Evidence Seminar:

Children and young people with learning disabilities whose behaviours challenge

6 July 2018

Summary

This note records the findings of a national research seminar attended by academics and policy makers, designed to draw out evidence of use to those commissioning, designing and delivering services to children and young people with learning disabilities or autism whose behaviours challenge. It should also inform development of the NHSE 10 year plan.

The seminar was delivered in partnership by NHS England, the Challenging Behaviour Foundation (CBF), the Council for Disabled Children (CDC) and the Sharland Foundation Developmental Disabilities ABA Research and Impact Network (SF-DDARIN). The day was opened by Jane Ramsey, Chair of the Transforming Care Children and Young People's Steering Group.

A huge amount of information was gathered during the day relevant to:

- NHS England, including evidence to inform development of the 10 year plan
- The Government, including the Department for Education, the Department of Health, the Minister for Disabled people
- All statutory services responsible for commissioning and delivering services to children and young people with learning disabilities, including commissioners of children and young people's services, SEND leads and CCGs
- Research organisations including those responsible for funding research, such as NIHR

There is much published research which is relevant to commissioners but those findings are not always publicly available or accessible. There are also significant research gaps (see page 30). Seminar attendees identified the need for a:

- National research and best practice forum to enable continued contact between academics and policy leads to facilitate evidence-based policy making
- Large scale RCT to focus on interventions for children with learning disabilities or autism whose behaviours challenge
- NIHR programme grant (similar to the call for research on dementia) focussed on children with learning disabilities, autism and behaviours that challenge and a longitudinal study of this group.
- Implementation framework to enable evidence informed interventions to be developed locally, regionally and nationally supported by effective communications with commissioners, professionals and families.

Contents

Acknowledgements

Aims of the seminar

Approaching the third year of the Transforming Care programme, NHSE, the CBF and CDC wanted to bring leading researchers and those who have been involved in developing evidence-based approaches together with the Transforming Care Children and Young People's Steering Group and Operational Delivery Group and other key decision makers to:

1. Look at what we already know from research and data

2. Understand the work is currently being undertaken in this area

3. Identify gaps

4. Prioritise recommendations going forward for:

    a. The Transforming Care Programme

    b. Direct work with Transforming Care Partnerships (TCPs) and SEND leads in local areas

    c. Future research

In doing this, we wanted the Evidence Seminar to build on work done to date to explore next steps that will benefit children and young people with learning disability, autism or both with challenging behaviour and/or a mental health condition and their families.

Opening remarks

With reference to the parliamentary debate on 5th July 2018 on Transforming Care; Jane Ramsey explained that evidence continues to emerge of neglect, abuse, poor care, and premature death of people with learning disabilities. There are also many people with learning disabilities inappropriately admitted to Assessment and Treatment Units (ATUs), and there is concern at the lack of capacity and capability of community services. It is predicted that the Transforming Care programme is unlikely to realise the ambitions set out in the 'Building the Right Support' strategy before it ends in March 2019.

The Government has been called on to commit to a programme after Transforming Care and invest in community services across education, health and social care. Such services should adopt a lifelong, early intervention and prevention approach, protect the human rights of children and adults with learning disabilities and/or autism, and promote independence and wellbeing through the right support with proper resources.

Data presentations

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Summary of key points from data presentations

- There are significant gaps in the data collected by both education and health meaning that we don't know enough about this cohort of children. Specific recommendations have been made to address these gaps, as set out in *Children with learning disabilities whose behaviours challenge: What do we know from national data? (Pinney 2014)*

- The residential schools data shows poor outcomes for children and inappropriate use of residential placements at high cost.

- The Transforming Care data shows that there has been an increase in admission of under 18 year olds to Tier 4 CAMHs (to 255 children) but a decrease in those age 18-24. The increase has mainly been young people with autism.

- Work with TCPs to improve local support and reduce admission includes linking to SEND reforms and mental health transformation plans, working in partnership with children and families, including children on dynamic risk registers and including Transforming Care provision within the local offer. 98% of areas now have a CYP lead responsible for this work. Six TCP areas have received funding to look specifically at alternatives to admission for children.

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Sue North NHS England (Children and Young People's Lead, Transforming Care, NHSE)

Sue North from NHS England reported on the current data and progress of the TCPs. The aim was to understand what the current data tells us about the children and young people (CYP) we are focusing on.

Tier 4 Child and Adolescent Mental Health Service (CAMHS) is an inpatient service for children and young people whose mental health has deteriorated so severely that their mental health issues cannot be managed as an outpatient. The data of the number of CYP with a learning disability (LD), autism or both in a tier 4 CAHMS service demonstrated a worrying increasing trend of children under 18 being hospitalised. However the data also demonstrated a downward trend of hospitalisation of 18-25 year olds.

Data on gender showed of those in tier 4 settings 44% of males and 55% of females under 18 with LD, autism or both. In the 18-24 year age group, 69% were male and 30% female. Over half of under 18s admitted were female and 30% were 18-24 years old.

The under 18s patient category data showed 65% have autism and no LD, with just 20% with only LD, 13% with LD and autism, and 2% with none.

In the 18-24 age groups only 23% have autism and no LD, 41% with only LD, 32% with autism and LD, and 4% with none. Therefore there are worryingly high proportions (78%) of individuals with autism under 18 in hospital.

The data showed 54% of individuals hospitalised with autism only were under 18 and male, and 74% were female showing a much higher proportion of females with autism only in hospital. There was no noticeable difference between males and females in the 18-24 year age group and no significant change in the proportion of young people in either age group with autism only in the last year.

We now have some understanding from the data. The task for Transforming Care was very much adult focused initially and now the work is much more focussed on children. The benchmarking work undertaken by the TCPs has helped to understand challenges, progress and areas to focus on. Overall progress has been made, however there is a long way to go to improve children's services.

The challenges that TCPs face are not insignificant. However, 98% of areas covered by NHS England now have a named CYP lead with responsibility for leading the transforming care work.

TCPs have been asked to link with special educational needs and disability reforms, and mental health transformation plans. TCPs should involve parent carers with lived experience of LD, Autism or both. TCPs should be ensuring that children are included in their at risk of admission registers and dynamic risk registers, and include information about transforming care within the Local Offer.

In October 2017 60% of TCPs planned for links with special educational needs and disability reforms, which increased to 90% in April 2018.   71% of TCPs planned to link with mental health transformation plans in October 2017 with an increase to 85% in April 2018.

