COUNCIL FOR DISABLED CHILDREN

CDC Digest

Summer 2022

Dear all,

The summer holidays are here. The end of an extraordinary period of political change and the end of the SEND and AP Green Paper consultation. This alongside the launch of Integrated Care Boards (ICBs) in the NHS, the Independent Review of Children's Social Care and some National Safeguarding work has meant a busy summer term. The break gives us a chance to reflect and refresh and look forward to the Autumn.

So, what are we expecting?

Further statutory guidance on ICBs and how children with SEND are supported at individual and strategic levels. Do keep in touch as this series of briefings develops.

Delivery and improvement plans from Government following both the SEND and AP Green Paper and the Independent Review of Children's Social Care. The sector has rightly put significant pressure on Government to make sure that disabled children, particularly those with the most complex needs, do not fall down the gaps between Reviews, we know we have been listened to, be good to see the outcome. One piece of work we are doing on this is working with local areas that have received Respite Innovation funding so that learning comes into the system quickly, look out for developments on this.

While the SEND Review process continues we are also continuing our work on improvement, working as part of our DfE contract, recent examples of this include the workforce survey that we have completed and ensuring parents and professionals are part of this and the developments. We are ready to launch a new What Works in SEND programme and interactive website which looks at how we really can make the system work and what has to be in place to make it happen.

In our work supporting the NHS Learning Disability and Autism team, we have been interviewing keyworking pilot sites to understand how they are making a positive impact for children and young people at risk of admission to an inpatient unit, and their families. The service leaders, parent carers and keyworkers we spoke to were all excited about building a genuinely new approach based on an ethos of co-production and rights. The end goal is a service that is both independent and influential, working with children, families and the children's system to identify and address problems and deliver positive outcomes by supporting families to navigate the system when needed and challenging services when necessary. We will be publishing our findings in a guidance document that will help the new wave 3 sites learn from the lessons of the pilot sites as the programme goes nationwide.

The world feels challenging again at the moment as we cope with uncertainty and some massive financial challenges for both families, and the services that support them. Over the summer we will also be thinking about the best ways we can make sure this is recognised and families of children with SEND are not forgotten.

Have a lovely summer, do hope you can all take an opportunity to rest and recharge.

Best wishes,

Dame Christine Lenehan

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Living the Values

Philippa Stobbs

CDC recently launched a new guide for schools*, Disabled Children and the Equality Act 2010: What teachers need to know and what schools need to do. To accompany the launch of the new guide Philippa Stobbs is providing a series of blogs that focus on different aspects of the duties that provide some challenges for schools. This is the fourth and final blog in the series.

*A new guide for early years settings is also about to be published.

In the first blog in this series, I focused on the fact that both SEN and disability legislation require us to do things differently for disabled children and young people and, in the context of schools, disabled pupils. At the same time different treatment can separate and stigmatise and, if not provided sensitively, often does.

In this blog, I want to look at some of the more subtle ways in which different treatment can, without us even being aware of it, put disabled pupils at a substantial disadvantage.

There are often subtle ways in which expectations of disabled pupils are compromised. If you dig around a bit, you can see this at all levels of our educational life, from pronouncements by secretaries of state, threaded through our education press, and in ordinary everyday conversations with children and young people themselves. Respectively:

Secretaries of state: I quote one, un-named here, who talked, in the same speech, about the need to ensure that our education system stretches the most able at the same time as talking about the children who need extra help, support and encouragement to get the basics right.

Threaded through our education press: developing effective independent work for the most able …and producing writing frames and help sheets for the least able; it being crucial that our most able students fulfil their potential, while providing help and support for students who struggle with learning.

The cumulative effect of conversations with children and young people, as reported to the Education Select Committee (2019) by children and young people themselves: [the Committee] heard from young people that poor support can result in them being isolated in school, unable to access the curriculum and find it hard to make friends. As adults, the training and employment opportunities were found to be poor, deriving from a fundamental lack of ambition for young people with SEND across the country.

