



**MCT Durham PCF Conference report.**

**Making Changes Together Conference  
XXIX**

**Monday 12<sup>th</sup> June &  
Tuesday 13<sup>th</sup> June 2023  
At Ramside Hall Hotel, Durham.**

*MCT DURHAM CIO - Registered charity number 1202217.*

[www.mctdurham.co.uk](http://www.mctdurham.co.uk)

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This report is distributed to many parent/carers and professionals who were unable to attend the conferences, alongside those delegates who did attend. It therefore contains all of the presentations made at both events.

All slides are also available to download via the "conference" tab of the MCT website - <https://www.mctdurham.co.uk/conference-info/>

### **Welcome by Marsha Dolan - Ellis. (MCT)**

Marsha was the spokesperson for both evening and daytime events. Marsha welcomed everyone to the conference and highlighted the usual housekeeping information.

Marsha informed delegates that after 12+ years of being part of MCT this was her last conference due to moving house. 😞

At the day conference on 13<sup>th</sup> June Marsha explained her journey and how MCT started. She also explained she still hears people say, "Nothing has changed over the years". Marsha listed examples of changes that have occurred since she has been part of the Parent carer forum e.g. To get short breaks you previously needed a social worker whereas now you don't.

Marsha put on a t-shirt which sums up her journey. Photo below...



Marsha's t shirt.

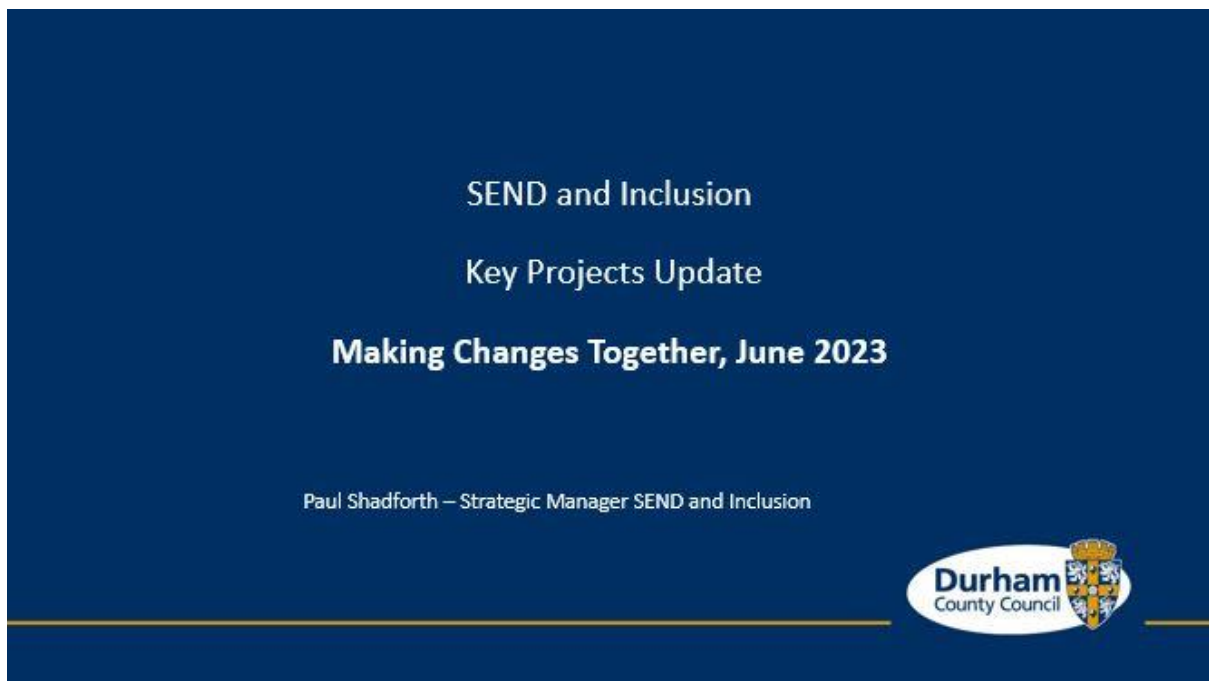
**Speaker - Paul Shadforth Strategic manager for SEND & inclusion.**

Unfortunately due to having to attend a DVB (Delivering Better Value) in SEND (Special Educational needs and Disabilities) - conference in Leeds; Paul was unable to attend in person, so sent a video instead.

Link to video here - [Paul Video](#) . Link will work until 1/6/2024.

( <https://1drv.ms/p/s!ArxABTsGy3FNkzBR-tZDI9dxHolw?e=CVb2Ib> )

Pauls slides below -



"I want to thank MCT for helping to facilitate me joining by a recorded presentation. Apologies for not being able to attend. The MCT conference is a key part of my working year. It is a great disappointment to me, to not be with you in person. I always see the conference as an opportunity to meet up with families and the professionals who support them and to learn from your experiences of living and growing up in Co Durham and exploring the opportunities to make it better for you and for others".

"I am currently in Leeds with the DfE working on the DBV programme. It provides me an opportunity to bring some new resources into Co Durham to help

us to further support our communities. It is the only reason that Amy would let me not attend in person, I hope you understand also. More on DBV later"



## Purpose

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To update you on the key change projects that are underway in County Durham at present and the opportunities that each project will offer to work together in Co Production. Projects Include:

- The Participation Strategy
- Home To School Transport Review
- IMPOWER North East Region Work
- Delivering Better Value (DBV) – A partnership review of High Needs Provision between Durham County Council, The Department of Education, Newton Europe and CIPFA



## SEND Partnership Review 2023

Ensuring we guide services to work positively with young people with SEND and their parents when they are reviewing or developing services

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# Durham County Council Home to School Transport Consultation and Review



## Eligibility & Numbers



Over **9,000** children use Home to School Transport Services



Over **1,000** contracts in place with over **300** transport providers



In 22/23 we have spent **£25m** and we expect to pay **£30m** in 23/24 due to contract inflation for new contracts and increased demand

"Over 9,000 children use Home to School Transport Services, over 1,000 contracts in place with over 300 transport providers, costs have risen from £20m to £25m and we anticipate spending £30m next year.

We are confident that we can provide a better offer for Children and Young People and improve costs This is why we are conducting the review."



The proposals that we have developed are designed to ensure that the changes will



"Continue to Meet Needs, Promote Independence, Deliver Efficiencies & Consider Environmental Impact"

## Consultation and next steps



The statutory guidance requires Local Authorities to consult on changes to their policy.



A Consultation process started on 27<sup>th</sup> February 2023 and ran until 12<sup>th</sup> April 2023.



The responses are being analysed and the outcomes of the consultation presented to Cabinet in Summer 2023.



[www.durham.gov.uk/consultation](http://www.durham.gov.uk/consultation)

"I want to thank all of those who responded to the consultation either in person through the workshops or in response to the survey.

We have had a really positive response and we are confident that we will be able to propose some positive changes to the cabinet later this summer.

I have left a link to the consultation pages which will be updated as progress is made."

# Delivering Better Value



## DBV Diagnostic Stages



"Module 1 - We looked at the things that were happening in our communities that stood out to us as being unusual and where we might be able to make positive impact.



We saw that most requests for a statutory assessment came just before a transition - This was in the early years moving into reception from nursery and from primary to secondary school. Prior to the assessment request young people had often been making their own progress in their community

We saw that we have a lot more young people in Special Schools than the rest of country.

We also saw that the steepest rise in demand was through young people being referred to us for their education because they had been permanently excluded or because they were too ill to attend. Those who were too ill to attend typically were struggling with anxiety.

Module 2 - We reviewed in partnership with schools and other professionals 50 cases of young people who fell into the categories.

We agreed that in the majority of instances (64% in SEND and 100% in pupils referred to us) needs could have been met in the child's local school.