In October 2017 50% of TCPs involved parent carers with lived experience of LD, autism or both. This increased to 71% in April 2018.   50% of TCPs included CYP in their at risk of admission registers and dynamic risk registers in October 2017, and 71% included CYP in April 2018.

Only 19% of TCPs included information about transforming care on the Local Offer. Inclusions increased to 54% in April 2018.

From 2016-2017 four TCP areas received transforming care funding to support CYP. In 2018-2019 six TCP areas will receive funding for work with CYP specifically looking at alternatives to admission, bespoke packages and use of individual personal budgets, key working, early intervention, autism and forensic services. We know what should be in place; we need clear guidance on how areas implement this. There is accelerator work being carried out in additional areas trialling work with reports of real progress. We need to ask accelerators to

be willing to share what they have learned regionally and nationally and keep people informed of progress.

We now have a better understanding of the population of CYP admitted into hospital have autism. However we need more detailed information, for example knowing how many of those CYP self-harm. The data only tells us the primary reason why these individuals are in hospital.

Anne Pinney: Independent Researcher

Anne had analysed national data in residential placements of CYP with LD in the areas of education, health, social care and mental health.

The data on children with LD in residential special schools in 2003 was not good; children were being excluded from school and moved out of area, some into mental health services. The effectiveness of local arrangements for safeguarding and promoting the welfare of children in residential placements were poor, transitions beyond school had poor outcomes and residential placements were used inappropriately at high cost.

Data like this eventually prompted the Department of Health to ask Dame Christine Lenehan (Jan 2017) to take a strategic overview and recommend practical action to co-ordinate care, support and treatment for CYP with complex needs and behaviour that challenges who have LD, Autism or both.

We needed more detailed data on numbers, what type of data local areas were using and if good pathway analyses were taking place. Researching residential placements for CYP with complex disabilities was a neglected research area with exception of the Tizard project (Magill, Tennyson & Cooper, 2005).

The national data relies on school census Special Educational Needs (SEN) data provided by SENCOs. There were some short comings in the reliance of SEN primary needs data of children with LD, autism or both. The full picture was not available, for example capturing challenging behaviour. There were 12,000 children in independent schools which still don't report pupil level data, and distinctions between BESD, SEMH and behaviour that challenges are not made, therefore outcomes data is not good or accurate.

In February 2017 Anne worked in conjunction with The Council for Disabled Children and The True Colours Trust and published national data on disabled children with complex needs and life limiting conditions. The data showed comparisons of numbers of children with profound and complex needs in 2004 and the latest data in 2016. There was an increase of nearly 50% overall and large significant increases of children with autism and children with multi-sensory impairments.

In terms of special school populations there are more children with complex needs with a primary need of autism. We need to be sceptical about the current data and have more

specific detailed data in order to understand exactly what's going on and have a more robust picture from research studies.

Research presentations

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<p align="center">Summary of key points from research presentations</p>

- Research clearly shows that children with learning disabilities or autism and behaviours described as challenging (and their families) are experiencing poor outcomes under the current system at significant human and financial cost. **Positive Behaviour Support** is the best evidenced approach to support this group of children and young people in order to improve quality of life and Gore et al have developed a framework to help understand and apply PBS.

- There is already a robust evidence base for early **parent training interventions.** Such interventions can increase family resilience, improve quality of life and reduce behaviours that challenge. Three studies are underway looking at parent training interventions tailored specifically to this group of children and their families.
    - A feasibility study of the **E-pAts** intervention for families of children age 0-5 with learning disabilities (Hastings and Gore)
    - A pilot RCT of **Incredible Years** for autistic children (Hutchings)
    - The clinical and cost-effectiveness of **Stepping Stones** (Hassiotis) for families of children with learning disabilities and severe levels of challenging behaviour, where the intervention was shown to be effective in reducing levels of behaviours that challenge.

- Emerging research about the links between learning disabilities or autism and **mental health problems** could help to enable much better support in practice for this group of children and young people, including the development of more effective pathways and treatments. For example,
    - Improving mental health support for children with learning disabilities and autism who are **non-verbal**. The University of Birmingham is developing a tool to help identify anxiety and depression in non-verbal young people to address the fact that mental health problems are often overlooked in this group.
    - Understanding and improving mental health support for children and young people with **autism**. A high proportion of people who commit suicide are autistic as are 25% of all women with anorexia. More research is needed to understand the underlying reasons, which could be linked to sensory issues. Autistica are also looking at practical ways to help young people with autism to manage anxiety (including an App).
    - The Ann Craft Trust research suggests that with the right help and training from the right professionals (good relationship based practice, good communication based practice, and good PBS practice) **breakdown and trauma** for children and their families can be avoided.

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- There is clear evidence of the links between **pain or ill health** and challenging behaviour. Research could help to improve specific health interventions. For example:
  - The LeDeR report found that **epilepsy** is the third largest cause of death of all people with a learning disability and 20-40% of people with autism also have epilepsy. Care and management of epilepsy should be improved for children and young people and more research is needed to understand the links between anti-psychotic medication and epilepsy.
  - There is a consistent association between pain, painful health conditions and **self-injury.** Birmingham University are developing a tool to predict which children are at the greatest risk of self-injury. They are also working with Birmingham Children's Hospital to develop tools to identify causes and health problems associated with pain such as gastro-oesphageal reflux in non-verbal children.
  - Dr Kate Oulton found that **hospitals** without dedicated learning disability staff felt less able to identify and meet the needs of children with learning disabilities, families felt less involved and children felt less safe in hospital.

- The research is clear that **emotional difficulties amongst parents and siblings** of children who display behavioural difficulties are high and that this in turn impacts on the support families are able to offer their child. Research is underway to better understand these interactions in order to identify support needed to improve family coping mechanisms; for example practical family support (such as short breaks or young carers groups) and mindfulness interventions.

Professor Peter McGill on behalf of the Challenging Behaviour Academic Expert Group

Peter focused on CYP with LD and behaviour that challenges. Our best estimate is that in England there were approximately 41,000 children with LD with behaviours that are challenging in 2014 (Emerson et al, 2014).

Children in this group are at a much greater risk of developing behaviour that challenges and as a consequence face social exclusion, institutionalisation, deprivation, misdiagnosis, exclusion from schools, ineffective interventions and fail to access evidence-based interventions (Emerson, 2004 &2012). There is also a substantial impact on families as parents and carers also face the risk of physical and mental ill health, increased financial burden and a reduced quality of life. There is strong evidence that causes and maintaining

factors of challenging behaviour can be changed preventing future admissions in residential settings.