The risk of compromised ambition is borne out in a report from a team of researchers who have carried out secondary analyses of some of the big longitudinal studies to identify the long-term impact of childhood identified SEN

and disability. One of these studies identified the compromised expectations of disabled teenagers of themselves, in terms of their future educational and occupational ambitions, compared with their non-disabled peers with the same outcomes at GCSE. This effect was identified even where their parents held higher ambitions for their child.

In the Select Committee report, quoted above, there is also a reference to the social isolation experienced by disabled young people. The same team of researchers referred to, above, examined the social isolation experienced by disabled adults. Drawing on three of the major cohort studies they traced the social isolation experienced by disabled adults to childhood identified disability.

There is a range of research that offers some explanation about the roots of this social isolation. Much of the research indicates that disabled children spend a disproportionate amount of time with adults, in comparison with their peers. This can compromise their ability to engage with their peers and form the social relationships that are part of growing up and growing independence, but are also an important part of the learning process itself. The unplanned use of teaching assistants can have the effect of isolating pupils from their teacher, their peers and the curriculum. Even in the playground there is some evidence that adults don't always encourage disabled children to engage in forms of play with their peers where they could, and where children would be interested in and capable of taking part. As one pupil said:

The school seems to think that just because I am disabled I need a lot of protecting ...This makes all my classmates think I cannot fend for myself without the help of an adult.

These are just two ways in which we can put at risk positive long-term outcomes for disabled pupils. But this is not about beating ourselves up about getting this wrong, it's more about trying to raise awareness of the very subtle ways in which we may unwittingly contribute to compromised ambitions and social isolation.

One of the most important ways in which we can address these issues is by listening to disabled children and young people themselves. If we engage with children and young people themselves in considering how best to support their learning, their access to all the education and benefits, facilities or services at the school, we often provide better solutions and better access than we can by devising our own solutions. We also create shared ownership of solutions which augurs well for their success and sustainability.

Support for taking into account the wishes, views and feelings of children and young people is clearly set out in the principles that inform the Children and Families Act, and are reinforced in the Code of Practice and other guidance under the legislation. Bearing in mind that many children with medical conditions are covered by the definition of disability in the Equality Act, it's not unhelpful to turn to the DfE guidance on Supporting pupils with medical conditions at school, for this point:

Pupils with medical conditions will often be best placed to provide information about how their condition affects them. They should be fully involved in discussions about their medical support needs and contribute as much as possible to the development of, and comply with, their individual healthcare plan. Other pupils will often be sensitive to the needs of those with medical conditions.

A helpful thought not just about disabled pupils informing and owning solutions, but also a reminder about the benefits of engaging the wider school community in understanding difference, and, though not explicit here, I would add, celebrating it too.

Council for Disabled Children

Updates

Health

The Health team have been busy getting to grips with the new Research & Improvement for SEND Excellence partnership (RISE), led by CDC. Delivery has already started, and we have recently been conducting some online training workshops with CAMHS practitioners in Wakefield, looking at where they fit in the EHCP process.

As part of RISE, CDC will design and deliver training and resources which further develop skills and knowledge across the SEND workforce. To cater to the needs of the workforce and better understand the needs of practitioners and professionals, we have developed a SEND workforce survey. We have asked for your input in order for it to be as relevant as possible. The survey closed on 2nd August, 2022. Analysis will inform the design of the training.

Work has also been well underway with our Learning Disability & Autism (LD/A) contracts, which has included writing a report for NHSE on how Annual Health Checks can better meet the sexual & reproductive health needs of women and girls with a LD/A.

Early Years SEND

The EYSEND partnership have received another year extension to continue to support local areas, parent/carers and practitioners on a range of topics within the early years. We are pleased to work with new local areas to support their early years vision and continue to follow up with previous areas. We are providing training on a range of topics such as the Equality Act and the duties within the early years and developing the 'ordinarily available provision' in the Local Offer.

Special Educational Consortium (SEC)

SEC has held a range of meetings in preparation for the SEND review Green Paper Response. We have met with different divisions in the DfE to share our concerns and approach to the review. We have also met to discuss the attendance guidance and the review of post 16 qualifications. SEC has also prepared briefings for the Schools Bill, supporting amendments to ensure children and young people with SEN and disabilities are supported within school.