Module 3 - Stakeholder and Parent Carer Survey. "

## Key Headlines from Parental Response to DBV Survey

50% of parents answered that they don't feel that their child's school has sufficient time or resource, but also that they don't understand the needs of children 50%

75% of parents agreed or strongly agreed that there is a trusted person in school who understands their child's needs well. In addition I believe the teaching at my child's school is delivered by highly skilled and qualified teachers

Parental Confidence is lower on average for children with SEN than for children with EHCPs

Children moved from mainstream schools because of low confidence in the school's ability to meet their needs and guidance from their community

Improving communication between parents and teachers and inclusivity of the child's peers would improve parental confidence in mainstream settings

"Parental Confidence is lower on average for children with SEN than for children with EHCPs - this promotes the need to get more help and advice to families with children receiving SEND Support".

## ● Core Areas Of Action



Training on the Graduated Approach



Parental Confidence around Mainstream



Clarity around SEN Support



Support at Transition Points



System Setup in Mainstream



Service Alignment



Support Around Families

"Opportunities to Work in Coproduction"

DBV Next Steps



" Thanks for Your Time. Get in Touch - [paulshadforth@durham.gov.uk](mailto:paulshadforth@durham.gov.uk) "

## Team Training Update.

### **Speaker - Victoria Robinson from MCT**

Victoria updated everyone on the changes within Team training. She explained we are all sad to see Rollercoaster Family support cease which means they are no longer part of team training and can no longer provide the full list of "Creative Education" training. There is still some free training available at <https://www.creativeeducation.co.uk/courses-for-parents-and-carers>

Victoria explained Margaret Brewerton from NHS is facilitating extra training for professionals and forensic CAMHS are now doing some training too.

Victoria also mentioned that the training often has high numbers of people requesting places BUT many people simply don't show up or send apologise.

If you sign up to workshops, training, conferences, or any other activity and cannot attend PLEASE let the organiser know asap so they can offer places to other people.

You can view all the team training available at <https://www.mctdurham.co.uk/parent-carer-training-workshops/>

**Team training slides below...**





Team Training is made up of :



## A sad goodbye to one of our members

- You may have heard about the changes taking effect from the end of June 23, Team Training would like to say a GREAT BIG THANK YOU to all of the Rollercoaster Team who have been part of Team Training and who have supported Team Training, you will be missed ❤️
- This means that there is no longer a full on-line offer for Creative Education, some free session for parents and carers can be found on their website.

<https://www.creativeeducation.co.uk/courses-for-parents-and-carers/>





## Sessions offered since Nov 2022:

- Transition from Education to Employment via Supported Employment
- Challenging Behaviour
- Calming an Angry Child
- Better Sleep for Children with Additional Needs
- Anxiety
- Understanding Why Children Might Be Anxious About School
- Access to the Creative Education Online Resources



## Durham County Carers Support:

### Feedback from DCCS workshops:

- *“Really helpful thanks, will try to keep my eyes open for any others [sessions] coming along.”*
- *“Really informative session, really useful strategies and helpful to look through a child's perspective of how they feel in crisis and how to deal with situations without diving in.”*
- *“Slides were clear and well delivered. Speaker was knowledgeable and friendly.”*



## Spotlight on CAMHS

"We have been offering online awareness sessions via MS Teams to parents and carers for over 2 years now. The sessions are facilitated by 2 CAMHS practitioners with many years of experience supported by our partners from Team Training most of whom have personal experience of many of the issues we are discussing.

We aim to offer a safe non-judgmental space where parents/carers can come and learn more about how to support the children and young people they care for. We offer conditional confidentiality in all sessions and ask that participants respect this and do not discuss anything other than general information and advice outside the call. Some participants are happy to share experiences while others prefer to observe and listen."



## Spotlight on CAMHS

"**To come:** a new presentation about Risk and Resilience. This will look at how we help our children to identify and manage risk and protective factors. It will also explore what Resilience is and how we can help our children and young people to build it and develop skills to manage adversity.

We also offer a portfolio of training for anyone working with children and young people in County Durham and Darlington. All training can be accessed via this link:

<https://www.tevv.nhs.uk/get-involved/training/camhs-county-durham/> or by emailing [TEVV.countydurhamcamhstraining@nhs.net](mailto:TEVV.countydurhamcamhstraining@nhs.net)"







## Coming up from Team Training:

- Emotional Wellbeing workshop in June - CAMHS
- Anxiety 5-11 years workshop in July - CAMHS
- Adolescent Sexual Development & Sexual Risk workshop in July - Forensic CAMHS
- Child to Parent Violence & Aggression workshop in July - Forensic CAMHS
- MCT & Sensory Worx are getting together for a little project – look out for more information on our website in the coming months.

So, look out for Team Training Publicity on our social media platforms. It will look like this....



### Understanding Why Children Might Be Anxious About School

This is an awareness session to increase understanding of why children might be anxious about school, identify potential triggers and look at available support and strategies. This session is suitable for parents/carers of all school aged children but may be of limited value to parents of children with more complex needs.

**Tuesday 6th June 2023 09:30-11:30**

**Anxiety (Two groups)** this session looks at what anxiety is, what the triggers might be, how to identify it and how we can support our children and young people.

**Tuesday 9th May 2023 09:30-11:30 – Over 11 years**

**Tuesday 18th July 2023 09:30-11:30 – 5-11 years**

**Emotional Wellbeing** This session will focus on emotional wellbeing, what it is and how can we improve it for ourselves and our children? This session explores the link with mental health and looks at how we can manage our own well-being as well as that of our children and young people.

**Tuesday 27th June 09:30-11:30**

To book places please email [tees.esk@camhs.nhs.uk](mailto:tees.esk@camhs.nhs.uk) or scan the QR code below to access the Trust website for further details. Please state which sessions (and dates) you'd like to attend. The sessions are aimed at parents of school aged children but parents of younger/older children are very welcome. The sessions will be led by a CAMHS trainer and will run on Microsoft TEAMS. If you have any additional needs, please mention this in the booking email.



## Future Plans:

We would love to hear of any ideas you have for future sessions.

There is a sheet in your pack for you to complete now, these sheets are shared with all members of Team Training and help us identify parent carer training needs.

Victoria explained she would take all training suggestions back to the team training planning and feedback meeting on 12<sup>th</sup> July 2023.

You can contact any of the following organisations through our social media platforms or website.



[www.mctdurham.co.uk](http://www.mctdurham.co.uk)



Tel: 0191 5873542 or  
03000 267 007

<https://durhamsendiass.info/>

## MCT - Have you say!



MCT asked parents and carers to grab a post it note and write: -

- Something in education, health, social care or in general that **IS going well**.  
And / or
- Something in education, health, social care or in general that is **NOT going well**.

This allowed parents and carers to share their praise and air their grievances. We got dozens of post it notes with both praise and issues written on them.



The feedback will be collated asap. We will try to raise issues with the relevant department, and we will feedback to everyone soon.

MCT also played a video over lunch showing what they have done since November 2022 conference., View the video on YouTube here-

[https://www.youtube.com/watch?v=-23EW07Kj\\_M&t=6s](https://www.youtube.com/watch?v=-23EW07Kj_M&t=6s)

## **DSCO - Designated Social Care Officer - Judith Bowman.**

Judith explained her previous role was One Point Operation Manager and her new job as DSCO is a brand-new role introduced in County Durham in February 2023. The main job as DSCO is raising the profile of SEND (Special educational needs and disabilities) within social care.

Judith explained she had introduced some MANDATORY training for social care staff.

