

RAINBOWS EDGE

A **HGPS** PUBLICATION



FORWARD

Over the next few pages you will read a lot about Autism.

However, this book is not really about Autism.

It is about respect and understanding.

It is about tolerance and acceptance.

It is about recognising our own and each other's gifts and talents.

It is about recognising that we are all the same but also different.

It is about embracing our differences and celebrating success –
however small.

Most of all, it is about love – the unconditional love of a family.

It is about our family.

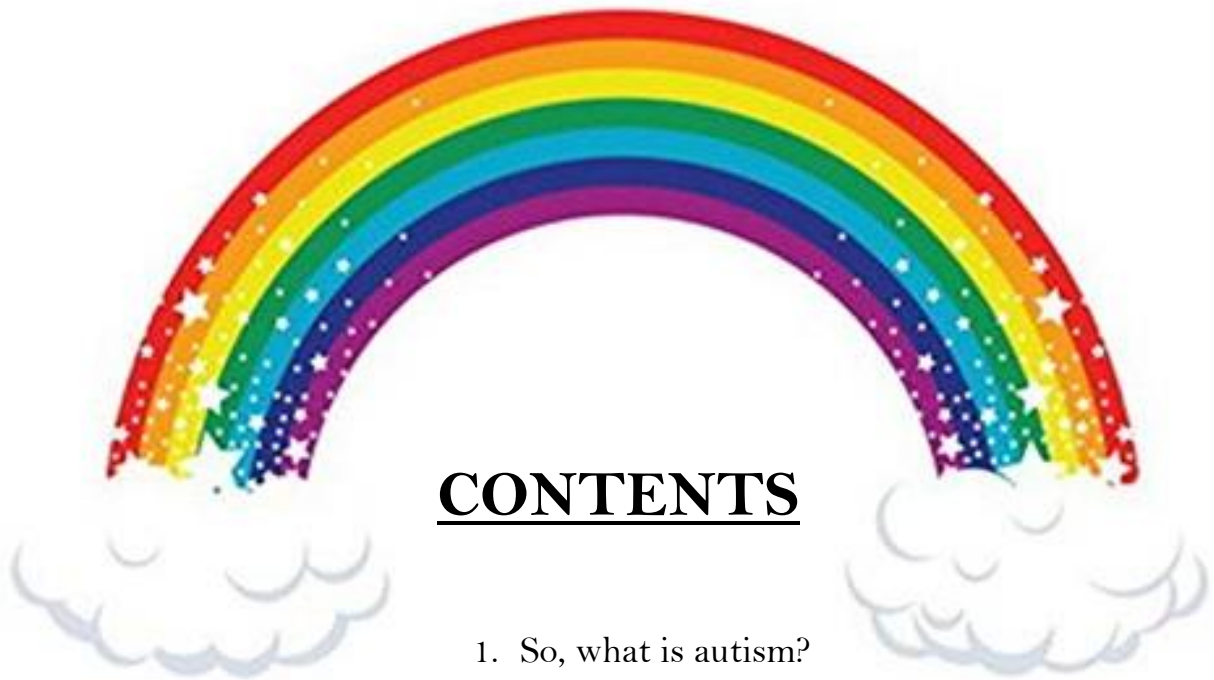
It is about our community.

It is about us.

HGPS.



Mrs Diane Smales HT



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So, what is autism?

Autism is a lifelong developmental disability that affects how people perceive the world and interact with others. Autistic people see, hear and feel the world differently to other people.

If you are autistic, you are autistic for life; autism is not an illness or disease and cannot be 'cured'. Often people feel being autistic is a fundamental aspect of their identity.

Autism is much more common than most people think. There are around 700,000 autistic people in the UK - that's more than 1 in 100. People from all nationalities and cultural, religious and social backgrounds can be autistic, although it appears to affect more men than women.

Autistic people often do not 'look' disabled. Some parents of autistic children say that other people simply think their child is naughty.

