COUNCIL
FOR DISABLED
CHILDREN

CDC Digest

Spring 2023

Dear all,

As we start a new financial year, we are able to have some space to explore our priorities.

We have recently completed our work supporting the Child Safeguarding Review Panel with the phase 2 report on Safeguarding children with disabilities and complex health needs in residential settings.

The review includes important recommendations into making sure that where children can live at home and families can be supported locally, this happens and that once some children need to go into residential settings, they are safe and have the best outcomes. This work would not have been possible without significant input from CDC members. A particular thanks to the Challenging Behaviour Foundation who supported CDC and parents through the process. Although the report is complete, the next stage of ensuring recommendations are implemented is key.

We are also working more broadly with the Department for Education on the implementation of the SEND and AP improvement plan and have begun to talk to a number of you about Education, Health and Care Plan templates, including members of our young people's advisory group. As the process rolls out, we will do our very best to keep you involved.

Our work on the RISE programme which supports improvements in local areas has also been reviewed. It is clear that the biggest challenge in local systems is about capacity and that we need to continue to report this and work with you on ways which support change which is possible, meaningful and makes a real difference.

Take care, remember we are all working for the best possible lives for the children and families who are at the heart of all we do.

Best wishes,

Dame Christine Lenehan

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Council for Disabled Children Updates

Health

The Health team have been continuing to deliver the Department for Education (DfE) funded RISE programme to local areas across the country. In 2022–23 we supported 23 local areas through 224 days of support (across CDC and NDTi), developed 2 new e-learnings, and designed and delivered a training package of a total of 50 sessions on Data, Voice and Commissioning, Social Care, SEND and Co-Production, and Preparing for Adulthood – Post 16 Pathways. 1119 people registered to attend these sessions and attendees across all sessions felt they were likely to use the tools shared in the training in their daily practice.

If local areas would like support through the contract, please speak to your SEND Adviser or Case Lead, or contact Philippa at CDC directly (pwatts@ncb.org.uk). CDC can also be commissioned directly if your area is not a DfE priority, please contact Sam (sgomarsall@ncb.org.uk) for more information.

We have also been working with NHSE Midlands, researching how effectively Liaison and Diversion services and Young Offender's Institutions in the area are identifying and supporting children and young people with a learning disability and/or autism.

In March, the team ran a national webinar on journeys from CCGs to ICBs. You can view the presentations and workshop recording here.

Social Care

The Social Care team have been busy delivering a series of flex days projects for the DfE through the Strategic Reform Partner contract. This has included an in-depth literature review on techniques and interventions to identify and support children and young people with social, emotional and mental health needs and communication and interaction needs for the DfE's policy development for new National Standards.

We have also published four learning examples to showcase reflections from local authorities participating in Year 1 of the Short Breaks Innovation Fund. The learning examples explain how local authorities developed their approach to support disabled children and young people. You can read more about these learning examples on page 11.

Special Educational Consortium (SEC)

With the start of the new year came the appointment of a new policy vice-chair, following Philippa Stobbs' (co-founder of SEC and SEND champion) retirement in December. Daniel Stavrou took the helm and submitted a response on behalf of SEC to the persistent absence and support for disadvantaged pupils' consultation soon after his appointment (see SEC's response here). Daniel, supported by the NCB policy team and SEC Secretariat, attended an Education Select Committee session on the SEND and Alternative Provision Improvement Plan in March. Daniel's response on behalf of SEC was robust, backed up by a wide range of evidence, and he ensured that children were at the forefront of the conversation. You can watch the full debate here.

Early Years SEND

The EYSEND Partnership has carried out a series of training, national seminars and events to bring together key stakeholders in the Partnership and celebrate the successes of the work undertaken this year. The main highlight this quarter has been the regional events that took place in March. Three in-person/hybrid events were held in Leeds, Birmingham and London, bringing together 200+ representatives across SEN, disability, early years and education sectors to carry out the collective aim of improving access and inclusion for disabled children and children with SEN in the early years.

During the events, delegates heard from guest speakers covering a range of topics and were able to participate in a number of workshops. We had speakers attend from Ofsted, the Office for National Statistics, Ambition Institute, University College London and the University of Huddersfield, presenting on a wide range of topics from organisational culture to improving mathematical outcomes for pre-schoolers with SEN. Our afternoon workshops were run by the six EYSEND Partners who co-presented with local authorities. Workshop discussions ranged from co-production and parental engagement to ordinarily available provision. To find out more about the events, including recorded presentations, see the website here.

The Information, Advice and Support Services Network (IASSN)

The IASSN have been focused on report writing, reorganising and developing resources and planning our suite of training for next year.

We have published and shared our Data Report and our Service User Feedback and Ofsted Report. Both reports highlight the challenges and pressures SENDIAS services face, but also the hugely positive work they do. Both reports also include an expert foreword by the IASSN children and young people's steering group. We have also started our survey of SENDIAS services to review our work and to support in planning for the year ahead by exploring training, resource and support needs.