The Information, Advice and Support Services Network (IASSN)

The IASSN have been focused on settling into life under our new contract with our new consortium partners and feeding into the consultation on the Green Paper.

We have been working with services to understand how best to meet their training and support needs. We have arranged new IPSEA training and worked with colleagues to provide training on Early Years and Admission Avoidance. We have also run a workshop to revaluate the Intervention Levels and reconsidered our data collection.

We have focused a lot of time on the SEND Green Paper consultation and have fed into this three times: with SENDIOG, bringing together the voices of colleagues in other national advice organisations; with SENDIAS services and with our young people's IASSN steering group.

Participation

The Participation Team have been busy delivering a variety of projects and continuing to involve children and young people in the National Children's Bureau's work. Through focus groups we have involved over 100 young

people's voices in our response to the SEND and alternative provision Green Paper. Our first Making Participation Work Practitioners Conference fed into Council for Disabled Children's wider response to the SEND Review and focused on how the SEND system must include children and young people in decision-making. The team helped with the planning and delivery of the Its Our Care Day of Action, an in-person lobby of parliament with over 100 care-experienced young people, by providing logistical and pastoral support and social media coverage of the day. NCB's youth-led podcast group are continuing to develop content based on topics they are passionate about, there are some great episodes in the works!

Social Care

The Social Care team are continuing their work to increase communications between the SEND sector and the Department for Education through our Strategic Reform Partner contract. This has included the recent delivery of four consultation events on the SEND and AP Green Paper, a joint ministerial roundtable and a CDC member's meeting. Planning for some delivery and training under the new Targeted Programme Improvement contract with the RISE partnership is also underway.

We have also continued to deliver local and regional work for authorities across the country, including a Children with Disabilities service review in Yorkshire and Humber, testing a newly developed model of flexible short breaks in the Midlands and exploring potential commissioning options for children and young people with Autism and/or SEMH at risk of becoming looked after or requiring an inpatient admission in London.

Council For Disabled Children

SEND and Alternative Provision Green Paper

The consultation for the SEND and Alternative Provision Green Paper closed on Friday 22 July. Thank you to everyone across the sector who attended the consultation events held in May 2022. The events were attended by over 300 participants including parent carers, health, social care, education and the voluntary and community sector (VCS).

How the events were run

- A short presentation from the DfE sharing an overview of the proposals in the SEND and AP green paper and sharing key messages
- An opportunity to ask DfE officials for points of clarification in a Q&A panel
- Discussion sessions with a mixture of parent carers; practitioners across education, health and social care; and the voluntary and community sector (VCS), to discuss the consultation questions and co-produce feedback to the consultation.

The presentation

- You can download the presentation here.
- A film of the presentation delivered by Charles Lang (Deputy Director, SEND and AP Directorate, DfE) can be found here.

Thematic feedback from the events

You can read a summary of the feedback from the events broken down into key principles, considerations for development, and concerns, for the topics below here:

- National Standards
- An inclusive system
- Education, Health and Care Plans (EHCPs)
- Accountability and Leadership
- Funding bands
- Implementation
- Key challenges

The information included in these documents is a combination of feedback across all of the four events and is designed to be a record of what was discussed at these sessions. These summaries along with the detailed notes from the events have all been shared with the DfE SEND and AP Green Paper Team as part of the consultation response.

You can read the Council for Disabled Children's consultation response here.

Children and young people's consultation

The participation team held a consultation for children and young people and they shared their views and opinions on the Green Paper. The report from the consultation will be published online shortly and has been submitted to the DfE. Here are some key quotes from children and young people:

"They should listen to our wishes to where we want to go at each stage of transition, as long as it meets our needs"

"We need to be able to disagree with support, all decisions should be jointly made with us and our families and if something cannot happen it needs to be explained"

"To decide on EHCP/support you should sit down with someone you know so you feel safe to talk about it, you should be involved, so you know what you're doing and why, give you a feeling of independence, and power to change it".

