COUNCIL
FOR DISABLED
CHILDREN

CDC Digest

Winter 2022/23

Dear all,

Welcome to the winter edition of the Digest. I do hope the festive season means that you will have an opportunity for some rest and relaxation.

It has been a challenging winter term as the political chaos has meant that timelines have been delayed and families and systems have had to deal with the cost of living crisis.

We now expect that both the SEND improvement plan, containing within it the Government's response to the consultation, and the Social Care implementation plan will be published in the New Year.

It is important to see them together as we know families lives are not lived in the boxes of service structure, but need all of them to come together to deliver the best outcomes. We are also seeing work in health as it progresses and it is good to welcome the new Children and Young Peoples lead in Integrated Children's Boards.

In the smaller world of CDC, we have just said goodbye to Philippa Stobbs, as she retires leaving an amazing legacy of 32 years of championing the best education for children and young people with SEND. She leaves us with some messages about seeing the world through the rights of children and families, starting early and always aspiring for the best. It will be these messages which we take into our New Year as we gear up to see what 2023 has to offer.

I wish you a peaceful happy Christmas and look forward to working in partnership with you in 2023.

Best wishes,

Dame Christine Lenehan

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Council for Disabled Children Updates

Health

The Health team have been delivering the RISE (Research & Improvement for SEND Excellence Partnership) programme supporting local authorities across England. The RISE partnership is made up of the Council for Disabled Children and National Development Team for Inclusion. We offer bespoke support to local areas regarding the strengthening of SEND practice and processes at strategic and operational levels. We have been delivering both in-person and virtual events.

We also continue our commissioned work for a number of local authorities, including a large survey of schools in Greater Manchester.

We have also published SEND Basic Awareness e-learning modules for Level 1 and Level 2 health professionals along with a Competency Assurance Framework for all levels of health professionals. The framework and the e-learning modules will improve professionals' competency around their knowledge and understanding of SEND. We are now gathering data to assess the needs of Level 4 health professionals in order to develop a SEND training that would cater to their needs. We hope to embed these trainings as mandatory trainings in the system for all health professionals to ensure competency assurance is equal and adequate across the nation. You can find the e-learning modules here.

Social Care

The Social Care team have been busy facilitating several stakeholder events for the Department for Education through our Strategic Reform Partner contract. This included a learning event for the Short Breaks Innovation Programme where all 7 pilot areas joined us for an afternoon of reflection and discussions on emerging themes across the projects. CDC will continue to explore where there may be service/systems learning in relation to social care and SEND and identify opportunities for examples to be shared with the What Works in SEND programme.
We also delivered the first of our Insights and Impacts Groups, a meeting bringing together all DfE SEND contract holders to discuss their programmes, emerging intelligence and any opportunities for joint working to meet shared aims.

As part of the RISE programme we have also begun delivering interventions in local areas and are looking ahead to delivering our regional SEND and Social Care Train the Trainer sessions in February and March. More details on this to follow soon!

Special Educational Consortium (SEC)

SEC has been focused on using its SEND Review Green Paper response and 20 Asks of the DfE to influence the SEND Review team's plans to move forward with the Green Paper. SEC met with the SEND Review team in November and DfE listened to SEC's comments, specifically relating to the proposal to implement national standards. SEC also produced responses to the DfE's national funding formula consultation and Ofsted SEND inspections consultation. SEC also emphasised to Ofsted the need for a focus on gathering more evidence directly from children and young people and their families, ensuring that their views and experiences are central to inspections. More information about SEC's consultation responses can be found here.

Early Years SEND

The EYSEND partnership has continued to deliver a series of open-access training to practitioners and parents as well as strategic support to local areas across England. Participants in our Equality Act training seminar in October found the session so valuable that they requested a follow-up discussion, which was held in November. Click here to sign up to the newsletter that posts trainings offered through the partnership.

CDC is supporting six local areas with their local offer through the development of 'Ordinarily Available Provision', bringing together stakeholders across the sector to discuss ways they can make mainstream settings more inclusive. CDC has also held follow up meetings with six local partners to feed back on their progress in improving transitions for young children into reception. A network 'action learning set' offered the opportunity for different local areas engaging in this work to come together to discuss their successes and some of the barriers they have encountered along the way. Despite the widely recognised difficulties in recruitment and retention in the early years, local areas are reporting high levels of engagement in this work and improvements in consistency, quality and engagement with parents.

The EYSEND Partnership has been recognised for its important work in the sector and was shortlisted for an Award for Early Years Provision at this year's nasen Awards.

The Information, Advice and Support Services Network (IASSN)

The IASSN have been focused on updating our resources and reporting and delivering this year's training programme for SENDIAS services. We collaborated with a group of SENDIAS services to revise the national intervention levels. They will be shared soon, alongside a series of webinars to ensure all SENDIAS services are completing them in a uniformed way. We delivered a data collection and information sharing workshop and developed further joint commissioning resources (to support the 36% of services that are not yet joint commissioned, a huge improvement from 98% 4 years ago).