Feedback from current training is overwhelmingly positive with 94% of those that responded feeding back that the training improved their knowledge.

Participation

Participation have been busy continuing to deliver the Making Participation Work programme, supporting children and young people and practitioners to further embed and direct strategic decision making for all. In February we held our incredible annual Youth Voice Matters Conference for children and young people, more on this on page 7. In March we delivered another national Practitioner's Conference, which was an effective learning opportunity for practitioners and managers from across education, health and care. There were a variety of youth-led and professional-led workshops receiving fantastic feedback from our delegates, as well as a plenary session from the DfE. You can register for the next Practitioner's Conference here.

The FLARE group also held two roundtable meetings with Minister's Coutinho and Caulfield, focussing on a number of important issues, including a truly accessible curriculum, effective pastoral wellbeing support and the limited aspirations professionals continue to have for students with SEND.

We also continue our work supporting the national evaluation of the keyworking programme. We are speaking to children and young people and their families across England, finding out their experiences of being supported by a keyworker, what difference they feel it may have made, and what they would like to see next for the keyworking programme. This qualitative data will significantly contribute to the evaluation materials. The evaluation will continue throughout this year, and we look forward to sharing with you the experiences of children and young people and their families. If you would like to find out more about the keyworking programme and who it is supporting you can read NHS England's update here.

A postcard from Sofia

Philippa Stobbs

The meeting in Sofia was only the second face-to-face meeting of the European Agency for Special Needs and Inclusive Education since the pandemic. There was still excitement about holding a face-to-face event and this was evident in the exchanges during the main sessions, in the more informal discussion groups and in the margins of all the organised meetings.

The main sessions always provide significant updates on current Agency projects. Projects usually run for two years, plus or minus and the meeting in Sofia gave us updates on projects that are just getting underway, progress reports on projects that are in full swing, and final reports on projects that are just concluding.

One of the final reports that has now been published is on the Changing Role of Specialist Provision in Supporting Inclusive Provision (CROSP) – as with all the Agency projects, an unwieldy full title, but a snappy acronym. At the last bi-annual meeting of the Agency, in Athens, we had spent some time discussing the review tool that had been developed in conjunction with the CROSP project. At the time, I had been struck by the strong framework of values and by the clear links made in the Agency materials, between the values and the more practical actions needed to realise those values. It seemed to me that, with a clear set of principles set out in Section 19 of the Children and Families Act (CFA), there were important messages for us about translating a framework of values into practical action.

One of the principles in s.19 of CFA focuses on:

"The importance of the child and his or her parent, or the young person, participating as fully as possible in decisions relating to the exercise of the function concerned."

The function concerned refers to functions under Part 3, the part of CFA that covers children and young people in England with special educational needs or disabilities. This principle sits at the heart of one of the Agency projects, the Voices into Action (VIA) project, for which we got a 'progress report' in Sofia. The work started in 2021 and examines the critical issue of how the voices of learners and their families are heard and more specifically, how learners and their families are included in decision-making. The project aims to promote a more participatory culture at local, regional and national levels and chimes nicely with our s.19 principles.

Phase 1 of the work included an analysis of the literature on effective involvement and the collection and analysis of examples of effective practice from member countries. Phase 2 started in 2022 and will conclude with the publication of the final outputs in 2023. The work has involved 'cluster activities' including workshops with representatives from three Agency member countries working with learners and families nationally to identify the essential elements of meaningful participation. The Agency regularly includes practical tools to support the implementation of the findings from projects and the VIA outputs will include an online toolkit.

In the words of the Agency:

"VIA outcomes will help the Agency staff, as well as Agency member countries, find inspiration for organising relevant activities with learners and/or families. They can use the outputs to ensure the meaningful participation of learners and families in their future work." – **European Agency for Special Needs and Inclusive Education**

The literature review is now published and is on the Agency website. It summarises important European and international policy information on the topic and sets out key research knowledge from the past 20 years.

Despite some impressive examples, including examples we submitted from England, the analysis of the literature highlights the patchy nature of effective participation across Europe.

From the recognition of children as agents to their effective enjoyment of this right, it has taken over 30 years of reiterated policy work and school practices. Children's rights to be heard and considered in matters affecting them extends to ALL children. However, even though European Union countries have ratified and signed legally binding treaties/charters that state and protect children's rights, this is not granted or systematised yet.

The Agency has started work on the toolkit to support the more systematic inclusion of learner and family voices in decision-making. In the final report, the toolkit will sit alongside existing theoretical models for learner and family participation, key principles and examples collected from member countries in phase 1. The whole package is designed to highlight important considerations for involving learners and families more systematically in educational decision-making at all levels.

