone of voice while providing adequate space for the client to digest what is happening within the sessions or what is being asked of them. Create an energy of calmness within the session.

There will be times, as a practitioner, when you observe and believe that a client you are supporting is showing traits of autism but this has not been previously recognised or they may be awaiting an official diagnosis. The start is in fostering and building on good relations with the family. Obtaining accurate information from families assists us to build a deeper understanding and therefore potentially more meaningful relationship with the client. For a young client under the age of 14 consent is required from families or carers. If a client is over this age, they will be consulted with and offered a choice in terms of family involvement or not and will have a voice in the referral process.

Some of the counselling practices and therapeutic approaches that can benefit the lives of people with autism and all the anxieties that comes with this territory include:

- Person centred approach
- Solution focused brief therapy
- Cognitive behavioural therapy (CBT)
- Dialectical behaviour therapy (DBT)
- Psychoanalytical approach
- Mindfulness
- Social stories
- Creative expression
- Role play / drama
- Positive behavioural approach
- Anger management
- Positive affirmations
- A multi-disciplinary approach
- Working systemically with families

I was facilitating a counselling session with a female teenage client. At our first session from my observations, I had thought that her characteristics had autistic factors. I asked the question "What is your favourite colour?" The client immediately replied "I like a very special shade of pink" so I engaged with her exploring over 20 different shades of pink, which made her very comfortable. This colour pink opened up our conversation, helping to build a rapport as she engaged in discussion.



YOU'RE MY CHILD..

..BUT I DON'T KNOW
HOW TO TALK TO
YOU



What are counselling and key-working?

It's a question pretty much all young people ask us. Practitioners can afford to be directive and talk positively about potential outcomes. For a client with autism asking the question here are some ideas:

“Counselling or key-working is a journey, a safe place to identify and express how you are feeling.”

“In the session you can express yourself and communicate about whatever you want to talk about.”

“It is a safe place to explore things you think about.”

You can affirm with the client with autism during your session.

“I will listen to what your world is like for you.”

Reinforce that the focus of a session is centred around the client with autism and admit that information overload is a possibility. Think about offering the client an opportunity to make a physical signal or movement that signifies a desire to slow down the session if they are feeling overloaded. This will sit well with individuals. You can also begin the first session by exploring what the client believes sessions are about and what the client wants from them.

Be clear about times and expectations, what time the sessions start and build in time for them to ask you questions. Affirm clearly how many sessions you provide and over what period of time. Reinforce the routines, for example that sessions take place same time every week at the same place, this fact will enable a client with autism to feel secure and minimise anxiety, creating stability through self-knowledge and the personal involvement in identifying fixed weekly timetables incorporating the clients' daily routines. Be totally honest and proactive in assessing risks and expectation of possible interruption, ie. what happens if or when sessions have to be changed. When the client or practitioner is on holiday, planned annual leave or cannot attend at short notice, in the case of either party being unwell and absent and therefore unable to attend sessions.

Establish and be clear about rules and boundaries within sessions. Offer reassurance that the client can take a break when they choose, decide an agreed signal or sign that the client can indicate when they require a break. Think about emotional and information overload, provide time for the client with autism to process the information, facilitate some mind space to digest what had been said.

Focus on the process moving towards tangible outcomes. Evaluate and link goals to what was described as the client's needs arising from the assessment, ie. need to reduce outbursts of anger and reduce levels of anxiety.

Towards the close of the sessions allow time for the client to process how the sessions are going, evaluate anything the client would like to change about the sessions. You can use a likes and dislikes exercise, ie. one thing you like, one thing would like to change.



Working in partnership with families

Involving family members can positively impact on your therapeutic relationship with the autistic client. Enabling you as a practitioner to gain additional insight from the family, in regards to personal history, examples of difficulties and behaviours that can at times occur within the home. Knowledge of what triggers the young person's anxiety and frustrations? What has been tried before in the support of the young person and family? What sensory needs or preferences the client may have? Evaluate previous person-centred strategies, exploring what has worked before?

As a practitioner these are some of the themes you may experience involving and supporting families who are carers of young people with autism:

- Lack of accessible family friendly information, where do you go to access autism friendly resources?
- Families feeling isolated and not listened to
- The families' lived experiences and knowledge not taken on board by professionals
- Frustration waiting for the assessment process or lack of response from local authority support networks
- The education system not understanding the needs of autistic pupils. Autistic children experiencing suspension and exclusions
- Their child with autism experiencing bullying by fellow pupils
- Coping daily with difficult behaviour challenges and associated risks and having to develop own coping mechanisms without professional input
- Lacking knowledge of autism, family members not involved in autism awareness training
- Experiencing feelings of being overwhelmed, constantly worried and exhausted
- Issues with anxiety and fatigue, little or no time and space for themselves
- No respite, holiday, short breaks
- Families balancing their daily lives, attending work, paying the bills
- Trying to maintain relationships while they support the needs and wishes of their autistic child
- Parents putting their own needs last, ie. career, financial stability and personal relationships
- Experiencing feelings of jealousy and resentment

- Withdrawal from/by non-autistic siblings, who feel left out due to all the focus, time and energy required for the member of the family with autism
- Difficulty in planning practical daily life issues, ie. getting the shopping
- Conflict arising within their own family network due to lack of understanding
- Power struggles between client and their family in regards to parental control.
- Families experiencing mental health issues
- A lack of community-based activities that meets the needs of young people with autism

It may be of benefit or a request of the client to involve their family members into counselling or key-working sessions. As a practitioner you will need time to build a therapeutic relationship with the autistic client before a process of honest communication can begin and the client may have difficulties managing some parts of their family relationships.

Discuss issues pertaining to family liaison requests with your supervisor or line manager, get support for you. In preparation for family liaison sessions, it is helpful to prepare with the client and explore what are their identified concerns first? What triggers the client in this situation? What issues would the client like to express and positively resolve?



Support the client to write a letter expressing how they feel and how they want to express and communicate their needs and wishes to their family members. The letter does not necessarily have to be shared with the family. The letter is to be used as a therapeutic tool, enabling clients to communicate their needs and wishes in a private, safe, confidential space.

Using role play can be a very helpful proactive strategy, the therapist acting the role of the parent. Asking the client 'what would you like to communicate to your family?'

In sessions, an empty chair can be used and the client can practice gaining self confidence by communicating what they would like to express to the parent, directed initially at the empty chair.

As a practitioner it may be helpful to suggest to the family the need for further specialist input. Use referral pathways to seek additional sessions from family support services and local advocacy services.



As a counsellor I supported a young female client with a dual autism and ADHD diagnosis who wanted to explore her sexuality and after we had worked together for a while, the client wanted to inform her mother that she was a lesbian. At first, we used an empty chair and the client spoke the words that she wished to express to her mother, our sessions then moved towards using role play, whereby I would take the role of the client's mother.

The final session was when Mum was invited to the counselling session, we spoke prior for ten minutes and then for a period of twenty minutes Mum was invited into the session and the client expressed her feelings to their mother, leaving ten minutes at the close of the session for a debrief. The start of the process was successfully achieved, opening a pathway so open and honest communication could grow between mother and daughter.

Feelings and emotions

In terms of autism and emotions, having different cognitive abilities can reduce levels of self-insight and reflection, such as having difficulties making connections to past and present or identifying and explaining a specific emotion.

"I have trouble in identifying how I feel."

The client may experience having barriers in recognising their own feelings and lacking awareness of emotional changes. Experiencing emotions but having difficulty expressing them. People with autism do possess empathy and they can sense and feel when others around them are upset, the difficulties are with the person imagining how others are feeling. This is where the cognitive difference in processing arises.

Themes such as feeling like an outsider and not being recognised as an equal citizen mean young people with autism experience higher rates of bullying, being targeted and becoming victims of grooming due to their vulnerability in social situations. Also, because of their different cognitive responses, which can be observed through their openness when interacting with people, this can make them more vulnerable.

Change is stressful for all people but for individuals with autism and ADHD, small changes can lead to long term trauma, excessive worry and major emotional disruption. Experiencing brain freeze and multi behavioural challenges, multiple fears and thoughts all entering the mind at once. Brain scrambling is caused by the disruption of our neurological patterns and pathways.

A central outcome for a counsellor or key worker is to engage with a client in supporting them to feel secure even during the unpredictability of life. Helping to facilitate calm during the times of storm.

The client can become emotionally overwhelmed and overloaded with sensory feelings. People with autism can have a rapid, high-level negative interference from stress that can go from a breeze to a tornado in a very short time.

Autistic cognitive rigidity leads to the need for routines, a need for perfectionism and encourages obsessive thinking patterns. This is where the focus of autism and people having super skills and talents derives from.