Council for Disabled Children

Making Participation Work: Practitioners Conference

On Wednesday 15th June we held the first Making Participation Work Practitioners Conference of the year. Rather than taking its usual form of interactive workshops on a variety of topics, this conference focused on the SEND and Alternative Provision Green Paper.

Participation, co-production, engagement practitioners and strategic managers from across children and young people's health, education and social care came together to share their thoughts on the proposals in the SEND Review. The key focus of the day was how the SEND system must include children and young people in decision-making. The elements of the SEND Review that we explored were the proposals to:

- Create a single, national SEND and alternative provision system
- Providing excellent provision from early years to adulthood
- Introducing a reformed and integrated role for alternative provision, for children who can't attend mainstream school, whether for behavioural, health or other needs
- Reforming system roles, funding and accountability

The day included a presentation from Fiona Nzegwu (Deputy Director, Special Educational Needs and Disability Improvement and Operations Divisions) on the SEND Review, and one from Emma Mitra (Communications and Stakeholder Engagement Manager, Council for Disabled Children) which looked at supporting the sector to respond to the SEND Review.

The views and opinions shared on the day fed into the Council for Disabled Children's wider response to the SEND Review, adding views with a focus on supporting the participation of children and young people with SEND.

Feedback from the day included

"[Its] always useful to hear other ideas and experiences"

"All very informative"

"Great event with valuable opportunity to hear from other colleagues in the field"

Ways to stay updated on the Making Participation Work Programme

Sign up to our participation newsletter

Join the Making Ourselves Heard Forum

Follow us on Twitter

Council for Disabled Children

Resources, Events and Research

Resources

Holiday Activities and Food Programme Toolkit

Data from the Holiday Activities and Food (HAF) programme delivery during 2021 showed that the proportion of disabled children and young people and those with special educational needs (SEN) participating in HAF activities has varied significantly across the country.

There are a number of challenges and barriers to participation that have been identified by HAF coordinators and providers.

This toolkit is designed to share information, tools and learning from local authorities and HAF providers to enable eligible disabled children and young people and those with special educational needs (SEN) to be as involved as possible in the HAF opportunities in their local area.

This resource is aimed at Local Authority HAF coordinators and HAF providers.

Decision-Making Toolkit

This decision-making toolkit is a practical guide to support parent carers, social workers and anyone working directly with children and young people with special educational needs and disabilities. It is designed to be used in partnership with young people to support them to make their own decisions and to participate as fully as possible in decisions made on their behalf.

It includes a template practitioners can use to support a young person who lacks capacity to go through a best interests decision making process based on the best interests checklist in the Mental Capacity Act 2005 code of practice.

Changing Places in the Early Years

Changing places in the early years is a transition resource to support young children with speech, language and communication needs. It includes information on how families, early years practitioners and local authorities can support transition and includes an example of a communication passport.

Special Schools/Workforce Attendance

To help specialist settings to maintain high levels of attendance, we've published case studies of specialist settings sharing their experiences with some ideas & solutions that have worked for them to stay open & keep their learners in attendance.

Events

CDC's National Online Event

CDC's next national online event is taking place on Wednesday 28th September, 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. If you're not in one of these roles but would like to attend, please email Adeeba at akhan@ncb.org.uk to be added to the waiting list.

Research Opportunities

- HOPE Study is looking for parents/carers, children and young people with SEND, and SEND professionals to complete a survey on SEND identification and provision across England. To take part and share your experiences click here.

- Are you a family carer of someone with a severe learning disability? Would you like to have your voice heard? Queens University Belfast are conducting focus groups with carers across Ireland & the UK to explore some of the issues carers faced during the pandemic. If you would like to register for this project or want more information please contact trisha.forbes@qub.ac.uk. They will be offering all participants a £20 gift voucher in thanks for their taking part.

National Children's Bureau

Stopping the Spiral – Children and young people's services spending 2010–11 to 2020–21

More vulnerable children than ever now need crisis support, after councils were forced to halve spending on services which help prevent them coming to harm.