Given where we are with the SEND Review, this is an important moment for us to consider how improved participation in decision-making could better support the implementation of the intentions of CFA. The recent Office for National Statistics (ONS) report on the educational experiences of young people with SEN and disabilities suggests that we have not yet personalised our responses to young people's special educational needs and disabilities in a way that recognises the wide variety and individual nature of those needs:

"A recurrent theme from young participants, parents, carers and staff was that a "one-size-fits-all" approach to support does not work when young people's needs and preferences are so varied."

The Agency's work acknowledges that every learner has their own unique experiences of discrimination and/or barriers to learning and that learner and family participation in decision-making is a key ingredient in meeting individual needs more effectively.

On the evening of the full day of the Agency meeting in Sofia, the Bulgarian government treated national representatives to a traditional Bulgarian evening meal in a restaurant in the mountains just outside Sofia. Along with the meal, which was of massive proportions, there was entertainment with a traditional band, traditional singing and traditional dancing. After the meal we were invited outside to watch Nestinari, dancing barefoot on red hot coals, traditional in Bulgaria and parts of Greece and Turkey.

It was quite spectacular. Initially, there was ritualistic preparation of the coals, with beautiful patterns created by the raking and turning of the coals in the cold dark night. Then the dancing began, with the dancing partners gradually increasing the speed and intensity of the dancing. Finally, a few members of the audience were carried across the red hot coals as the partners continued to dance.

I am not particularly seeking a metaphor here for the next steps in the SEND Review, just seeking to convey something of the spectacular nature of the end of the evening. And, on a personal note, as I step into retirement, an amazing end to my last meeting as National Coordinator for England with the European Agency.

Wish you were here!

Philippa

Council For Disabled Children Annual Youth Voice Matters Conference

On Thursday 16 February, More than 100 disabled children and young people and/or those with special educational needs came together to take part in our annual Youth Voice Matters conference.

The national conference is co-developed and co-delivered by FLARE, the young SEND advisors to the Department for Education. The event, delivered as part of our Making Participation Work programme, provided attendees with the opportunity to build on their participation skills, develop their voice and feel empowered to participate in decision-making at a local, national and strategic level.

At the start of the conference attendees watched a video by the Minister for Children, Families and Wellbeing, Claire Coutinho MP who said: "To support a culture of inclusion, we need to deliver improved mainstream provision with prompt access to targeted support where it's needed."

Young people had the option to take part in workshops throughout the day which covered a variety of important topics. FLARE members Carys, Louise, Pavan and Jonathan and NCB Trustee Bethan, delivered a workshop on using social media for advocacy. Participants learnt about the different social media platforms available, the impact young people can have online and how to create accessible and engaging content.

In a separate workshop, FLARE members Jacob, Rowan and Sam led sessions on how to get the right education support, where participants were taught about their rights and discussed the best ways to overcome challenges in their education.

KIDS delivered a workshop on co-production; Young Minds spoke with attendees about the importance of looking after their mental health; and the Council for Disabled Children delivered an interactive session on the future of the SEND and Alternative Provision system.

In between workshops, children and young people had the opportunity to make friends, take selfies in the photo booth, look at our visual minutes and take part in news-style interviews with our young roaving reporters Jacob and Sam. Watch the roaving reporters here.

Feedback from the day included:

- *"Too often disabled young people have been made to feel voiceless and powerless. Youth voice does, will and always should matter".*
- *"I had an amazing day sharing issues SEND people face on a daily basis so thank you for giving me the opportunity to share my voice".*

If you would like to find out about future events and other opportunities from the Making Participation Work programme you can register for the Making Ourselves Heard Forum here.

If you would like to find out more about how young people got involved on the day you can read FLARE's blogs here.

You can read Dame Christine Lenehan's reflections on the conference here.

Phase two report published on abuse in residential special schools in Doncaster

On Thursday 20 April, The Child Safeguarding Practice Review Panel published the phase two report on safeguarding children and young people with disabilities and complex health needs in residential settings. This follows the phase one report which was published in October 2022.

The phase one report highlighted appalling standards of care and failings in oversight in three Doncaster residential homes: Fullerton House, Wilsic Hall and Wheatley House – operated by the Hesley Group.

The catalogue of abuse suffered by the disabled children and young people living in these homes has been harrowing for even the most experienced social care professionals to review.

Today, we have the second report from the Panel which draws on the learning from what happened to those children and sets out a case for change in the quality, oversight and regulation of all residential settings for children with disabilities and complex health needs.

With an ongoing criminal investigation still underway, the Child Safeguarding Practice Review Panel has revealed:

- A culture of abuse and harm, including evidence of physical abuse and violence, neglect, emotional abuse and sexual harm.
- Evidence that medication was misused and maladministered.
- An over-use of restraints, and unsafe and inappropriate use of temporary confinement.

