

<b>UNDERSTANDING</b>		
Lack of understanding of Masking in schools	Difficulties experienced by young people masking	Professionals / Schools do not understand masking
Poor understanding of autism in schools	Better neuroaffirming understanding	Everyone blames the parents
Lack of genuine understanding of how to support autistic people	Lack of Pda understanding. Services not following through	Interdependence (not independence or resilience)
Attendance issues/ challenges = blaming parents. 'Evidence needed'.	We need better understanding of autism from all services without parental blame	Changing the narrative around Neurodivergence (Ableism)
Social care don't understand Autism or additional needs – too many families are MASH'd, blamed when actually need support not judgement	Opportunities in communities for people, so an understanding and acceptance of autism – culture (reasonable adjustments)	Masking – professionals / schools do not understand masking, fawning. A CYP exploding after school is often unmet need at schools not parenting

<b>BEING HEARD</b>	<b>TRANSITION</b>	<b>INCLUSIVE</b>
Childs voice not central to any support models	Children to adulthood – “The Cliff”	Devon is a wonderful place and has such potential
Being heard. Parents are their child's expert!! Parents feeling valued and involved in their child's support	Children to adult transition service and understanding (or availability of) options for Community engagement or employment sustainability	Neurodivergence is a Super Power
Understanding and action not just awareness – Adult Autistic Voice	PFA should be automatic. Lack of further education services	We need to meet the needs of ALL of our children
Child voice is not always heard or well listened to, shared. – not always 'seen'		Language: inclusivity all children opportunities
Ensuring the CYP voice is heard in service development		
Lived experience of adults needs to be considered. Co production needs to be easier to access.		
Connection to other autistics important.		

<b>EMOTIONAL AND MENTAL HEALTH</b>	<b>ACCESS TO EDUCATION</b>	
Where is the neurodivergent pathway? Autistic suicidal kids are being refused support	Schools not reducing/ removing education provision to manage support a child with ASD	No funding in schools to access alternative provision without EHCP - huge delays
Improved tailored mental health support for neurodivergent	Supporting children not accessing/ struggling to access education	Suitable level of education and access
Mental health services for autistic CYP	DOESNT' WORK - Focus on change within families rather than with schools	Appropriate outcomes in EHCPS – stop having targets that are discriminatory
We are forcing neurodivergent people to be neurotypical and this is destroying their mental health	Appropriate education setting that truly meet needs – stop trying to fit people in to a box	EP reports not specific enough or personal enough and assume schools is the best option
CAMHs refusal because Autistic	CYP not in education	Dyslexia provision in schools
Wellbeing, mental health and authenticity includes diagnosis need less deficit based assessments. Autistic people have mental health issues too.	Mainstream schools 'working to rule' if child can't access classroom they shouldn't be in mainstream - so aren't making provision for them	Stop parent blaming. Stop threatening and fining parents for non attendance
	Access to the right level of transport with reasonable travel times (2hr travel time to school si to long for any child.)	Parents being fined/ court due to school attendance when child is struggling due to unmet unidentified needs
	The school system is based on behavioural teaching & lacks understanding of nervous system & defensive states – rewards and punishments don't work	

		<b>LONG WAITS</b>
		Reducing waiting list for diagnosis
		As a provider of the ASD assessment service I want children & parent/carers not to wait a long time to be seen
		Long waiting times for diagnosis
		Waiting times reduced
		Blocks in the system – endless waiting lists

