



“Supporting Your Neurodiverse Child” Feedback Survey

Total of 245 responses received by Survey Monkey between 6th and 19th Nov’23 and shared through EFF Social Media network.

In what format would you prefer a copy of the 'Supporting Your Neurodiverse Child' publication?

Digital/Online	3%	8
Hard copy of book	64%	158
Both	32%	79

Which format of the publication did you find easier to use?

Hard copy of the book	92%	225
Digital/Online version	8%	18

Why?

It's easier to navigate, flick through, follow contents pages etc. Also more accessible for me on terms of being likely to read it as it's there and visible, a download I will forget about.

Always to hand no computer and find it harder to read on my phone

Because I like to be able to pick it up and refer to it. It is also available in my staff room for people to flick through

I like a book to pick up and turn too

It lives on the side in my house like a bible

Ability to flick through and notate and put post its in

Pick up anytime you need . Take with you to .

It's a bit much to read on a phone, tablet is fine

I just prefer a hard copy

Easier to look through

There is too much content in a digital format to browse through, many parents and grandparents have been sent digital copies but only seem to take in the content when presented with a physical book.

Document would be too big online to navigate

I like to have a hard copy when there is a lot of information to digest.

It was easier to reference from

Because I prefer a book.

I can store it better, find what I needed quicker

I much prefer a reference point not on a screen.

Easy to digest and keep referencing back to.

It suits my reading needs

I could access this and didnt want to stop others who would need a hard copy from accessing it

I mostly use my smart phone for reading, the battery on it s not great ,

Easier to refer to

I learn better from physically touching the book and words

I can read it better,as its a larger format.

I enjoy holding books and am old so Ilike looking in the index for th8ngs i need to find

I could easily flick through to pages that I wanted to look at. It was easy to dip in and out of

Prefer books

So it's faster to search - often shattered by the time we are searching for help



“Supporting Your Neurodiverse Child” Feedback Survey

It was easier to just take a quick glance when I had time, rather than needing to sit down, find it, read a bit. The hard copy is easier to keep going back to.

Environmentally friendly

Prefer to read an actual book

Website easier to share and use with screen reader

I prefer a book so I can bookmark the parts that our benefits me.

It's easy to find the section you need with the contents page and I like being able to use it as a handbook rather than as a search engine online

I need to physically hold it or I can't seem to retain the information

It was easier to read when I could see as a digital version the text was smaller

I don't always want to be on my iPad, easy to flick through

It's easily accessible.

Easier to keep to hand for reference

I prefer a hard copy

I like having both, however being able to download the digital version of the book to my phone means that I always have it to hand, if I wanted to refer to something specific or show a fellow parent something it's there as I always have my phone on me.

Always to hand and show other people, maintain interest and attention rather than a screen

I could read it together with my husband

I find it easier to look through when it's a physical copy.

Just easier to refer to

Easier to bookmark certain pages

Like to refer to it from time to time

Easy to refer to certain points quickly

It is tangible and you can go straight to the section you need.

I like to be able to easily find it and re-read it

I can write notes and use post-its to refer back to at a glance

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I prefer hard copies so I can carry them around and not try to read them on my phone.

As PACT For Autisms Adult Support Manager I would personally comment that it is a fabulous resource, that can't be forgotten about, as a link can to share with families. I would love to have one adapted for our Adults.

I am neurodivergent and find reading on a screen challenging.

As a support group resource the hard copy can be used and referred to in real time.

I prefer reading from a page then going to a website for more information

It is easier to show to parents of my school

Easy to put down & come back to

A hard copy has been helpful and have found it more engaging when illustrating its content.



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I find it hard to process information online

Easier to hand for families

I started with digital then received the hard copy I now use it frequently to refresh my memory when something new occurs I have two ages 4 & 6 both with different needs.

It's easier to have on hand and can share with family members

I can bookmark and refer back to it easily

Made notes in book

I struggle to read long texts on screens and prefer a book where I can mark paged and make notes

Did not know there was a digital one

Making notes, can quickly refer to, less screen time

Easier for my child and I to look at together

I don't like looking at a screen for too long.

I prefer paper

I find it easier to read a hard copy

I prefer to read from a book and i can pick it up any time instead of fusing with online.

I find it easier to find things in a book

Refer to and have in front to easily find what is needed

Easier reference and child could read it too

I struggle to process things online

Easy to read, put down and pick up. Pencil in items that may help. Show other family members

Easier to flick through

Easier and can share

It a very good resource to dip in and out when you have a concern

As well as for myself I was able to showing to the families that I work with.

Easier to move back and forth between pages and easier to lend to family members

I can just pick up and read when needed

I can go back reading the page i wanna read and concer the pages

Just personal preference

Easy read easier to scan read. Having SEND children is stressful and easy read is essential for access.

Visual hardcopy much easier to use

able to read together with family and then pass it around

It's easy to navigate, can bookmark a page, I don't need to have access to the internet to read it, a physical copy has more impact and using a computer or phone to access it brings distractions and that's a real issue when you have ADHD

I find it easier than digital. It's right there to pick up and look through anytime rather than getting distracted on a digital device

I find hard copies easier to deal with and refer back to

Instant read

A great reference guide, highlighted important parts

I only received hard copy it's nice and big, easy chunked layout

To quickly pick up and refer to different sections

I was able to attach stick note tags then pass on to family members to draw their attention to relevant sections

I prefer to read a physical book than a screen

Much easier to have a book copy to refer back to as and when needed.

I know it isn't as good for the environment but I find it easier to navigate around in hard copy when you are looking for relevant sections rather than reading in order

Can make notes in the book, highlight areas of interest etc.



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Because it was there to share with all family members including the elder generation. More likely to refer to appropriate sections at time of need if it's sitting on the coffee table.