The costs of caring for children in this group are high. The cost per year for a 52 week placement in a residential special school is £171,176 and the average cost per year for an inpatient of 17 years or younger in an ATU is £250,000.

The CBF Academic Group recommends focusing on prevention and developing skills by implementing early intervention support for families, (for example Stepping Stones, Incredible Years, E-PAtS).

Families need early identification and rapid response. Families say they don't get the support they need (McGill, Tennyson & Cooper, 2006) and the challenging behaviour becomes worse and spirals out of control. This can lead to families eventually being unable to cope and experiencing high levels of stress and emotional difficulty (Hastings, 2002), children may become institutionalised at high financial cost, and high emotional and personal cost to them and their families when separated. This often leads to an adult life away from families with half of those individuals that leave children's residential placements then going on to out of area placements, and many never return to their local areas.

Expert led evidence based early intervention is needed for children and families to experience good quality of life, to improve and achieve better outcomes and to reduce the impact on families. The main evidence based intervention for challenging behaviour is Positive Behaviour Support (PBS).

Dr Nick Gore: Tizard Centre-University of Kent

Early Positive Approaches to Support (E-PAtS) is a co-produced and co-facilitated support programme available to family caregivers who have a child under 5 years of age. It comprises of eight sessions to families in a group format and aims to reduce risks of challenging behaviour and support positive skill development to provide effective long term support. The study is free of charge to participating families and is delivered by trained facilitators in partnership with family carers.

GO- for- IT (Goals and outcome for InTervention) are direct approaches supporting CYP with LD and complex needs and a history of challenging behaviour. Caregivers assess their needs and aspirations and then select goals for the future. Both children and caregivers play an active role in assessment and intervention.

Positive Behavioural Support (PBS) Framework and Services

PBS supports individuals with LD who are at risk of behaviour that challenges. A PBS framework can be used in any services such as early years, health and education settings.

The PBS framework is made up of ten core elements (Gore et al., 2013). The main aim of PBS is the improvement of quality of life for the individual and their families. Supporting an individual within a PBS framework reduces the likelihood of challenging behaviour as PBS practitioners help to develop and build new skills for the individual. PBS also helps to support families and care workers which involves including them all in the whole process of assessment and implementation.

PBS practitioners look at the function of behaviour and use Applied Behaviour Analysis (ABA) principles and evidence based practices such as a functional assessment to understand why behaviour happens and to form plans of action to help with individual needs and reduce the likelihood of further challenging behaviour.

Nick talked about the concerns of how children end up in residential services, how can we avoid it and improve transitions from residential schools to adult services. Nick suggested identifying characteristics of good services and removing barriers by introducing co-ordinated assessments and plans across health, education, and social care. He also suggested working with families to support systems and interventions.

By developing conceptual models of support and frameworks and using communication-based interventions (such as Functional Communication Training) as well as supporting inclusion more broadly by including children with LD in social groups and mainstream services, we can greatly improve their quality of life.

Professor Richard P. Hastings: University of Warwick

Professor Richard Hastings gave a brief summary of the current research he is leading or involved in, relevant to the seminar.

Professor Judy Hutchings of Bangor University is taking forward a pilot Random Controlled Trial (RCT) of a parenting/family based support programme for language delayed children with autism called the Incredible Years programme, funded by Autistica.

A feasibility RCT of Early Positive Approaches to Support (E-PAtS) with Dr Nick Gore from Tizard University , funded by NIHR Public Health Research Programme.

Dr Vaso Totsika of Warwick University is researching early family pathways for mental health and behaviour problems in children with LD; funded by the Baily Thomas Charitable Fund.

Suzi Scott, University of Warwick is conducting a study looking at barriers to access for early years and early intervention support for families of children with LD and/or autism, what family experiences are and what support they are currently getting. This is part of a PhD and is in collaboration with with Mencap, Cerebra and Ambitious about Autism.

Michelle Underwood at the Centre of Behaviour Solutions is conducting as part of her PhD, a study looking at researched school readiness for children with developmental disabilities.

The Association Objectif L'autisme funded the Swiss Early Intervention Project for Autism (SwEIPA). This included an analysis of educational, mental health and family outcomes.

The Australian Research Council funded the study of school non- attendance in children with LD with Montash University. Predictors included mental health and behaviour problems. The study looked at patterns of attendance, and when they don't attend why they don't attend and is challenging behaviour associated with attendance.

Cardiff University researched the effectiveness of sensory integration therapy for sensory processing problems in school age children with autism in mainstream schools. This is funded by NIHR HTA.

The Bailey Thomas Charitable Fund funded a feasibility RCT of online mindfulness intervention for parents of children and adults with LD.

A study funded by Cerebra and involving several PhDs and projects with 1000 families is looking into family factors associated with mental health in children with LD and their families.

Gemma Nicholls from Calthorpe Academy in Birmingham is conducting research on using PBS for challenging behaviour in special schools settings. Her PhD is funded by Ambitious about Autism.

Nikita Hayden is doing PhD research funded by ESRC and SIBS that focused on sibling mental health and sibling well-being of those with a sibling with autism. There is not much research in these areas and there is a need for further research here.

Jon Spiers: Chief Executive of Autistica

Jon Spiers from Autistica reported on relevant current and recent research.

Professor Chris Oliver from the University of Birmingham is leading a research project to find ways to distinguish between anxiety and depression in the non-verbal population. Many autistic people with LD have untreated mental health problems. The researchers are developing an assessment tool to help healthcare professionals to identify anxiety and depression more reliably amongst autistic individuals who speak few or no words. The research is hoping to identify issues that underlie behaviour that challenges to reduce the use of restraint and sedation, and to improve the quality of life of autistic people in inpatient care.

Dr Will Mandy from University College London is leading a research project in Anorexia and autistic populations. Approximately a quarter of all women with anorexia are autistic and the worst outcomes are for anorexic autistic people. Researchers are exploring the

differences for autistic people and what implications that has for intervention and service design. Are sensory issues for example leading to anorexia? This is a complex area. However we know large numbers are being admitted for eating disorders. Services should review their pathways for CYP with anorexia using the outputs from this research.

Dr Sarah Cassidy from Nottingham University is leading a research project regarding suicide for young and older people with autism. A significant proportion of people who commit suicide are autistic. Between a third and two thirds have attempted suicide and we know suicide looks different in autism populations. One study found 14% of CYP on the autistic spectrum attempted suicide compared to 0.5% of their non-autistic peers. Autistic people may consider suicide differently to non-autistic people. Asking autistic individuals to phone a helpline is unlikely, so what will work? We need to understand what will work to help autistic people not to commit suicide. Services need to ensure staff and systems are up to date with emerging evidence. Mental health services are likely to be using assessment tools that do not accurately account for risk of suicide in the autistic community therefore we need more research in this area.