Alternatively, what can also happen is low levels of concentration spans whereby individuals can spend long periods of time in the completing of actions, being lethargic, unmotivated or avoidant at completing tasks.

The need for fixed routines, ritualized routines alongside an unwillingness to be

flexible can, at times, provide serious challenges for individuals with autism when entering into education and employment.

Role play can be very beneficial for a person with autism, developing skills in gaining a better understanding of human reactions whilst exploring feelings and emotions and empowering the client towards maintaining positive healthy relationships. In role play sessions unmet older adolescent and young adult needs are encouraged to be explored in areas such as dating, sexuality and adult appropriate relationships.

The issue faced by many autistic people and those who have traits but are undiagnosed, is the lack of self-understanding and awareness. Imagine trying to get other people around you to understand your autism, when you have never been taught about your own diagnoses and its effects on your day-to-day life?

And even if an individual has been 'officially' diagnosed don't assume they will know everything about autism, never assume autistic people have ill-intent, in fact never assume anything!



The person may have a need to ask themselves self-exploratory questions such as:

"Who am I?"

"Why does my body feel like this?"

"Why do I feel like an outsider?"

"Why do I get anxious?"

"Why do I have angry outbursts?"

"Why can't I have friends like everyone else?"

A key achievement within the practitioner's outcomes is to support autistic individuals to understand about 'autism' in relation to their own feelings and emotions and all the sensory perceptions, behaviours and communication that follows. To support the clients to gain confidence of engaging with the wider world, to reduce levels of fear to being manageable. These processes occur with a person with autism first gaining knowledge of self, this in itself can be a challenge for many individuals that have autism traits.



I have been supporting a young boy with autism who was in the process of being assessed by Child & Adolescent Mental Health Services (CAMHS) for a possible Autistic Spectrum Disorder (ASD) diagnosis. I observed that he also struggled to understand the flow of communication, making hyperactive movements, flapping his arms when distressed, unable to maintain eye contact and having a preference of being by himself.

After several sessions with this young person, with his permission, I involved his Mum much more and she assisted in the process by helping her son prepare for the sessions by thinking ahead about what he wanted to say during the counselling and writing his ideas on her mobile phone. The client shared his past and present fears and worries. He was managing to set his own goals, exploring his worries and had a goal to have a wider social circle. He gained a more accepting, better perception of himself and began tackling his fears of socialising linked to the external perception of him by others.

Our work was aided by working in the same environment every week with the same toys. Our relationship grew deeper through understanding his special interests and extensive knowledge of dinosaurs. He would use the word 'break' if he required some time out of conversations and engagement during the sessions. In the break he usually chose to draw or speak about his love of dinosaurs.

He enjoyed having some control over what he wanted to share and being empowered to make the choice whether to share something, or not.

By the end of the sessions, this young client had shared many of his worries through topics such as school, life, death, home and family. He began to push himself outside of his comfort zone and attend outside groups. His Mum was so amazed that her son had made an active effort to speak to fellow pupils in his class and invite them to his forthcoming birthday party, something Mum would never have imagined before.

For a client with autism to establish, identify and recognise their own feelings try using emotional cue cards, pictures, emoji faces which all help to support the identification of sad, happy and angry human expressions. Help the client to link a memory they have had and connect it to a feeling and connect the emotion to an emoji face.

Reinforce by exploring several practical experiences and support the client to describe times when they have felt clear emotions such as sad, happy or angry. The more often the client practises the use of this exercise the greater awareness of their emotions, increasing self-recognition helps the client express how they are experiencing life at any given time. To balance the sessions, facilitate the client to recall positive experiences, connected to memories, past and present events.

It is helpful during sessions to support clients to explore, establish and connect to their thoughts. Connecting to the inner values and asking "What is important to you?"

If the client is nervous, anxious and negatively experiencing stress, you can explore grounding techniques such as body scanning (a relaxation technique that raises awareness of tensions felt in the body) and mindfulness techniques. Build in space and time for these exercises for the client with autism to feel their own presence, enabling the individual to gain a better understanding of their emotions and physical body presence. Develop exercises of breathing regulation to pro-actively reduce stress and reduce heightened levels of anxiety as these can lead to panic attacks or as some people describe, experiencing emotional meltdowns. Sensory need and movement breaks are helpful.

Animals are known to have a therapeutic relationship with individuals with autism and helping to expand understanding of relationships and social interaction. Learning and developing empathy skills of caring for another. The required routines for looking after an animal can help reduce anxiety as well as encouraging laughter and smiling. During sessions it may be helpful, as a practitioner, to establish a point of reference if a client has a favourite pet and it can be of benefit to support the client to identify their pets' emotions as a way of getting a better understanding about distinguishing when their pet is getting needs met, or not. Identifying when their pet is happy or sad or fearful through their body language; tail wagging, barking, whining, purring, meowing. You may be able to build by linking the clients' own emotions and feelings with those of their pets.

As we are always mindful to avoid stereotypes, remember many individuals with autism may be fearful and dislike keeping pets in their personal space or have various phobias and triggers attached to seeing animals. As ever, do not assume anything.



Communication and processing information

There are multiple types and ways of communication, depending on the individual needs of the autistic person's use of both verbal or nonverbal communication.

In sessions and in written publications ensure that the material is user friendly. Do not use an excessive number of words, be aware of using abstract language and professional jargon. Pace and space communication, break information down into smaller bite-sized chunks, to make it easier for the client to take time to relax and digest.

Transitioning and change are main factors that present challenges in the lives of people with autism. Taking longer to process information and having difficulty switching between procedures, ie. getting prepared for a new term at school, finding a new route to travel or meeting people for the first time. Engagement can be very challenging for individuals with autism on so many levels. It is supportive to ask the client what physical factors they have difficulties with, ie. some autistic individuals find direct eye contact can actually feel painful and can be very disorientating.

Practitioners will be required to use directive questions as opposed to familiar counselling techniques of asking open questions such as 'how are you?', 'how are you feeling?' or 'how's your week been?' This type of curiosity can appear too abstract for some autistic clients to understand and comprehend.

Be specific, working with actual tangible outcomes is the best and most supportive way forward. Use language that is literal with reduced number of words and short sentences.

"What did you do on Monday?" or "What did you do yesterday?"

"What has been good this week?" or "What has been not so good?"

Think out of the box and be directive when requiring individuals with autism to engage in this approach. Be totally prepared to explain what technique or model you are using. This will help the client know where they are with you and feel grounded, connected and focused. Enabling the client to be conscious and aware of boundaries too. Because of the neurological make up of people with autism you may experience unfiltered conversation, getting straight and directly to the point. Sometimes a client's comments may appear rude and harsh but this is just unfiltered verbal communication.

Specific questions can be supportive:

“What do you like about playing the guitar?”

(Highlight the specific area of interest)

“I wonder what you are thinking about?”

(Replacing the word feeling with thinking)

“What has been good at school this week?” or *“What has been bad?”*

“What do you do when bad things happen to you?”

Understand that a client with autism can become overwhelmed by having too much information and struggle to process it. In particular the client facing challenges with transitions and trying to adhere to socially-constructed expectations about what is required of them in any given setting.

The autistic client may have an overwhelming feeling of being unusual and misunderstood, centred around the person expressing their communication needs and wishes differently from mainstream society. Be patient and positively engage with the client during the sessions, enter into their world, listen, explore and support the client towards self-expression.

Difficulties can occur when a client becomes frustrated with not being able to identify their own emotions alongside having difficulty comprehending what are the expectations of others, ie. ‘what do I say when I feel like this?’ or ‘what do I say, how to answer if someone was to ask me a question?’

Role play within sessions, can be a helpful and supportive practice within a safe space. This provides an opportunity for a rehearsal time, exploring and acting out what the client would like to say. Individuals with autism can benefit from using drama therapy in enhancing communication and helping build their own self-confidence.

Develop a holistic and creative approach to person centred communication by using tools such as:

- Expression cards
- Utilising objects of reference
- Pictures and drawings
- Colour therapy and painting
- Use of technology/IT/apps
- Role play
- Using social stories
- Zones of regulation
(eg. red = angry, yellow = nervous, green = happy, blue = sad)

Offer practical support in assisting individuals with transitioning and change. Help the client to have reduced levels of anxiety when moving from place to place in their lives. Use diaries and visual weekly activity timetables to support the client with self-knowledge of structures and routines.

A young male was referred following the tragic murder of his uncle which occurred a few months prior. He wanted to talk about the nature of his uncle's death so I worked non-directively to explore what he wanted and how he wanted it.

There were subtle signs of ASD I was picking up on such as a lack of eye contact and difficulty in understanding metaphors. As I wasn't aware at the stage of the client's neurodiversity, using imaginary situations and exploration of his emotions was difficult. This led to a stumbling block and I felt awkward. If I wondered if I had prior knowledge that this young man was awaiting a CAMHS assessment, could I have helped more and practice in a way that could help the client explore the loss of his uncle by using comic strip stories or emotion cards.