Much easier to navigate

Simply prefer books to screens

Easier to navigate

Easier to keep notes on and quick reference

It was much easier to use and refer to

It's easier to dip in and out and find what I need

Online I'm never sure if I've clicked into another resource

It was easier to flip back and forth through the pages

Could refer to marked pages in meetings with school

Easier to read

Having a physical reference was much easy to manoeuvre around the information

It's always on hand to refer to when things crop up in life

Easier to go back to when needed and to navigate

Easier to grab and flick through

It's easier to look at and not everyone is mobile literate

Easy to refer back to and pass to friends & family

Easier to read and navigate, also meant I could show to grandparents and book mark pages to take with me to meetings. Format also more accessible for my partner who has difficulty with long screen use

A lot of information, I was able to pop post-it notes, book marks etc. it's an amazing resource, too big to look at on my mobile phone

I could keep it to hand and available at home.

Much more accessible and I struggle with the Internet.

I'm used to having a physical book that I can flick through, make notes on, I can find & see it easily, not reliant on technology to access the information. It's my preference

It's been kept in perfect condition for me to look and check facts whenever needed .

It's much easier to dip in and out of the hard copy and find what you need. Also better for sharing with family and having a read with a cuppa!

I find it alot easier to read a hard copy. It's user friendly
easy access

Because I can really take in the info without the pressure of a screen.

Prefer to reread if needed

Easier to look through for me holding it and flicking through to relevant pages

It was easier to share with friends and family.

Easier to get my hands on when home

I could easily find information I needed

Prefer hard copy and personally found it more accessible

I find reading information on paper etc resonates with me better, than digital form.

User friendly

It was great to flick through and easier to share with others / show my family certain pages. It is quite big but that's a positive because it is long lasting and doesn't get lost in paperwork like a leaflet or flier

Meets the needs of the families I support

I only have a phone to access the online version and it's possible to use but easier with a book.

I found it is hard to read online, it hurt my eyes.

Great to look though

Easier to access. Can be taken with me and shared with others



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Visually it's so much easier than trying to look on a screen

Better absorption of information

I personally find I'm more focused when reading a physical book rather than a digital copy on my phone due to not having notifications pop up which lead to me going onto other things. It's also easier to mark specific pages which are useful for exploring further and I can make notes. This was helpful when sharing the book with family members to give them a better understanding of my children.

Easier to read and refer back to.

I didn't get the hard copy but I printed the online one.

I can mark the pages/make notes

Use tabs for bits I need

I read better with a book / hardcopy than by digital versions

It's handy to be able to read it hardback and flip between the relevant pages and when showing people, far easier than scrolling and searching on small screens

I prefer something on front of me to read

Easy to use

Easy to flick through and share

Ease of access... it was just there on my phone.

I struggle to read things online

Easier to go back to

I know exactly where it is

Finding information quicker

I don't want to be always on a screen

Easier to use.

Because I don't want it hanging around

I find it easier to get back to the place I stopped and don't have an additional book laying about adding to clutter

It's something that I can read as and when I want to, I can dip in and out, usually when I'm sat down after the children have gone to bed

I like to have a physical book to handle. I have marked certain pages that I use & highlight bits. I use it for reference with my family, point out bits to show them for understanding of my sons needs.

Online information can be harder to navigate

Because I have it in front of me & can refer back to it as I need it.

I could add bookmarks to parts I wanted to revisit

Easier to find info

Easy to flick through and have

I like paper

At the moment only have a phone and tablet to look at it on so hard copy is easier to look through

Easy to refer to without putting on a computer

I haven't had a copy to read yet

Easy layout to read

Just easier to pick up/put down. Reading stuff on your phone is only useful to a point!

Easier to process than on screen

Easier to annotate

Having information to hand, and being able to bookmark parts and refer to them as required

Better to sit down with other parent to look through

Easier to flick back and forth

Because I prefer to read from a book- and go back to it easier



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I can show family members and have left it with family to also understand our son when they didn't really understand before

Easier to read together ad a family, including grandparents

Nice to have to flick through by hand

You can refer back to it easily and show others, which you don't do with a digital copy

I'm old fashioned and seem to process information better when presented in physical form

Object Permanence, if it were PDF only, I'd forget it existed. Having the physical book feels easier to navigate, especially when I'm feeling overwhelmed and don't want to be tied to a screen.

Just find it easier not on a screen

It good to have it to hand and reference back to it not everyone can afford Internet

It lays out everything neatly and you can read bit by bit and come back to it without the need to scroll back to where you left off. It's so overwhelming already being a send parent it's nice to have something to flick back to when you need guidance

You can see what sections there are and flick between them more effectively. I don't like reading whole books on screens.

It's easier with a book to pick up and read rather than having to log in all the time

Disability

It's much easier to to refer back to when you have learning differences.

Found it more easier to read, I could also put post it notes on pages that I wanted to refer back to.

It's easy to flick through to the relevant section or just browse as a coffee table book

I could make notes and annotate

I could skip to the relevant sections

Can bookmark pages. Easy to dip in and out of. Can take to meetings

Digital is just a pdf

I keep it to hand

When or if you were going through the referral or diagnostic process, did having a physical copy of the book help you track your journey and refer to it when issues arose?

Yes	56%	136
No	10%	25
Not Applicable	34%	82

Do you feel more equipped to support and advocate for your child because of this publication?

Yes	98%	239
No	2%	6

Have you shared the book with other professionals?

Yes, with education	54%	132
Yes, with health	22%	55
Yes, with Social Care	15%	37
No	40%	97

Did the information in this publication provide you with more knowledge, understanding, and empowerment while reducing anxiety and overwhelm for your family?