Many autistic people have intense and highly-focused interests, often from a fairly young age. These can change over time or be lifelong, and can be anything from art or music, to trains or computers.

How does autism affect people?

All autistic people share certain difficulties, but being autistic will affect them in different ways. Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support. With the right sort of support, all can be helped to live a more fulfilling life of their own choosing.

Some autistic people say the world feels overwhelming and this can cause them considerable anxiety. In particular, understanding and relating to other people, and taking part in everyday family, school, work and social life, can be harder. Other people appear to know, intuitively, how to communicate and interact with each other, yet can also struggle to build rapport with autistic people. Autistic people may wonder why they are 'different' and feel their social differences mean people don't understand them.



AMAZING FACT



The average human processes between 13 and 30 cycles per second of brain wave energy in a conscious state. A child with autism can process over 250,000 cycles per second of brain wave energy in their conscious state. Because of this brain wave energy, it is believed that children with autism have a brain that processes at genius levels.

A growing number of our families are experiencing the challenges and rewards that autism brings. Here are some of their thoughts.

A day in the life of an ASD parent

Morning time - *The alarm is going off which means it's time to get my tired body out of bed for another day. Before getting in the shower I venture into child's room to gently wake him from his slumber but get no response.*

I take a shower, dress and return back into his room to try to wake him up again but the toil of not being able to switch off for him at night means very late nights but once asleep he is difficult to wake up.

Further attempts to coax him out of bed eventually erupts with him shouting at me that he is awake.

Having got his sisters up and dressed there is still no sign of the said child so I ask him again to get up - I get shouted at again that he is doing it already.



Breakfast time –

“Would you like toast or cereal?”

“No I don't want toast.”

“What about cereal?”

“No I don't like cereal.”



“Well what are you going to have?”

Child now shouting again “I told you already, I want toast!”

Okay, go off to make toast, presents it to the child only to be told he didn't want toast he wants Frosties!

After breakfast, numerous reminders to clean his teeth and find some socks to wear. He goes upstairs, cleans his teeth but comes down without socks! Reminded again to find some socks. Goes back upstairs! 2 minutes later a full meltdown occurs because the socks he was happy to wear for the rest of the week, are today not acceptable. They are hurting his feet and he can't find a comfy pair so he doesn't want to go to school. Eventually he finds a pair of socks acceptable to wear and comes downstairs. Asked to put school coat on and shoes as it's time to leave for school. He wanders into the lounge and sits on the sofa.

When asked what he is doing he is unable to voice his intentions. Asked again to put coat and shoes on - no response! Told that we are getting in the car- further meltdown over fear of being left! Shouts from child that he hasn't been told to put his shoes on, now crying as fear he will be late for school and doesn't want to get into trouble.



Eventually gets coat and shoes on (further issues with his shoes - the Velcro has become stretched as child attempts to pull the straps as tight as they will go). Get in the car where his sisters are already sat waiting for him and we drive to school. No doubt he must be as exhausted before getting to school as I am!

We go into school with no problems. Child spends the day with his friends at school trying to keep a lid on his emotions and making sense of the world through his hypersensitive senses (again this must be exhausting.)

After school - child collected from school. I can sense he is like a coiled spring so I avoid any meaningful conversation for fear of overloading his stress bucket and erupting into a meltdown at school. As we drive home I am conscious that his sister is adding to his stress bucket through wanting to talk her day through - this leads to loud screams from child and bickering on the journey home.

Child goes off to have some down time (sometimes this is sitting quietly in his room rocking on his bed, sometimes this is playing of the switch, sometimes it is playing football outside and other times it's running around the house making lots of noise - I assume it is like a release from a pressure cooker!).

Tea consists of the same pasta dish he has every day. This rarely changes despite offers of different things! Then bath and bed time (this can be anywhere from 8pm to 2am, depending on how full his stress bucket has been during the day) but once asleep that's it until the morning.