Judith also wanted to share the training from EPEC (Empowering Parents Empowering Communities). A 12-week course for parents and ran by parents who have been fully trained. For more info on EPEC email [EPEC@durham.gov.uk](mailto:EPEC@durham.gov.uk) or read about it on the LA website here

<https://www.durham.gov.uk/article/28221/Help-a-child-get-their-best-start-in-life-by-training-with-Empowering-Parents-Empowering-Communities-EPEC>

**Judith's slides below -**

## **Designated Social Care Officer**

**Judith Bowman**

**Early Help, Inclusion & Vulnerable Children**





## Who will I be working with?

- One Point-Early Help Service
- Statutory Social Care e.g. FF, Disability, LAC, YPS
- Parents and Carers
- Health
- SEND Case work

**Early Help, Inclusion & Vulnerable Children**



## Overview of role

- Raise awareness of SEND in social care
- What difference have we made to children and YP
- Workforce development
- Good quality and timely social care advice
- Ensure we contribute to the statutory annual review process
- Support SEND Champions

**Early Help, Inclusion & Vulnerable Children**



## Overview of role

- Work strands e.g. neurodevelopmental pathway, graduated approach.
- Link with Designated Clinical Officer for SEND-Diane Watson

**Early Help, Inclusion & Vulnerable Children**



Judith's contact details are -

Email - [Judith.Bowman@durham.gov.uk](mailto:Judith.Bowman@durham.gov.uk)

Telephone - 03000 261550



## Neurodevelopmental Pathway Update - 1

### **Speaker-**

**Alison Ayres - Commissioning Manager for Children's Services.**

At our evening conference we had Alison Ayres as our speaker for this topic. For the daytime conference we had Rachael Allen and Paula Gardner who gave an update on "County Durham and Darlington Needs Led Neurodevelopmental Pathway" plus Alison Ayres again who gave an update on "Building a needs-led system for families with neurodivergent children and young people".

### Alison Ayres slot slides summary

County Durham  
Care Partnership 

# **Building a needs-led system for families with neurodivergent children and young people**

MCT Conference 12<sup>th</sup> and 13<sup>th</sup> June 2023

**Alison Ayres**

**Commissioning Manager for Children's Services**

Working together to help keep the people of  
County Durham happy, healthy and at home



# In November

- Aim to move from a diagnostic focussed system to a needs-led system
- Survey
- Changes made as a result of the survey
- Paper to County Durham Care Partnership Executive

# What are we doing now?

- Setting up a multi-agency project board
- Identifying workstreams and task and finish groups
- Piloting support to schools

Alison explained she wants to improve support and advice for neurodiverse parents and carers.

Alison explained the money for a pilot of supporting teachers in schools is currently taking place North Durham Academy, Stanley, and Consett Academy plus their primary feeder schools.

# What can you expect to see next?

- One of the workstreams will be around co-production
- If you gave us contact details, we'll be getting in touch shortly
- If anyone wishes to join the project, please contact [necsu.durhamneuroproject@nhs.net](mailto:necsu.durhamneuroproject@nhs.net)

# Questions?



Someone in the audience asked Alison-

- "How long is the waiting list to be assessed via the Neurological pathway?" (To be assessed for Autism and / or ADHD)  
Alison's answer was "Around 40 months!" (Over 3 years wait)

## Neurodevelopmental Pathway Update - 2

### **Speakers -**

**Rachael Allen - Team Manager at Tees, Esk & Wear Valleys NHS.**

**Paula Gardner, Clinical Nurse Specialist at Tees, Esk & Wear Valleys NHS**

At our evening conference we had Alison Ayres as our only speaker for this topic. For the daytime conference we had Rachael Allen and Paula Gardiner who gave an update on **"County Durham and Darlington Needs Led Neurodevelopmental Pathway"** plus Alison Ayres again who gave an update on **"Building a needs-led system for families with neurodivergent children and young people"**.

Rachael & Paula's slot slides summary

County Durham Care partnership hosted webpage for the Neuro pathway here - <https://nenc-countydurham.icb.nhs.uk/our-work/needs-led-neurodevelopmental-pathway/>



## What do we mean by “Neurodevelopmental”?



- Lifelong
- Difficulties including:  
Cognition, language, motor development, attention and concentration, emotional regulation, social communication and social interaction
- Evidence that neurodevelopmental conditions co-occur
- Two of the most common Neurodevelopmental conditions are ADHD and Autism

## Why “Needs Led”?

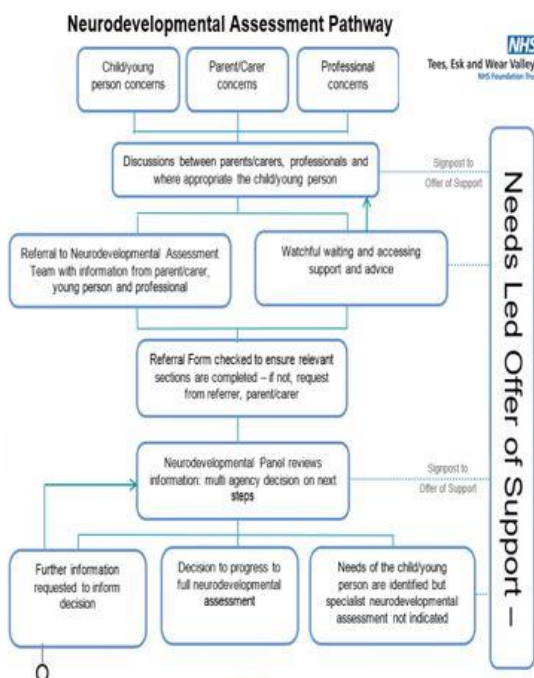
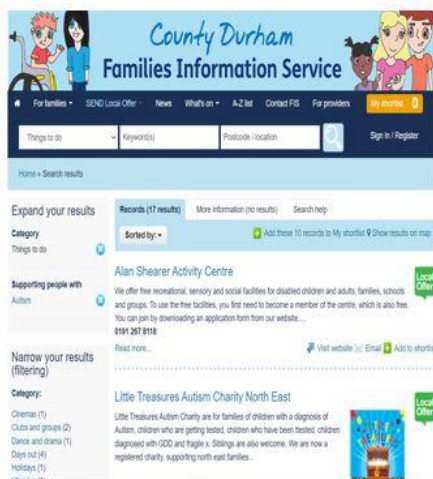
- Parents highlighted the importance of needs being met, regardless of diagnosis
- Confusion over what services were available without diagnosis
- Importance of a culture change across the system away from diagnosis



## Needs Led 'Offer'

- Information brought together for the local area
- Some additional funding available to minimise 'gaps' identified
- Emphasis on support and advice being available regardless of diagnosis

[County Durham's Families Information Service | Search results](http://countydurhamfamilies.info)  
(countydurhamfamilies.info)



## County Durham Needs Led Pathway

Link to clearer image of the slide above can be found here -

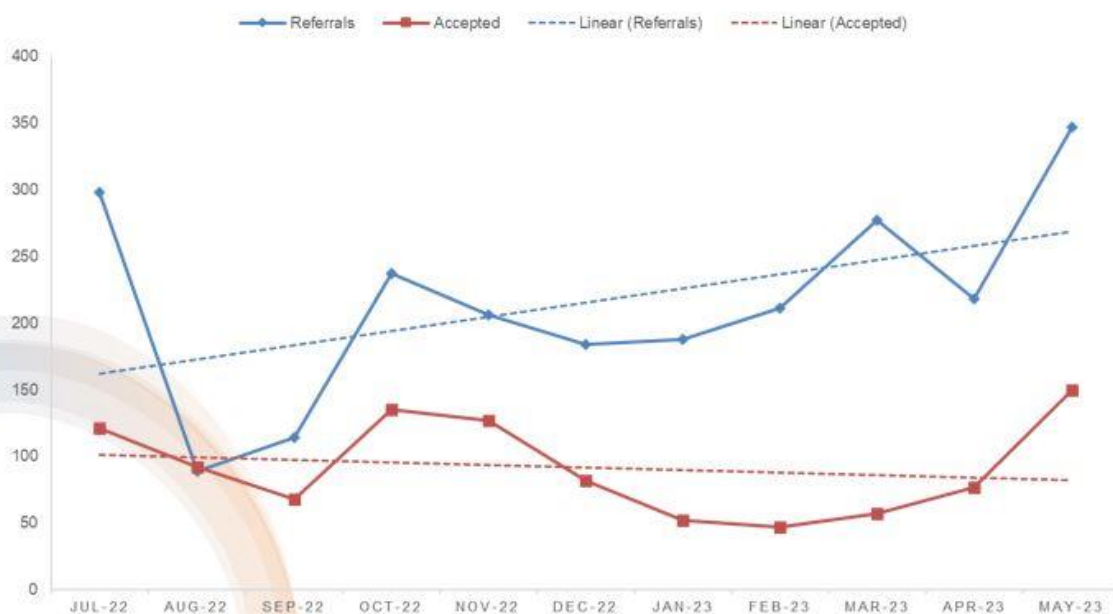
<https://nenc-countydurham.icb.nhs.uk/wp-content/uploads/sites/13/2021/10/0001-scaled.jpg>