A great deal	77%	188
A moderate amount	22%	55
Not at all	1%	2



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Please tell us what aspects of the publication you found useful

Almost every single page, it is a brilliant publication

Ehcp Adhd info

It is very well laid out and serves as a good reference particularly for new people working in my team.

Made me feel stronger

I found the info about pda and adhd great

Easy to read and find the info that you are looking for

Everything in one place

Properly laid out move to any section you need and easily explained di you can understand

The structure and layout of the information. I have used it as a reference text. It's easy to go directly to the information you need.

The hard copy layout is good it's small chunk Ed to that topic. It is thick tho.

All of it. The fact its in non professional jargon is great and the pictures help to give a visual too.

All

Explanations and visuals , quick refernces to give families a taste of each area so they can begin to explore and understand, the physical copy holds the attention in a way that the digital copy doesnt.Links to services

Resources

Simply understanding my child's behaviours.

It is useful to have contact details in one place

All of it and will be a good reference guide to return to going forwards.

All of it gave us a greater understanding of issues and has helped us as a company that provides SEND Transport

I found it helpful, I still refer back to it from to time and bow using it for my daughter

It's been so helpful, supporting my family and other people , having the information made things a little calmer

Thinking ahead about school transitioning. Clear examples of traits of adhd and autism which was helpful for me.

Lots of information I'd not been aware of or was unsure of. We don't have a diagnosis and are currently on the long wait to see a paediatrician. In some ways it helped me understand my daughter better

I gave it to a friend to help them with up and coming diagnosis

We all know the systems arent perfect. (despite how hard the poeople in them try) This helps those who down know navigate them. It is fundamental this publication continues.

It was very informative about what aid equipment can be used to reduce anxiety and improve concentration.

Explaining the ADOS process as needed to re-educate myself re school provision in Secondary school

I was able to guide family and photograph pages for them to read. Mine is actually now with my sister who lives in Cornwall to read up, it's going to my mum next in Colchester then my sister in shoebury.

ALL OF IT

Quite a bit of it

As they get older what's available



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The format of the book makes it really easy to navigate. It's visually pleasing. It's broken down in to manageable chunks so it doesn't overwhelm. It's been helpful for showing family members and helping them to understand the differences

All of it

It covers so much. It really helps

The rules surrounding EHCP assessment.

Knowing timelines and strategies to try when issues arise. First hand knowledge from other parents that can help.

The whole book was a useful guide through and beyond our journey, I can't pick out a particular area that I found most helpful.

Every section was helpful. It is so clearly laid out and very easy to access information.

The variety of problems

Really useful tips for effectively helping my child

ASD

All of it really, it has helped me understand a lot more about my child.

What questions to ask schools/preschools

Everything

I felt like this is the first time I have been understood. We are only at the referral stage but it was nice to have my thoughts on my child's behaviours accepted as not the “norm”

all

The education and school part was very helpful to us as a family.

All areas give u a broad understanding

As so little information is provided otherwise, it is all useful

Schooling Communicating

The entirety of this book is a godsend, the explanations of the different processes like diagnosis and EHCNA. Providing links to additional services we were unaware of. The book is informative and clearly breaks down information in a way that's understandable

The linked issues

It was very clear and easy to read

Time frame for EHCP process.

Awareness of wider NDD issues

The links, examples

The tailored local support, the wide range of information

All of it

Having information when needed

The practical support and sign posts to other support resources.

All of it.

All of it. All of the time frames aren't adhered to and no one knows what to do next

All if it! Its written in a simple to understand relatable way, with great advice and gives a clear understanding of what to expect etc.

Not feeling alone and that there is help there.

All, I am very grateful for this resource.

Written in a user friendly way

The broad range of subject matters that are delivered in a friendly and family friendly format.

The layout is so easy to read and navigate.

It was good to refresh my knowledge and to find access to support. I passed it on to a friend who is seeking a diagnosis who also found it so helpful

ASD section, Ehcp and where to get help going forward



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The mobile phone example

All of the support and practical advice

Understanding asd

I regularly refer to this book when dealing with my children and also make reference to on a daily basis through work purposes.

About the different conditions and how they might present. Helped me to understand my child more especially about sensory processing as I didn't know much about it

EHCPs and rights in schools

As a kinship foster carer I deal with a LAC Social worker who knows nothing of Autism and doesn't realise the impact her decisions have on the children and our family. By sharing it with her I believe the book as a whole will help her understand why I am constantly having to fight her every decision.

Overall the book has been hugely helpful in all aspects. In particular, understanding Autism, the diagnosis process, Education and support and child unable to attend school. The links for support and websites have been invaluable. I've recommended the book to so many other families

The layout. Each issue having its own section

Some of the guidelines, explanations and terminology

Every piece in the book. Truly made me realise how much easier it was having this book to follow the processes

Examples and where to go for help

Information for every step of our journey so far, links to resources, guidance for applying for ehcp

Easy to understand, written for parents by parents

Helping to understand the EHCP process.

I love that it shares a lot of live experience

Showing family and helping them understand

Gender dysphoria Support groups Charities, bed wetting. Adhd Actually everything. Before I had no knowledge

resource help

The asd diagnostic process Masking

Tips to handling an autistic child and sign posts to other info

All of it to be honest, the way the book explains neurodivers everything seem to make sense

Very easy to read, good layout

The fact that the book goes through all ages rather than focused on younger children

Seeing things in black and white in a book seems more "real" than online. I shared the book with my family so they could better understand my son's needs.

Easy to read, index at front

Guidance

All of it

There was a lot to my children's diagnosis I didn't understand and the book made me realise more behaviours my children were related to other diagnoses they now have been diagnosed with

The understanding of my child's disability

Autism, sensory issues

The easy to access information and the way it flows. You can what is relevant to you and your child at the time easily when it is needed.