Over the ten years between 2010/11 and 2020/21, investment in early intervention support by councils in England fell from £3.8bn to £1.9bn (50%) according to a new report commissioned by The Children's Society, Action for Children, Barnardo's, National Children's Bureau and the NSPCC.

The coalition of charities says councils have struggled with the impact of funding cuts, with many of the poorest areas hardest hit.

The research, by Pro Bono Economics, found dwindling funding for early support services – ranging from children's centres and youth clubs, to targeted support with issues like drug and alcohol misuse – means families miss out on getting help early enough to stop problems spiralling out of control.

This has created a vicious cycle, where councils are forced to spend more on costly crisis support, leaving more children and young people exposed to risks like exploitation, neglect and mental ill-health.

Mark Russell, Chief Executive at The Children's Society, said: *"Behind these shocking figures, which saw spending on services for young people fall by three-quarters (74%) from £1.3bn to £300m, are children who have missed out on vital early support, many of whom end up in care.*

"Young people have told us they felt they needed to get hurt or harm someone in order to be taken seriously.

"It's a big concern that children in deprived areas, where needs may be greatest, are often among those least likely to get help before problems spiral out of control.

"If ministers are serious about Levelling Up they must better target funding to the areas that need it most. But councils everywhere have struggled amid government funding cuts and this is why we are calling on whoever becomes the next Prime Minister to ensure children's services teams across the country get the extra funding they desperately need, sooner not later."

The report, Stopping the Spiral, found spending on crisis and late intervention services soared by more than a third (37%) over the decade, from £6bn to £8.2bn. This was fuelled by a 24% rise in the number of children in care to almost 80,000, costing an extra £1.3bn. Four-fifths (80.5%) of local authority children's social care spending went towards these services, which are more likely to be reacting to harm and which councils have a legal requirement to deliver, up from just 58% in 2010–11.

The analysis by Pro Bono Economics estimates that government funding available to councils for children's services fell by 22% from £10.4bn to £8.1bn between 2010/11 and 2020/21, with the poorest local authority areas – where children's and families' needs may be greatest - often forced to make the biggest cuts to early support services. In these areas, early intervention spending per child was reduced by 61% on average, while 25% more was spent on late intervention. The West Midlands (66%) and North East (63%) faced the biggest falls in spending on early support per child over the decade, with the East Midlands (59%) and North West (54%) not far behind.

The coalition of charities is calling for the next Prime Minister to invest £2.6bn in children's social care, as an absolute minimum, as recommended by the Independent Review of Children's Social Care. They say that while investment is needed everywhere, there is a particular need for deprived areas to be

given targeted funding – with the cost of living crisis and increasing numbers of children and families experiencing poverty making this particularly pressing. The care review recommends new investment from 2023/24, but the charities say funding is urgently needed now to help the rising numbers of children needing support and counter the financial crisis facing councils.

They are calling for local authorities to be awarded extra funding in the next Prime Minister's first Budget – including money to open more family hubs, offering vital early support for children of all ages and their families. The children's social care review warned that if current trends continue, 100,000 children could be in care by 2032, with costs to stretched councils rising from £10bn a year to £15bn.

Imran Hussain, Director of Policy and Campaigns at Action for Children, said: "Across political divides there has been recognition of the value to communities and the public purse of investing in services that help individuals and families early, before more serious and more costly problems develop.

"Town halls are being placed in an impossible position by decisions made in Whitehall. The Government has to give local authorities the resources they need to invest in preventative services to stem the tide of children coming to harm before they're helped."

Josh MacAlister, chair of the Independent Review of Children's Social Care said: "These worrying figures support my call for a radical reset of the system to shift the focus towards intensive earlier support for families. It's crucial that reform comes with the investment needed to boost support for families so that more children can grow up in loving families and that the care system can provide the same foundations.

"Tinkering at the edges while continuing to pour money into a crumbling system is unsustainable and it's vital that the next Prime Minister seizes this opportunity to make a difference to the lives of children and families, now and in the future." Spending on children's social care plummeted by £249m over the decade, a 2.4% fall, despite rising numbers of vulnerable young people. Overall, councils spent on average £36 less on each young person – £580 in 2020/21, compared to £616 in 2010/11.