Professor Emily Simonoff from Kings College London and Dr Jacqui Rodgers from the University of Newcastle are leading a research project in Anxiety and autistic populations. Four in ten autistic CYP have an anxiety disorder and continue to struggle with mental health issues to adulthood. The researchers from Kings College London and Autistica have developed a smartphone App to help young autistic people to manage their anxiety based on Cognitive Behaviour Therapy (CBT) techniques as increasing evidence suggests mental health interventions such as CBT need adapting for individuals with autism.

The University of Newcastle is running a feasibility trial on intervention to help CYP with autism cope with uncertainty in everyday situations. The emerging research could help services intervene more effectively to prevent CYP with autism struggling with anxiety and related mental health problems.

We also know that epilepsy is the leading cause of death in autistic populations and most autistic individuals with epilepsy don't reach the age of forty. The annual report of the Learning Disability Mortality Review (LeDeR) has found epilepsy is the third largest cause of death of all people with LD. Between 20% and 40% of autistic people have epilepsy and epilepsy in autistic people appear to be more resistant to treatment.

Which medication is needed? We don't know as autistic individuals are excluded from treatment trials. Anti- psychotics have an epileptic effect so are we encouraging epilepsy? Should we look at the pattern of anti- psychotics to bring on the onset of epilepsy? This is not a well-researched area, therefore more research is needed.

Professor Francesca Happe and Dr Freya Rumball form Kings College London, Dr Dheeraj Rai from the University of Bristol and Dr Sarah Griffiths from the University of Cambridge

researched trauma and the autistic population. Research suggests autistic people's traumatic childhood experiences are associated with developing long term mental health problems and an increased risk of suicide.

Some of the CYP and adults in the transforming care programme may have experienced childhood trauma therefore there is an urgent need to help CYP with trauma and prevent possible suicide. This area is also under researched and more funding needs to be found for further research into what types of experiences are traumatic for autistic people and what interventions can help.

Dr Caroline Richards: University of Birmingham

Caroline's research with Professor Chris Oliver focused on children with profound or severe LD and challenging behaviour with a high rate of self-injurious behaviour. The team focused on three primary strands of work:

Prevention in young people, causes of self-injury-pain, and assessment and intervention protocol for self-injury.

The team are working on the development of a screening tool with a predictive algorithm built in that can be used to predict which children are at the greatest need for preventative early intervention for self-injury. This can then be used to develop different levels of intervention to suit different individuals.

There is a consistent association between pain, painful health conditions and self-injury. The research team are collaborating with Birmingham children's hospital to develop more robust tools to identify causes and health problems associated with pain such as gastro-oesphageal reflux in non-verbal children and evaluating the impact of identification and treatment on the presence and severity of self-injury. For example we need to know which children we should use endoscopies with or should we use less intrusive ways?

Caroline and her team have also developed a clinical assessment and intervention protocol for self-injury looking at various causes of self-injury and the most severe self-injury where restraint might be used.

Gareth James: Department of Health and Social Care

Gareth reported on current research funded by the Department. There is also work being conducted on data outcomes and improving data sets, data quality and community services data sets to give us more information on disability.

Dr Victoria Grahame (Northumberland, Tyne and Wear NHS Foundation Trust) is leading a research project in managing repetitive behaviours and looking at clinical and cost effectiveness of a parent group intervention to manage restricted and repetitive behaviours in young children with ASD.

Dr Kate Oulton (Great Ormond Street Hospital for Children NHS Foundation Trust) led a study called 'pay more attention' to research mixed methods to identify the barriers and facilitators to ensure equal access to high quality hospital care and services for children and young people with and without LD and their families.

Professor Alan Colver (Northumbria Healthcare NHS Foundation Trust) led a research project on how health services contribute most effectively to facilitating successful transitions of young people with complex health needs from childhood to adulthood.

Professor Emily Simonoff (South London and Maudsley NHS Foundation Trust) led a study into improving outcomes for people with autism by reducing mental health problems.

Dr Robert Hodgson from the University of York led a research project in intensive behavioural interventions for young children with autism implementing a systematic review and cost effectiveness analysis.

A Longitudinal study of effective treatments for people with autism and attention deficit hyperactivity disorder across the lifespan is currently being conducted by Murphy et al and Professor Johnathan Green (Manchester University NHS Foundation Trust) conducted by the Paediatric Autism Communication Trial.

Debbie Sanders: The Department for Education

Debbie Sanders reported on the Special Educational Needs and Disability (SEND) research and data collection.

DfE collects annual data through the school census, national pupil database and local authority to give an overall picture of who CYP are and where they are, their needs, their progress in early year's schools and Post 16 education, and can see when they are excluded, absent or in alternative provision.

DfE are aiming to deliver an effective SEND support system with good quality provision to meet the individual needs of CYP with SEN. From the 1st April 2018 98.4% of SEN statements were successfully transferred to Education, Health and Care (EHC) plans or assessed as not needing EHC plans. Pupils with an EHC plan has remained constant at 2.8% of all pupils, but due to growth in population there are more EHC plans which has increased the cost of spending per pupil which increases the pressure on budgets.

DfE have also raised the profile of SEND through local authorities published 'Local Offers' and funded independent supporters. Data, reviews, reports and research inform SEND policy development and influence policy have been shared across the Department such as Christine Lenehan's (Jan,2017) review of provision in residential settings "Good intentions, good enough", Edward Timpson's current review (March, 2018) of exclusions and John Bercow's (Dec, 2008) review of services for children and young people with speech, language and communication needs.

There is also research commissioned as part of the specialist tools and training delivery, including work on areas such as workforce development, work placements, tribunal evaluation and autism awareness. For example, DfE contracted research from UCL and Nasen to provide understanding of the demand and need for continuous professional development for both generic SEND needs and for specific conditions. This supports the workforce development to meet local area and educational settings' duties to meet SEND needs.

A range of Initial Teacher Education/ Training providers will also be looked at to identify the best 20 to show the best examples of SEND training for new teachers. A SEND Index will also be created by September this year to see how local school improvement networks are including SEND. Local results will be compared with those of the local area Care Quality Commission (CQC) and Office for Standards in Education (Ofsted) SEND inspections.