**SUPPORT**

Parent / carers – opportunities to meet each other & better sharing of information & support	Quick access to support in school, health, social care and my community	Access to services throughout pathway (when needed – mental health; other additional needs)
Referrals - unclear – no pre service support system	Enough of the right people to give support	Post diagnosis support and advice through health – ongoing
Local bodies offering support aren't utilised	Shouldn't be a fight – joined up holistic support for families	Increased support for families pre and post diagnosis
Lack of support/ understanding after diagnosis for children, parents and professionals (education staff) to access education and well being	Lack of support and communication whilst waiting to be assessed. Including understanding	I hate the idea that there are children that won't be able to enjoy their lives because they aren't getting the support they need
Lack of support and challenges to assess (parental blame!)	Support at start of journey and throughout no just at crisis point	Support earlier with or without a diagnosis - locally
Lack of pre and post support and before and after assessment – communication	Lack of preventative skilled support (families should not have to reach crisis for support)	SIBs UK – support siblings of disabled children (but there is none locally)
Prompt support before and after with or without a diagnosis from the right people	SEND support & awareness in schools is so variable. Children hit crisis before identification	More help for parents/ young people throughout the pathway process
Parent peer support	Early support	Early Help is often not able to provide or fund the services needed
Stop everything being a fight + battle. Meaningful support for parents – key workers to help them navigate the system	Local neurodiversity run businesses/ charities that support parent/ carers	Neuro Dive AUSENDS SEND family Instincts NAS Exeter
Get autism diagnosis but no OT, no mental health support, no dyspraxia assessment – not holistic	Lack of supported living or housing options with enablers	Families are being supported by Early help (TAF level) – lead professionals are struggling to support the families with no services to access.
Lack of timely early intervention capacity at a less complex level to support transition into mainstream	Parents in crisis lack support and direction through ED, health and social care. Parents don't know what they don't know	Improvements to social care access short breaks, respite allowing/ trusting families to use funding in what that support them
More education on what parents can get DLA; Short Breaks		

<b>FEEDBACK</b>	<b>PARENTING PROGRAMMES</b>	<b>MISCELLANEOUS</b>
Dimensions for Autism – AIG Autism Involvement Group – Autistic YP/adults	Parents sent on courses aimed at neurotypical parenting and NOT parent neurodivergent parenting	Autistic teen 16 – when asked Do autistic chose their behaviors? We're not able to make coherent decisions how do you expect us to make coherent choices
Online, email, phone. Text. Surveys with space for comments (DSR)	Pressure on families impact on parental relationships. Parents drive to advocate for their children impacts significantly on family life and parental relationships	Consideration of the impact of the incoming Attendance Strategy (Sept 2023)
Use Menti metre – app for capturing language	If a parenting course isn't working for a neurodivergent child it probably isn't honouring a NT child either	DLA & PIP not autism friendly ridiculous phone consent process
Commission a letter to all EHCP parents	Schools are creating trauma which is long lasting and cant be fixed with EHCPs.	The door is a sensory nightmare
Autistic Girls Network – published a reasonable adjustment in schools guide		Complex needs team – what is the criteria – refused as kids didn't have LD
Invite SOCOPs autism youth Club to in put into the strategy and engagement for Child Voce		Whenever you're suggesting an intervention as yourself 'Why?' If it's to change the autistic child or prepare the for the 'the real world' it's probably not good for them, no matter what the parents or professionals think.
Are CYP going to have a say on the Autism strategy and How?		Parent carers assessments – and support as discrimination in equality of support compared to carers of adults
I would like people who use our services to have a good experience & to feel helped		Lack of carers assessment – lack of parent support impacts on siblings
I would like our service to align with what families want and need		I am in awe of the families that relentlessly fight for their children and young people but I want to make system where this isn't needed.

<b>COMMUNICATION</b>	<b>TRAINING &amp; RESEARCH</b>	
Clear communication of the pathway process, even for CYP e.g. in PECS from start – to after	Working with PENCRU.org (peninsula childhood disability research unit) - re research with Exeter university.	Greater access to CPD for supporting professionals & practitioners
Communication between services – not knowing EHCP law	High quality autism training for school staff & social & health professionals particularly CAMHS	Professionals that think they know better/did a course or because they read
Making sure people know what's available	Greater awareness of neurodivergence – training – inclusivity, PDA profile; schools; medical settings; leisure centres	You can only 'educate' professionals that want to learn. How do you ensure professionals aren't just ticking boxes.

<b>Local Neurodiverse run Business / Charities that support parents/ carers</b>		
NeuroDive (training)		
AUSENDS (training)		
SEND Family Instincts		
NAS Exeter & District		
Dimensions for Autism (over 18yrs young people)		
Tissues & Issues (Torbay)		
ES?EM Team CiC		
Devon Champions for Change		
NAS Plymouth		
Parental Minds (Honiton)		