We have also delivered training for SENDIAS services on topics including: tribunals, exclusions and IPSEA legal and refresher courses. In co-production with our children and young people's steering group we are also developing training for SENDIAS services on what they need to do to include children and young people in their steering groups.

Participation

The Participation Team have been busy engaging children and young people in our work at CDC. FLARE, the DfE's national SEND advisory group, have been feeding into and leading on very important discussions focusing on the SEND Review Green Paper. They have also been planning the Youth Voice Matters Children and Young People's Conference, you can find out more or register your group of young people here.

Our Shared Support meetings have continued to facilitate joint learning and problem-solving with practitioners, sign up to the Making Ourselves Heard Forum for information about next month's session.

To ensure that the DfE's proposals will reflect the needs of children and young people with SEND we have been gathering their opinions to create a children and young people's response to the Green Paper. You can access the report here.

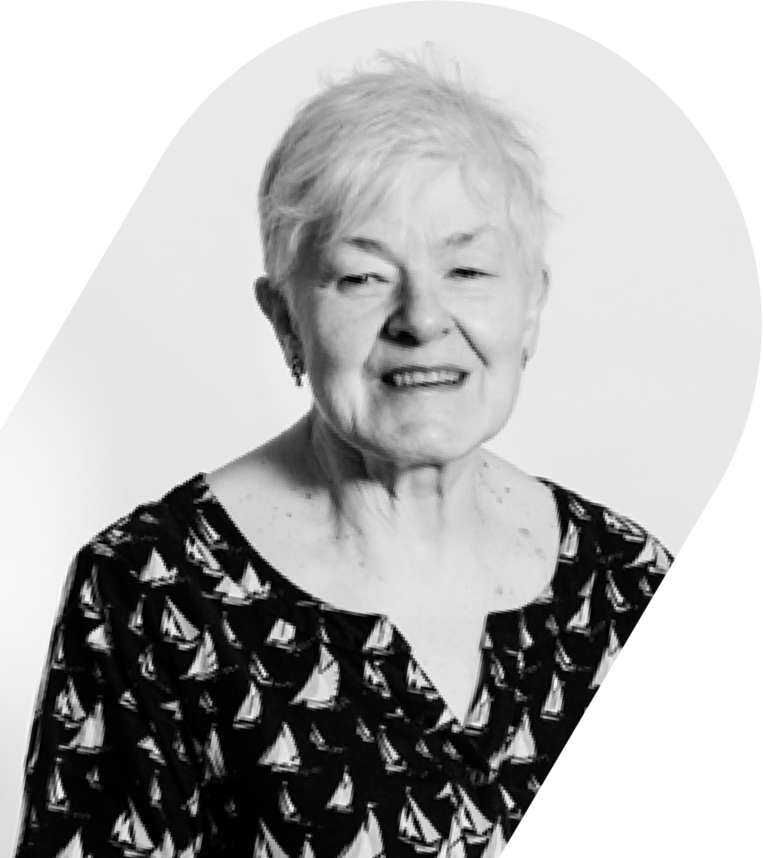
We have also recruited a Young People's Advisory Group for our Keyworking Evaluation Project with NHS Arden and Greater East Midlands Commissioning Unit, interview conversations with children and young people and with parents and carers are taking place in January – August 2023.

A postcard from Athens

Philippa Stobbs

Like so many other meetings, the bi-annual meetings of the European Agency for Special Needs and Inclusive Education have been held virtually for the last couple of years. In fact, the first meeting in the pandemic was cancelled. It had been planned for what turned out to be the period when everyone was frantically moving everything online, getting to grips with the technology, changing face-to-face training materials into online versions, getting used to the domestic backdrops on Teams and Zoom and, for presenters especially, learning to live with the challenges of interruptions by children and domestic pets.

With the Athens meeting being the first face-to-face meeting for two and a half years, there was a real buzz of excitement. This was an opportunity to catch up with the projects run by the Agency, but also the opportunity to hear about developments in different nations across Europe, which we always talk about in the margins of the main meetings. The excitement this time was amplified by celebrations for the 25th anniversary of the European Agency. This included cake: a big one.



There is always a European Agency project that is just being scoped or getting under way, others for which we receive updates and, almost always, a final report on a project that is just concluding. A key focus of the meeting in Athens was on the final stage of the project on Changing Role of Specialist Provision in Supporting Inclusive Provision, with the catchy acronym of CROSP.

The project had started with a mapping exercise based on past, current and forecast trends in the support that specialist provision makes to mainstream schools in the 26 Agency member countries that took part. The mapping was followed by two rounds of workshops, focusing on the four main themes that had emerged from the earlier activities: governance, funding, capacity building and quality assurance.