Anna Feuchtwang, Chief Executive of the National Children's Bureau, said: "The Independent Review of Children's Social Care has provided a vision for strengthening families based on the premise of taking action early to prevent children from reaching harm. But this blueprint cannot succeed unless the Government urgently allocates money in the Autumn budget and beyond to reverse the trends of the last decade.

"Our research clearly shows that Government funding for children's social care has fallen away, forcing councils to spend less on early help, abandoning families to slide further into crisis. We call on leaders from national and local government to seize this moment to transform children's lives for the better and invest in prevention."

Matt Whittaker, CEO of Pro Bono Economics, said: "The Independent Review of Children's Social Care rightly called for a 'radical reset' to shift provision away from crisis management and towards preventative support. Our new analysis highlights the urgency with which a reset is required. Under sustained financial pressures, too many councils have opted to cut back on early intervention services, such as Sure Start children's centres.

"Yet this often means they must spend more further down the line on taking children into care and other crisis measures. This is a false economy which lets down the thousands of children at the

sharp end of the care system and the taxpayer. It's a lose-lose situation born out of a short-termist approach to local government financing."

Sir Peter Wanless, CEO of the NSPCC, said: "Given the political turmoil at the moment it is crucial that Government – and in particular the new Education Secretary – does not lose focus on children and the vital role children's services play in keeping them safe.

"For far too long local authorities have been struggling to meet the growing need for children's social care, with first the care review and now the Stopping the Spiral report showing how the system is increasingly skewed towards crisis intervention.

"With the cost-of-living crisis likely to get worse impacting more children and families and putting councils under further strain, it is vital this funding gap is addressed sooner rather than later through significant and sustained Government investment and support."

Barnardo's Chief Executive, Lynn Perry MBE, said: "Far too often families reach crisis point before they can access support and our new research shows the situation is getting worse every year.

"It is critical that vulnerable children can access the right services at the right time, to help reduce the numbers going into local authority care, and improve their chance of gaining good qualifications, staying healthy, and moving into employment.

"Providing the funding necessary so that children and families can access support early must be a key focus for the next Prime Minister, to improve their life chances and achieve longer-term savings for the Treasury."

Read the full report here.

National Children's Bureau

Lifeline offered to thousands of young people leaving care with insecure immigration status

Providing help to young people leaving care with uncertainty looming over their immigration status, can improve lives, save money, and strengthen the system of wider support, finds a new report published by the National Children's Bureau.

The research, funded by Paul Hamlyn Foundation, followed the work of four charity projects over the course of three years, as they worked with local authorities to support young people leaving care with insecure immigration status.

It is estimated that nearly 19,000 looked after children and young care leavers in England have not had their immigration status resolved.

These young people are at risk of losing their entitlement to housing, benefits and access to work and higher education if they are not given the right support whilst still in the care of the local authority.

Care leavers can have insecure immigration status for many different reasons. Some arrive in this country as unaccompanied asylum seekers or victims of human trafficking, while many others have been taken into care from families subject to immigration control in the UK.

Often left deeply traumatised by their experiences in their home country, their journey to the UK or within our borders, these young people often struggle to cope. Mental health difficulties can further hamper how they engage in the complicated process of resolving their immigration status.

Researchers highlighted how the projects being studied helped these young people get back on their feet. This included giving expert guidance on the immigration and asylum systems, but also offering holistic support to improve young people's wellbeing, mental health and ability to engage with services.

The research showed that this type of early intervention work to identify and address the needs of these young people can help avoid costs later on which would normally be borne by local authorities. Researchers estimated that these savings could be as much as £100k for just one young person. If these figures are multiplied by the number of young people with insecure immigration status supported by the local authorities, the potential cost savings are significant.

Young people described how they benefited from the projects, helping them to understand their rights whilst supporting them to engage in informal support networks, and access education and training opportunities.

Crucially, the projects enabled local authorities to better meet the needs of young people with insecure immigration status under their care. Local authorities particularly valued training for professionals and carers, and support for social workers and personal advisors on individual cases.