I found it especially helpful in helping family members to understand why my child is the way they are

All of it to be honest

Discussing specific conditions

All of it, especially odd as it helps me to have a bit of understanding

All



“Supporting Your Neurodiverse Child” Feedback Survey

Helping us to navigate this world we suddenly found ourselves in.

All of it

I liked it was a hard copy as I find it easier to read than an online format

anxiety, school refusal etc

The lack of jargon, the friendly nature of the book, the huge amount of easily accessible information and the comfort it gave me whilst reading it and knowing my family is not the only one experiencing these things

Everything. In such a daunting, hard and confusing time is so helpful

The ehcp process

Explanations of conditions

The visual layout and having something to hold

Knowing my rights, understanding that it wasn't the preschool fault the EHCP didn't go through within 20 weeks, so my child missed out on send place as ehcp, took 4 months over the 20 week deadline, took over 40 weeks from when preschool submitted it, to education.

References to other sources of info Also breaking down of conditions, diagnosis, different considerations at different ages / stages of education and / or life Not too detailed so easy to flick through at future dates getting the headline info The important bits to remember

Simple jargon free language, lovely illustrations. Sound bites for other readers to validate feelings

After reading all signs and symptoms relating to ASD & ADHD I was in absolute no doubt about my daughter's ASD so much so that I was able to talk to her about the possibility/likelihood before diagnosis and this significantly reduced her anxiety about symptoms and feeling different.

The book is very easy to navigate and find exactly the information you need quickly.

All of it through different stages of my child's development.

All of it but understanding potential diagnosis when the concerns were identified and how to get support / navigate the system. I found that the signposting to other agencies / info was really helpful in gathering info

To know who was available to help. When you start on your journey, you have no idea what's out there. Obtaining a copy of this book was the first point of reference for us after diagnosis. When your child is diagnosed and discharged on the same day and you're left to seek your own support and information you have no idea where to start. This guide therefore was a big help.

The book is so informative and easy to follow. It's easy to find the section appropriate. It covers so much!

Very informative and reassuring

The whole book is literally invaluable, I wish it was available years ago it explains a lot about different disabilities/ how to get help and also what the abbreviations mean, it is very confusing when you have no idea about special needs/disabilities to be able to give this book to families telling them all about disabilities/send and no waffle written by send parents for send parents !!

Resources and clear chapters about post 16

All of it!

Easy style and graphics Good references

Ehcp bit as we are going through that process now but in general all of it is very good and have recommended it to family so as they can be better aware of what my sons needs are and how they can help

The fact that everything is together in one place to refer to when needed

All of it was useful

The section on autism was HUGELY helpful in identifying traits in my daughter for her referral to the GP. It helped me to recall so many examples that I'd either forgotten about, sometimes not even considered or just couldn't bring together for a bigger picture. It also made me realise my other daughter has many traits of ADHD and I am now looking to have her assessed too. I have



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recommended this book to several other mums whose children are on the diagnostic pathway and I know it has been hugely beneficial them also.

Really useful to have sections of information for different conditions such as ADHD/Autism/Dyslexia. Invaluable list of resources and websites listed at the back of the book. Helpful to refer to during SENCO meetings.

All of the book!

All helpful. We used the section around school a lot which helped us navigate the system, prepare for One Plan etc

Everything

Local reference points , website, where to find help with various organisations

This was absolutely essential for our journey through diagnosis and placement into a specialist provision

ASD

Personally I haven't needed any help but I have helped other parents thanks to the book.

The whole book. It enlightens everything and helps with good advice

All of it

Useful guidance on how to get help in education and advice on the transition from primary to secondary which will happen for us in a couple of years. This book has longevity for me as we can keep returning to it when challenges arise

Wide range of information covered. I wish this had been available when my son was diagnosed. I think it should be handed to all parents in diagnosis.

I found the whole book useful. My child's father was skeptical during the diagnosis process and this helped

Useful directory of contact details for services

All of it and sharing with family members so they have a better understanding.

Learning about the senses, behaviour

All of it as a joined up and complete package

Strategies to support with behaviour, one plan and EHCP, contacting other charities for support

Parts about education

I haven't got a copy but would really love a copy.

There is so much information all in one place with clear statements of facts to understand, further advice of where to go for more information. Providing a brief overview of other areas & difficulties that you may not have thought were associated, or become relevant at different times. The most useful one stop, comprehensive guide to understand & step through understanding the neurodiverse family both on a personal & professional level that I have come across.

From start to finish, surprised myself how little knowledge I really knew

The easy to read format not too lengthy. Easy to find the bits you need.

Clear layout. Good combination of words and pictures

Gave me some reassurance that I was going down the correct pathway for my daughter

All of it - it's a wonderful, comprehensive source of information.

I used it to find how to approach a discrimination issue.

Personal budgets, EHCPs, traits and behaviours to be honest there is not 1 page that is not helpful

It was written in a way that was understandable so I found it all useful

It is so full of information which is easy to access and it's a great reference and I use it a lot

Strategies, pathways and resources

All aspects I feel within the publication were useful

Sensory info

I especially found the sensory diet information helpful.



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Certain terminology, information & subjects

All the information - I love the term neurodiversity and knowing that there are many ways in which our brains can be different I liked it being across all the age ranges I feel like it's something I'll come back to over and over as my child ages The local resource section is helpful I love the whole design of it the images the sketches and drawings the mix of theory real life practical things and real life stories

All of it.

How each aspect of life is broken down in easy to reference sections.

I found the book is very informative and it really helps to support my journey.

Just feeling more confident in approaching people with my sons needs

Clearly set out. User friendly. Understandable language.