Yes, it is hard work and some of these behaviours would be normal and to be expected of a child younger than his age. His size also makes people's perceptions skewed. They expect him to behave the same as children his height (so older than his actual age) but a child will always function socially at a third less than his actual age.

how do you spell love?

- piglet



you don't spell it.

you feel it.

- pooh

He will have to learn coping strategies as he gets older to find what works for him to enable him to cope in society. The things we take for granted are significantly more difficult for him to process and result in emotional and physical exhaustion which, in turn, erupt into meltdowns when things get too much.

He is eager to have friends and to fit in and on the whole that does happen but he just has to work 10 times harder at it than others.

If you ever want to know about autism, come and spend the weekend with us!! We are one big, very special happy, loving family!!



My very own Super hero!

When my child was first diagnosed with autism at 3 years old I grieved. I felt a loss for a future that should have been. My husband bluntly told me that our child was no different now walking out of the assessment room as he was walking in. He was right! It just meant we could now fit the jigsaw pieces together and try to understand as much as possible in order to help with the difficulties our little boy faced.

*What a whirl wind we've had since! Our child has also been diagnosed with **SENSORY PROCESSING DISORDER** and has previously developed stress alopecia and tics, (**not because he's not built correctly for this world, but because us in this world are sometimes not built correctly with full understanding on all types of disability.**)*

Why I feel autism awareness is massively important is that people without much understanding can sometimes (not always meaning to) make an already hard life even harder!

I've been in supermarkets where people look at me or my child funny. Just because he doesn't "look" disabled that he's being naughty or that I simply can't control him, wondering why he may be clapping frantically, making animal noises or with ear defenders on but not plugged in to an iPad!

*I've had the comments, the stares, the insensitive "cures" or people feeling sorry for me that I have a son with autism. No one could ever understand the daily challenges both autistic people and the families of autistic people face just over the smallest of things. I cannot lie and say that there are no negatives or downsides of living with and helping a child with special needs. However, he is special alright, and I am **NOT** unlucky.*

My boy has taught me more this last 5 years than I have ever learned in my 29 years. He is unique, hilarious, his different perspective on life and attention to detail makes him more intelligent in so many ways than most. He gives me the most honest opinions (sometimes too honest!) and his regimented preferences keep us all in check, and for all that, plus more, makes me one of the luckiest and proudest mums of all. I will continue to fight and be the voice for my little superhero and autism and I hope that one day everyone can have the understanding and be educated on autism awareness.



MY VERY SPECIAL MR. MAN!

My son he has a special power,
They call it ASD.
He sees the world differently,
To his family, friends and me.

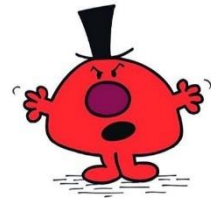


He memorised the Mr Men,
At 2 could do times tables.
But hates to wear socks and coats,
And is sensitive to labels.

He likes to talk of googolplexes,
He loves to dance and sing,
But change causes melt-downs, and,
Sleep is definitely not his thing.

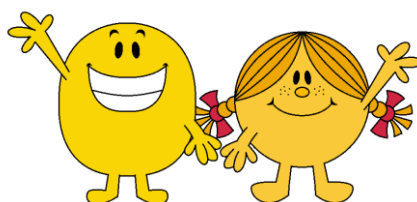
At playgroup, nursery and at school,
He had to learn so much,
Not about maths or abc's,
But about rules, norms and such.

He feels, smells and hears things,
So very strong it hurts.
Just one instruction at a time,
Any more and he's fit to burst.



Society makes him adapt his ways,
So that he can thrive,
But he has taught me more in the last few years,
Than in my other 25.

My son he has this special power,
They call it ASD.
Don't change him, or tease him, just help him grow,
Into the boy he wants to be.





When my child was told they had autism, my heart sank. I knew the heartache that came with it; the long journey ahead of us.

But, it's not all doom and gloom, as a child with autism brings lots of happiness and is very loving.