The leadership and management in the three settings was inadequate and actively concealed incidents of abuse from authorities. When there were complaints and concerns about the settings from whistle-blowers and parents, these were not sufficiently brought together by authorities. Therefore, the safety net that should have protected the children was ineffective.

The recommendations urge government departments to work together to transform the education, health and care offer so that children with disabilities and complex health needs thrive and are supported to achieve.

Dame Christine Lenehan, Director at the National Children's Bureau and Council for Disabled Children said:

"The appalling harm these children suffered was a result of grievous failures in both their day-to-day care, and within the system of oversight that should have guaranteed their welfare.

"We've been here before. Earlier reports have catalogued how disabled children with a complex mix of autism and health needs can be locked away behind closed doors, often in placements far from their families, with little concern for their quality of life or futures.

"These recommendations set out a roadmap to more humane treatment of these children. But without the wholehearted commitment to implement these measures fully, these failings will come back to haunt us when the next group of disabled children fall foul of services that cost the taxpayer dearly but rob vulnerable children of their basic humanity."

Annie Hudson, Panel Chair said:

"There was widespread public shock and distress when we published our initial findings about the extremely disturbing neglect, abuse and harm experienced by a large number of children with disabilities and complex health needs living in residential settings run by the Hesley Group in Doncaster.

"However, despair and shock are never enough and will not address the fundamental and systemic problems that contributed to the children's unspeakably distressing experiences, over an extended period, in environments that should have kept them safe.

"Today's report draws on the learning from what happened to those children to make national recommendations that must be secured so that this very vulnerable group of children thrive, are safe and enjoy the rights that every child should be able to enjoy."

Dr Susan Tranter, Lead Panel Member said:

"The stories of the abuse that children at Hesley-Doncaster suffered are dreadful and harrowing.

"This review has highlighted an acute need to do things differently, not only to prevent this repugnant story from being retold in another setting, but also to transform the education, health and care offer for children with disabilities and complex health needs.

"We are recommending measures to ensure the care of children with disabilities and complex health needs is more joined up across education, health and social care.

"Additionally, we are urging Government, Ofsted and the CQC to ensure there is a major overhaul of the arrangements for quality assurance and regulation of residential settings to help prevent abuse but also that when there are complaints or concerns, action is swift and purposeful."

Recommendations

The Panel is making nine recommendations for government departments, inspectorates and NHS England that aim at ensuring children with learning disabilities, autism and complex health needs have the support they need to thrive.

These include:

- The Department for Education and Department of Health and Social Care should develop statutory guidance to require local authorities and integrated care board (ICBs) to jointly commission safe, sufficient and appropriate provision for children with disabilities and complex health needs.
- The government should commission an integrated strategy for the development of the children's workforce in residential settings. This should include training on the appropriate use of physical restraints and restrictive interventions and their authorisation.
- The government should ensure all children with disabilities and complex health needs have access to independently commissioned, non-instructed advocacy.
- Systems for the early identification of safeguarding risks in residential settings should be strengthened through an enhanced role for host local authorities and ICBs in the oversight of residential settings in their area.
- The Department for Education and Department of Health and Social Care should revise the regulatory framework for residential settings and immediately establish arrangements for joint inspection by Ofsted and CQC of residential settings for children with disabilities and complex health needs.
- National leadership and investment by providers is urgently required to address the longstanding challenges in recruiting, retaining and developing a skilled workforce is residential settings.

If you suspect or know that abuse of disabled children and/or young people has taken place please visit the Council for Disabled Children's dedicated webpage developed in partnership with the Challenging Behaviour Foundation here.

Council for Disabled Children

Short Breaks Innovation Fund Learning Examples

The Short Breaks Innovation Fund consists of £30 million designed to support local authorities to establish new Short Breaks services via innovative projects.

This three-year programme (2022–2025) is helping to improve health, education and well-being outcomes for children and young people with SEND and their families. It aims to address gaps in current Short Breaks services, reduce pressures on High Needs and other budgets, and inform future structural reform and service design.

Year one of the programme saw £5 million awarded across seven successful bids from local authorities (and their consortium partners) from across England. The projects support children and young people with a variety of needs and conditions, including learning difficulties and complex needs, to access Short Breaks services closer to home, targeting support where there is unmet need and creating positive opportunities for children and young people.

In our role as Strategic Reform Partner to the Department of Education, the Council for Disabled Children has collaborated with local areas from year one of the programme to create a series of learning examples. These examples set out how local authorities have worked with their partners to plan and implement innovative Short Breaks provision and showcase the difference their projects are making to the lives and outcomes of children and young people.

The learning examples in this series include:

- A motivational coaching programme with young people with SEND and/or SEMH needs
- A transition group to develop the independent living skills of young people with SEND
- A project to support young people with SEND and complex needs to prepare for adulthood
- A short breaks provision for children and young people aged 6 – 18 years with social, emotional and mental health needs, Autism and learning disabilities.