The workshops were based on a peer-learning approach and helped representatives to reflect on their own systems and on each other's. With a focus on effective improvement strategies, representatives worked with each other on mapping where they were on the journey, identifying next steps and planning ways of developing quality in the role of specialist provision supporting inclusive education.

Through this process a CROSP Review Tool was developed and we all had sight of the final draft before the meeting in Athens. If it all sounds a bit high level so far, when you look at the actions set out in the tool it gets down to the day-to-day detail of, for example, decisions about identification and personalised provision.

Thinking about the role of special schools in supporting inclusive provision always presents a bit of a challenge for me as I remember one Ofsted report concluding that effective partnership work between mainstream and special schools on curriculum and teaching is the exception rather than the rule. Another Ofsted report found that work to promote links between special and mainstream schools, specifically to provide SEN and disability expertise to mainstream schools, led, in the end, to more pupils being placed in special schools rather than improvements in inclusive provision in mainstream.

So what is different about this piece of work?

Browsing through the Review Tool gave me pause for thought: it is very strong on the articulation of a shared set of values to underpin the work across mainstream and special schools. The tool opens with a set of 6 principles, these inform the policy priorities and the strategies that are picked up in the self-review tool; the policy priorities and the strategies are, in turn, seen as fundamental to meeting the values expressed in the guiding principles. There is therefore complete linkage between the values and actions taken to realise them.

The first principle is about developing a shared commitment to inclusive education; and the first policy priority under this principle:

1.1: There is a shared commitment to inclusive education supported by a political will to encourage long-term change

Then, sitting under this policy priority, there are actions that might be judged to be evidence of this as a priority or, if the actions are not yet in place, important to making a reality of this priority. In this Review Tool, there is real coherence between the principles, the priorities and the actions to achieve these.

This made me reflect on the extent of the references to inclusion and inclusive schools in the Green Paper. Might we use the period following the consultation on the Green Paper, to consider whether and, if so, how these references fit into a framework of values? And whether, collectively, as a nation, we share that ambition for inclusive education? Since many of our indicators point to the opposite in terms of current direction of travel.

If we do share that ambition, the test for the proposals in the Green Paper is whether they help us towards realising it; and what else we might need to do, beyond the Green Paper proposals, to realise this ambition. The CROSP Review Tool takes us into leadership, funding systems, initial training and continuing professional development and other areas we would need to visit to test that coherence between ambition and practical proposals.

It's food for thought.

Talking of food for thought, I said the cake to celebrate the 25th anniversary of the Agency was big. It was but, in case there wasn't enough to go round, everyone was given an individual one too. It was tiny, but incredibly sweet!

Wish you were here!

Philippa

Council For Disabled Children Making Participation Work Practitioners Conference

On 18th October 2022, CDC held the second of three annual national practitioner's conferences. 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 chose two workshops to participate in. These included:

- Co-production and next steps in the SEND Review Green Paper. This workshop explored young peoples', practitioners and organisations ideas of what co-production in the Green Paper proposals should be.
- Do we truly work in co-production? This was co-designed and co-delivered by two FLARE members and explored how youth-led , rather than organisation-led co-production and co-design works in practice. Jacob and Grace outlined the pros and cons of youth-led versus organisation and sector-led engagement, and the wide-ranging impact both approaches have on all those involved.
- What Works in SEND. This workshop gave an introduction to CDC's programme of research into what makes an effective SEND system and is part of the Research & Improvement for SEND Excellence partnership (RISE) contract.
- The Road Blocks, delivered by KIDS, looked at the barriers to embedding children and young people's participation and some of the practical examples for how to overcome these.
- Decisions, capacity and an introduction to the Liberty Protection Safeguards, led by CDC's Social Care Team, focused on the importance of involving children and young people in decision making in line with the principles of the Mental Capacity Act 2005.

Feedback from the day included:

- *"Really informative and collaborative sessions"*
- *"[The input from young people] was helpful and encouraging"*
- *"Really interesting and resourceful"*
- *"The content and facilitation was great".*

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 Grace's blog here.

Council for Disabled Children

Liberty Protection Safeguards – System Readiness Tool

What are Liberty Protection Safeguards?

The law to deprive someone of their liberty will be changing from Deprivation of Liberty Safeguards (DoLS) to Liberty Protection Safeguards (LPS). Introduced in the Mental Capacity (Amendment) Act 2019, three Responsible Bodies will authorise LPS through a streamlined assessment process that puts the rights and wishes of individuals who lack capacity at the heart of all decision-making.

Liberty Protection Safeguards and 16 and 17-year-olds

This transition brings many key changes, most notably that all settings will now be covered and that the safeguards are extended to 16 and 17-year-olds. Now the LPS covers 16 and 17-year-olds, you might want to remind yourself of the case law in relation to young people who lack capacity. CDC's case law directory on Re: D outlines the ruling by the Supreme Court that those with parental responsibility cannot consent to the deprivation of liberty of 16 and 17-year-olds.