## Challenges we are facing

- Increased referral numbers
- Additional referral screening and discussion
- Increased demand for responding to queries from professionals and families
- Development of a NICE compliant standardised single assessment pathway
- Retention and recruitment of highly skilled clinicians – those who can diagnose autism/ADHD

## Referrals into the Service



## What we've achieved so far

- Go live dates:  
Darlington 1<sup>st</sup> April 2021 and County Durham 4<sup>th</sup> October 2021
- Multi-Agency panel to identify needs
- Streamlined the referral process with speedier feedback
- Local website for needs-led offer
- Begun single assessments to consider both ADHD and Autism for some children and young people
- Recruitment: expanded the team by over 30%

## What we are working on

- Partnership working to improve access to advice and information on what support is available, regardless of diagnosis by changing the "local offer" website.
- Updating the Referral Form
- Improving single neurodevelopmental assessment for all young people based on national guidelines and family feedback
  - Introducing a 'neurodevelopmental key worker' to guide families through their assessment journey
  - Individualised assessment planning aiming to improve outcomes
- Recruitment and retention of staff – creative thinking across MH services
- Communication – TEWV working ICB and service user and carer groups to improve this, reviewing the information that is sent out with suggestions of support that is available

## Key Worker Model

### Aims

- To keep the child and family at the centre of the assessment
- To be confident that the information we are using in our decision making is current and accurate
- To reduce families having to retell their story
- To use standardised paperwork
- To reduce the number of appointments needed to make a decision
- Ensure we are following a NICE compliant process
- To streamline the process, and cut out unnecessary steps and assessment for the young person
- Early indications suggest that this has a benefit for YP, family and staff

## Assessment Process

- Initial appointment with family and young person
  - Background information
  - Clinical impression
- School information
- Assessment planning meeting
- Assessment appointments
  - Developmental history (1, 2 or more appointments)
  - Additional observations
  - Standardised assessments
  - Information gathering from other agencies (social care, mental health, health)

## Further information / queries?

 [Rachael.allen13@nhs.net](mailto:Rachael.allen13@nhs.net)

Some questions asked by delegates to Rachael and Paula-

- "How many young people are on the waiting list to be assessed via the Neurological pathway?"  
Rachael answered, "Around 5000 over Durham and Darlington".
- "How does it work to get a diagnosis private and not via the NHS pathway?"  
Rachael answered "We are looking at options to bring down numbers on waiting list. This may include private companies." Rachael wasn't sure on the full details on the "right to choose" options which means going to your GP and being referred to a private company or another area for an autism and / or ADHD assessment to get it quicker. Many GPs will not refer to a private company.
- "How long is the waiting list from a diagnosis of ADHD to getting an appointment within CAMHS for medication?"  
Rachael wasn't sure and said she would check. MCT will update this info asap via our website new section.



**SENDEIC - (Special Educational Need empowering Inclusive Communities) - Short breaks.**

**Speakers -**

**Lyndsey Dunn - Commissioning, Planning and Policy Officer (Project lead)**

**Ruth Pope - Enabling Inclusive Communities Co-ordinator.**

**Danielle Pope - Inclusive Communities Co-ordinator.**

- Link to short breaks information here - [www.durham.gov.uk/shortbreaks](http://www.durham.gov.uk/shortbreaks)
- Link to new YouTube video here - [www.youtube.com/watch?v=oH52uc15Ow8](http://www.youtube.com/watch?v=oH52uc15Ow8)
- Link to register your young person with Childrens and Young people's network and to get a max card - Ring 03000 265 792 , email [cypn@durham.gov.uk](mailto:cypn@durham.gov.uk) or do it online <https://www.durham.gov.uk/cypn> .

Lyndsey explained that new name for short break solutions was "SEND empowering Inclusive Communities" as they wanted parents to be empowered and not feel they need solutions,

She explained Danielle Pope was first single point of contact. She would check what activities were out there already for young people in order for parents / carers to get a break from their caring role. She would also signpost to other organizations and activities. If Danielle was unable to find anything available for a young person in their area, she would then pass the case on Ruth Pope who would try to enable access and remove barriers for a young person to enable them to attend a local, community activity.

Lyndsey explained they hoped to help build family confidence so children were able to access mainstream activities they otherwise couldn't.

## Short Breaks in County Durham



Lyndsey Dunn,  
Project Lead



Ruth Pope, Enabling  
Inclusive Communities  
Co-Ordinator



Danielle Pope, Short  
Breaks Solutions  
Officer



Sara Rawle –  
Parent / carer  
lead

### We want:

Parent/ carers of  
children/young people  
with SEN/D to be able to  
have a short break from  
caring when needed.

County Durham  
Care Partners



Working together to help keep the people of  
County Durham happy, healthy and at home



## Short break offer

Advice, signposting and enabling access

- We provide funding to an external organisation, Durham County Carers Support, to work with parent carers to help understand what they need to support them in their caring role, including short breaks from caring and how these needs can be met. Parent carers can have a carers assessment completed as part of this service.

- We provide SEND Empowering Inclusive Communities (SENDEIC) who will work with families to help you develop a personalised response to meet your needs for a short break. This will include:

Providing information, signposting and developing potential solutions to meet individual needs. Help you find a suitable local community activity for your child/young person to access which will allow parent carers a short break from a caring role.

Working with parent carers who need a break from caring but are experiencing barriers in accessing a local community activity. We will work with you to personalise innovative, creative ways to help remove barriers, fill any gaps in provision and enable access where possible.



Current short break offer  
Additional support

- ▶ • **SENDEIC will work with families and organisations to develop local community activities with additional support for children/ young people who require this to enable them to take part in an activity to allow parent carers to have a short break from their caring role**

Current short break offer  
Specialist support

- ▶ • **For families who feel they require more specialist support for children/young people with a range of complex needs that are unable to be met within the existing offer, they can access a statutory assessment to help identify unmet needs and work on potential solutions to meet these needs.**



## We have been working with families and a range of professionals to find out more about accessing the community and barriers

In response to this engagement, we are moving away from 'short break solutions' towards an approach to empower everyone to be part of the solution.

### SEND Empowering Inclusive Communities (SENDEIC)

This is not just about supporting parent/ carers with solutions but to support wider communities to be part of this.

We have updated the Short Breaks Statement to reflect this approach and developed an animation working together with families to describe what a short break is and how this can be accessed.



**WATCH OUT FOR**

**SEND only Fun and Food – summer holidays**

For families unable to access the existing community activities



Family trips outs

Supported families youth groups

Preparation and transition sessions

Virtual gaming session

Additional support social sessions  
e.g. Gym, swimming, cinema

Supported physical activity sessions



Specialist small youth groups

Weekly family groups e.g.  
Taekwondo, trampolining



Working together to help keep the people of  
County Durham happy, healthy and at home

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If you remember anything from this presentation, please remember to access the activities in the local community for children with special educational needs and/ or disabilities to allow you a short break.