The University of Manchester and UCL are also working on understanding the supply of Educational Psychologists, finding the gaps and how we may link up with higher education to fill the gaps. All this information and research can help towards identifying and addressing weaknesses and gaps and improve the system for CYP.

Dr Kate Oulton: Great Ormond Street

Kate Oulton's study "Pay more Attention" used mixed methods to identify barriers and facilitators to ensure equal access to high quality hospital care and services for CYP with and without LD and their families. The study involved 24 hospitals, 2000 + staff surveys and 65+ staff interviews that asked questions about flagging, LD nurse provision, complaints, training, knowledge, skills, environment, safety, communication and how staff manage pain and challenging behaviour.

Results showed variations in practice with 8 out of 15 children's hospitals having dedicated LD staff and uncertainty of identification of CYP with LD. Staff without LD experience and training felt less confident and capable of meeting their needs. Parents of CYP with LD felt less involved with decision making when planning services, and CYP felt less safe in hospital. Furthermore, current LD provision did not make a difference.

The study showed further research is needed for developing and testing screening tools, risk assessment tools, staff training and development and testing of a training intervention package for healthcare staff. Further research is also needed to evaluate the impact of specialist LD nurse roles.

Professor Angela Hassiotis: Evaluation of Parent Intervention for Challenging Behaviour in Children with Intellectual Disabilities (EPICC-ID) study-NIHR-HTA.

This study researched the clinical and cost effectiveness of a parent mediated intervention to reduce challenging behaviour in pre-schoolers aged 30-59 months old with moderate-severe LD.

The intervention of choice was Stepping Stones level 4 Triple P (SSTP) conducted over 9 weeks in 6 community based group sessions and 3 telephone/face-face sessions. Triple P is a positive parenting program designed for parents of children with severe behavioural difficulties to acquire skills and support that can be adapted to a range of parenting situations. It aims to prevent challenging behaviour and further development of family, school and community issues.

The comparison group received usual treatment of GP and parenting advice and support sessions, early intervention linked to children's services and the contact of a family guide.

The RCT aimed to compare the usual treatment and the (SSTP) delivered over 9 weeks on the reduction of challenging behaviour in children with moderate to severe intellectual disability at 12 months post randomisation and as a secondary objective to assess the cost effectiveness of the intervention compared to treatment as usual.

Results showed that there was a reduction in reported challenging behaviour across 4 locations.

Sarah Goff: Ann Craft Trust, University of Nottingham

Based on the current legal framework all children have the right to support and to be brought up at home. Sarah reported on attachment, trauma and loss in CYP with LD, and the support parents need and lack to care for their children at home. 36 different experienced professionals from across health, education, social and medicine went into residential homes and schools that were happy to showcase their practice and demonstrate good relationship-based practice, good communication-based practice, and good PBS practice. They observed and talked in depth to staff and young people about their care.

The results were very positive with observations of good relationship-based practice and attentive 1-1 care. An understanding of challenging behaviour on the whole was good, and staff understood most challenging behaviour was a communication of distress and that anxiety provoking situations were avoided or managed discussed and supported. Positive behaviour support plans and communication plans were in place, and links with families valued, often being repaired and developed.

There were frequent reports of previous histories of trauma prior to breakdown at home and school. Stories about lack of CAMHS/Mental Health or specialist support for carers, parents, TAs and teachers prior to breakdown and placement. There were also frequent accounts of issues for young people in ATUs and lack of outside advocacy, with significant concerns about lack of transition plans.

Workers in the residential schools and homes had skills and service supports that families with CYP with LD could benefit from. There were many teenage boys in residential homes

and much trauma faced by families. The findings suggest with the right help and training from the right professionals breakdown and trauma for CYP and families can be avoided.

Discussions to Clarify Understanding and discuss priorities for implementation

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<p style="text-align:center; color:#1F6FBF;">Summary of seminar discussions</p>

- We need to see improvements in **data quality** and more detailed pupil level data (eg where autism is the primary need what other needs does a child have – complex health needs, learning disabilities, behaviours described as challenging?)

- We know certain interventions could make a difference, for example better screening and identification tools and pathways, PBS, early parenting training programmes, functional communication training, learning disability nurses. Mental health programmes such as IAPT could include specific focus on learning disability or autism as they are often excluded from CAMHs support. Interventions that work should be clearly identified and supported by an **implementation framework** which is well communicated. (see page 25-27)

- **Diagnosis** is a big issue. Both improving diagnosis (eg teenage girls with autism, young children with learning disabilities) but also diagnostic overshadowing where health or mental health problems are seen as "part" of a learning disability or autism and therefore not treated.

- The **workforce** is key to delivering better support for this group. We know we are losing the integrity of interventions in delivery through workforce and provider gaps. How do we address this? (eg behavioural intervention mapping). Good CPD for clinicians and practitioners is also needed to develop and improve practice.

- NICE need to think about their criteria for what is considered as robust evidence and the implications of **gaps in NICE guidelines** for prioritisation of interventions and treatments by NHS England.

- We need to **improve learning** from where implementation happens well – skills, relationships, best practice case studies.

- Not all implementation requires research evidence eg where it is covered by policy and legal frameworks (Equality Act, Human Rights Act, Children and Families Act, Care Act and others). There is also a need to capture hearts and minds through **culture change** in commissioning and services.

- Specific areas of concern were discussed including transition to adulthood, understanding of the contributory factors to eating disorders, routes into the forensic system, variations across the country and better understanding of the tipping points which leave families unable to cope. These fed into the discussion on **research gaps** (see page 30)

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- We need more understanding and reassurance about the strength of assurance across Government regionally and locally for children and young people (as a whole and within TC), EHC plans and achieving the right outcomes (including employment) there needs to be greater **accountability** at all levels.

- LSE research on the **cost effectiveness** of local support for children whose behaviours challenge should be made more widely available.

- Health, education, social care, family support and CAMHs are still very disconnected both nationally and locally. There is an urgent need to look at funding and support across these services so they can work together and avoid **financial decisions which lead to admission**.

- NHSE can't deliver all of the change needed. We need clarity of expectations about **roles and responsibilities** to move change forward.

The seminar discussed the concerningly high levels of CYP with autism under 18 being hospitalised. Some primary data had been collected however this was considered to be insufficient to identify specific need for individuals. A more comprehensive data system was suggested to gather more detailed information, for example information on how many of those children self-harm and to identify other associated factors and a need for scoping to work out how to fill in the data gaps.

With reference to Kate Oulton's study further development and testing of robust LD screening tools and risk assessment tools in hospitals was also suggested as an area to research along with the evaluation of LD nurses. The need for more LD provision, development, training and understanding of LD in general in hospitals was also highlighted.