Liberty Protection Safeguards (LPS) – System Readiness Tool

As part of the CDC's role as Strategic Reform Partner to the Department for Education and recognising the need to support local authority children's social care services to plan their journey to implementation of the LPS as they apply to 16 and 17-year-olds, we have created the LPS System Readiness Tool.

What is the tool for?

The purpose of the tool is to support local authorities to effectively implement their statutory duties in the Mental Capacity (Amendment) Act 2019: Liberty Protection Safeguards (LPS). It asks to rate your progress across 5 key areas, with helpful prompts and indicators of effective implementation. These audits should be completed at different stages, to measure progress.

By completing the tool and submitting surveys on your progress, we can identify implementation support needs and share data and information to feedback to the Department for Education.

You can find out more information about the tool and how to access it here.

The NHS Safeguarding Team have produced this helpful animation that explains the transition from DoLS to LPS, which you can watch here.

Philippa Stobbs, Assistant Director at CDC gives valedictory speech to parliament

On Wednesday 23 November, Philippa Stobbs gave a valedictory address to delegates in parliament, marking her retirement after working at the Council for Disabled Children (CDC) and the National Children's Bureau for more than 32 years.

The parliamentary address provided an opportunity to hear Philippa's reflections on developments in Special Educational Needs (SEN) and disability, and inclusion over recent decades and her insights into what needs to happen next.

Philippa has dedicated her entire career to improving outcomes for children with special educational needs and disabilities, having started as a teacher and inspector and then spent over three decades here at CDC. Philippa is a prolific, powerful advocate for children with SEN and disabilities and it's hard to imagine how anyone could have made more of a difference to the SEN and disability community; she continues to be an inspiration to the entire sector.

Philippa has accomplished so much in her career and this has been acknowledged within the sector, most notably, when she was awarded the prestigious 'Person of the Year' award from nasen. Her achievements and contributions are unequivocal. Below we list highlights of the work that Philippa has played a key role in.

Key highlights of Philippa's work at the Council for Disabled Children:

- The Special Educational Consortium (SEC): In 1992, Philippa set up the SEC to create a national campaign and lobbying voice for the disabled children's sector. Under Philippa's guidance and leadership, SEC brought about a number of important changes to the Children and Families Act in 2014, including the application of the legal framework to young people in custody, and stronger duties on health and social care services.
- The Early Years SEND Partnership (EYSEND): Philippa directed the EYSEND partnership, a national programme supporting professionals and parents with training, resources, and an approach to sharing learning, with the aim to increase access and inclusion in early years for children with SEN and disabilities.
- Philippa helped to establish and develop parent partnership services – now known as the Information, Advice and Support Services Network.
- Philippa is the national coordinator for England in the European Agency for Special Needs and Inclusive Education.

Key resources developed by Philippa at the Council for Disabled Children:

- The Council for Disabled Children Inclusion Policy
- Disabled Children and the Equality Act 2010: What teachers need to know and what schools need to do
- A series of blogs that focus on different aspects of the duties in the Equality Act 2010 that provide some challenges for schools:

  1) Difference and disability

  2) Knowing who is disabled

  3) Patterns and duties

  4) Living the values

The Council for Disabled Children would like to thank Philippa for her hard work and dedication during her career. Philippa has worked tirelessly to campaign and effect policy change at a local and national level to improve life chances and outcomes for children and young people with SEN and disabilities. Philippa has made such a difference and we are grateful that she chose to spend over 30 years working with us.

Dame Christine Lenehan, Director of the Council for Disabled Children said:

"Philippa has made an unparalleled contribution to the lives of children with SEN and disabilities in her 32 years at NCB. Her detailed knowledge, her forensic use of evidence and her absolute passion that children with SEN and disabilities should get the very best out of education and learning has meant she has dedicated her time to making a difference. This difference can be felt nationally by leading policy on the Special Educational Consortium and working with the Government as a professional advisor, and locally, working with numerous Local Authorities, schools and early years settings to make a practical and evidenced change."

To watch Philippa's valedictory address please click here.

Education Secretary updates on the SEND and Alternative Provision Improvement Plan

On Tuesday 29 November 2022, the Department for Education published a letter from the Rt Hon Gillian Keegan MP, Secretary of State for Education, sent to those working across the Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) sector.

In the letter, the minister clarifies her commitment to improve the experiences of children and young people with SEND or in AP, within a fairer, more inclusive, and sustainable system across education, health and care.

She sets out plans for publishing a response to the SEND Review consultation, working alongside the new ministerial team to understand the extensive feedback, before publishing a full response, in the form of an improvement plan early in the new year.

Ahead of the improvement plan being published, the Education Secretary has confirmed that children and young people with SEND will benefit from wellbeing and technology support straight away, with new funding announced for educational psychologists and assistive technology. This money will continue to support the system to deliver change and continue to improve the outcomes and experiences of children and young people with SEND and those who need alternative provision.