Pop online and check out the updated short breaks statement.



Single starting point for contact -  
Telephone: 03000 260 270 or  
Email: [SENDEIC@durham.gov.uk](mailto:SENDEIC@durham.gov.uk).



Register on Children and Young Peoples Network to receive regular updates.



We can work together to co-ordinate a creative response for families.

Working together to help keep the people of  
County Durham happy, healthy and at home



## SENDIASS UPDATE

**Speaker** - Lisa Kirton - County Durham SENDIASS Co-ordinator & North East Regional IASS Representative.

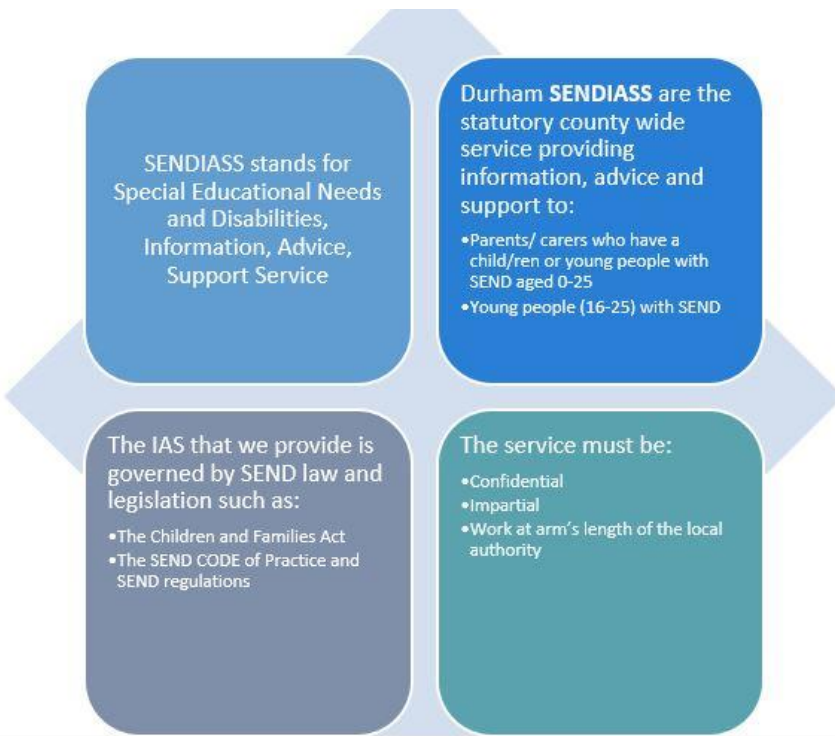
At the end of her slot Lisa asked delegates to fill in a form which asked 3 questions -

1. What does SENDIASS do well?
2. What could SENDIASS do better?
3. How could SENDIASS develop the offer to families?

**SENDIASS Slides-**







# Who are SENDIASS?

46% of all requests are from families who have a child on the Neurodevelopment Pathway

I am worried that my child's school are not meeting their needs	How will my child be supported at school?	How do I make a Parental Request for EHC Assessment ?	What can I do when my child has been refused an EHC Needs Assessment?
How do I appeal sections of my child's EHCP?	What can I do when my child with SEND is being excluded?	What can I do when my child can't attend school due to anxiety and their mental health?	What can I do when my child is not allow on a school trip?
I am worried about my child's transition (starting primary, secondary school or college)	How do I make a complaint about my child's education?	Can I have some support to prepare for a meeting with my child's school?	What are my options for home educating my child?



## Area of SEND Needs

Social, Emotional & Mental Health 49%

Communication & Interaction 41%

Neurodevelopmental Assessment Pathway 46%

Cognition & Learning 8%

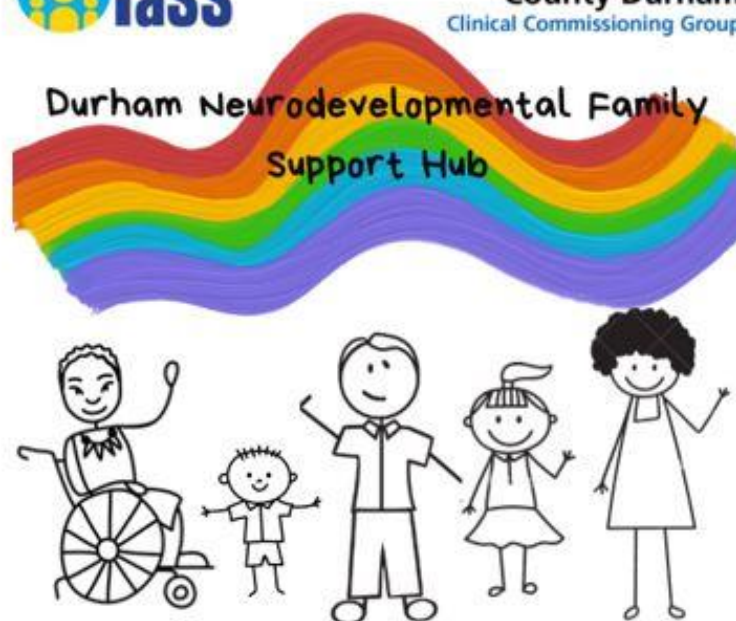
Physical and Sensory 3%

## How Many families have received support in 2022/23?

1044 existing cases which rolled over from 2022

673 new cases since January 2023

Currently working with over 1700 families

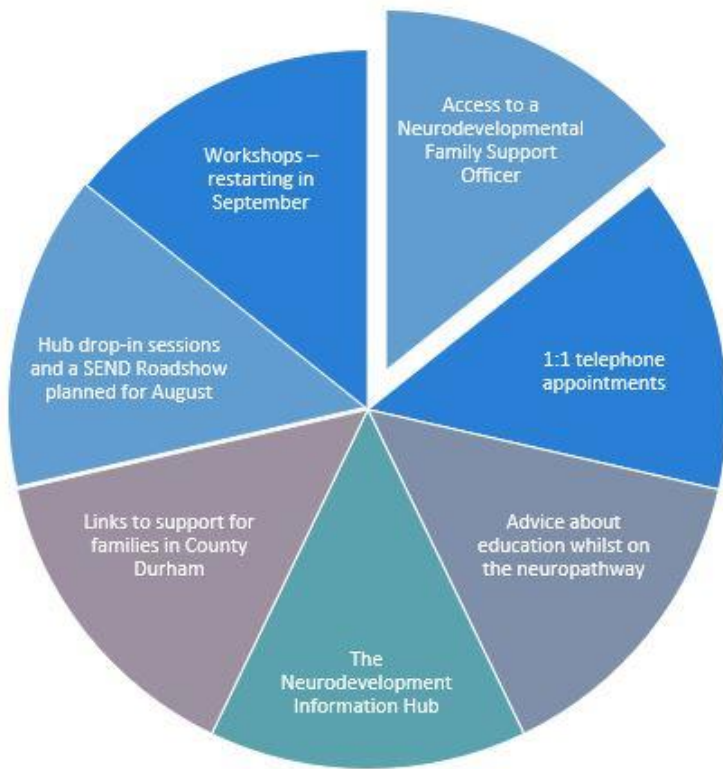


In 2021 SENDIASS proposed the development of a County Durham Neurodevelopmental Family Support Offer within the core provision of County Durham SENDIAS Service.

Who can access the offer?

The service is for families pre, during and post diagnosis for children and/or young people aged 0-25 if they:

- Have concerns their child or young person may have Autism, ADHD, FASD or who display characteristics.
- Are undergoing a Neurodevelopment Assessment.
- Have a diagnosis of Autism/ADHD/FASD



What Support is available?

NEURODEVELOPMENTAL FAMILY SUPPORT OFFER UPDATE





# Feedback from 2023

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Many thanks for attending the meeting today, as always, your input was extremely valuable. You really helped clarify what we need too do about the EHCP, its guidance we really need.