Holly Donagh, Director of Strategic Learning, Insight and Influence at Paul Hamlyn Foundation, said:

"This research shows that embedding voluntary sector expertise on migration within local authority children's services improves outcomes for young people with insecure immigration status. Early intervention is key, so that immigration issues are identified and resolved before a young person turns 18, thereby enabling them to lay down roots and thrive in the UK.

"It also saves significant sums of money for local authorities because the charities support young people to resolve their immigration cases more quickly, and avoid years of unnecessary accommodation and legal costs. We are delighted that the outcomes have been so positive and there is much to be learnt about these successful models of practice up and down the UK."

A key aspect of the approaches developed by the charity projects was organising a range of activities to give young people a voice, so they can influence the system they rely on. Co-producing services is important as often these young people's trust in the system has been severely undermined.

Frances Lyons, Head of Research at the National Children's Bureau, said:

"These young people are becoming independent adults with no certainty over their future in the UK. If they can't navigate the bewildering bureaucracy of the immigration system, their problems will deepen and social care services will be left to pick up the pieces.

The Independent Review of Children's Social Care has set out a roadmap for improving children's social care, but this vision will never be achieved unless the Government allocates the funds required to put it into practice. This must include funding for effective support for young people leaving care with insecure immigration status, building on this evidence of what works."

Read the full research report here.

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 an evidence-based, peer-led, group-based programme, developed by the University of Exeter, in collaboration with parent carers, disability charities and commissioners that focuses solely on promoting health and wellbeing of primary carers.

The programme has been extensively researched, gaining glowing testimonials from parent carer forums and parent carers alike:

"The programme provided me with actually useful tools that helped me implement small changes that have positively affected my health and wellbeing." Ayan, parent carer, Enfield

"I have learnt so much about myself and how important it is to look after myself, it has made me determined to pass this on to others." Denise, programme facilitator

"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

The 12-module programme is now being rolled out across the UK. If you would like to train facilitators in your area, we have online training programmes starting in September and November 2022.

For further information about training and opportunities contact Alice Garrood a.garrood@exeter.ac.uk or visit the Healthy Parent Carers webpage here.

Contact

Finding suitable childcare during school holidays and term time

The summer holidays are well underway and for the families we support there is lots to look forward to in the school holidays – but finding suitable childcare isn't easy. Although childcare settings and holiday clubs are meant to welcome and include disabled children, in practice this is often not the case. Many families report that childcare and holiday clubs can be unsuitable, expensive and availability limited for disabled children.

Some families with disabled children recently spoke to the Metro newspaper about their difficulties finding suitable childcare during the six week summer holidays.

While local authorities in England have a duty to provide childcare for all, a third admit there is not enough childcare for children with special educational needs (SEN), due to a lack of funding. As a result, there continues to be a gap in take up of free childcare hours for disabled children.

And in a move that Contact fears will make the situation worse, the government has been consulting on reducing staff ratios in childcare settings in England. Contact is against the proposals which seem certain to make settings less accessible for children who may need additional support.

Una Summerson, Head of Policy at Contact, said:

"High quality, flexible childcare helps children's educational and social development. It also enables parents to maintain paid employment. But for too many, suitable holiday clubs and childcare remain a pipe dream. The shortage of staff with disability experience and low levels of pay in the childcare workforce is an issue. In addition, research shows families with disabled children pay eight times more towards childcare costs than other families, making it unaffordable for many.

"We would like to see an increase in the child disability addition under Universal Credit to enable more families to afford holiday clubs and childcare. There also needs to be more funding for local authorities and childcare providers to help improve the quality and number of places for children with disabilities. Parents need to feel confident that childcare or summer holiday club can meet their child's needs – good communication, inclusive and welcoming attitudes, a willingness to take small steps to make the activity or experience inclusive, taking parents' views on board to make this happen."

Contact has put together template letters for parent carers in England whose children are refused childcare. These are based on the most common barriers to accessing childcare for disabled children and what can or can't be done to overcome them.

Contact's Out of Energy campaign

In April the BBC exclusively revealed findings from Contact's Out of Energy survey on their new Access All podcast.