I love this guide. The fact that it's written by parents for parents means it's an invaluable resource.

There is nothing I didn't like and I recommend it both as a parent of an autistic child, an autistic adult and a health professional.

Signposting of services and representation of situation

I personally really found the diagrams clear but very effective at breaking down a chunk of information into easier to read information. When you research asd for example you are often met with a lot of detailed paragraphs which can often be overwhelming. The book is written in a way that vital information is given but in a less overwhelming way. The tips are great and I would love to see certain tips explored more perhaps links to videos modelling different approaches.

All of it, I've used it myself and shared with other parents/carers.

Education support, one plan to EHCP application and timeline Many of the outside references

Sensory information

Sectioned out well with clear, easy to understand information

Resources

The guidance and help in the book

EHCP process, pushing for the right professional help, sign posting others to get the information. It was a wealth of help and so clear and simple to understand in this jungle we live in

All of it a very useful guide for parents of neurodivergent children

I did it as a demonstration in my English class and passed my speaking exam with it at same time making other aware

All

All of it. Was the first resource that I found helpful on a very stressful journey.

Bullet points, easy to locate information

All of it. It's enabled everyone to understand my daughter better. I've also shared this with other parents and people to support them.

For such a dense book, the structure and layout was very easily digestible. I found it really useful to just put down and come back to, as and when needed.

Not seen the publication at all but would like to please.

Asd and adhd

All of it

Easy to read understand, lots of helpful information which isn't available else where .

Resources like websites for the local area; types of behaviour and strategies to put into place to support the child

Tips for what to expect at various point in journey. The vast amount of information on who to contact for various things.

Having lots of information in one area.

I felt as a general guide it was useful.

guide to diagnosis and points to consider



“Supporting Your Neurodiverse Child” Feedback Survey

I loved the parent perspective - it felt great to know that other parents had been through this and felt the same - I didn't feel quite so lonely

I find it all useful, at different stages of need. The support is there. Also the websites at the back are so useful, all in one place, so I don't have to remember them all.

The entirety of the book- having everyone in one place as a starting point for parents

The understanding of Dyspraxia & autism.

So much information

All of the info was useful, I didn't find anything unuseful

The breakdown and explanations

Resources and contacts

The support and advice during the lead up to and immediately post diagnosis. It's an essential tool as you feel so isolated. There is nowhere else to find all the information in one place and in a supportive and easy to use format.

Just being able to read about everything helped me.

Excellent resource all round. Feedback from parents regarding the book has been exceptional

A copy to read

All

I love that it's written by parents and is clear and factual. It's easy to understand

I didn't know about some of the more subtle aspects about ADHD & the book had really helpful links to find out more (eg. Rejection dysmorphia - my son has that in bucketloads - so we approach things completely differently)

All of it

Really well laid out and lots of key information for diagnostics.

The information on ASD/ADHD

Factual parts but also the quote sections

Description of executive functioning skills, general advice on what to expect

Iv not read it yet

Explaining to grandparents and other people in a way that didn't feel like I was lecturing them. Finding out that some things we thought were just 'odd' were actually signs of our son being ND

Lots but the explanation of ASD and the accompanying graphics were particularly powerful.

The ehcp process breakdown

It is the first time I have seen “hyperlexia” mentioned. I've not seen the term used before in anything in the uk and local people such as teachers and speech therapists have not heard of the term. I would like to see more on hyperlexia if there is to be a 2nd edition.

All if it, I like to be informed and have all the information, even though not all applies to my 2 neuro diverse children.

The explanations are well written.

Signposting to places for further info or support

Sensory Processing disorder, autism, social communication difficulties, signposting

I found the whole book insightful, it also told me how much more help there was out there

Good visuals and infographics so easy to access and 'digest'. Good at considering root causes for challenging behaviour and useful ideas for accommodations. Well researched and inclusive. Lots of useful signposting for further support. A really useful resource.

I found the whole book helpful

All of it was top level.

Simple language, helpful diagrams and images and easy to read

All of it



“Supporting Your Neurodiverse Child” Feedback Survey

The areas covered that were aimed towards girls with autism. I found it covered pretty much everything to do with my 3 children who all have different needs.

It's larger print, easy read, written in language that parent carers speak and understand.

Bite size information felt less overwhelming than a lot of resources available online. Being able to write notes in hard copy allowed me to return to it later on.

How everything was explained in easy to understand sections

Very accessible. All information in one place. Very easy to reference.

All of it. It tells you exactly what you need to know and can dip in and out as required.

We thought my child had asd and through reading the book it helped us narrow it down to Asperger

Being able to use post it's to mark pages and make notes. Revisit sections in a bitesize way.

Was there anything that you found unhelpful?

Almost every single page, it is a brilliant publication

Ehcp Adhd info

It is very well laid out and serves as a good reference particularly for new people working in my team.

Made me feel stronger

I found the info about pda and adhd great

Easy to read and find the info that you are looking for

Everything in one place

Properly laid out move to any section you need and easily explained di you can understand

The structure and layout of the information. I have used it as a reference text. It's easy to go directly to the information you need.

The hard copy layout is good it's small chunk Ed to that topic. It is thick tho.

All of it. The fact its in non professional jargon is great and the pictures help to give a visual too.

All

Explanations and visuals , quick refernces to give families a taste of each area so they can begin to explore and understand, the physical copy holds the attention in a way that the digital copy doesnt.Links to services

Resources

Simply understanding my child's behaviours.

It is useful to have contact details in one place

All of it and will be a good reference guide to return to going forwards.

All of it gave us a greater understanding of issues and has helped us as a company that provides SEND Transport

I found it helpful, I still refer back to it from to time and bow using it for my daughter

It's been so helpful, supporting my family and other people , having the information made things a little calmer

Thinking ahead about school transitioning. Clear examples of traits of adhd and autism which was helpful for me.