The sessions were successful at meeting the client's goal in regards to sharing the news about his uncle's murder, alongside lowering his YP-CORE (a scoring questionnaire used to monitor change) score to which the client positively responded at the end of his sessions. There were several clear positives to take away and within the discussions in supervision, revealed a gap in my knowledge. I have been able to learn, re-train, develop my knowledge of young people with autism and reflect on my own best practice.

Professionals and practitioners, you need to use your instincts as well as relying on good clinical supervision!



Mental health

People with autism have higher levels of anxiety and depression than the general population. 84% of individuals with an autism diagnosis have clinical levels of anxiety with many requiring prescribed medications. (*1 Ref. White et al 2009)

Individuals with autism, especially with a dual diagnosis of ADHD, have designed for themselves several levels of masking. Putting on layers of protection to cope and run the daily gauntlet of social norms with all the multiple expectations and requirements to engage. At emotionally low times, many individuals with autism have experienced some type of suicidal thought compounded by lack of self-confidence and negative interaction with the non-autistic outside world.

Picture the last time you were in a panic and weren't sure what to do, describe your feelings and emotions, ie. public speaking, performing, entertaining others, doing a new task, attending an interview or being involved in conflict with others.

Some autistic people experience a constant feeling of fight and flight that is present at all times, 24/7. An exhausting, constant strain and stress with re-occurring circles of fear and anxiety, overwhelming feelings of not being able to cope with everyday life, periods of depression and self-injurious behaviour and a lack of motivation to live life.

Struggling to express empathy, lacking the knowledge to identify and interpret other people's emotions and most importantly, having difficulty understanding their own emotions.

There can also be common health issues such as lacking vitamin input, being dehydrated, difficulty sleeping or requiring excessive sleep with inner fears giving client's feelings of what has been described as intense combustion.

Depression resulting from being an outsider, being misunderstood, not fitting in and the emotions connecting to not being valued or understood as a person with autism. Anxiety and trauma-driven compulsions such as phobias which seek to avoid and escape from feelings of being trapped. Eating-related behaviour, addictions, cravings and impulsive behaviours enable autistic people to cope with everyday life.

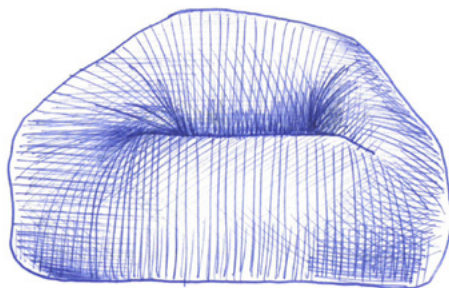
Plan sessions to be proactive in reducing stress whilst working through helpful and supporting positive behavioural strategies. Facilitating a person-centred approach to focus on clients' good past memories, exploring what the individual likes and enjoys, what makes them happy. Using psychoeducation (sharing information to better understand a person's mental and physical well-being) will enable the client to normalise their state of being.

Behaviours that you may find challenging

All behaviour is a form of communication - a person who becomes angry or lashes out is trying to be heard. By exploring the client's likes and dislikes and gaining personal knowledge, they can begin to gain an understanding in regard to their personal triggers and work towards establishing the root causes of the behaviours.

Below are some factors in terms of individual behaviours that you may find challenging:

- Cycles of addictions that are linked to negative habits, phobias and fixation, developing obsessive and compulsive behaviour (ritual reassurance)
- Objection against demands and developing avoidance strategies
- Portraying signs of self-injurious (not just self-harming) behaviour
- Triggers from unrecognised sensory needs
- History of past or present incidents when the individual client is verbally or physically aggressive
- Reacting to boredom, frustration, social isolation and loneliness
- Not willing to engage and detaching
- Inappropriate internet and website usage
- Possible forensic factors with the risk of criminal conviction
- Involved in unhealthy relationships (on many levels)
- Experiencing or perpetrating bullying and victimisation
- Fragile balance between care and control within the family group



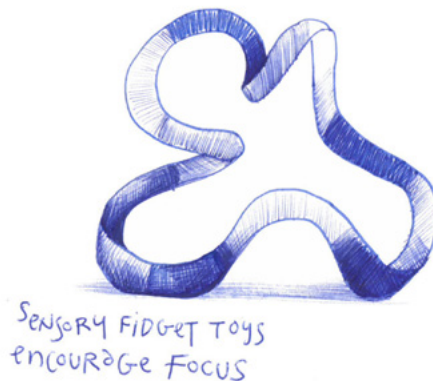
REPLACE UNCOMFORTABLE
CHAIRS WITH BEAN BAGS

Don't assume there is any common ground and remember there is no baseline for 'normal'. Practitioners, parents or carers may also have their own issues around neurodiversity. Be curious about living, studying and working environments.

An 8-year-old boy with ASD attended our play therapy. He was referred for anxiety, bullying, eating and relationship issues. Over time he began to enjoy the play sessions as he started to understand how the sessions worked and that he was in charge of the process. I established that a behaviour trigger was when he thought I was copying him and stealing his lines, during play therapy, this would make him annoyed with me.

So instead, he led the process of making up characters for me to play as counter characters to his own, telling me what to say and when. I became like a listening sister to him, addressing issues such as sleep and nightmares. We negotiated boundaries, for example when we met people outside in the corridor we would pretend to 'freeze'.

I participated in this play but on one occasion we were blocking the way, so I 'unfroze' and asked him to proceed to the therapy room. He was very angry with me for breaking out of role play as he felt I should do everything he says. I accepted his anger and I was willing to accept his instruction within certain boundaries.



Over time he accepted this and at the end of our sessions, he was much more confident walking around school and he learnt how to negotiate with others better.'

Autistic people can experience negative reactions to waiting as well as to sudden changes and uncertainty whilst a fear of the unknown can ignite a trauma response reaction resulting in a behavioural trigger.

The client may mask their feelings due to fear of being the person who is saying something different from others. Acting from a point of demand avoidance (not being able to do certain things at certain times), agitation, anxiety and impulse.

Other challenges include experiencing different sensory arousal patterns, difficulty in regulating one's emotions, difficulty maintaining boundaries and having problems associated with inappropriate behaviours.

There can be a lack of understanding of risks due to cognitive difficulties with imagination and foresight, ie. it won't happen to me so help the client picture a risk before it occurs.

There are many potential aspects of vulnerability, personal safety and security as persistent incidents of behaviour potentially further isolates the individual. There is the possibility of breaching the law so practitioners need to explain and making real the negative impacts on a client's lifestyle and personal freedoms. Actively support your clients to avoid receiving criminal records or facing imprisonment by being open about consequences of unlawful behaviour.

Good preventative work will sometimes use 'what if' questions to bring forward the reality and consequence of committing a crime. 'What would happen if you were arrested and taken to prison?' Be sensitive and cautious, do not use this as a threat either. Create a picture of consequences such as being taken away from friends and family, no gaming or laptop or mobile phone, no netball or football. Develop scenarios to enable clients to assess risk and help prevent them from occurring.

A nephew within our family who is a male teenager with an autism diagnosis, had an obsession and fixation of smelling the bottom of woman's shoes. He enjoyed the sensory smell but this behaviour would occur on the London Underground. This got him in trouble with the transport police on numerous occasions, he sadly ended up with a criminal record.

Involvement of families can also be of great benefit in terms of developing strategies to counter behaviour that you may find challenging. The key in reducing behavioural triggers lies with a person-centred client approach; building the sessions around the individual's needs, building a relatedness and a relationship of understanding and trust. It never works to address a person's emotions when angry and they have shut down or have an outburst. Use de-escalation techniques, always speak calmly and with understanding after an episode of behaviour that challenges you.

Anger management charts can be utilised indicating visual colours and signs for identifying behaviour that challenges and the person's individual triggers. Use the Red Amber Green traffic light system and ABC (Antecedent/Behaviour/Consequence) monitoring charts.

Always involve the client in assessing their own risks and developing their own behaviour strategies and use questions such as:

“What do you think you should do when this risk or trigger occurs?”

“What works for you to make you less angry or anxious?”

Establish what personal comforters they have and what ways of coping do they currently use in their daily life. Use positive thinking strategies and explore special interests with the client:

“What are you good at doing?”

“What good things are you going to do for you today?”

“What makes you feel good or happy?”

Once a person with autism finds a chosen skill and niche it will help to become focused on hobbies and interests because this is where their expertise can flourish.