The kids are starting school tomorrow and I just want to say thank you for helping me through the admission process, I am grateful.



I am so grateful for all of your help and advice; I couldn't have done it without all that. Thank you from the bottom of my heart.



Thank you for the information, it is very useful, and I have passed it on to the relevant staff. Please can I say a huge thank you for your support yesterday.



Thank you, I really appreciated your call today as I was on tenterhooks awaiting what was happening and next move. Thank you again.



Thank you so much for your contribution to the coffee afternoon, it was great and very much appreciated and all very positive. Would you also pass on my thanks to your Short Breaks colleagues?

Feedback from families to develop the information, advice and support we offer.

What do SENDIASS do well?

What could SENDIASS do better?

Ideas for development?



## Meet the TEAM

Lisa Kirton  
SENDIASS Manager

Ann Connor  
SENDIASS Triage Support Officer

Catherine Winn & Angela McGinlay  
SENDIASS Officers

Christine Close and Kirsty Blake  
Neurodevelopmental Family Support Officers

Ruth Pope  
Enabling Inclusive Communities Co-ordinator

Danielle Pope  
Inclusive Communities Coordinator

## How to make a referral



Telephone: 0191 5873541 or  
03000 267004 including 24  
hours answer machine



Email:  
[sendiass@durham.gov.uk](mailto:sendiass@durham.gov.uk)



Website Contact Form



Professional Third Party referral  
form to be completed

## Investing in Childrens - eXtreme Group

### Speakers -

**Freya - Young person & long-time member of the eXtreme group.**

**Louise Frost - Project Worker/Peer Support Worker at IIC.**

Louise explained about Investing in Children - They are an organisation that helps empower young people, to help empower their rights in day-to-day life and to help improve lives.

Louise explained that Freya had been attending the eXtreme group for 7 years and had better experience than her 😊.

Freya told us that the eXtreme group meet once a month to discuss issues and anyone ages up to 25 can attend. Young people get paid to attend and Freya explained young people **do** get their voices heard.

Louise explained the new "your autism" website and Freya read her story from the screen. Find the website and young people's stories here - <https://yourautism.co.uk/> . Freya got the BIGGEST applause of the night after this slot.



**Why get involved**

- You can have a voice and speak up to make things better for young people in County Durham with SEND.
- You are respected.
- It's good experience and will help when applying for a job.
- You get paid to contribute your ideas and there are snacks.
- You can speak your mind without being judged.
- You can meet new people.

**Where and when are the meetings**

- Monthly meetings take place at the Sjøvøll Centre, Pity Me, Durham, DH1 5BZ. Please contact us for the upcoming dates - see contact details below.

The infographic features a light blue background with white arrows and a cartoon illustration of a person with teal hair wearing a yellow shirt and white pants, sitting in a wheelchair. The text is in a blue, hand-drawn font.

eXtreme group slides here -



Promoting the Rights of Children and Young People



## The eXtreme Group Investing in Children



Promoting the Rights of Children and Young People

## Investing in Children : Our Vision

- ★ Children and young people possess the same rights as the rest of humanity.
- ★ Young people experience a better quality of life in society in general terms.
- ★ The services they access recognise and respect their human rights.



## Investing in Children : What do we do?

- ★ liC creates opportunities for children and young people to become genuine participants in decision making processes
- ★ liC works with a range of organisations to promote and engage in dialogue with children, which leads to real change
- ★ We provide a platform for children and young people to share their ideas for creative and supportive projects.



The infographic features a light blue background with white hand-drawn doodles of a thumbs up, a lightbulb, a cactus, and a hand. At the top is the Investing in Children logo. Below it, the text 'extreme Group' is written in a bold, blue, lowercase font on a yellow brushstroke background. To the right of the text is a small cactus in a pot. Underneath, the heading 'What the group do' is followed by a bulleted list of four points. At the bottom left, there is a cartoon illustration of a young boy with blonde hair, wearing a blue t-shirt and red shorts, standing on a green patch of grass and leaning against a vertical line.

Investing in Children

### extreme Group

#### What the group do

- We listen to the ideas of young people in County Durham with SEND.
- We help young people speak out to make services better for young people with SEND. These services include schools and colleges, health services like Doctors surgeries and hospitals, leisure services and transport.
- We go to events and organise events for young people.
- We support the work of Durham County Council and the Health Commissioners (CCGs) in County Durham.



## What we have been working on

- Language of Autism
- Your Autism
- SEND Promise
- Transport
- Leisure
- Key messages for social workers



## Thank You!

Find out more or get in touch:

[info@investinginchildren.net](mailto:info@investinginchildren.net)

0191 307 7030

<https://investinginchildren.net/>

<https://yourautism.co.uk/>

## Sensory Worx

**Speaker** – Claire Stirland – Occupational therapist, advanced sensory integration practitioner and director of Sensory Worx.

Claire spoke of her younger life and sensory overload experience in the local shopping centre.

Claire brought out a full chocolate cake and some dried mealworms. She portioned the cake up and distributed it to delegates along with pots of mealworms to represent cream. This demonstrated to the room how their reaction to seeing mealworms on a cake and to be expected to eat it has similarities to that of a child or young person with food based sensory difficulties. Claire then tipped the mealworms onto the cake, brushed the mealworms off and proceeded to offer the "worm dust topped" cake representing how the "repulsive item" was not completely removed. This analogy showed how children and young people with sensory / food issues feel if certain foods are mixed, touching or remnants of food removed from their plate by a parent / carer and same plate given back. If child or young person feels this way, they are not having their sensory needs met.

**Sensory Worx slides -**



**Improving Understanding of  
Sensory Issues**

Claire Stirland MSc BSc (Hons) PgCert PgDip  
Advanced Sensory Integration Practitioner  
Specialist Occupational Therapist

## Who are we?



Major Sensory and Developmental  
Therapy Service

Research

Understanding

Education

Sunderland University

Sheffield Hallam University

Ulster University

Sensory Integration Network UK

NHS England

## How do we help?

Education

Supporting families

FASD based understanding

Trauma based understanding

Neurodevelopmental difference

Developmental interruption

Atypical developmental experience

## What do we help with?



Sensory reactivity (aka sensitivity)

Emotional regulation issues

'Behavioural' issues

Attention/concentration issues

Sleep issues

Eating/drinking issues

Toileting issues

Hygiene tolerance issues

Clothing tolerance

Controlling interaction

Social isolation

Poor change tolerance

Reliance on routine

Organisation skill difficulties

Transition difficulties

Eating non-food items

Mouthing non-food items

Chewing non-food items

Immature physical skills





# Who do we work with?



- Families
- Adults
- Children
- Schools
- Organisations
- Charities
- Carers
- Supported living

- Day centres
- Universities
- NHS clinics
- SEN teams



# Assessments



- Sensory
- Sensory Integration
- Dyspraxia
- Visual perceptual
- Praxis
- Fine motor
- Gross motor
- Skill based
- Play

- School based
- Home based





# Therapy & Services



Short term or ongoing support  
Sensory integration  
Sensory regulation experiences  
Emotional regulation & understanding  
How are you? sessions  
Social stories  
Thoughts feelings and emotions sessions  
Social skills  
Tailored visuals packages  
School engagement and support

Sensory yoga  
Talking mats  
Family support and mentoring

Group  
Or  
Individual

## Coming up....



Holiday children's group programmes:

- Sensory Yoga
- Sensory regulation
- Movement development
- Playing to write better
- Social skills

Family support:

- General family support group
- Eating/drinking support group
- Family information sessions
- Making visuals

Therapy packages:

- Eating & drinking family support



## Contact us



- Refer to us directly
- Ask us a question
- Get information or advice



### **PCP - Learning disability & autism project**

**Speaker - Paula Meale - Senior research officer.**

PCP is the Pioneering Carer partnership who are a third-sector charitable organisation aiming to improve health, wellbeing and learning for all.