Lots of information I'd not been aware of or was unsure of. We don't have a diagnosis and are currently on the long wait to see a paediatrician. In some ways it helped me understand my daughter better

I gave it to a friend to help them with up and coming diagnosis

We all know the systems arent perfect. (despite how hard the people in them try) This helps those who down know navigate them. It is fundamental this publication continues.



“Supporting Your Neurodiverse Child” Feedback Survey

It was very informative about what aid equipment can be used to reduce anxiety and improve concentration.

Explaining the ADOS process as needed to re-educate myself re school provision in Secondary school

I was able to guide family and photograph pages for them to read. Mine is actually now with my sister who lives in Cornwall to read up, it's going to my mum next in Colchester then my sister in shoebury.

ALL OF IT

Quite a bit of it

As they get older what's available

The format of the book makes it really easy to navigate. It's visually pleasing. It's broken down in to manageable chunks so it doesn't overwhelm. It's been helpful for showing family members and helping them to understand the differences

All of it

It covers so much. It really helps

The rules surrounding EHCP assessment.

Knowing timelines and strategies to try when issues arise. First hand knowledge from other parents that can help.

The whole book was a useful guide through and beyond our journey, I can't pick out a particular area that I found most helpful.

Every section was helpful. It is so clearly laid out and very easy to access information.

The variety of problems

Really useful tips for effectively helping my child

ASD

All of it really, it has helped me understand a lot more about my child.

What questions to ask schools/preschools

Everything

I felt like this is the first time I have been understood. We are only at the referral stage but it was nice to have my thoughts on my child's behaviours accepted as not the “norm”

all

The education and school part was very helpful to us as a family.

All areas give u a broad understanding

As so little information is provided otherwise, it is all useful

Schooling Communicating

The entirety of this book is a godsend, the explanations of the different processes like diagnosis and EHCNA. Providing links to additional services we were unaware of. The book is informative and clearly breaks down information in a way that's understandable

The linked issues

It was very clear and easy to read

Time frame for EHCP process.

Awareness of wider NDD issues

The links, examples

The tailored local support, the wide range of information

All of it

Having information when needed

The practical support and sign posts to other support resources.

All of it.

All of it. All of the time frames aren't adhered to and no one knows what to do next



“Supporting Your Neurodiverse Child” Feedback Survey

All if it! Its written in a simple to understand relatable way, with great advice and gives a clear understanding of what to expect etc.

This should be given at some point in the diagnosis, very close to the beginning to support parents

The time it took to receive one due to overwhelming popularity

No it is excellent

The terminology should be changed from neurodiverse to neurodivergent

No was the best book ever

The steps to help my child

Yes most pages

No, although more about home education as a valid option would be nice

The lack of physical copies to share with people who need them

No, more info re PDA would have been helpful

No, it's a great resource.

No - thought this was an invaluable resource.

It only says what 'should' happen in an ideal world, so I didn't find it particularly helpful when

navigating mediation/appeals, and is very much bite size comments rather than in depth information.

In lots of places it says "click below" (in a physical book). Under 'professional support available'

sections - no, it really isn't!!

Only that I downloaded the online copy and it was too large for my phone

No it's all really helpful & would be great if it can be kept updated now. Not being able to have this

book in a hard copy would have been unhelpful, so I feel thankful to have a physical copy.

No the entire book has something for everyone on the spectrum and knowledge for all this people

who know very little info around neurodiverse children adults

Signs and symptoms Going forward after diagnosis

No nothing unhelpful at all. The title needed changing grammatically I didn't notice but someone

else pointed it out I believe this is going to be changed in updated versions - to me this shows how

much things change especially our language grows and it's great that this fairly new term is being

used so much more rather than labels that are based on deficits.

More schools and professionals need to read this

Things change in the SEND system often so an updated version would need to be regularly issued.

Although there was lots of links to national websites there isn't really any links to local groups/sites. I

as a parent found myself searching fb, Google and asking other parents what's available to physically

go to for support or just ho have a cuppa and talk. I still don't really know what's available for children

under 5.

Nothing, it was all useful.

If you click a hyperlink it takes you back to the start of the text which is annoying

No nothing, everyone I've shared it with has asked how to obtain a copy

Wish it was smaller in width but thicker so it could fit in my bag.

I think some of the terminology has been used incorrectly. I would like to see that reviewed and

updated.

We have not received a copy of the publication.

I felt the Tourettes section could have benefitted from being a tics section with information about the

different tic disorders.

It made it easy to understand.

No it was informative and so helpful to have it all in one place

Not having received a copy yet

No. We have found the whole book to be amazingly well thought out

It's a fantastic resource and GPS and pediatrician should be giving them out not the rainbows course

that know costs £300



“Supporting Your Neurodiverse Child” Feedback Survey

I think the title should be neurodivergent not neurodiverse.

Everything is the same place. Sometimes it's hard to get the information required

Online PDF hard to read especially on my phone and not very practical at meetings to be looking at a device. Plus you can't bookmark and make notes in the same way online.

As a support group do you find it useful having hard copies of the books for families?

Yes	96%	106
No	4%	4

If you run a support group, how has the publication impacted the families you support?

We have had lots of families order a copy

Available in school as a borrowable resource

I am a SENDCO in a preschool and we share this book with all of our families.

Enormously beneficial. They say its a nice positive thing to recieve, like a gift to help them begin.

"Wow this is amazing "is often the response and more below "I keep it on my kitchen side and often show it to friends and family to explain. " "I look through and learn something new each time." "My bible "

As a transport provider we have been able to share this publication and it's very useful content with parents and pointed them in the right direction to get their own copy

I am a member of Strm support group, and their support and knowledge has been invaluable for my family.