When the client becomes bored, disengaged or triggered and frustrated use redirection techniques to lower anxiety. As a practitioner invite the client to think, talk about and focus on something they like and enjoy or memories of a past event that summons up good memories. Allow the client to remove from their mind the present emotional tensions they are experiencing and don't be afraid to change the subject in mid flow.



Also think about:

- Mindfulness exercises
- Engaging with Cognitive Behavioural Therapy (CBT)
- Practical problem-solving exercises
- Re-framing clients' view of themselves or situations around them
- Working through established patterns
ie. negative thoughts leading to negative behaviours
- Using their special interests as topics
- Using visuals and print resources in advance and get the art materials out
- Intersectionality
- Using positive rewards systems as a motivation to reduce incidents and behaviour that challenges

Gaining and understanding of their own selves before understanding the complications of others is crucial so the practitioner needs to find relatedness to interests the client has, ie. TV series, favourite films, food, holiday destinations – draw a map together. Central to building a therapeutic relationship with the client is to find, explore and become familiar with what the person likes.

Help them develop behavioural strategies for when triggers do occur and encourage the client to verbalise the words as this will help to take ownership of behaviours. Establish a key word or a sign when anxiety is building up inside the client so they can let you know without having to offer a lengthy explanation. Redirection strategies.

Being pro-active in planning always helps reduce anxiety:

- Encourage the client to have a non-sugary drink before they attend sessions or participate in activities
- Support the client to use Google maps when planning a journey
- Travel routes before they are expected to attend schools, meetings or events

Safeguarding and disclosure

Be vigilant for signs of abuse within the following categories:

- Financial
- Emotional (psychological)
- Neglect
- Modern slavery
- Discrimination (hate crimes)
- Institutional
- Sexual
- Physical
- Domestic

For practitioners working in an organisation if a client makes a disclosure, then follow the established policy and protocols to guide your appropriate action.

If as a practitioner at any time, you feel concerned for your personal safety during counselling or outreach sessions firstly try to remain calm and focussed on the young person's body language and be mindful of your tone of voice. If you feel confident address the way you are feeling and experiencing the situation, try to establish what is happening for them and look towards colleagues who may be in the vicinity. Again, if you are working in an organisation make sure you are familiar with the Safeguarding Policy and the Staying Safe in the Workplace Policy and always debrief with your line manager and in clinical supervision.

I was supporting a thirteen-year-old female, who revealed to me within the sessions that they had been exploring their sexuality. Staying with their exploration I asked what was happening for them and they disclosed that they had accessed an adult pornographic site, a live masturbation suite online. I asked what the site was called, explaining they were not old enough to access this kind of material. Being clear, honest and letting them know I would have to break confidentiality they agreed for me to help them talk to their foster carer. They appreciated the opportunity to take responsibility for what they had done, understood it was unlawful (after we had discussed it thoroughly) and had placed them at risk of exploitation.

I reported this breach as a safeguarding incident to my line manager. I checked out the website and found out it was a banned, underground site located on the dark web so reported it to Social Care and NHS Sexual Health team who knew of the site being the type of site that would attract vulnerable people. Although this incident ruptured the relationship for a short time with the client being silent with me, with patience we were able to repair it as we addressed what happened and acknowledged they were unhappy with me whilst also pointing out how brave they were in speaking with their foster carer.

Sensory and neurological processing

People with an autism diagnosis have unique sensory processing. If a person's sensory needs are not met it will raise anxiety and create imbalance in their life. There can be neurological challenges for a client in identifying the following human experiences: what is pleasant or unpleasant, real or unreal, fantasy or reality, healthy or risky, good or bad?

Experiencing a constant flow of high levels of anxiety and trauma negatively impact on emotions and can shut down the top part of the brain. This higher brain holds intelligence, creativity, rational thinking, reasoning and reflection. If we freeze in response to a perceived risky situation, we then activate the lower part of our brain which is centred around flight and fight and moves our bodies into survival mode. The main message we hear is 'I am under threat' which drives up our anxiety.

People with autism experience sensory overload occurring when the cognitive pathways freeze and shut down. Individuals will require either a decreased impact of sensory stimuli, defined as Hyper sensitive, or an increased and heightened need for sensory stimuli, defined as Hypo sensitive. To support calmness and assist with such experiences it can help by facilitating the client to participate in a mindfulness body scan, either at beginning or end of sessions so the client can begin to think and maybe verbalise what they are feeling.

Sensory needs are identified and assessed in six areas:

1. *Taste*
2. *Smell*
3. *Sight*
4. *Sound*
5. *Bodily awareness*
6. *Balance*

Be aware of your space, your own use of aftershave, perfumes or bodily aromas as such sensory sensations can overwhelm and distract some individuals with autism. Don't predict what they will or won't like, be prepared for the discussion. Alongside these aspects, vivid colours and multiple patterned clothing that you may wear as a practitioner can cause a sensory distraction for some individuals on the spectrum. Rugs and carpets on the floor, wall hangings, tones and levels of voice can all be a sensory overload trigger.

This guide includes a sensory awareness checklist and action plan for you to use to support the client and their family. The outcome is for the client and you to have a clearer understanding of them, their needs and preferences. Hyper sensitive or Hypo sensitive?

Encourage the client to bring sensory comforters of their choice to the sessions and these may include a preference of wearing head phones, wearing weighted waistcoats or rucksacks, sun glasses, hats.

A person-centred environment

To support a client with autism to engage with a therapeutic process and to enable the client to feel less anxious and insecure it is imperative to be proactive and welcome the client to visit the space beforehand. If possible, provide a special designated, autism friendly sensory room or think about how you could use some of these ideas in your own space. Inside a sensory room there are special features such as changing lights, a projector with audio function, boxes of sensory gadgets or fidget toys, bubble tube and lamps, comfortable bean bags, a vapour machine and blinds to block out light which can distract some individuals.

Ideally the decor of the environment will be in neutral shades and colours, including the walls and carpets.

Assess the environment, exploring the clients' sensory requirements and preferences. Consult the client about the space. Prior to sessions adjust the sensory room to ensure it is meeting the client's needs, hypo or hyper sensitive?

Within the environment be flexible to adjust timing of sessions, modify sessions and build in breaks suitable to the client's wishes if the need arises, be aware of the client's energy and concentration spans. Keep the space calm and be aware of distraction around you and enable a place of peace so the client can focus and express themselves.



Materials included in this guide and how to use them

Any person-centred process will assess what are the client’s sensory needs and wishes and completion of the action plan can assist clients in improving the quality of their lives in terms enhancing the individuals’ sensory preferences, so the client can take charge of their own regulation.

In this guide we have provided:

<i>Questions to ask yourself as a practitioner</i>	37
<i>Questions to think about with clients (and how to have them conversationally)</i>	38
<i>Questions to think about with parents and carers</i>	40
<i>Self assessment: The sensory needs</i>	41



Questions to ask yourself as a practitioner

1. *Do you feel that you have a good understanding of autism? Or would you like to improve your level of autism awareness?*
2. *What difficulties or challenges do you experience during sessions when supporting clients with autism?*
3. *Are you happy to include parents or carers in the process of working with their children, ie. having three-way meetings or supporting clients to discuss issues affecting the whole family?*
4. *What do you feel would support both you and the client with autism during sessions?*
5. *What current strategies do you provide that you have found successful in positively engaging client with autism during your sessions?*
6. *Do you currently have adequate background knowledge in relation to the needs and wishes of the autistic client?*
7. *Are there specific needs or resources required within your working environment when supporting individuals with autism?*
8. *Are you aware of the sensory needs of the clients with autism?*
9. *How aware are you of your own sensory needs?*

Questions to think about with clients (and how to have them conversationally)

1. *What would you like to change in your life?*
2. *Would you like to use different communication during your sessions, such as use of IT technology, photographs, artwork, objects or pictures?*
3. *Would you like to bring a personal item to the sessions to make you feel more comfortable?*
4. *Have you had a sensory assessment? Do you know what sensory needs you have?*
5. *Would you like to use our sensory room when working with us?*
6. *How long do you think we could work together in a session?*
7. *If you have one, what does having an autism diagnosis mean to you?*
8. *Would you like to know more about autism?*
9. *What are you not happy about in your life?*
10. *Have you attended counselling or keywork sessions before? Did you have a good or bad experience?*
11. *How can counselling or keywork sessions help you?*
12. *Do you experience times when you are very anxious and nervous? What do you find makes you feel this way?*
13. *Have you ever hurt yourself?*
14. *Do you feel lonely and would like more relationships?*
15. *Frustration, loss and joy: do you recognise these emotions when they happen in your body?*
16. *What makes you feel happy and relaxed?*
17. *What are you interested in? What do you like to do?*
18. *What makes you angry and frustrated? What triggers you?*
19. *What skills do you have?*
20. *Do you break or throw items when you become upset?*
21. *Did you have difficulty finding out about me/us?*

22. Do you like your day to have regular planned activities, so you know what is going to happen and when it is going to take place?
23. Would you like to visit our space before you start coming to sessions?
24. Would you feel okay if your parent or carer was to attend a session with you?
25. Is it important to keep to time when planning things with you?
26. What is the best way to communicate change with you?
27. Would you like to attend group workshops on topics that may affect your life, such as autism, ADHD, sexuality/gender identity, bullying, gaming and internet activities?