You can read the letter here.

To read about how the Department for Education are improving support for children with SEND please click here.

Dame Christine Lenehan, Director of the Council for Disabled Children said:

"We welcome the letter to the sector from the Secretary of State for Education. It is important that the feedback from the consultation stage of the SEND and AP green paper is reflected on and heard. Children and young people need our support more than ever and we look forward to hearing more about the focus on delivery and the immediate steps that need to be taken to ensure systemic change and better outcomes for our children and young people."

Council for Disabled Children

Resources and Training

Resources

Keyworking Function

We've published a new resource on the early experiences of Keyworking Service pilot sites. Keyworking Services support children and young people with a learning disability and/or who are autistic and who have been, or are at risk of being, admitted to, a mental health hospital. Keyworkers were introduced following a recommendation by Dame Christine Lenehan in her review "These Are Our Children" and this Addendum builds on the Keyworking Workforce Competency Framework and Function Guidance developed in the lead up to the launch of the programme.

It is based on interviews, case studies and workshops with pilot sites and explores how they developed the vision for their service, the process of getting it up and running and how they are working with children, families and services to reduce admissions to, and length of stay in, mental health hospitals. It highlights how services have approached the key strategic and operational challenges and balanced the challenge of combining independence and influence in a way that enables them to deliver change for children and families.

You can view the guidance here.

Our Turn to Talk Podcast Episode 6

Our Turn to Talk is NCB's youth-led podcast programme! In episode 6, Lotte shares her own experiences of having an EHC plan and how she thinks young people can be better supported. Listen here.

Bullying, school experiences and wellbeing: a picture of pupil experience in 2022

The Anti-Bullying Alliance published a report summarising findings from their first collection of pupil bullying and wellbeing questionnaire, which forms part of their United Against Bullying programme. The report paints a worrying picture of levels of bullying, findings include that pupils with special educational needs and/or disabilities (31%) are significantly more likely to be frequently bullied.

Learning example: supporting inclusive education – Newcastle's graduated response

We have identified examples of good practice taking place to improve outcomes for children and young people.

This learning example sets out Newcastle's approach to effectively implementing the graduated response to SEN support in mainstream schools and settings. It explores the development of their SEND Outreach Service which can be accessed via the SEND Advice and Support Allocation Panel (ASAP).

Training and Events

Overview of EHCPs and the SEND process – Training for kinship carers

With the charity Kinship, CDC have been delivering workshops to kinship carers. The aim of the workshop is to help kinship carers understand the processes for accessing any support available for children and young people with SEND, understand the EHCP referral, assessment and plan process, and how to access other support services for children with SEND, such as the virtual school.

Delivered online, these free workshops are also an important opportunity for kinship carers to come together and share their experiences of navigating the SEND system for the children they care for.

If you are a kinship carer living in England who is interested in attending a workshop, or know someone who might be, you can find out more information here.

We will be delivering a few more sessions in December, with more dates added for the new year.

CDC's National Online Event

CDC's next National Online Event will be on the theme of co-production with children and young people and will take place on Thursday 2 February 2023, 10.00 – 13.30. You can register here.

This online event is aimed at SEND Leads, Commissioners, DSCOs, DMOs and DCOs – we would also welcome attendance from Parent Carer Forum regional representatives. Priority will be given to these roles.

RISE SEND Workforce Training

We're excited to launch our RISE SEND Workforce series of training for professionals working across the SEND workforce

Under the RISE programme, funded by the Department for Education, the Council for Disabled Children and NDTi have conducted a workforce survey to identify learning needs across the SEND System.

The following topics have stood out as areas of need, and training sessions have been developed to meet these learning needs:

- Data, Voice and Commissioning
- Social Care, SEND and Co-production
- Preparing for Adulthood, Post 16 Pathways

Each training session will run multiple times and will be delivered online, using MS Teams. Please click on the links above to view dates and register.

United Against Bullying Free CPD Training

The Anti-Bullying Alliance are offering FREE CPD training to schools in England as part of their United Against Bullying (UAB) whole-school anti-bullying programme. It aims to develop your understanding of bullying, those most at risk and improve confidence in preventing and responding to bullying. The final session of the course is an optional workshop for schools registered on UAB to provide practical support on the programme.

Find out more and register here.

National Children's Bureau

United for a better children's social care system, All-Party Parliamentary Group for Children Event

The children's sector, statutory services and Parliamentarians have united to call for urgent social care reform and resourcing that prioritises early intervention and co-production with children and families. These pleas were made in November, at a packed meeting of the All-Party Parliamentary Group for Children, coordinated by the National Children's Bureau.