Each learning example contains useful reflections on how local authorities went about developing their approach in different contexts, to ensure each intervention was person-centred, prioritised the relationship between the young person and the practitioner, and was supported by effective multi-agency collaboration.

You can view the learning examples here.

Council for Disabled Children

New guide for parent carers and professionals on effective conversations around use of medication

The Council for Disabled Children recently carried out a project funded by NHS England to support the appropriate use of medication for autistic children and young people and those with a learning disability.

We know that too many children and young people are receiving medication that is not right for them and parents can feel unsure about the right options of their child, including non-pharmaceutical interventions.

We spoke to both parent carers and professionals to identify the main areas of concern and what would improve communication and decisions about prescribing, using and reviewing medications for this group of children and young people. From these discussions, reviewing existing research and guidance and working alongside a parent carer with lived experience as a co-project lead, we co-produced a guide that set out clear messages and bring together existing resources to help parent carers and professionals understand each other better and make better decisions about the appropriate use and monitoring of medication.

"It's really important that all parents understand what we mean when we talk about 'medication'. That they know where to find clear information that is relevant to their child or young person and that they are able to be part of the conversation around prescribing medication. Parents aren't clinicians, but they know more about their child/young person than anyone so they have a wealth of knowledge and information that can help when decisions are being made." – **Parent/Carer Co-Researcher**

This project stemmed from NHS England's STOMP (Stopping The Over-Medication of People with a learning disability, autism or both) and STAMP (Supporting Treatment and Appropriate Medication in Paediatrics) campaign which was launched in December 2018 and aims to:

- Stop the over-medication of autistic children and young people and children and young people with a learning disability
- Ensure children and young people get the right medicine, at the right time, for the right reason
- Improve access to wider (non-medical) support that gives children and young people choice, control and a good quality of life

Two clear concerns emerged from the parent carer and professionals focus groups: that children and young people were being prescribed medication that they did not need and sometimes for the wrong reasons (for example to meet a 'behaviour' need rather than a health one) and that medication is being prescribed without clear information about its impact or how it will be reviewed.

The guide addresses these concerns by focussing on five key areas where effective conversations could make a difference. Within each section there are tools and downloadable resources and checklists that both parent carers and professionals can use to gather evidence and make decisions together in the best interest of the child or young person.

You can see the overview of the different sections below as well as some useful resources we have picked out:

- Why are conversations about medication more complex for autistic children and young people and those with a learning disability? – The importance of understanding communication, diagnosis, and exploring all support and treatment options. This section contains some useful resources such as a who's who list of medical professionals and teams and a medication 'jargon buster' to help explain some of the terms used.
- Parent and carers views about what works and doesn't work in conversations about medication – messages from parents and carers about the importance of being listened to and being given the right information. This section has a medication pathway resource and medication information leaflet that provides information for parent carers around medication, prescription and reviews.
- How to have effective conversations when medication is being considered – what do professionals and families need to understand during conversations about medication, in order to make good decisions. You can find a checklist in this section for both parent carers and professionals looking at what needs to be asked/ discussed before putting a child or young person on medication as well as some resources around communication needs/ passports, decision-making tools, legal handbooks and NICE guidance.
- How to have effective conversations when medication is started for the first time – what do families and professionals need to be clear about when medication is being prescribed. Checklist B in this section can be used to discuss points around dosage, storage, side effects amongst other things. It also contains medication passports, medication records and some free e-learning on medication.
- The importance of medication reviews and how to get the most out of them – when reviews should happen, who they might be with, and the aim and structure of the conversation. This section contains 'Checklist C' focussing on points around medication reviews as well as resources on monitoring side effects, quality of life and sleep diaries.

The above are only a few of the resources and tools that the guide provides for parent carers and professionals to have effective conversations around medication, to see the full guide please click here.

Council for Disabled Children

Resources and E-learning

SEND and Alternative Provision Improvement Plan Hub

Visit our SEND and Alternative Provision Improvement Plan hub for a range of resources to help you learn more about the plan. Resources include:

- An animation video
- Easy read version
- British Sign Language version
- A roadmap

Exclusion resources: Equality and Human Rights Commission

To support disabled pupils and pupils with special educational needs who have been permanently excluded from school, the Information, Advice and Support Services Network (IASSN) in partnership with the Equality and Human Rights Commission (EHRC) have published resources for SENDIAS practitioners to appeal exclusions.

Disabled Children and the Equality Act 2010: What teachers need to know and what schools need to do

This guide is designed to help teachers understand the legislation and how it applies to their work with disabled pupils. It draws on examples of practice that may amount to discrimination or that may help schools to avoid it.