## **Transitions and Changes Learning Disability & Autism County Durham Study**

Paula Meale - June 2023



## Situation

### Prevalence

County Durham has significantly **higher prevalence** of LD&/A than England in 2020. Only **23%** of the projected LD&/A population can be found on GP registers, leaving **77%** unaccounted for.

Populations are on the **rising and ageing**, in County Durham, residents with a LD&/A aged 65 or over is expected to grow by **27%** between 2020 and 2035.

**Healthy life expectancy (HLE)** is lower still, males spend an average of **19 years** and females **21.4 years** in poor health. This is lower still in the LD&/A community.

**HLE and ageing is an additional challenge** for healthy living and independence for both individuals living with a LD&/ASD and those that care for them.



## Situation

### Wider Determinants of Health

Healthy Life Expectancy is linked to the wider determinants of health, there is evidence the **LD&/A population are extremely affected** by these.

**Social isolation** is common in the LD community; **77% are lonely**, and **33% have no friends** and fewer opportunities to make new connections.

Violence is an area of concern; prevalence of **domestic abuse** is greater for people living with a disability. Trends were also recorded in cases of **sexual assault and hate crimes**.

County Durham has one of the **worst rates of unemployment** among adults with learning impairments in England.





## ●●● Situation

### Care and Support

Many people in the LD&/ASD community, live with and are **cared for by a family caregiver**. Many care for that individual for more than **100 hours per week**, and most have done so for **over 20 years**.

As people are living longer, an **increased demand on services and growing complexity** of needs is expected, which requires a deeper understanding of how care and support **can and should** be delivered in the future, to ensure people with LD&/ASDs **live and age well** in County Durham.



## Ambition

What people **who have a learning disability and/ or autism** want and need to live well, including home and family life:

- i. Communication and staying connected
- ii. The right support
- iii. To love and be loved
- iv. Have an effective voice
- v. Employment and contribution

*Better Lives and Good Lives Framework, 2021*





## Questions for the audience



Paula asked, "Does your child or young person **HAVE** everything they need to live a happy ordinary life within County Durham". A few delegates raised their hand.

## Ambition

What the **UK government** want people with a learning disability and/ autism to be able to say.

"I live an ordinary independent life in my community. I get high-quality treatment and support in the ways I want and need to live my life. I receive high-quality care and assistance in the ways that I want and need to live my life."

*Building the Right Support for people with a learning disability and autistic people action plan, 2022*



## Questions for the audience



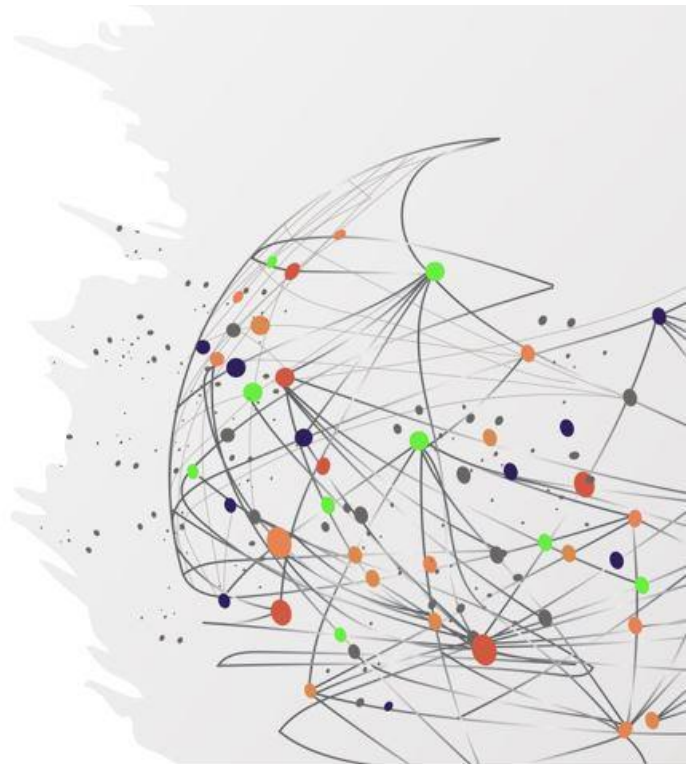
Paula then asked, "SHOULD your child or young person HAVE everything they need to live a happy ordinary life within County Durham". All delegates raised their hand.

Paula then asked, "COULD your child or young person HAVE everything they need to live a happy ordinary life within County Durham". A large number raised their hand.

A delegate raised her hand and pointed out that she is an autistic adult and "Doesn't want to live an ordinary life and is living the life she wants & the government shouldn't be putting wording into her mouth."

## What are we aiming to do?

- i. To **understand** the support **experiences** of people who have a LD&/A, particularly but not exclusively during times of **life transition**
- ii. To discover areas of **unmet need** and find **opportunities** to improve support and experience
- ii. To decide the **top support priorities**, and create a **solution** led by and for persons with a LD&/ASD



## Who do we want to talk to?

### Study Population

Individuals with a learning disability &/ autism aged **≥ 16 years**

Family members (aged **≥ 16 years**) related to an individuals with a LD&/A who is aged **≥ 14 years**

Professional providing specialist/ non-specialist services to individuals with a LD &/ or ASD aged **≥ 14 years**



# Who do we want to talk to?

## Population

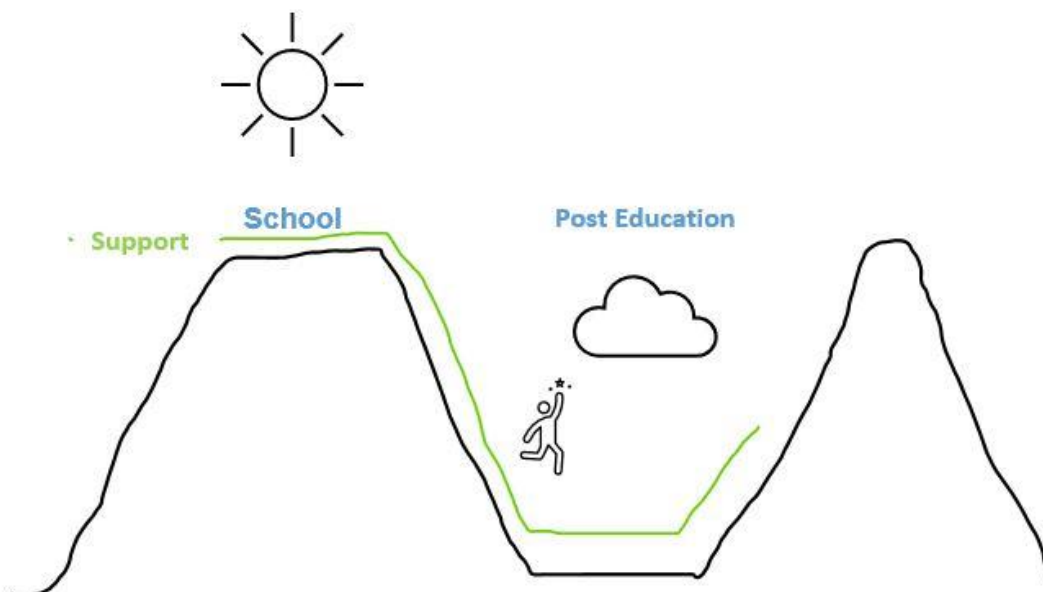
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Professional providing specialist/ non-specialist services to individuals with a LD &/ or ASD aged  $\geq 14$  years

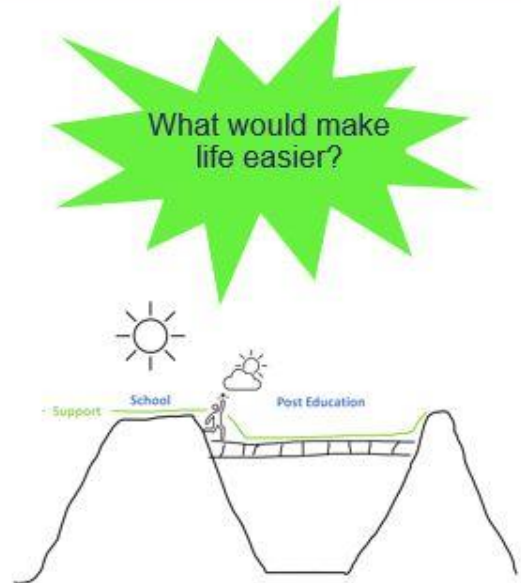


## We know life transitions are hard





## We need to know more



## How to get involved?

Talk to us today

Contact us via  
[research@pcp.uk.net](mailto:research@pcp.uk.net)

Encourage eligible people who  
have a learning disability and/  
autism to take our survey

<https://www.surveymonkey.co.uk/r/J9PPSY2>



At the end Paula asked delegates about funding in County Durham and a member of the audience said he thought it was a "Postcode lottery".