Yes, it can be draining when the meltdowns last for hours and when they don't sleep well at night; you're up and down all night! Sleep deprivation can feel terrible.

But, I wouldn't change my child for the world, it's who they are!

I've learnt to take a step back and not feel so panicky when things are going wrong. Yes, I do have to think ahead all the time, put things in place to help stop the anxieties. But also, I have to give my child the life skills and tools to cope in life if they're to succeed in life.

Sometimes, I can feel quite alone.

If you haven't got a child with autism, you wouldn't really understand; it is hard - 24/7! You lose who you are as you have to breathe their life for them. You don't have time to be you.

Yes, it's hard but they weren't asked to be born this way; it's not their fault! As an adult, their mother, I have to do this for my child. I want to do this for my child.

I have a lot of techniques now, mostly learnt through trial and error. You start to learn what works for your own child and you start to see the signs and when melt downs are going to happen. I try to nip them in the bud before they happen. So, yes, you are always one step ahead of them – of course it doesn't always work!!

I make sure my child knows it's okay to have autism. Their brain just works differently to other children's and that's why they feel like they do. I always try to make sure they feel safe and VERY loved no matter what happens.

We will always work it through together!

My big, little boy!



He is my big, little boy!

*He was diagnosed with autism two weeks ago.
In my head, I knew there was something 'wrong' for a number of
years, but I thought it was just him!*

*When we were told about ASD, my heart felt like it
had been torn apart and the bottom had fallen out
of my life.*



*People say it is a good thing we have a diagnosis for him, but to me
it is like a label has been attached to him that will be there for the
rest of his life.*

That really upsets me!

*He is struggling with his school work and is on the SEND register
too. It seems he is being given more help and support in school
which I appreciate very much.*

*I need to learn how to differentiate his
behaviour.*

What is him just being him?

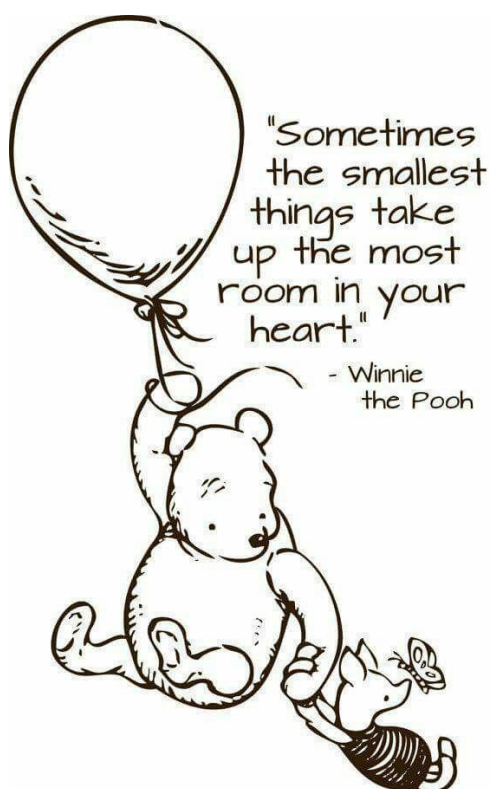
What is him just being naughty?

What is his autism and ASD?

...and how to react accordingly.

BUT...

*He is still my little boy and
always will be!*



*"Sometimes
the smallest
things take
up the most
room in your
heart."*

*- Winnie
the Pooh*

Our RAINBOW family

A growing number of our children are being diagnosed with autism. Whilst we are becoming more aware of ASD (Autism Spectrum Disorder), do we really know what it's like for the children?

Do we really understand the struggles that children with autism have to face every day?

These are just a few things the children with autism would like you to know. They hope this may help you to understand them a little better.

'I get stressed easily! I get stressed if I do something I don't know about.'

'I can't cope with some things so it causes me to cry.' (Anxiety!)

'I worry most of the time about things and if I don't understand or get things wrong I get stressed out!'