Following the current research reported by Jon Spiers from Autistica on anorexia and suicide in autistic populations it was noted further research was needed in both these areas. Large numbers of autistic people are being admitted for eating disorders which include anorexia. The attendees identified further understanding is needed of contributing factors to anorexia and to research ways into tackling the decrease of anorexia diagnosis and eating disorders. It was also noted that services should review their pathways for CYP with anorexia using the outputs from the research reported.

There is also emerging research on autism and suicide and it was suggested that services should be kept up to date with any emerging research. The development of assessment tools to accurately account for the risk of suicide in autism populations was also considered ready for research along with researching links to suicide with specific experiences of trauma. We know there are also many people with LD inappropriately admitted to

Assessment and Treatment Units (ATUs). The stories of abuse in ATUs and provision and support for individuals and families after trauma in ATUs were also noted.

The current research reported on suicide and mental health conditions such as anorexia and anxiety in our population generated much concern. Anxiety is often seen as part of learning disability or autism and therefore the appropriate support is often not being accessed. It was noted TCPs should be addressing better identification of mental health in our population and addressing their needs as deterioration in mental health can also often lead to the risk of behaviour that challenges such as self-harm.

When discussing mental health provision for autism and LD it was suggested joining up The Improving Access to Psychological Therapies (IAPT) programme to LD. It was also suggested that it is often unclear where people with autism go for mental health services, as autism diagnosis may exclude or hinder people from mental health support. On the flip side to this there was also concern about the levels of admission into the forensic mental health system, and that non-diagnosis of autism and LD can lead to further admissions and further risk of behaviour that challenges to others. It was also noted this can then lead to an increase of CYP ending up in the criminal justice system. Questions were also asked on how we prevent admissions into the forensic system and the suggestion that there is a gap in the research here.

With reference to the current research into epilepsy and autism this was also an area briefly discussed. There is an issue of exclusion of people with autism in treatment trials. Researching patterns of anti-psychotics were considered a possibility to further research to explore links with anti-psychotics and epilepsy.

The attendees also reflected on the issues highlighted by Anne Pinney's report. Concerns were raised at the lack of quality and accuracy of data from independent residential and special schools on pupil level data on behaviour that challenges. There were also concerns expressed on the impact this has on accurate data for local authority dynamic risk registers. The distinction in definition between BESD, SEMH and the definition of behaviour that challenges is not made. Researching the differences in language and terminology used across services was also discussed, and the development of a more accurate system to collect pupil level data was also suggested.

Anne also reported the increase of children with multi-sensory and complex needs with a primary need of autism in residential special schools. Anne suggested that there could be a possibility that the trend in autism is obscuring the data on other needs of those children. It was noted by the attendees that this is still a neglected area of research with the exception of the Tizard project (Magill, Tennyson & Cooper, 2005); and more detailed data and research is needed in order to understand exactly what's happening regarding behaviour that challenges and complex need in our population, and exactly which children with LD are in residential schools.

Although the school census data has provided some useful primary data this is not sufficient to provide the full picture to establish the exact needs for these children. It was also agreed that more professional development and training for generic SEN needs and in particular specific complex conditions is needed. Independent scrutiny of Education and Healthcare (EHC) plans was also discussed.

The improvement of services to enable CYP with disabilities to stay at home and to improve transitions from home to residential placements if this was not possible, was another issue raised. CYP have the right to schooling in their community. Lack of placements nearer to home to facilitate frequent family visits was flagged up as a common problem along with the need to establish which CYP with what specific needs are out of area, and the reasons why. For example there are many teenage boys in residential schools and homes.

The transitioning of CYP to adult services was also raised. It was agreed that identifying and removing barriers concerning transition and formulating person centred co-ordinated plans across health, education and social care with the development of conceptual models of support and training (such as functional communication training) ; this could help families cope at home and most importantly help to increase the inclusion of adults and CYP with LD and/or autism in their community and enable them to participate in social groups and mainstream services such as youth clubs and leisure centres and maintain relationships with others. This would then improve their overall quality of life and the quality of life for their families.

A research gap was also identified around family experiences and the understanding of parent tipping points. We need to know how we address this and prevent crisis. What is it that makes the situation overwhelming and how to define 'not coping' or demonstrate 'coping'. Risk factors for crisis were suggested as an area to research; for example social factors and social deprivation and lack of access to support. Listening to families and understanding how information overload can affect them was also an area suggested to research. Concerns were also raised over the lack of research of parents and siblings of CYP with disability and how their mental health needs are met.

The research demonstrates that prevention by early intervention works (e.g. Stepping Stones & Incredible Years programmes) and that there is help out there for early intervention with behaviour that challenges (E-PAtS & PBS), and that commissioners should risk stratify their populations of children with LD and/or autism and provide early intervention like this to reduce the future risk of behaviour that challenges.

It was noted that it is often problematic accessing and making this provision available. The attendees agreed that prioritising the dissemination of research and intervention and getting information out there to families and other services was the next step forward.

It was also commented that there are lots of projects going on and information to be had, but it presently doesn't feel like there is any co-ordination of this and that families and services don't really know about it. The suggestion of a platform such as a research and practice forum as part of a much bigger framework to disseminate what is achievable and available for CYP with LD and/or autism was discussed. This would ensure services across education, health care, social care and families in communities are informed and that the right services can be accessed.

It was also agreed that identifying, observing and learning from reports from residential homes or special schools and particular individuals with particular skills or qualities that demonstrate best practice can greatly benefit CYP and families. In a sense this keeps it 'real' by showing what can be achieved and is being achieved with the right support and knowledge. The information can then be passed on to commissioners and families to influence strategy and policy.

Autism diagnosis is often needed for families just to access early behavioural interventions and benefits, even though the need is still there regardless of diagnosis. It was agreed early identification will help in the long run, but dealing with labels is not giving us a clear enough picture. There is a need to know why we are seeing characteristics of autism and research what's associated; for example social deprivation and cultural differences. TCs should be addressing individuals with LD or/and autism that may not always be known across services (for example traveller children). There are lots of other things we need to know as diagnosis doesn't provide specific enough levels of need or support. Support is presently generic and not provision specific to individuals. By identifying needs earlier the right support can be provided and prevent the possible risk of behaviour that challenges.

It was also noted that there is a huge variation of people doing the identification and looking at the symptoms. It was agreed there is a need for assurance that CYP are getting the right identification and provision and we have knowledge of who is doing the labelling.