Requirements to provide health advice within 6 weeks

The regulations which support the Children and Families Act 2014 place a duty on local authorities when carrying out an EHC assessment to obtain 'medical advice and information from a health care professional identified by the responsible commissioning body'. There is then a legal responsibility placed on NHS bodies to respond to requests for advice and information as part of EHC assessments within six weeks of the date on which they receive the request. This briefing sets this out in more detail, as well as specific points which apply in certain circumstances.

Improving outcomes for children and young people: learning examples

We have identified examples of good practice taking place to improve outcomes for children and young people. Learning examples in this series include:

- Newcastle's approach to effectively implementing the graduated response to SEN support in mainstream schools and settings
- Wakefield's approach to effectively implementing a bespoke supported internship programme; one of their pathways to employment.

E-learning courses

Register to complete our free e-learning courses. Our training catalogue includes the following courses:

- Holistic Outcomes in Education, Health and Care Plans
- Expert Parent Programme
- SEND Basic Awareness Level 1 and 2

View our e-learning courses here.

Council for Disabled Children

Making Participation Work Practitioners Conference

As part of the Department for Education funded Making Participation Work programme the Council for Disabled Children are delivering our next national practitioner's conference on Tuesday 13th June 2023. The conference brings together participation, co-production, engagement practitioners, and strategic managers to discuss how SEND youth voice and engagement plays a role in developing quality local area provision.

Making Participation Work's learning events are for professionals and practitioners designing and delivering participation and co-production at a strategic level across children and young people's health, education, and social care.

Attendees will select two workshops to attend from a variety of topics, and a plenary session, all focusing on giving participants more tools for engaging with children and young people with SEND. It will be a fantastic opportunity to connect and develop knowledge and skills. The event will be interactive and attendees will be able to contribute via discussion and online tools.

Workshops will be announced in the coming weeks, keep an eye out for an email inviting you to make your workshop selections using a Google Form, these will be allocated on a first-come-first-served basis.

Feedback from our past conferences includes:

- "The fact that this workshop was run by the young people it impacts was brilliant!"
- "Really good to have the chance to speak directly with those creating policy"
- "Fantastic session, very powerfully delivered by the FLARE members too. I found it highly effective and engaging and thought provoking for taking forward"
- "Helpful, informative and an opportunity to connect with people in similar roles".

If anyone is concerned about accessibility, engaging during workshops, or their computer skills please do get in touch so we can be mindful of access needs and inclusion.

The conference will be held online via Zoom. The deadline for registration is Monday 15th May 2023.

Register for the conference here.

Council for Disabled Children

FLARE Recruitment

The Council for Disabled Children are looking for disabled young people and young people with special educational needs (SEN) aged 12 – 18 years old to be part of our young people's advisory group FLARE. FLARE stands for Friendship, Learning, Achieve, Reach and Empower.

FLARE represents the views and voices of disabled young people and young people with SEN all over England. FLARE works together to share their views and experiences to help the Department for Education and other teams to understand how disabled children and young people and those with SEN want to receive the support and services they need.

Being part of FLARE will mean participating in 6 meetings a year and feeding back to professionals about how to make positive changes to improve things for all disabled young people and young people with SEN. These meetings are held in-person in London, and we will support the young people with their travel arrangements.

Find out more and access application forms here

The deadline for applications is Friday 19th May at 5pm.

National Children's Bureau

COACHES Study: Expert help wanted

COACHES (CAMHS Referrals and Outcomes for Adolescents and Children with Social Workers) is a four-year research collaboration between the University of Cambridge, Kingston University, King's College London, the National Children's Bureau (NCB), the British Association of Social Workers (BASW) and the Care Leavers Association, examining data from over 70,000 young people across two NHS trusts.

As part of their research, Cambridge University have put together a survey to understand types of mental health interventions offered in CAMHS. Robbie Duschinsky, Head of the Applied Social Science Group within the Primary Care Unit, and Director of Studies in Sociology at Sidney Sussex College, University of Cambridge, and his team plan to survey mental health researchers, mental health practitioners, social workers, and patients who have previously received mental health interventions in CAMHS – as well as their parents.

The team now have enough experts by experience signed up but would like to welcome more mental health researchers, mental health practitioners and social workers to take part.

The survey will have three phases, each including a different questionnaire. Participants will have two weeks to complete each questionnaire. The time required to complete the questionnaires will range between 10 and 60 minutes.

This survey is voluntary, and all data will be treated anonymously. The survey has received ethics approval from the University of Cambridge Psychology Research Ethics Committee.

You can find out more information and complete the surveys here

Contact calls for free school meals as 1/3 eligible disabled children miss out

Research carried out by Contact reveals that a third of eligible disabled children are unable to access their free school meal due to medical and sensory reasons. As a result, families are missing out on the equivalent of £570 a year of financial help. This comes at a time when every penny counts, causing some families to get into debt, increasing stress and making children feel left out.