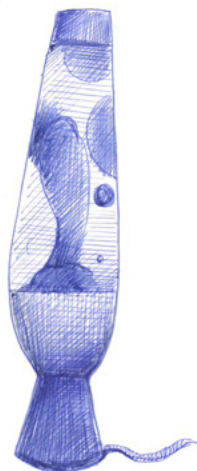
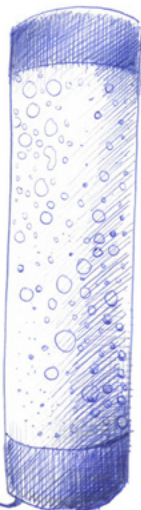
BRIGHT
idea



REPLACE BRUSH
LIGHTING WITH
SOMETHING
MORE AMBIENT

NO BRIGHT LIGHTS AND
DEFINITELY NO
STRIP LIGHTS UGH

TRY 2 LOVE LAMP
OR SOMETHING
MELLOW



WHAT OTHER CHANGES COULD YOU MAKE

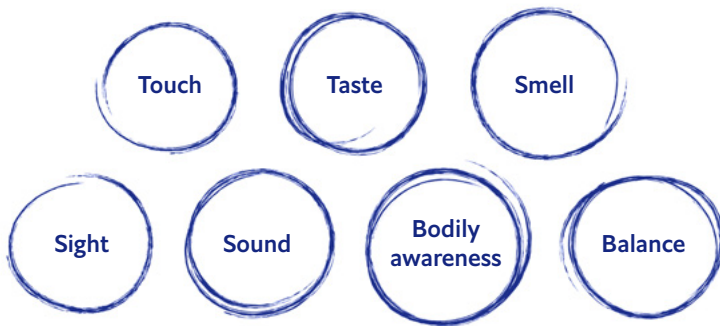
Questions to think about with parents and carers

1. *Has your child received a sensory diagnosis in relation to autism?*
2. *If you have had one, what was your experience of obtaining an autism diagnosis for your child?*
3. *Do you feel your views, experiences and opinions are taken into account in terms of planning and support around the needs of your child's autism?*
4. *Are there any key issues you would like to share with the practitioner working with your child?*
5. *Would you describe your child as having a fulfilled life?*
6. *Are there enough available and suitable activities for your child?*
7. *Do you feel that you receive adequate support from services and multi-disciplinary professionals?*
8. *In your experience, does the education/school system understand your autistic child?*
9. *Has your autistic child been excluded from school or college or threatened with exclusion?*
10. *Do you require more resources, partnership working and information to support your autistic child?*
11. *What expectations do you have from the outcome of your child receiving counselling or keywork sessions?*
12. *What support would you benefit from in relation to your child's autism?*
13. *Would it benefit you to attend a three-way meeting, family liaison session involving a practitioner and your child?*
14. *Are you confident at introducing changes and negotiating changes with your child?*
15. *Do you have successful strategies in supporting your autistic child's needs?*
16. *How do you usually process and use the information that is presented to you?*

Self assessment: The sensory needs

Sensory processing guidance

Every individual has their own different and unique sensory processing systems that it is inbuilt inside us all. Our human senses are divided in the following areas:



The two categories that we will focus on as outcomes to support you to assess yourself within each sensory category are as follows:

Hyper sensitive:

Overdeveloped senses, a person that already has a lot of electricity going around their own body, quite a lot of motivation happening naturally. You can become overwhelmed and anxious by having your senses over engaged. You will have a low threshold to being sensory over stimulated and this may have a negative impact on your daily life. You need less activity not more.

Hypo sensitive:

Underdeveloped senses, you have a low threshold to sensory stimulation. You need more activity not less, to enable you to become engaged and focused. You may require lots of activity and interaction to help you feel alive and well.

The objective of this self assessment is to empower in the knowledge of your own autism self-awareness. It is not to replace any expert diagnosis but a person-centred process that can help you with accessing circles of support from friends, family and professionals in your life.

How to complete the self assessment

Hyper sensitive and **Hypo sensitive** are the two categories that you will be required to look at here.

Completion of this self assessment will empower you to recognise your own needs and help identify areas such as improving your living environment or creating a suitable diet tailored to your tastes. Develop a person-centred action plan, enabling you to gain a greater awareness of yourself. Establish what you want and what you need in your daily life. A guide to support your personal preferences, ideas to improve your relationships and develop new strategies with the aim of reducing your anxiety levels and improving the quality of your life.

Each sensory area described here asks you **five questions** that require you to answer **yes** or **no**. When you have completed the form, add up your scores and look at your answers under the headings then look at our **assessment guide** and **action plan**.

If you answer **Yes** then score **1**.

If you answer **No** then score **0**.





Hyper (avoid sensory stimulation)

1. *I dislike touching certain materials.*
2. *At times I don't like to wear clothes because of the different feel of the materials and I dislike the feeling of labels in the back of my clothes touching my skin.*
3. *I don't like being touched or hugged by others.*
4. *I don't like running water on my body such as a shower.*
5. *I don't like having my hair cut or my hair being brushed.*

Total

Hypo (seek sensory stimulation)

1. *My body can't feel the cold, as I have circulation problem. I have difficulty keeping my body warm and comfortable.*
2. *I like body pressure; I prefer tight clothes and I like to sleep with lots of quilts and extra bedding to feel the heavy weight, this relaxes me.*
3. *I like people tightly holding me or shaking my hand.*
4. *At times I get injuries such as bruise or cut but I don't know how it happened on my body.*
5. *People say I can be heavy handed or quite rough with people and objects.*

Total



Taste

Hyper (avoid sensory stimulation)

1. *People sometimes say I am fussy and don't like different foods.*
2. *I don't like flavoured, seasoned or spicy food, meals that are too hot or cold.*
3. *Some food textures cause me strange feelings in my mouth.*
4. *I try to avoid experiencing different tastes in my mouth.*
5. *I don't like having varied different foods on my plate and I like plain foods without too much flavour, mashed potatoes, pasta, plain bread or crisps.*

Total

Hypo (seek sensory stimulation)

1. *I like to see varied colours of types of foods on my plate.*
2. *I enjoy different types of food, hot food and spicy food such as curries.*
3. *I like hot drinks, fizzy cold drinks and ice cream.*
4. *People are surprised how quick I consume my hot and cold drinks or meal.*
5. *I like eating alongside other people during meal times.*

Total



Hyper (avoid sensory stimulation)

1. *I dislike people wearing perfumes, deodorant, shampoos or aftershave.*
 2. *I can smell lots of different smells when I go into a room and this can distract and disturb me.*
 3. *I don't like being close to other people because of their body smells.*
 4. *I don't like air freshener being used in places that I am present.*
 5. *Having different smells around me can be very overpowering, making it difficult for me to focus and concentrate.*
- Total**

Hypo (seek sensory stimulation)

1. *I don't notice strong smells when I go into areas.*
 2. *I don't notice the smells of different people around me.*
 3. *I dislike wearing deodorant, perfume or aftershave.*
 4. *Sometimes I like to smell my own hands.*
 5. *I don't like foam or perfume smells in my bath.*
- Total**



Sight

Hyper (avoid sensory stimulation)

1. *I do not like bright lights or unexpected light around me, this can hurt my eyes.*
 2. *I prefer darkness than light, I like curtains closed or blinds pulled down to keep out the light.*
 3. *I find the sun and natural light very bright, so I like to wear sun glasses.*
 4. *I have difficulty looking into people's eyes or faces as this can cause me physical discomfort.*
 5. *I don't like to sleep when lights are on.*
- Total**

Hypo (seek sensory stimulation)

1. *I have difficulties, measuring space and distances between myself and others/objects.*
 2. *I like bright coloured lights.*
 3. *I like seeing or wearing bright colours.*
 4. *I like sunny days.*
 5. *I like my bedroom to let the natural light in the window, without curtain or blind.*
- Total**



Hyper (avoid sensory stimulation)

1. *I have difficulties concentrating when there are background noises around.*
 2. *I like wearing headphones or pulling the hood of my jumper or coat over my head to block out sounds.*
 3. *I don't like the sound of clocks ticking, road works, police or ambulance sirens, planes flying overhead, traffic in the street. Alarm clock, hoovers or hair dryers or other unexpected strange noises.*
 4. *I like a quiet environment; I have difficulty sleeping and I am very sensitive to sounds around me.*
 5. *I like calm soft gentle music or I dislike listening to music.*
- Total**