'I may just need 'alone time.'

'It helps when I sit for a while in a quiet space.'

'Loud voices are just too much for me!'

'When I was younger, I didn't like loud noises.'

'According to my mum, I have a great memory!'

'I get bored easily!'

'I find wearing shoes, socks and coats difficult.'

'When things get crowded and noisy, I can't cope with it and I feel stressed.'

'I don't like crowded spaces. I feel claustrophobic!'


'I don't like changes, so I like to be informed about things.'

'I don't like male teachers and supply teachers!'

'I AM PROUD OF WHO I AM!'

I have Asperger's.

It's a form of autism. My Super Power is Maths. I'm much better at Maths than a lot of people, even Mrs Smales! Sometimes I struggle to tell people how I'm feeling. I love Mario, so I chose some of my favourite characters to help other people understand my emotions.

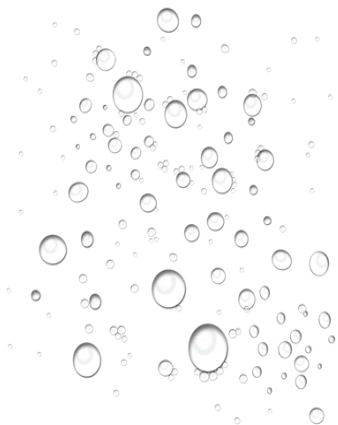
	<p><i>I am really not happy. I am filled with rage!</i></p>		<p><i>I am feeling a little angry and I might want to punch or kick.</i></p>
	<p><i>I am feeling a little scared and might want to talk about my feelings.</i></p>		<p><i>I am feeling embarrassed. I might just want to sit quiet on my own.</i></p>
	<p><i>I am feeling energetic. I might want to run around, or punch or kick.</i></p>		<p><i>I am feeling a little anxious and might want to talk to someone.</i></p>
	<p><i>I am feeling sad and might want to talk to someone.</i></p>		<p><i>I really need to be on my own.</i></p>
	<p><i>I am a little confused and might need help with my learning.</i></p>		<p><i>I am feeling a bit weird and don't know how to explain my feelings.</i></p>
	<p><i>I am really happy and enjoying my work and play.</i></p>		<p><i>I am feeling really confident and happy with myself.</i></p>

A Champion Swimmer!

I always wanted to learn to swim. It looked fun! So Mummy took me to the local swimming pool for the first time for some swimming lessons. I was so excited! I had my stuff packed ready and although I was a bit nervous, I couldn't wait!



When I got there, I began to feel very different. It was a big pool with lots of noise and lots of people. It was really 'echoy' and I didn't like it at all.



I began to feel very scared. It felt like I had lots of bubbles bubbling up inside of me and filling me up. The longer I stayed there the bubbles got bigger and bigger until eventually I knew I was going to burst!

I was really sad because I still wanted to go swimming just like my friends but I was scared of the place and the people.

My Mummy found another place with a much smaller pool and not as many people. I decided to try it.

As soon as I got in, I felt a lot calmer. It wasn't as scary. There wasn't as much noise and I only have about four or five people in my group.

I've been going for a little while now and I LOVE IT!!

I can swim in the deep end and I just got my first certificate. Everyone is really proud of me and I am really proud of myself.

I didn't tell my friends at first because I didn't think they would understand. I thought they might laugh at me because they could all swim already and I couldn't even go in the pool.



I think I am going to talk to my friends about my swimming now and show them my certificate. After all, I am a champion swimmer!!