Sen school group friend the book a very good aid.

It helped

IT has got them started, helped them knwo what is out there, know what they should expect

Provided info for every step

Families have felt more empowered to support their children after reading the book. It has helped them understand the different processes for diagnosis and support at school

Helped a lot

Huge amount, they all say how useful it's been for thier own understanding, ti support their children.

We could look at it together

Absolutely positively impacted and supported families.

A fabulous, one stop shop and guide when families are overwhelmed and do not know where to start..... I fabulous resource I believe for anyone applying for an assessment to have access to if they do not already.

This resource is been described as a life saver for many, they can access at any time, they can put post it notes for reference purposes and take it to meetings to refer to.

Yes, handing over a hard copy is like a gift. A link doesn't have the same impact as it is easily forgotten a book is there on the coffee table with so much information.

It has benefitted the families a great deal as it helps them not to feel alone and like they have somewhere to turn with other strategies to try

Families are able to advocate for themselves



“Supporting Your Neurodiverse Child” Feedback Survey

I'm a Senco in a pre-school & I signpost parents to this book online to help support their journey as being so young it is often hard to get a diagnosis

N/A Have recommended it to friends.

It has helped volunteers that support children better understand because the parents are clearer on required support and communication

Working with children and families in court proceedings, this book has been helpful when I have worked with parents who have neurodiverse children and need to understand and build their knowledge on their child's needs.

It helped me, I got it from preschool, at a one plan meeting. It helped me to see why they do things the way they do and the processes in county

No I don't I got this through a support groups it made me feel recognised and validated to be given a physics book to take away that spoke to me, a parent of a Sen child

A great deal, it gives parents and carers the tools and information to help themselves to help their children.

I have passed the books on to all medical professionals and education staff that will find it relevant to help understand my daughter. But also to help understand all neurodiverse children.

Immensely. We give a hard copy to all parents who enter our SEN Projects and they have all received it positively.

Alot.

Don't run support group but part of support group and we have told parents about the book and it has helped them a great deal

Has helped families understand, do their own research and advocate for themselves, reducing the impact on the time and resources of LA and other organisations

I'm a parent of a child with SEN, but also a health visitor. I share my copy at every contact with families with SEN children and encourage them to request a copy, the feedback has been very positive Only heard good feedback.

It's a gentle introduction to neurodiversity which can then be explored for more specific information. Parents have used it to understand their child's specific needs better and the type of support they need at home and at school.

I have shared with many parents

I don't run a group but I have sent on links to parents I know so they can get themselves a copy Some say they use it regularly and have mentioned it to other parents

Fantastic resource to share with families.

I could refer new families to the book so they can absorb information in their own time. It's made giving advice as a volunteer much easier and less overwhelming for families. Each family needs a different level of information and information individuals can choose how deep they want to learn

I don't run a support group but I have shared the digital link with families I support.

I am an autistic health professional in the health visiting service in Thurrock. I support families in identifying children that are neurodiverse and this book has been outstanding I can't express this enough!!!!

N/A however as a parent I have recommended it to everyone I know within my world

N/a - collect from a support group

I've shared it in all of my networks.

Yes

Every family I have shared this with, has said how useful it is and obtained their own copy.

Increased awareness of services. It is always a shame at coffee mornings to say, no sorry you can't take this book with you.

Massively as in my initial comment above

They have been grateful for the resource



“Supporting Your Neurodiverse Child” Feedback Survey

I don't run a support group as such but do speak to lots of other parents. Always suggest downloading but often asked “ is there an actual book?” If I have copies with me, I will give them to other parents but otherwise I share the link to EFF website. I get lots of messages saying they ordered the book and how amazing it is. (Can't recall any that only downloaded the digital version).

I run two community groups and have given out just under 150 copies to families they are so thankful for the book so they can understand their children and learn more to support their children

I don't, but heard about it through the Maze parenting programme I was attending last year. It was shared with everyone in the group.

They ask for more Copies for their friends.

The families I support love this book. It's easy to read, large enough print you don't have to find your glasses and so accessible to share information with others. It's also helpful to have to hand when supporting a parent carer going through a difficult time - the pictures and little pop outs make it accessible.

I use it to help colleagues who are either getting their child diagnosed or through a diagnosis themselves.

Other written feedback received by EFF with consent to share:

From Sue (MAZE)

You can probably check how many copies of the FRP I have given to families, and I imagine this is now over 200. Families have been reporting what a huge help it has been to them, with so much vital information. They report that being a SEND parents means that you have to learn an overwhelming amount of information about how the education, health, and social care systems work, on top of trying to process what it means to have an ND child, thinking about their future and trying to get the services/therapies etc that they might need. Therefore, having all of this information in a printed catalogue is invaluable. They know that all the information that they need is in the pack and they don't need to learn it all in one sitting but can return to refer to it at every stage of their journey. I am sure many families have downloaded a digital copy and this is great for them, but many families will forget about it because it is not a physical copy. Some families cannot process information in this digital format -especially when there is so much, and some parents do not have the skills to be able to go to the website and download it. Furthermore, many parents only have their phone and downloading/reading a document of this size is impossible on a phone. I would say that it is the most vulnerable families, living with additional needs/MH needs themselves, living in areas of deprivation and with limited IT/academic skills who benefit the most from the pack and would consequently be the most severely impacted if a paper copy were not available to them. These are the families that need the most support, over a longer time domain and for whom it takes a lot more input to get positive long-term outcomes. The information in the pack is a big part of this process and is a resource that we can also use as practitioners when we are working with these families. This way we have a shared framework of reference when it comes to available services and information about how best to support children.