Hypo (seek sensory stimulation)

1. *I like to hear lots of different sounds.*
 2. *I like fast, loud and high energy music with a strong beat.*
 3. *I make and create sounds when it is too quiet around me.*
 4. *I like lively places with dancing, music and fun.*
 5. *Sometimes I have difficulty concentrating on what other people are saying.*
- Total**



Bodily
awareness

Hyper (avoid sensory stimulation)

1. *I do not like fast rides or any moving rides at the fun fair.*
2. *I find it difficult using small buttons, zips on clothing or using screwdriver to fix things.*
3. *I can slam doors or break objects by applying too much pressure. I don't realize my own strength.*
4. *I will avoid eye contact with others.*
5. *I don't like busy social gatherings and overcrowded places.*

Total

Hypo (seek sensory stimulation)

1. *I like being on transport moving. I like fast rides at fun fairs.*
2. *I like swimming and or trampolining.*
3. *I cannot feel my own body sensations and feelings such as pain, tiredness or hunger.*
4. *I enjoy physical contact and being held or holding others.*
5. *I may at times walk into objects, furniture and have difficulties measuring spaces and gaps.*

Total



Balance

Hyper (avoid sensory stimulation)

1. *If I want to look at something, I may turn my whole body instead of just my head to see.*
2. *I find it hard to walk on pavements with gaps, different textured floor surfaces.*
3. *I dislike using stairs or climbing up ladders.*
4. *I dislike dancing or moving my feet from the ground to balance. It makes feel unsteady within my body.*
5. *At times my body does not feel balanced and feels all out of place. Moving my body can make me feel dizzy.*

Total

Hypo (seek sensory stimulation)

1. *At times I walk on tip toe and I enjoy this sensation.*
2. *I have difficulty catching objects or playing sports due to my hand and eye coordination.*
3. *I can bump into objects and people around me and this provides me awareness of where my body is moving and the space around me.*
4. *I have accidents quite a lot and I can stumble, trip up or fall over.*
5. *I like jumping, twirling, spinning, running and rocking in my chair. I don't like to sit still.*

Total

Interpreting your scores

After completing the sensory assessment, add up your overall score. This process will support you in identifying yourself as having either **hyper sensory** or **hypo sensory** needs.

	Hyper	Hypo	Comments
Touch			
Taste			
Smell			
Sight			
Sound			
Bodily awareness			
Balance			
Total			

On the following pages are some guide examples of areas of change that support you in your daily life. Add any examples that suit your needs and write them in your personal sensory action plan.

Touch

Hyper

- Purchase a weighted blanket for when you sleep
- Purchase a weighted waistcoat
- Use a bath instead of a shower
- Remove all labels from your clothing.
- Grow your hair long or get it cut very short or get your haircut at home

Hypo

- Try to shake people's hands when greeting them
- Wear extra layers of tight clothing

Taste

Hyper

- Add plain foods of your choice to your diet
- Avoid spices, seasoning and additives to your food
- Eat your meals in peace and quiet, without distractions
- Develop a set weekly food menu, using varied coloured foods on each day

Hypo

- Build time during your week to eat with others
- Avoid spice and flavouring added to your meals
- Try adding juice to sparkling water instead of caffeine or fizzy drinks
- Develop a set weekly food menu, using varied coloured foods on each day



Smell

Hyper

- Ask people you live with not to wear perfume/aftershave
- Don't use fragranced cleaning chemicals at home, use ECO-products
- Don't use air freshener in your home
- Use non biological fabric cleaner

Hypo

- Build in sensory routines regarding smell and personal care. Wear aftershave/perfume
- Use stronger smelling fragranced products
- In your home use an essential oils aromatherapy humidifier
- In your home use a reed diffuser

Sight

Hyper

- Wear sun glasses or ask opticians for anti-glare lenses
- Use heavy lined curtains and thick blinds to block out natural sun light
- Look just above people's heads when communicating
- Decorate your room/home in calm, pastel colours

Hypo

- Decorate your room in bright colours
- Use bright sensory lighting
- Wear bright and fashionable clothing of your choice
- Don't lower blinds or draw curtains in the daytime, let in natural light
- Watch You Tube clips of destinations featuring the sun and sunlight

Sound

Hyper

- Use headphones or ear plugs
- Wear hats that cover your ears
- Visit quiet places outdoors and be in nature

Hypo

- Use headphones
- Attend live music events or go clubbing
- Get a studio, download a music-making app
- Learn a music instrument, ie. attend drumming, guitar classes

Bodily awareness

Hyper

- Use Velcro to fasten your clothes
- Wear sunglasses or glare reflector lenses (from the opticians)
- Look just above people's heads when communicating
- Build quiet time in your day, lay on the floor or on the bed

Balance

Hyper

- Try yoga and slow body movement exercises
- Try mindfulness exercises
- Build quiet time in your day, get comfortable, lay on the floor or on your bed

Hypo

- Wear a weighted waistcoat
- Use a weighted blanket at night
- Attend the gym or engage in physical exercises and movement
- Attend exciting and vibrant places/events of your choice

Hypo

- Learn skills in gymnastics or yoga and body movement classes
- In your home have non-textured, non-patterned plain flooring
- Build quiet time into your day



Action plan

	Actions Take from the sensory guide any areas described under Hyper or Hypo that you wish to add to your daily life.	Timescale When would you like add to your daily life
Touch		
Taste		
Smell		
Sight		
Sound		
Bodily awareness		
Balance		

Useful contacts and support networks

A2ndvoice: Supports autistic people and their families, raising awareness and understanding from different perspectives, tackling the taboos and myths around Autism. We host a range of events and activities looking at the needs of the family. info@a2ndvoice.com | www.a2ndvoice.com | www.autismthriveservices.com

Access Studio: runs in partnership with Croydon Council SEND service weekly dance and drama sessions for young people aged 13-25 at the Waddon Youth Centre on Thursday from 5-7pm | www.croydonmusicandarts.co.uk/access-studio

Ambitious about Autism: Supporting children, young people, their parents and carers. Ambitious Youth Network for people aged 14-25 with autism. 020 8815 5444 | info@ambitiousaboutautism.org.uk | www.ambitiousaboutautism.org.uk

Autism and ADHD: Campaigns for change, provides specialist training and support plus we're a friend you can call on for help. Parent toolkit download form. info@autismandadhd.org | www.autismandadhd.org

Autistica: UK's leading autism research and campaigning charity. Their vision is a world where every autistic person lives a happy, healthy, long life. They enable breakthroughs by funding research, shaping policy and working with autistic people to make a difference. Molehill Mountain (free app) co-owned by Autistica and King's College London, helping autistic people understand and self-manage anxiety. www.autistica.org.uk | www.autistica.org.uk/molehill-mountain

Autus: Charity creating opportunities for growth, learning and work for young people with Autistic Spectrum Conditions. Using an innovative and engaging virtual environment we offer a range of programmes, activities and support to help build confidence and develop social communication, digital and employability skills. 07432 300287 | info@autus.org.uk | www.autus.org.uk

AutiQuest: Supporting autistic adults to achieve more in their lives, especially with regard to gaining and maintaining employment. admin@autiquest.co.uk www.autiquest.com

Simon Baron-Cohen: Autism Research Centre Autism Research Centre – University of Cambridge.

Beautiful Octopus Club: The Albany Empire, Deptford

CASPA: Providing virtual and face to face meetings for parents, autistic children and adults, regular newsletters, supported trips, events, drop-ins, holiday clubs and youth clubs. membership@caspabromley.org.uk | www.caspabromley.org.uk

Challenging Behaviour Foundation – Family Support Service: Telephone support for families of children and adults with severe learning disabilities and behaviour described as challenging. 0300 666 0126 (Monday to Thursday: 9am-5pm, Friday: 9am-3pm) | 01634 838739 | info@theCBF.org.uk | support@theCBF.org.uk www.challengingbehaviour.org.uk

Croydon Autism Pub Experience Group: This group is for people with Autism who would like to explore Croydon's pubs and cafes with other people. We meet every last Thursday of the month in different venues in Croydon. A facilitator will be at the venue between 6pm-8pm. To find out more, contact Maria Esteban 020 8255 5473 | 07742 405 348 | maria.esteban@croydon.gov.uk

Cherry Hub: Autism family carers group: A support group for parents, families and carers of adults and teenagers with autism, offering mutual support and a space to talk about their issues. Every second Monday of each month from 6.30pm-8pm. The group is supported by the Autism Service Croydon and is run by family carers. No need to book, no referrals. 020 8255 5473 Ext 88920 | nickyselwyn@talktalk.net or maria.esteban@croydon.gov.uk

These clubs are delivered by Croydon Council support young people with autism, but are not autism specific clubs and have children and young people with varying needs and abilities attending.