Claire Coutinho MP, in her first speech as the new Minister for Children, Families and Wellbeing, told the assembled audience of practitioners, campaigners and people with lived experience of the social care system, that she was passionate about giving children and families the best possible start: *"I look forward to working with everyone in this room," she said. "Please be assured of my commitment to this area and my ambition to do as much as we possibly can... This whole area wouldn't exist without you and I really look forward to learning from you and seeing what we can do together."*

In his keynote address to the meeting, Josh MacAlister, Chair of the Independent Review of Children's Social Care, summarised his recommendations for strengthening early intervention:

- Where possible, family support should be locally-based and build on existing assets in the community
- Family help is not just the job of social workers – it is a multi-agency exercise requiring close collaboration
- Support should be well-resourced and evidenced
- There must be a resolution of the tension between the child welfare and child protection systems.

He said that without intervention now, the bill for children's social care would rise by 50 per cent within a decade to £15bn a year while outcomes could worsen:

"Something major needs to change," he concluded. "We need to set a new direction that improves outcomes for more children and families, reduces long-term costs and crucially permanently shifts £1bn of government spending from care to help for families."

Introduced by Professor Julie Anderson from the University of Kent, Experts by Experience from NCB's Living Assessments programme played a crucial role in proceedings, setting out what early intervention means to them.

"For family help to be effective, we need investment in social housing, the benefits system and equitable healthcare," 14-year-old Udi told the audience. "Too many families – particularly those with disabled children – fall through the cracks in the system. Every family deserves the right help at the right time in the right place."

Calls for collaboration and collective action to deliver change to improve outcomes for all children, young people and their families were also echoed by the outstanding discussion panel, which included:

- Steve Crocker OBE – President of the Association of Directors of Children's Services
- Dame Rachel de Souza – Children's Commissioner
- Indra Morris – Director General of the Department for Education
- Helen Hayes MP – Shadow Children's Minister
- Amanda Spielman – Chief Inspector, Ofsted

Further information about the meeting is available on the National Children's Bureau website here.

National Children's Bureau

First Stronger Practice Hubs announced

The Department for Education (DfE) has announced the first 13 settings in England that will be early years Stronger Practice Hubs.

Early years stronger practice hubs will provide advice, share good practice, and offer evidence-based professional development for early years practitioners. The hubs are part of the early years education recovery support programme which also includes the early years experts and mentors programme. The DfE's ambition is to fund two hubs in each region of England (a total of 18 once a further five are appointed next Spring).

The early years stronger practice hubs programme is supported by the Education Endowment Foundation and the National Children's Bureau.

Stronger practice hubs will support other nurseries and childminders in their area to adopt evidence-based practice improvements, by:

- Establishing local networks of early years educators to share knowledge and effective practice
- Proactively sharing information and advice on evidence-based approaches – for example, through newsletters, blogs and social media
- Acting as a point of contact for bespoke advice, and signposting to other funded support
- Working with the Education Endowment Foundation to select evidence-based programmes to fund and make available to nurseries and childminders.

The full list of hubs is available here.

National Children's Bureau

Young NCB Advisory Group Recruitment

Do you know a young person who would like to have a voice in decisions that affect their lives? We are recruiting young people to join the Young NCB Advisory Group.

The group is 20 children and young people, aged 11–24, who get together to help decide and plan what work Young NCB does, including the issues it deals with and the activities and events it organises. Being a member of the Advisory Group is an excellent way for young people to get their voices heard and represent the views of other young people. Advisory Group members get to travel across the country to take part in meetings, consultations and workshops. They get to have their views and ideas heard by talking to other children and young people, politicians and decision-makers. Above all, they get to meet loads of other children and young people and have lots of fun!

Advisory Group members can come from anywhere in England and do not need to have done this sort of thing before, it's easy to learn and everyone is welcome to take part. We will cover the cost of all travel and expenses so it won't cost a penny!

To discuss in more detail or to make an application, please email Rory at rsheridan@ncb.org.uk or visit the website to read more and make an application.

Healthy Parent Carer Programme

Are you a Parent Carer Forum member or representative, Local Authority SEND manager, NHS commissioner, or charity who is looking for ways to improve the lives of parent carers and their families in your area?

The Healthy Parent Carers programme is a 12 week programme designed to improve the health and wellbeing of parent carers of disabled children. Unlike other self-help programmes it is exclusively run by parent carers for parent carers. Developed by the University of Exeter in collaboration with parent carers and disability charities it is extensively researched and tested.

We are currently training facilitators across the UK, so if you would like to run the programme in your area, or just find out more about us, please get in touch here.

"This programme has a long term impact. By investing in the parent carer, you're investing in the whole family." Chris Morris, Manager for SEND Programme, Bedford Borough Council.

Contact

Families with disabled children cutting back on life-saving equipment

Over a third (39%) of families with seriously ill and disabled children have cut back or stopped using essential disability equipment due to rising energy costs. That's three times more than in March, before energy bills started to soar. Of those, 40% say this is making their child's condition worse.

These are the worrying findings of Contact's Out of Energy research which were revealed exclusively in November on Channel 4 News. As a result, Contact is calling on the government to deliver urgent targeted support to avert a deepening cost of living crisis.