85% families feel pressure on weekly budgets

1,500 families with disabled children eligible for free school meals took part in Contact's free school meals survey. In total, 471 (33%) told the charity that their children can't access their free school meal for a variety of reasons:

- 45% said they can't eat due to dietary requirements or sensory processing difficulties.
- 22% reported that it was because their child is off school due to a long-term illness or medical condition.
- 15% said their child can't eat in the canteen due to sensory needs.

85% of families said missing out on free school meals increased pressure on their weekly budgets. When asked about the impact of this on their families:

- 67% experienced more stress as a result.
- 22% got into debt or had to borrow money.
- 21% reported it made their child feel left out.

Of those children missing out, 28% have never been able to access their free school meal and almost a third (32%) have not been able to access them for two or more years. Almost half (49%) of families are paying £20 a week providing meals or packed lunches to replace the free school meals their disabled child is entitled to.

Disabled children facing disadvantage and discrimination

Kirsty, mum to Tyler, 12, who is autistic and has a related mental health condition, said:

"A small bit of free school meals funding can be an incredible lifeline for people in my situation, even more so with the cost of living crisis. I'm a full time carer to my son who is home 24/7. I did not choose for him to be out of school or to give up my career. It really highlights the disability discrimination that is happening on a daily basis. Tyler has not had a free school meal for around 130 weeks. This would add up to £1,950. This is a huge amount of money for a family and could have made a big difference over the last four years."

Contact's head of policy, Una Summerson said:

"Many UK families with disabled children are having to provide a school lunch when it should be free. They are being unfairly disadvantaged and put at greater risk of experiencing food poverty. There is a drive to expand free school meals in Scotland, Wales and London, as they are known to improve a child's achievement and wellbeing as well as help towards family finances. But there is a group of children already eligible who are missing out.

"That's why we are campaigning alongside affected parents for schools and councils around the UK to offer an alternative, such as a supermarket voucher, so disabled youngsters have access just like their non-disabled friends."

Contact supports campaign for alternatives and reasonable adjustments

Contact's research found that some parents have successfully argued for a food voucher instead of a cooked meal in school. They used the law that says that schools should make reasonable adjustments for disabled people so that they don't face disadvantage. As a result, Contact is calling for the government to update national guidance to make this clear to schools and councils.

Natalie Hay, parent campaigner, said:

"When my son got Chronic Fatigue Syndrome as a result of Lyme disease, I had to give up work as a teacher. Despite being entitled to free school meals, my son never got them, apart from during lockdown.

"When every child was learning from home during pandemic lockdowns, reasonable adjustments were made. Every child got help. When disabled children are learning from home or are unable to eat the school meal due to sensory or dietary needs, no reasonable adjustments are made. Barely any get help. This needs to change. I set up an online campaign group, which now has 1500 parent carer members seeking free school meals for their eligible child. Some of these parents have two children with a disability and are on Universal Credit. Others are so busy caring for their child they do not have the time and energy to fight this discrimination."

You can support the campaign and find out more here.

The Council for Disabled Children has produced a guide titled 'Disabled Children and the Equality Act 2010: What teachers need to know and what schools need to do'.

This guide is designed to help teachers and schools understand the legislation and how it applies to their work with disabled pupils. It draws on examples of practice that may amount to discrimination or that may help schools to avoid it. It also includes a section on reasonable adjustments.

You can read the guide here.

Disabled Children's Partnership Update

Our research

In March the Disabled Children's Partnership were incredibly proud to launch our new research report, Failed and Forgotten. We surveyed 2,200 parent carers of disabled children in October and November 2022 to understand their experiences raising disabled children as we move past the pandemic. Their responses were eye-opening. Alongside the survey responses, the report also included Freedom of Information responses from local councils and health boards, and analysis of published government datasets.

The work, led by our Research Manager Dr Cath Lunt, was intended to function as a sort of 'state of the nation' for disabled children and their families across England. However, our findings made it clear that the issues we were finding were much bigger and needed to exist beyond a research report.

Disabled children and their families are currently facing the most challenging times yet. Post-covid recovery has left disabled children facing "record breaking" delays and backlogs to health and social care services.

Our report covered a wide range of issues extending from the delays to services, relationship breakdown and the broader theme of isolation.

Some key findings from our research include:

- Half of parents of disabled children are unable to work and have experienced poverty, because of lack of support for their child.
- Three in four parents have had to give up employment or their whole careers, due to lack of support.
- Seven out of ten parents said their disabled children's health had deteriorated because of lack of support.
- Only one in three disabled children has the correct level of support from an education setting.
- Only one in seven families had the correct level of support from social care.
- Only one in five has the correct level of support from health services.
- Only one in five felt their family received the support needed for their child to fulfil their potential.
- Over a third (38%) of parents have experienced marriage/relationship breakdown in the last 12 months as a result of lack of support for their disabled child.

Our launch event

We launched our report with an event in Parliament.