Monday SEND Youth Club (Waddon Youth Centre): Informal education, social, positive life skills activities; including arts, music, sports, and cooking for young people with autism (16-25). Monday from 6.45pm-9pm (£3.00). 07701 398442 (Mon-Wed) | luke.stevens@croydon.gov.uk | cydp@croydon.gov.uk

Tuesday SEND Youth Club (Bensham Manor School): Informal education and social skills activities; including sports, arts, and adventure playground. For children and young people with autism, disabilities and additional needs aged 8-18. Tuesday from 3pm-5.30pm (£3.00) | anne-marie.abalo@croydon.gov.uk | 07587656449 (Tues-Thurs) | cydp@croydon.gov.uk

Tuesday SEND Youth Club (Waddon Youth Centre): Informal education and social skills activities; including sports, arts, music, and cooking. For children and young people with autism, disabilities and additional needs aged 8-18 years on Tuesday from 3pm-6pm (£3.00) | 07732 074288 | cydp@croйдon.gov.uk
wayne.stevens@croйдon.gov.uk

Wednesday SEND Youth Club (Waddon Youth Centre): Informal education and social skills activities; including sports, arts, music, and cooking. For children and young people with autism, disabilities and additional needs aged 8-18 years on Wednesday from 3pm-6pm (£3.00) | 07732 074288 | cydp@croйдon.gov.uk
wayne.stevens@croйдon.gov.uk

Thursday SEND Youth Club (Bensham Manor School): Informal education and social skills activities; including sports, arts, music and cooking. For children and young people with autism, disabilities and additional needs aged 8-18 years. Thursday from 3pm-5:30pm (£3.00) | anne-marie.abalo@croйдon.gov.uk
07587 656449 (Tues-Thurs) | cydp@croйдon.gov.uk

Croydon's Special Educational Needs and Disabilities Information Advice and Support Service (SENDIAS): Free, confidential and impartial information, advice and support. We aim to promote good working relationships between children, young people, parents, education settings and the Local Authority (Croydon Council), whilst seeking to empower parents to play an active and informed role in their child's education. We can support children, young people, parents and carers, in a number of ways and provide a range of services for more information: croйдon@kids.org.uk | www.kids.org.uk/croydon-sendiass

SEND Drop In: Every Friday 10am-12pm (term time only) at the Carers Information Centre, 24 George Street, Croydon CR0 1PB. No need to pre-book.

Croydon Drop In: Free confidential counselling for 10-25 year olds with wide range of presenting issues including Autism (6 days per week operating after school and Saturday mornings). Sensory room available. 020 8680 0404
enquiries@croйдondropin.org.uk | www.croydondropin.org.uk

Croydon Mencap: Provides support services, and a voice for Croydon children and residents with autism, and/or learning disabilities, their families and carers, promoting positive attitudes and improving the quality of their lives. 020 8684 5890
info@croйдonmencap.org.uk | www.croydonmencap.org.uk

Employment Autism: Supporting autistic people to have fulfilling, productive working relationships in inclusive and positive environments. We do this by enabling autistic people to find, and be successful in suitable work. Encouraging providers of work to employ autistic people and recognise the benefits they can bring to the workplace | 07703 666401 | contact@employmentautism.org.uk
www.employmentautism.org.uk/forms/contact-us

Inaspectrum: Adult Autism for free adult autism support and self-help. Social, educational, employment, health and well-being in neurodiversity. Inaspectrum Women in Autism, run by women for women | inaspectrum@hotmail.com
07900 990292 | inaspectrum.home.blog | www.meetup.com/inaspectrum
www.inaspectrum.com/women-in-autism

Gig Buddies Croydon: matches adults with learning disabilities and autism to volunteers who have similar interests to go to events together that they both love. Gig Buddies is about empowering people, building friendships and giving people choice about what they do with their own lives. We run monthly social events in local venues. cherilyn@gigbuddiescroydon.com | www.gigbuddiescroydon.co.uk

LWFCI UK: Provides tutoring and creative social activities for children with autism or special needs, also free support group forum for their parents and carers. For more information: 020 3583 3005 or 07950 746544 | info@lwfc.org.uk

National Police Autism Association: The NPAA offers free membership to all UK police officers and civilian staff (including special constables and police volunteers). We host the Police Neurodiversity Forum, a unique online support and knowledge hub, and we maintain a network of champions: offering provide peer support to officers, staff and volunteers through our team of coordinators.
Membership: www.npaa.org.uk/membership | Police Neurodiversity Forum and network of champions: www.npaa.org.uk/coordinators

National Autistic Society (NAS): National charity supporting people with autism to be independent, to build confidence in day-to-day activities, training for families, carers and communities. Providing Autism support, information and advice services, one-to-one or small group support to help deal with difficult issues, autism-friendly events and clubs, autism awareness sessions for support staff, employers, parents, professionals and local communities. | www.autism.org.uk

National Autistic Society – Croydon Family Support Service: Support for families after diagnosis. Practical and emotional support, advice, information and strategies for families of autistic children and young people living in Croydon.

Courses: For a chat about courses contact Alex Dimond | croydonscd@nas.org.uk

Post-diagnosis consultation: Opportunity for parents and carers to meet with our Family Support team (via home visit, online or telephone). Booking only via Family Support Team.

Social Skills groups: Fun, interactive football and lego skills sessions for autistic children and young people aged 5-18 years who attend mainstream school, and live in Croydon on Tuesdays after school. Booking only via family support team.

Clubs and Fun days: Activities and days out during school holidays contact: 020 3005 4335. Family support team: croydon.familysupport@nas.org.uk
Short breaks/clubs team: nascroydonclubs@nas.org.uk

Off The Record: Free confidential counselling for 11-25 year olds with wide range of presenting issues including autism, across Croydon, Merton and Sutton. Services also for young carers, refugees and online: info@talkofftherecord.org
Off the Record Youth Counselling | 0800 980 7475 | talkofftherecord.org

IPSEA (Independent Provider of Special Educational Advice): Support for special educational needs. Free legally based advice. You can book an appointment online www.ipsea.org.uk

SOS!SEN: Independent charity providing free, independent and confidential telephone helpline for parents and others looking for information and advice on special educational needs and disability (SEND) advice nationwide.
0300 302 3731 | 020 8538 3731 | sossen.org.uk

Special Needs Jungle:
www.specialneedsjungle.com/finding-racial-minority-voices-send

Willow Learning for Life: Offers a mix of education, training, and work experience for people with a learning disability and/or autism who live in Croydon.
07515 028382 | tanya@willowlearningforlife.org | www.willowlearningforlife.org

Autism resources

'Right from the Start' toolkit:

Information for parents of children with autism: www.ambitiousaboutautism.org.uk/sites/default/files/toolkits/right-from-the-start-toolkit-ambitious-aboutautism.pdf

Autism and Dental Care:

www.autism.org.uk/advice-and-guidance/topics/physical-health/going-to-the-dentist/dentists

Information and tips for maintaining oral health in children with autism: www.dentalhealthcareeoe.nhs.uk/wp-content/uploads/2021/03/0007-Dental-Care-Autism-Information.pdf

Autism Eye:

Autism and bereavement – free digital subscription to magazine and newsletter for parents and professionals. To subscribe: www.autismeye.com/subscribe

Beyond Autism:

Employability toolkit giving people with autism improved access to, and support in, employment. Download the free toolkit and additional resources. 020 3031 9705 info@beyondautism.org.uk www.beyondautism.org.uk/professionals/employability/toolkit/employment-toolkit

Hunrosa:

Sleep consultancy, resources and apps for children, young people, families and professionals. www.hunrosa.co.uk

Molehill Mountain:

Free app helping autistic people understand and self-manage anxiety. www.autistica.org.uk/molehill-mountain

Robyn Steward:

Autistic speaker, trainer, consultant and author. The Autism Friendly Guide to self-employment and The Autism Friendly Guide to Periods www.robysteward.com

The A-Word:

BBC television drama series, based on the Israeli series Yellow Peppers. This contemporary series follows a young boy with autism and how their family learn and understand that autism is all around us. Highly recommended viewing (3 series).

Genius Within:

Passionate about neurodiversity www.geniuswithin.org

About the author – Mark Wallis

I first began supporting people in the 1980's, employed at a large, long stay learning disability institution, Darenth Park, situated in Dartford, Kent. Due to what I witnessed as a young adult within the walls and wards I became one of the country's first whistle blowers concerning disability abuse, resulting in the publication of a book entitled 'Prisoners, Patients or People' written with co-author Ricky Henderson. We received positive reviews and support from leading international practitioners and campaigners at the time such as Dr. Wolf Wolfensberger, famous for his land-breaking normalization and humanitarian concepts, alongside support from the pioneering Professor Jim Mansell at The Tizard Centre at University of Kent, situated in Canterbury.