There are also new families coming to see us at every coffee morning and most are bewildered, in turmoil, very emotional and (we know) they have a long and difficult journey ahead. Having this information in a printed format provides a physical reference point and



“Supporting Your Neurodiverse Child” Feedback Survey

gives parents the sense that they are leaving with something valuable that will help them and this is a profoundly different experience that someone telling them to go to this website and click this link.

I hope that my ramblings here can be useful in your discussions as you make the case for the continuing resourcing for printed copies, which have made such a positive difference to families.

SEND Parent/SEND Coffee Morning:

"I attend a group for parents who have children with ASD and we have used the 'neurodiverse pack' countless times as it provides a wealth of information. A few of us have copies and share it around with new parents if the parents cannot source their own. It is an amazing resource and provides insight from other parents in the same situations as us. The fact that it is written by other parents is genuinely lovely. Considering the distinct lack of support and resources available to parents within this community, it is invaluable. It's one of the best tools I have and has been so helpful during and after the diagnosis of my daughter."

SEND parent:

"There is so little that can be offered to families whilst they wait for anything - whether it is diagnosis or educational support. This book has been my lifeline"

Support Group:

I've had feedback on more than one occasion that a hard copy has been useful for parents/grandparents that might be resistant/in denial about their children's issues/diagnosis - when left lying around they've tended to pick up and read and have understood more that way. This wouldn't happen if only the online version

School SENCO/Home School Support

"I give the postcards with the QR code to all families who receive a new diagnosis or are on the diagnosis pathway and I recommend to them that they either download or apply for a paper copy of the book. Lots of parents only have phones so it is not practical for them to simply download a copy. They need a paper copy. I recommend to them that they dip in and out of it and use it to note questions to ask medical professionals and external agencies who may be involved. It is a valuable resource and it would be a real shame if there is yet another barrier put in place for parents to get useful information and advice. So many parents tell me that they simply get a diagnosis and if they are lucky a few leaflets, from the doctor. I have no data on how many of the parents actually do use the card to get a copy of the book and I don't keep a record of who I give this advice to but I know that most parents will struggle if the book is not available in a hard copy."

"We work with the families that attend Shorefields School – a school which caters for 149 children (3-19 years old), all of whom either have Severe Learning Disabilities or Profound and Multiple Learning Disabilities.



“Supporting Your Neurodiverse Child” Feedback Survey

We have been lucky enough to have access to some copies of your book “Supporting Your Neurodiverse Child”. Since having these books, not only have we been able to add to our own knowledge, we have been able to share them with our families who often turn to us seeking help around many of the topics covered. Being able to hand out a hard copy means our parents can turn to this at a time that suits them. Many of our parents often don’t have time to research the hundreds of internet pages that cover these subjects, so being able to flick to the relevant page and get information instantly is priceless. The book also contains helpful contact numbers which can sometimes be near on impossible to find.

It is really important to us that you are recognised for the great impact these books have had on us, the families we support and hopefully future families too. “

SEND Parents:

“I forget to read stuff online but not a book”

“It’s on my dining room table so I can read the bit I need”

“I can take it with me (to meetings)”

“Not all parents can access online”

“Hard copies are essential”

“It’s early intervention - for the cost of a book”

ECFWS

“They are ideal when doing home visits as parents use them to discuss anything, and we cannot always get online to use so a Hard copy is vital.”

“We can talk through specific pages with parents (easier than on a phone)”

“Families take them into meetings with them (TAF / One Planning etc) to support what they are asking for. EG. Parent wants EHCP, school says need diagnosis. Parent points to the part in the book that states otherwise.)”

“Some parent/carers not able to read easily online, especially those that might be ND or have needs themselves”

“I love this this book and always share with my families. I take a copy with me to appointments and also the card, so families have choice to order a hard copy or an online version. They all choose a hard copy.

My parents want to look through when they have five mins spare, they can leave it in the kitchen and flick whilst making dinner. If it was online only they wouldn’t be able to do this.. you’d have to find the copy, scroll till you find the page you wanted- what if you don’t know what page you wanted? Kids are yelling at you ‘why are you on your iPad’ you can picture the scene. We need to make parents lives easier not harder.

The want to share it with grandparents/aunties to read. Please please keep hard copies of this valuable book”



“Supporting Your Neurodiverse Child” Feedback Survey

Specialist Health Visitor

We had previously been signposting parents to this resource before we were able to offer it as a hard copy, however we were reliant on the parent accessing this themselves.

Some parents may not be able to access it online for a number of reasons and now the pressure is taken off them, as they have the resource available at the time of an ASD diagnosis.

Parents/carers whose child has received a diagnosis of ASD at our MDT feedback clinics have all been very appreciative of this resource as a hard copy.

Having the option to offer a hard copy, at the time of diagnosis is so valuable for the family.

Dr C Doughty (CADU)

We find them incredibly useful!!

Often parents already have one from other sources, but its good to be able to give something physical to refer to, esp in CADU.

It often feels like we deliver a diagnosis which has huge implications/ effects/ reactions – and then nothing...! I think the physical copy helps with that particularly (I hope...)

Although I usually give the link for them to self request in older kids, there are parents who aren't going to do this for various reasons. It's good to be able to have some books handy for these families.

Laindon practice manager

My ND book/tool kit is so well written and gives families a real understanding of jargon, process and systems. It helps parents come to terms with some difficult choices and brings all the information together so it feels less daunting.

Clinicians have also used them to explain to patients the different options.

Dr Helen Aladabe (Consultant Community Paediatrician, ESNEFT)

We were asked to provide feedback about the Supporting your neurodiverse child resource - I think they are brilliant and parents seem to love them, particularly if we are able to give a copy in clinic as they feel they are 'getting something' rather than just a list of links (which they also get!!)