*We encourage eligible people who have a learning disability and/ autism to take the survey below - (Survey closes July 2023)*

<https://www.surveymonkey.co.uk/r/J9PPSY2>

## **Raffle and Close.**

Raffles took place at both events with a range of lovely prizes won by delegates. Marsha thanked everyone for coming and asked delegates to complete the evaluation forms.

At the day conference other MCT members thanked Marsha for her years of hard work within the forum and gave her a leaving gift. Her knowledge and experience will be sorely missed.

## **Conference Evaluations**

### ***Daytime conference.***

***Head - Something I've learnt from today.***

- Short break offer
- That there isn't enough funding or staff for our kid's needs.
- SENDEIC - support for young adults with severe anxiety issue.
- Learning more information.
- What SENDIASS offer.
- Sensory needs and their impact on individuals affected.
- My child has unmet needs, and the local authority needs to implement support for this.
- About the services that Sensory Worx offer.
- CYPN offer a discount card.
- The dental team.
- What services are available in my area.
- To know there is a support setting for my older son for his future.
- Smile through sport.
- Change in assessment process.
- Information regarding early help & access to carers breaks.
- To be my daughter's voice and advocate!
- Changes to transport to be considered.
- 12-week course to deliver training.
- Throughout the holidays they are looking into groups for children to stay by themselves - SENDEIC.

- What support is available from SENDIASS 😊
- Many professionals offered evidenced based advice and support for various aspects of day-to-day life with a child with SEN.
- There are lots of organisations out there who are willing to support. Working together is important.

### ***Heart - Something I've felt / experience today.***

- Not everyone understands the processes & why should they?
- Proud of MCT but upset there is nothing available to help my socially anxious 20-year-old.
- To note how passionate but frustrated parent carers are feeling. I feel very sad for those parents who are trying to help their young person to lead, as much as possible, a successful & happy life.
- Food was lovely.
- That I am not alone. There are other parents in the same boat.
- Sense of empowerment.
- Disappointed in strategic services presentation and plans using stats to justify their poor planning and future services.
- I'm not alone - others are experiencing similar difficulties.
- Angry and upset - that the "business" of the broken system is affecting my daughter care.
- Having conversations with other parents and carers who understand.
- The passions of people attending to make changes better for CYP & families. Enjoyed Clare (sensory Worx) presentation.
- Enjoyed & learnt a lot.
- Some nice positives & heard some nice things.
- Opportunity to talk to people from different organisations about SEND.
- Happy sensory issues are becoming more recognised, Sad the assessment process still has such a long waiting list.
- Emotional but comfortable. Seen! Heard! The amazing network that's available! Alive- not alone!
- How everything is so delayed in implementing changes.
- Support from Claire at Sensory Worx. As I currently feel overwhelmed with lack of professional support for my son.
- eXtreme Group. Have your say - good / not do good.
- It has been a friendly & welcoming day by all professionals and attendees supporting one another in similar situations.

- Conflicted?! While the support is there- I don't feel it's always advocated via schools etc and what kind of things they can provide with their services.
- Although there is still a way to go County Durham still seems to be doing well too other part of the Country.

***Carrier Bag - Something I'll take away from today.***

- Some parents still have limited information/ understanding of services.
- A full tummy 😊 Thank you.
- DSCO - Social care - linking in social work.
- Freebies.
- SENDIASS info
- Lots of support services to look into.
- Freebies- thanks!
- Information to share with other parents & carers at my son's school.
- Links with services & professionals.
- Info.
- Lots of useful leaflets and more knowledge on things that are available.
- Good info & goodies.
- Upcoming sessions with sensory Worx
- Where to access help with respite / carers breaks.
- All the support that's available to make the links.
- Sensory Worx information.
- Aware not that my son with additional needs as well as my "neuro typical" daughter are both able to attend activities together. Looking into Taekwondo.
- Food (lunch).
- In it together.
- My voice so I can ask / express what I feel "We" need / expect and / or if those are going to be met / accessed.
- Knowledge of different support networks available and the ease of access to these.

***Dustbin - Something that was not good about today.***

- Waiting lists.
- Hearing there's a recruitment drive but no staff available.
- Nothing 😊



- Can't think of any.
- Paul Shadforth's presentation.
- I had to leave early and missed the sensory Worx presentation.
- Nothing- thank you 😊
- Wordy PowerPoints.
- Air con 😊
- Virtual presentation not as good as the live presentation (even if it is unavoidable)
- Some of the professionals lack the knowledge around waiting times for treatment after diagnosis.
- How broken this system is. Waiting lists people in roles who don't understand.
- Focus on autism instead of learning disabilities. Not all LD are diagnosed ASD.
- Lack of being able to give timescales of the Neurodevelopmental team waiting list.
- Nothing
- No negatives
- Nothing - it was a great day.

## *Evening conference:*

- People at MCT are lovely!

### **Head - Something I've learnt from today.**

- Waiting list times for assessment.
- Team training
- SENDEIC offer.
- About the teams that are helping us try and help our daughter.
- Love the changes so far. 😊
- Learnt SENDIASS are working with 1700 families and 46% of carers seeking SENDIASS assistance have neurodivergent children - Didn't realise it was this high.
- Professionals talk a good game but what you say & what they deliver is very different things. Clearly don't live in the real world.
- There is a website with all the information held centrally.
- Things about home to school transport.
- There is a lot of information out there.
- 

### **Heart - Something I've felt / experience today.**

- Opportunity to talk to other parents.
- Anger, frustration & maybe hope.
- Hope.
- Shared experiences.
- Things about SENDIASS.
- SENDIASS developing information and advice for 16-25 years and this is currently missing. I hope it provides opportunity for individuals to make decisions independently.
- We've asked for help for months & received very little support. Feel very angry and disappointment.
- There is a lot of others looking for the same information & support.
- Welcomed.
- Included.
- Included.
- There are a lot of departments all doing similar things. A little overwhelmed but thankful.

### **Carrier Bag - Something I'll take away from today...**

- Info on services
- The information & services
- Freebies
- Empowering Inclusive communities - short breaks- very positive steps for families.
- Self-congratulation for yourselves. (Professionals not MCT)
- To look for more help & access to services that are available.
- Things discussed at the last conference WAS NOT forgotten about and has been updated.
- Information leaflets.
- Information.
- It was good to put a name / face to phone calls and some more contact details for new opportunities.

### **Dustbin - Something that was not good about today.**

- All good stuff. Nothing for the bin 😊
- Nothing of note.
- Too hot
- What's been said does not reflect the support you say is available. How come you don't show negative feedback?
- It was all great.
- Nothing.
- It was all good - just a lot of info for a first timer.

*MCT DURHAM CIO - Registered charity number 1202217.*

[www.mctdurham.co.uk](http://www.mctdurham.co.uk)