Diagnostic overshadowing was also raised. Overshadowing is where health professionals wrongly presume that present physical or mental symptoms are a consequence of LD or autism. This then becomes a barrier to proper evaluation that anyone without disability would expect. This can lead to very poor outcomes such as behaviour that challenges and even lead to premature death in some cases.

Non-diagnosis of LD or/and autism in teenage girls was also highlighted as an area to research. Teenage girls are often left undiagnosed in the system and tend to mask autism well. There were concerns raised that this may lead to social isolation, self-harm and mental health issues.

The recurring issue of funding more research, and the cost of good research provision was raised and it was agreed that there were also questions around the spending culture that

need addressing. It was decided that there is a need for a coherent financial strategy to meet the range of costs. It was suggested that a good financial model could encourage more cost effective interventions and early intervention. There was also a suggestion that the DfE and the Department of Health and Social care (DHSC) could split funding for research and intervention.

Essentially it was agreed there is a need to close the gap between research and practice and to conduct more RCTs. However issues such as cost and lack of capacity in the workforce in the research community are big problems that need addressing and we need to find ways to tackle this.

There were lots of gaps identified concerning LD and/or autism and ethically this is a huge issue. The Lenehan review (2017) states CYP with LD, autism or both have a right to live valued lives, and concerns were raised on the inequality of provision for our population. Discussions focused on the demand for research measure quality of life and the impact of intervention on the lives of people and their families living with LD or/and autism across many areas of need.

It was also suggested that by national data scoping we might improve on the current data and use this to inform commission of services. It is clear from the evidence that current existing data systems are not good enough; until they are we can't access accurate data to help inform research.

Implications for Local and National Implementation

The attendees split into three groups to discuss implications for local and national implementation and implications for future research.

Seminar attendees agreed that a strategy and implementation framework to share and capture research needs and to disseminate the most impactful evidence-based research findings now was a key priority, both locally and nationally.

The implementation framework should be designed as a tiered approach to connect everything that includes intervention and dissemination to parents and families and across education, health and social care services, with a higher level framework that looks at research. CYP and families should be involved with every aspect of development and planning for the services that should be available to them, and to have the option of commissioning their own care to tailor for their own specific needs. The implementation framework will help to achieve this.

We have the evidence base for early intervention for children with LD and/or autism and we know the importance of short break provision for families to recuperate and that it works. The framework can enable this and assure us that we know right outcomes are being provided, and that there is accountability in the system. Commissioners can then plan

strategically in the community and feedback to researchers. It was also suggested that a proposal should be made to The National Institute for Health and Care excellence (NICE).

The general opinion was that by sharing research and evidence heard in the seminar, and sharing best practice and improving services with the help of experts, we can utilize those key messages to disseminate and drive agendas. It was agreed that the steering group will take this forward.

It was also agreed that there was a need for a platform for sharing information to all and to create closer connections with families and researchers. This helps to ensure families are more informed about research evidence and emerging research evidence and what it means for them.

At the moment there isn't a standard baseline for the minimum amount of support you would expect to receive for your child (e.g. clinical psychologist, behaviour support team, and speech and language therapist). Families don't always know what's possible for their children; by sharing the research and creating a forum or network they can then see what's possible and also see what's available and find out how they can access services. However, services are not always available currently; therefore we need a solution on how to tackle this.

Concerns were also raised about losing the integrity of intervention in delivery such as issues with gaps in provision, commissioner issues, workforce capacity issues and finding solutions to this. It was suggested the voluntary sector could possibly help to fill in the some of the gaps.

It was also agreed that we can do so much if we all work together and learn from research, case studies and best practice. By sharing when implementation happens well and looking at the characteristics and people applying those skills practiced well, (e.g. people who are great at making relationships with staff and CYP or implementing particular skills with CYP) we can make it real and make a difference. The groups agreed we need to know more about this process.

The groups also raised the issue of identifying barriers to family support and that families don't get the right amount of support or training at home due to it being a very personalised model at home. We need to find ways to tackle the delivery, cost and the capacity to provide this and assess the quality of any current personalised support. The lack of local family carer groups was also noted.

The issues of autism diagnosis were also considered a national problem. There are limited services to diagnose autism and a lack of workforce nationally to deliver timely autism diagnosis which has a huge impact on families gaining access to services.

Key priorities were better physical and mental health provision. It was also highlighted that there is a lack of local strategies to access physical health provision for our population, and financial provision and more support is desperately needed for the improvement of CAHMS Tier 4 provision.

Other key local priorities were: the right to effective educational support with proper connectivity between TCs and the education system; early intervention and prevention; improved post 19 provision; and focusing on quality Care, Education and Treatment Reviews (CETRs) to ensure CYPs needs are met.

Figure 1: Implementation Framework
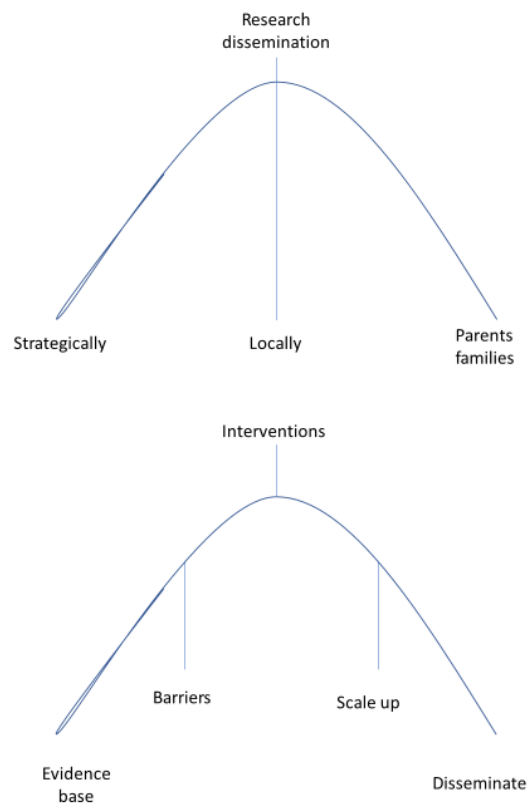
Implications for Future Research

Summary of implications for future research

- An NIHR commissioned call on learning disability and autism (similar to the recent call on dementia) would help to give this area the priority and funding it deserves and to increase research capacity

- The group proposed a large scale RCT to focus on interventions; the range of factors which affect children's lives; and outcomes. The design could draw on some of the new USA methodologies. Significant development and feasibility testing would be required with user involvement in the design from families and young people.