We were joined by Let Us Learn Too, the parent led campaign group to launch their new #LetParentsBeParents campaign. For the event we were joined by 9 year old Nate, his dad Alan, members of the DCP and parent campaigners.

Nate had written to the Prime Minister to call for more support for families with children who have disabilities, saying his parents feel "forgotten".

MPs and their teams from more than 20 constituencies came to our event. They were engaged and receptive to our asks. We are currently speaking with MPs about future meetings and they are submitting Parliamentary Questions on our behalf.

We are also using our findings and recommendations as a basis for ongoing conversations with the major political parties with the aim of influencing their manifesto process.

Recommendations to Government

As part of the report, we developed some immediate asks for the Government. It is imperative that they extend support for families with disabled children during the cost of living crisis. Some of our immediate asks include:

- An energy assistance payment for families of seriously ill and disabled children to cover the cost of running lifesaving medical and disability equipment.
- Bring forward the further £150 Disability Cost of Living payment and benefit uplift announced in the Autumn statement.
- Reverse eligibility changes to the Warm Home Discount that excluded disabled people.
- Social tariffs for households on disability benefits.

You can read the report and find alterative versions here.

To keep up to date with the work of the DCP, sign up to our mailing list, and keep an eye on our website.

You can follow the Disabled Children's Partnership on Twitter at @DCPCampaign, or on Instagram and Facebook at @ DisabledChildrensPartnership.

Shining the Spotlight

CDC Members

We are really proud of our members and will jump at every chance to shout about them and their achievements! This is a dedicated place to showcase our members and to shine the spotlight on their projects. Keep scrolling to hear from our new member the Peter Pan Centre.

How it works

At the Peter Pan Centre we are dedicated to life-changing care and education for children with special educational needs and disabilities and the support their families deserve.

At our centre in Newcastle under Lyme we support around 120 children each year through weekly specialist Education, Care and Development sessions that follow the Early Years Foundation Stage, delivered by our team of dedicated and caring expert Specialist Practitioners. We work closely with the professional teams involved in children's care to ensure consistency of support throughout the early years. Our school transition service helps families through the sometimes emotionally-taxing process of navigating the SEND system and securing the most appropriate school place for their child. We also provide advice and guidance to schools and other settings to enable them to better support children with SEND.

At Peter Pan we are here for the whole family, providing respite, home visits, weekend social activities, training courses, help with form-filling and meeting children's needs in the home, signposting and more. We also deliver weekly stay and play sessions for 0–5 year-olds who need extra support, at children's centres across Staffordshire and Stoke-on-Trent.

What has been achieved?

We were awarded Outstanding in all areas by Ofsted for the fourth consecutive time in August 2022. We also won the local 'Your Heroes – Inspiration in Education' Award for the difference we make to children and families across Staffordshire, Stoke-on-Trent and Cheshire East.

Next steps

During the next three years we will develop our Family Support Service to reduce parent carer isolation and improve wellbeing through more social events and expanding our stay and play sessions into new locations. As well as continuing to develop our practice, we will further develop our partnerships with local settings, FE colleges and universities to share best practice and widen inclusion in the early years.

More information

Website: www.thepeterpancentre.co.uk

Twitter: @peterpancentre

Facebook: @peterpancentre

Instagram: @peterpan.centre

Email: info@thepeterpancentre.co.uk

About the digest

The CDC Digest is a quarterly round-up of all the essential policy, practice and other news involving disabled children and young people, and their families.

If you would like to be added to the list to receive this digest, please visit our website and tick 'CDC Digest'

About CDC

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to other UK nations. We are the only national body that brings together the diverse range of organisations that work with and for disabled children to support the development and implementation of policy and practice. Our work impacts on over 800,000 disabled children and their families. CDC hosts Making Ourselves Heard, the IASS Network, the Special Educational Consortium and the Transition Information Network.

Find out more

councilfordisabledchildren.org.uk

facebook.com/councilfordisabledchildren

@CDC_tweets

linkedin.com/company/council-for-disabled-children/

INFORMATION,
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INFORMATION
NETWORK

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OURSELVES
HEARD

SPECIAL
EDUCATIONAL
CONSORTIUM

COUNCIL
FOR DISABLED
CHILDREN
Part of the family

COUNCIL
FOR DISABLED
CHILDREN

United for disabled children

The Council for Disabled Children brings people and organisations together to drive change in society and deliver a better childhood for disabled children the UK. We interrogate policy, uncover evidence and develop more effective ways of supporting disabled children and their families. Together with National Children's Bureau we are united for a better childhood.

Let's work together: 020 7843 6000 | cdc@ncb.org.uk

London: 23 Mentmore Terrace, London, E8 3PN

Part of the family
NATIONAL CHILDREN'S BUREAU

National Children's Bureau is registered charity number 258825 and a company limited by guarantee number 00952717. Registered office: 23 Mentmore Terrace, London E8 3PN.