Contact's research of 3,893 families with disabled children found that households are paying on average £1,596 extra a year to run vital equipment. This is up almost £600 since April 2022. The findings also found that:

- Over three quarters (79%) have reduced the amount of energy they use in the last 12 months because they can't afford their bills.
- Almost half (45%) say they have not been able to keep their home warm enough for their child's needs.
- Only 3% get an NHS medical grant towards the costs of running disability or lifesaving equipment like oxygen concentrators. Families who managed to get a grant said not all equipment is included, and grants rarely cover true running costs.

The Chancellor's Autumn Statement

The Autumn statement included:

- Means-tested benefits, including Universal Credit, to rise from April 2023 in line with September 2022's inflation levels of 10.1%.
- The household energy price cap to be extended by one year beyond April 2023, but made less generous. Typical bills will be capped at £3,000 a year instead of £2,500, as they are now.
- Households on means-tested benefits to get a £900 cost-of-living support payment next year.
- Individuals on disability benefits to get a second £150 cost-of-living support payment next year.

Although there will be an increase of benefits in line with inflation, extra payment of £150 for individuals on disability benefits, alongside an additional payment of £900 for households on means-tested benefits, this won't be enough to help families with very sick and disabled children who need support right now. These families are already incurring extra energy costs because they run life-saving and other health-related electrical equipment, like ventilators and SATs monitors, which they can't switch off. It was also disappointing that there was nothing in the Chancellor's announcement that will help families with extra disability and heating costs get through this winter.

Find out more about Contact's Out of Energy campaign.

Read Contact's response to the Autumn Statement and what the changes to benefits and other financial support mean.

NHS England and Improvement

Updates to two key personal health budget guidance documents have been published to reflect the introduction of integrated care boards (ICBs) in July 2022.

Guidance on direct payments for healthcare: understanding the regulations provides guidance for commissioners to support the implementation of the National Health Service (Direct Payment) Regulations 2013 and amendments 2014 and 2019, and deliver on the ambition for 200,000 people to have a personal health budget by 2023–24. Updates to the previous version of this guidance (version 1, published 20 March 2014) are highlighted in yellow in the PDF document.

Guidance on the legal rights to have personal health budgets and personal wheelchair budgets supports ICBs and other relevant bodies to meet their duty to ensure eligible groups of people benefit from the legal right to have a personal health budget or personal wheelchair budget. This includes people eligible for NHS Continuing Healthcare, children and young people's continuing care, people eligible for after-care services under section 117 of the Mental Health Act, and people eligible for NHS wheelchairs. Updates to the previous version of this guidance (version 1, published December 2019) are highlighted in yellow in the PDF document.

Disabled Children's Partnership Campaign Update

In the last issue of the Digest, our then Campaigns and Public Affairs Officer, Aidan Smith, wrote about our #SENDABetterMessage campaign. That campaign was launched in response to the government's SEND Green Paper.

Through it, we supported parent carers, young people and allies to engage in the Green Paper consultation. As a result of our campaigning, more than 1,300 people emailed their MPs. And 1,800 took part in the consultation using our 'Six simple questions'. We have sent all of these to the Department for Education, where they are being treated as a full part of the consultation.

Since then – like everyone else – we have been eagerly awaiting the government's response to the Green Paper consultation, as well as its plan for children's social care following Josh MacAlister's independent review. It is vital for disabled children and their families that these two major pieces of work together, and in particular that social care support for families with disabled children doesn't fall between the cracks between the two.

It is fair to say that, since the Green Paper consultation has closed, there has been a little bit of political turmoil. Of course, the focus has been on the top of government, but the level of change has been matched at all levels. During this period, we've taken parents to meet officials working on both reform programmes. But with all the instability at Ministerial level, it has been difficult to see what the way forward for the reforms is.

This does not, of course, mean that we have not been busy at the DCP. We have asked parents and young people for their one message for the new Minister (Ms Tolhurst at the time we launched the action, but now Ms Coutinho.) We've been collecting these messages through the autumn – more than 300 of them – and will be sending them to the Minister shortly. We have also been asking MPs and peers to sign our pledge to support a fairer and more accountable system of support. Around sixty Parliamentarians have signed the pledge so far, and you can ask your MP to join them here.

Also during the autumn, we've been running a major survey of parents to help paint an accurate picture of life for families with disabled children, in the context of the cost of living crisis, the end of covid restrictions, and backlogs in public services. More than 2,200 people completed the survey and we will be publishing the results shortly.

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 Helen Arkell.

How it works

We support people with dyslexia to bring about positive changes in their lives. We share information and advice to change attitudes towards dyslexia and we remove barriers to learning and life for children, young people and adults with dyslexia and other specific learning difficulties by providing expert, personal and life-changing support. We also support parents of dyslexic children, their teachers, and employers of dyslexic staff.