Following in their footsteps

Famous Autistic People in History



Dan Aykroyd – Comedic Actor



Hans Christian Andersen – Children’s Author

Tim Burton – Movie Director

Lewis Carroll – Author of “Alice in Wonderland”

Charles Darwin – Naturalist, Geologist, and Biologist

Albert Einstein – Scientist & Mathematician

Bobby Fischer – Chess Grandmaster

Bill Gates – Co-founder of the Microsoft Corporation

Daryl Hannah – Actress & Environmental Activist

Steve Jobs – Former CEO of Apple



Michelangelo – Sculptor, Painter, Architect, Poet

Wolfgang Amadeus Mozart – Classical Composer

Sir Isaac Newton – Mathematician, Astronomer, & Physicist

Satoshi Tajiri – Creator of Nintendo’s Pokémon



Nikola Tesla – Inventor

Andy Warhol – Artist

Sir Anthony Hopkins CBE - Actor

Anne Hegerty - The Governess from ‘The Chase’

Guy Martin - Motorcycle racer

Lionel Messi - Footballer





Alan Gardner

Alan has Asperger's Syndrome.

He was 15 when his love of gardening flourished. He puts it down to two things – a cactus he purchased from a local florist which he nurtured on his bedroom window sill and a seed catalogue.

'When I looked at that catalogue and saw all the things that you could grow the family garden quickly became a menagerie,' says Alan. 'To be honest, it was a welcome relief to my parents as neither of them were gardeners.'

'Gardens make me feel happy, says Alan. 'I have the need to grow plants. I have the need to plant seeds and watch them grow. I like being outside, I like being in the environment, I like every kind of weather, the light. Every good gardener needs to love the outdoors.'



Alan lives with his wife, Mandy, and their three children in the Midlands.



Chris Packham

Chris spent his early childhood in Hampshire and natural history was his main passion. He found his time at school very difficult, being socially excluded and regularly bullied by fellow pupils.

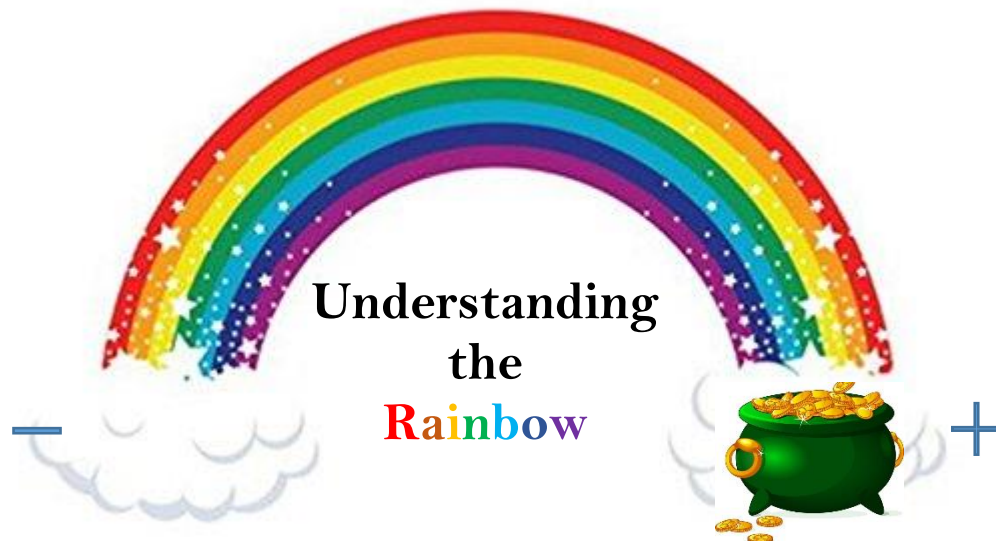
In 2003, at the age of 42, Chris began seeing a therapist after the death of his dog, Fish. As his work with the therapist concluded in 2005, Chris was diagnosed with Asperger syndrome.

Susan Boyle

Susan Magdalane Boyle (born 1 April 1961) is a Scottish singer who came to international attention when she appeared as a contestant on the TV programme Britain's Got Talent on 11 April 2009, singing "**I Dreamed a Dream**" from Les Misérables. Her debut studio album, *I Dreamed a Dream*, was released in November 2009 and became the UK's best-selling debut album of all time, beating the previous record.