- A longituidinal cohort study could address a number of the research gaps, including a focus on medication and the impacts on behaviour of early intervention.

The group discussed and agreed that there is a need for a large scale RCT that will focus on providing intervention for children with LD and/or autism whose behaviour challenges and will focus on the outcomes from this study. The group discussed their initial thoughts on the features of the trial.

The four broad areas that should be considered are:

1. Is there a distinction between severe and complex learning disabilities and autism and milder levels? Are their issues different? Is that distinction more relevant in terms of service response than the distinction between learning disability and autism? Who to target for interventions and who gets more intervention support.
2. How to target? How you measure outcomes and the models you apply. Risk stratification and how this is linked to commissioning.
3. How to organise and deliver good services for this group. Good evidence is required. We have service models but do they work? When you reflect on the evidence base they all fail to deliver on how we deliver services, how do we organise and best deliver services?
4. Outcome measures should draw on some of the better RCTs. What makes good implementation? Going that extra mile. What makes it really effective?

Research priorities should have a broad holistic and integrated approach that looks at all the factors that affect CYP lives. Research should also include what works and why it works and a range of outcome measures.

Significant work will be needed developing and feasibility testing before implementing such a trial. Children and families should be included in its development and it should look at whether interventions are delivered at the right time in the right way.

Research should also draw on some of the new RCT designs from the USA and learn from their experiences there.

The impact of different interventions and child and family outcomes would need to be studied over a suitable period of time.

Early Intervention
The group discussed the case for early intervention for our population of children from a research perspective. The case is similar to that made by early intervention in psychosis. Early intervention can lead to better outcomes and quality of life; however it does not mean that other support needs will be less for children with severe learning disabilities or autism. It was felt that there were some misconceptions surrounding this.

Behaviour that Challenges
Research evidence has already given us enough information to enable monitoring of risk factors for behaviours that challenge. This should be used to develop a tool to identify risk factors that can identify known "flags" and that can review and take into consideration child, family and environmental factors.

Longitudinal Study
The group discussed the need for a longitudinal study. The group wanted to see a NIHR programme grant focussed on children with learning disabilities, autism and behaviours that challenge and a longitudinal study of this group.

The Medical Research Council (MRC) was previously going to invest in a cohort study of children with LD but it only focussed on biological issues. There was a call for an urgent review of the latest medication research, looking at the pharmacological responses of different drugs following questions raised by the STOMP data. The STOMP project looked at stopping over medication of people with LD and how the use of drugs for mental health affected them.

Research should look into the use of these drugs (e.g. risperidone, aripiprazole) and looking to see if there is a link to mental health issues such as anxiety. Is uncertainty being treated as anxiety? Only further research will tell us the answers.

Identification of gaps

Data

- Behaviour that challenges. Language/terminology definition defined across services. BESD, SEMH distinction made. Research into definitions.
- Quality and accuracy of pupil level data on behaviour that challenges in residential and special schools/homes
- Establish who exactly are out of area and why? Why so many teenage boys in residential?
- Is current data accurate enough for the dynamic risk registers?
- Research to improve data collection system for pupil level data.
- Improving data systems for national data. National data scoping.

Research

- More detailed information/data on individuals with learning disabilities/autism who are hospitalised.
- Independent scrutiny of EHC plans
- Research on the mental health of parents and siblings of CYP with LD or/and autism
- Research of contributory factors leading to anorexia e.g. sensory issues?
- Why large numbers of autism in eating disorders?
- Development of assessment tools to assess risk of suicide in autism
- Trauma experiences linked to suicide?
- Evaluation of LD nurses in hospitals
- Is trend in autism obscuring data? Why increase of children with multisensory complex needs in residential special schools? Which children with LD are in residential settings? More detailed data and research. Existing primary data does not provide the full picture.
- Autism research into epilepsy. Anti-psychotics link?
- More research into one or more additional disorders in autism
- Research of what's associated with autism to establish levels of need and support
- Research into why teenage girls are not being identified and diagnosed

Implementation Gaps

- Improvement of mental health services for LD and autism. Better mental health identification. Clear on where to go to get provision for mental health.
- Better physical health provision locally
- Financial arrangements and more support for replacing CAHMS tier 4 provision with local support
- Staff training for healthcare staff
- LD provision in hospitals
- The development of more robust screening and risk assessment tools in hospitals
- Use of current research study reported by Jon Spiers to review pathways for CYP and Anorexia

- Professional development and training for generic SEN and in particular complex conditions and needs
- Improvement of services to enable CYP with disability to stay at home
- Improvement of transitions from home to residential if this is not possible
- Nearer placements to home
- Identify and remove barriers of young people transitioning to adult services
- Formulate co-ordinated plans for adults and CYP across health care, education and social care.
- Develop conceptual models of support and training for inclusion for our population in the community
- Research gap around family experiences and understanding tipping points
- How to address and prevent crisis for CYP and families
- Defining and researching 'coping' and 'not coping' what does this look like?
- Research into how information overload may affect families
- Research into parents and siblings of CYP with disability how their mental health needs are met.
- Remedy issue of possible loss of integrity of intervention (e.g. gaps in provision, commissioner issues, workforce issues)
- Increase access to preventative early intervention
- Dissemination and demonstration of best practices in schools, homes and of standout individuals that demonstrate particular skills and qualities. Research more about this process.
- Tackle national issue of services for autism diagnosis and workforce in this area. More timely diagnosis of autism nationally
- A need for assurance CYP are getting the right identification and provision
- Addressing the issue of diagnostic overshadowing
- Identifying barriers to family training and support
- Family training opportunities and how to tackle this as it is a very personalised model at home
- Review the capacity to provide family training
- Review the cost of family training
- Lack of family carer groups
- Better educational support and connectivity between TCs and education system locally
- Focus on quality of CETRs
- CETR experiences-diagnosis of LD after admission
- Safeguarding

Sharing the research with those who need to know

- Co-ordinated dissemination of research and intervention
- Development of a implementation framework locally and nationally
- Dissemination of the most impactful evidence based research findings NOW.
- Platform for dissemination such as a research and practice forum
- Proposal to NICE.

- The TC CYP steering group to take forward the research evidence from experts in the field heard in the seminar to drive action
- Making sure TCPs are aware of the economic data

__Future research__

- Funding for research and the cost of good research provision
- A need for a coherent financial strategy to meet the range of costs
- Closing the gap between research and practice
- More Random Controlled Trails (RCTs)
- A need to tackle capacity in the workforce in the research community
- Research to focus on measuring quality of life for CYP and families living with LD and/or autism across areas of need