At the launch of the 1990 Community Care Act, I continued my career working towards the closure of long stay hospitals to promote resettling and supporting individuals, who had previously been patients, to transition as free citizens across London communities. Working in partnership with NHS, local authorities, housing associations and social services, I became a member of the founding support teams that put community care into practice.

For over forty years I have worked within the health and social care sector, receiving outstanding status awarded by CQC when managing residential and support for living homes in South London. Within this period of time, I have emotionally and practically supported families while co-ordinating respite environments.

Using knowledge and experience in relation to supporting people across the autism spectrum and working with individuals with complex needs and nonverbal communication, I utilised person-centred tools such as Intensive Interaction Techniques and Person-Centred Active Support to reach the inner world of the clients. Monitoring body language linked to clients' emotions, this communication process empowered individuals to make choices in their daily lives. I have also supported individuals with a diagnosis of high functioning autism and ADHD during multiple counselling sessions.

In my experience of managing services, it greatly concerned me that many individuals were labelled and treated as having 'challenging behaviour' but in the majority of cases the individual clients involved in incidents would clearly be portraying undiagnosed autistic traits. I observed that clients with autism were being triggered because of lack of awareness from service providers for their autistic needs. In my role as a care manager, I began designing and facilitating autism awareness training, alongside working with services implementing autism friendly, person-centred support plans.

During my career I have supported individuals with autism from childhood provisions transitioning to adult services. Providing Positive Behaviour Support and successfully reducing risks. This work was also done in conjunction with social services, Metropolitan Police and the Sapphire Unit investigating high profile safeguarding situations. I have provided family liaison support and worked towards the implementation of various person-centred and family focused support strategies. I have experience supporting individuals with autism pertaining to employment, also enabling clients to gain media recognition for their person skills and achievements. One such opportunity led to one young man winning an Autism Hero award and a feature on him in The Guardian newspaper.

I worked a business project entitled 'Hops Not Hate' with a local brewery and a team of autistic people. Together we received great reviews for producing a special form of flavoured fruit beer, that sold out in the supermarkets alongside the product being used to advertise awareness of hate crime.

My passion to improve the lives of individuals and families led me to work alongside various local, national and international user groups with key autism experts and campaigners such as author Robyn Steward from National Autistic Society. I have worked in partnership with several prominent psychologists and various experts within multi-disciplinary sectors and with the specialist forensic services of RESPOND, supporting young people with autism who are at risk of offending.

Over an extensive period of time, I worked in partnership with Dr Neil Hammond who successfully developed weekly counselling sessions, supporting individuals with an autism diagnosis at the Maudsley Hospital, Camberwell.

My current thinking is influenced by work we did with individuals that:

- used a mixture of therapeutic practice, psychotherapy, Cognitive Behavioural Therapy and mindfulness techniques
- encouraged awareness of self and a focus on learning 'what having an autism diagnosis meant for the client'
- explored the client's personal history and life journey with the involvement of their family
- used positive behavioural techniques with the central involvement of the client reviewing their own personal risks
- worked alongside the autistic client with the objective of helping the client take personal responsibility for their actions
- empowered the client to review their relationships and, for example, discuss their sexuality for the first time in their lives

I noted that the main central part of the sessions responsible for producing such a positive interaction was that fact that all aspects were autism friendly and the weekly sessions maintained a person-centred approach.

My goal then moved to support therapeutic practitioners in their roles and began when I was invited to provide an autism training session for Croydon Drop In practitioners. Arising from recommendations from the day, Croydon Drop In designed an autism friendly sensory room, enhancing sessions in recognition of young people's sensory needs and has now published this unique guidebook. Thank you for reading!

Mark Wallis

London 2023



Thank you

To all the parents and carers and to the children and young people for sharing your lived experiences with us and who tolerate us in your lives – we are doing our best, we promise!

To the young and older adults who helped bring this book together – Michael Arhin-Acquaah, Anna Austin, Jannelle Dawson, Dr. Neil Hammond, Hilary and Alan Hodgson, Connie Ikhifa, Rochelle Jeffrey, Rhona Kenny, Angel Knott, Nicola Newman, Kevin Oakhill, Angela Sterling, Robyn Steward and Tanya Wallis. And to all the practitioners who contributed their thoughts, experiences and case studies and whose identities are not revealed so as to protect the individuals with whom they connected.

Reference:

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Supporting children, young people and families since 1978.
Information, advocacy, counselling, outreach and health support
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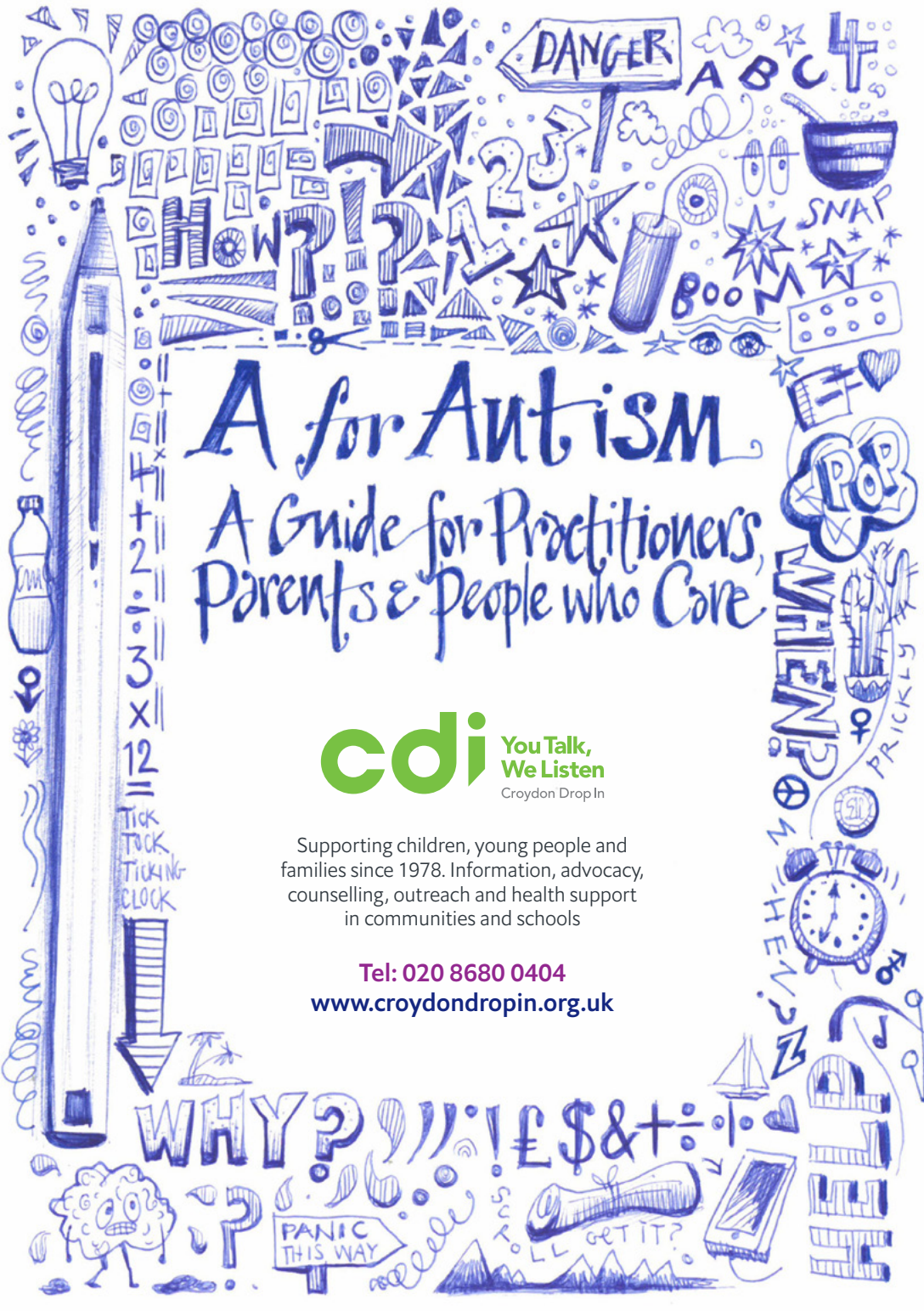
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Facebook: www.facebook.com/CroydonDropIn

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A for Autism

A Guide for Practitioners, Parents & People who Care

cdi You Talk,
We Listen
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