As a child she was labelled as 'brain damaged' due to complications at birth. She was bullied and often called 'Susie Simple.' Later in life she was diagnosed with Asperger's with a higher than average IQ. She now feels she has a clearer understanding of what is wrong, is relieved and able to relax a little more. She hopes that people will treat her better now they understand.



Helping children to understand autism or indeed any ‘special need’ can be problematic. They often feel different to their friends and this can lead them to feeling isolated and lonely. By using the idea of the rainbow, it helps children to understand that we are all different; we all have different qualities, different strengths and different challenges. We are all part of the same rainbow but are made up of different amounts of each colour!

Each colour represents a different characteristic.

For example...

- ✚ Red - sporty and competitive.
- ✚ Orange – enjoys art and music, very creative
- ✚ Yellow – mathematical and a logical thinker or scientist.
- ✚ Green – a love of the outdoors and nature.
- ✚ Light blue – reading and making up stories, very imaginative
- ✚ Dark Blue – loves problem solving and investigating things.
- ✚ Purple – socially outgoing, confident, enjoys being with people and doesn’t mind noisy places.

The two ends of the rainbow represent how strong each characteristic is.

For example, if you are very creative and can play an instrument and enjoy learning music, you would place yourself near the pot of gold in the orange band.

If you really don’t like being with lots of other people and find crowds difficult, you would place yourself at the cloud end in the purple band.

Especially for children with autism, it is important to point out that you can never have a ‘wonky’ rainbow!! Every rainbow has to balance.

If you have a characteristic at one end of the rainbow it has to be balanced out by a super power at the other end for a different characteristic.

Why not try it for yourself and see what your rainbow looks like? How different is it to your family and friends?

RAINBOW NETWORK

Our Rainbow Network is a group of parents who have experienced the joys and challenges that autism brings. They meet in school on the first Monday of every half term at 9am; for a coffee, a natter, a catch up and to share advice and support. Everyone is very welcome. They also have their own closed Facebook page where they can share more personal messages with each other.



Don't ever forget...no one is ever on their own in the Rainbow Network!!



About Sparkle Sheffield

Started by parents of autistic children, Sparkle Sheffield exists to help families with autistic children meet the challenges they face, feel less isolated, less

frightened and more empowered. Autism affects families in different ways but only the parent of an autistic child can truly understand what life is like for us.

Sparkle Sheffield is a registered charity which looks to benefit children and young people from birth to 25 who suffer a disadvantage through disability in particular autism, which is a commonly misunderstood disability. This is done by providing parental support, education about this complex condition and coping strategies to deal with the challenging behaviour that autism often presents. Helping the parent/carers to understand and help their children have a better quality of life and increase the child's opportunities by targeting their main care givers understanding of the complex condition.

Our Address:

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Email: info@sparklesheffield.co.uk

Web: www.sparklesheffield.co.uk

The Sparkle Team are available *weekdays* during term time between 10am and 2pm.

Final thought...

My Beautiful Child

When you were born, you never came with instructions.

I know I have made some mistakes along the way and for those I am sorry.

I am far from being perfect, but I have always done the best I could.

The mistakes I have made came from a lack of understanding, not a lack of love.

From the moment you were born into my life, I knew I would love you with all that I am.

On the day you were born I looked into your eyes and all my dreams came true.

I love you more than you will ever know, now and for eternity.

I wish I could give you the ability to see yourself through my eyes.

To see how beautiful you are.

To see how much you have grown as a person.

To see how you have the ability to light up my life without even saying a word.

To see and understand what unconditional love really is.

Then you would know how special you are.



***The greatest gift that you can
give to others is the gift of
unconditional love and
acceptance.***

~ Brian Tracy



**...a child who knows unconditional love, has the
greatest gift of all.**



***With very special thanks to all the parents and children who
have contributed to this book and allowed us all to have a little
window into their world.***

"The things
that make
me different

are the

things
that
make
me."



winnie the pooh