Our team of specialists provides help through dyslexia assessments, consultations, 1:1 tuition and training as well as a variety of online and in-person courses, workshops, information and advice. So that we can help people who would otherwise be unable to pay, we provide free support to many individuals from lower-income backgrounds.

What has been achieved?

Last year, we directly supported over 1000 children, young people and adults, through specialist 1 to 1 dyslexia assessments, tuition and coaching. In addition, nearly 1,300 individuals attended dyslexia-related training, courses and workshops.

The impact on individuals cannot be overstated:

'I am taking my degree – a dream of mine I never thought would be possible and would not be if it wasn't for the Helen Arkell Dyslexia Charity. Without their help and support I wouldn't be where I am today.'

'Being able to get my son a dyslexia assessment was a godsend. Finally, he was able to understand why he was finding school so difficult, he wasn't stupid as he believed, but he had dyslexia and he could learn like everyone else but differently. It helped his self-esteem immensely.'

'I was unable to pay for a [dyslexia] assessment and feared I had reached the end of my options when Helen Arkell was recommended. They were incredible! Without the bursary an assessment would still not have been done. … from the day the results came through my son changed, he was more confident and happy to learn. Once he realised his struggles were due to dyslexia he understood why he was finding learning more difficult. … it has had such a huge positive impact on his life and I couldn't be more thankful to everyone involved!'

Next steps

We are committed to increasing our reach and impact in the coming years through a mix of online support and face-to-face regional teams to increase the number of children and adults we can help, particularly those who are on lower incomes.

Our consultations, tuition, skills-building, courses and, where possible, assessments are now available online so that many more people can receive the support they need at home, school or at work.

More information

Website: www.helenarkell.org.uk

Twitter: @ArkellDyslexia

CDC Staff

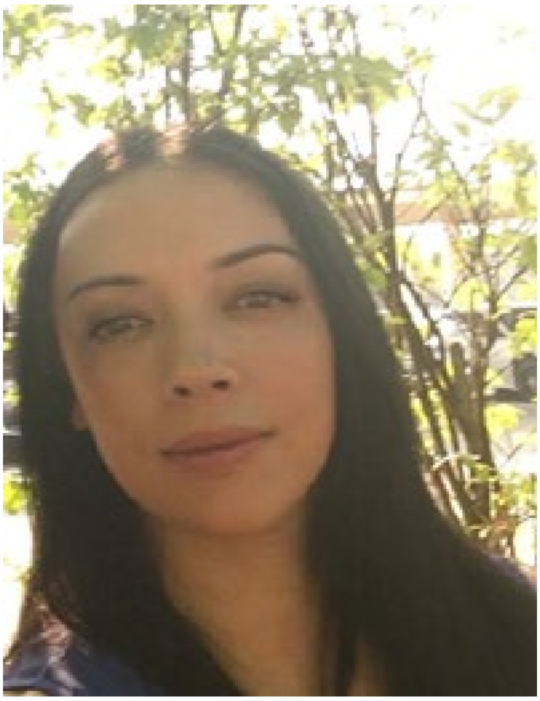
We want to shine a spotlight on some of the lovely people that work at CDC and make lots of great things happen. In this edition, we hear from Reshmi Copperthwaite, Programme Lead in the Education and Equalities team.

As the Programme Lead for the Education and Equalities team, my job entails leading on the coordination and delivery of our contract work and partnerships. One of our main contracts is the EYSEND Partnership programme, funded by the Department for Education.

The EYSEND Partnership involves working alongside a range of specialist organisations with the aim of increasing access and inclusion for children with SEN and disabilities in the early years. We bring local authorities together with early years providers, SENCo's, parents/carers and health teams within a local area to develop a strategic and collaborative approach to SEN and disabilities for young children based on the specific needs of the local area.

I have responsibility for the programme management side of things to ensure systems, processes and how we organise ourselves is producing the best outcomes for children, partners, and local areas. I also contribute to development and growth plans which aim to build upon the great work taking place and maximise outputs.

A highlight within my role involves leading consultations and delivering action learning sets with local areas wishing to make improvements in the early years. We work together to identify strengths, needs, vision and objectives. Local areas then take ownership of figuring out who to bring together and how this work can be achieved. Being part of the process and seeing the creativity and commitment from a range of sectors with a common aim, is rewarding in itself. To then see tangible changes in classroom practice or within childcare settings that demonstrate that children with SEN and disabilities are not only welcome but with high aspirations for their learning and wellbeing; that's priceless.



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, the Transition Information Network, and the Independent Support programme.

Find out more

councilfordisabledchildren.org.uk

facebook.com/councilfordisabledchildren

@CDC_tweets

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

INFORMATION,
ADVICE & SUPPORT
PROGRAMME

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OURSELVES
HEARD

SPECIAL
EDUCATIONAL
CONSORTIUM

TRANSITION
INFORMATION
NETWORK

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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

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NATIONAL CHILDREN'S BUREAU

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