Based on responses from 5,499 families in March 2022, Contact found that:

- UK households with disabled children had average energy bills of £1,909 per year in the last 12 months – £600 more than the average household bill.
- During this winter, 42% went without heating and 10% went without vital electric-powered disability equipment because they were unaffordable to run.
- Families estimate they pay £74 per month to run disability aids and equipment, such as adjustable beds, ceiling track hoists, wheelchair chargers, feeding and suction pumps.
- From April, families with disabled children expect their annual energy bills to be more than £3,000 per year – almost double that of an average UK household.

Download the full survey report and national/regional breakdown.

As a result, Contact's Out of Energy campaign is calling on the government for targeted support for disabled households to help with soaring energy bills.

In May, the Chancellor unveiled new measures to help UK households, including support for disabled households. But Contact's campaign doesn't end there. In May the Chief Executive of Ofgem Jonathan Brearley said the energy price cap could rise to £2,800 in October however, our research found that many families with disabled children are already facing bills of that size. Without better support now and in the longer-term, families could find the gains from the government's latest support package wiped out.

Thousands of families showed their support for our Out of Energy campaign by signing our letter to the Chancellor and families spoke on TV, radio and to newspaper journalists to highlight why disabled households have unavoidably high energy costs. Parent carers like Amy Jonson from Cardiff. Amy is a sandwich carer for her elderly mum and son Jayden, aged 10, who has Cerebral Palsy. She says she has always been good at budgeting, but is struggling to manage these unprecedented rises in energy costs. Amy says:

"My son has cerebral palsy and needs electrical equipment for his care and to take part in everyday life – electric hoists, bed, wheelchair and communication devices. We would be at a complete loss without this equipment. On top of that Jayden, can't regulate his body temperature. When he is home and it's cold, we need the heating on."

While we're pleased that the Chancellor has finally acknowledged the extra costs disabled households face families Contact supports still face worrying times, and one-off measures won't be enough in the longer term. There's a danger that any gains made could be wiped out if a family with a disabled child has to claim Universal Credit, which for 100,000 families will mean being worse off by more than £1,800 a year as a result of the 50% cut to the lower child disability addition.

Find out more about Contact's campaigning work.

Disabled Children's Partnership

#SENDABetterMessage Campaign Update

Aidan Smith – Campaign Officer at the Disabled Children's Partnership (DCP) – gives an update on the #SENDABetterMessage campaign.

What an intense few months. Following the launch of the government's 'SEND Green Paper' consultation on reforming disabled children's support on 29 March, right up until its closure on 22 July, the DCP's #SENDABetterMessage campaign has been firing on all cylinders.

Together with thousands of parents, young people, charities and supporters across the country, we have challenged the most concerning elements of the government's plans, and worked as hard as we can to raise the voices of families with disabled children in the process.

We can't thank all of the amazing campaigners and professionals that have joined with us and taken action for a fairer SEND system enough.

Here is a short update on how the campaign has gone, and what is next.

What is the #SENDABetterMessage campaign?

Firstly as a quick reminder, #SENDABetterMessage calls on the government to use its SEND reform programme to create a more just, fairer system of support for disabled children and families – one that is easier to navigate and gets them the services they're entitled to without having to fight for them.

The campaign aims to help amplify the voices of families with disabled children during the government's reform process, enabling as many people to get involved in as easiest a way as possible.

Although many of the aims and some ideas in the government's plans are welcome, the campaign also works to challenge the proposals in the SEND Green Paper that could further restrict support for families: such as limiting the choice in schools parent carers have, or making it harder to reach the SEND Tribunal.

Getting politicians to hear the voices of disabled children and carers

We started the campaign by creating a simple way for people to email their MP and share their thoughts on reforming SEND with their local representative.

In total, over 1,300 people emailed their MP, massively raising awareness of the issue with politicians.

As a result, several MPs sent letters to the government, tabled parliamentary questions to get responses from ministers, and raised the campaign in parliament.

In addition, more than 30 MPs, members of the House of Lords, and parliamentary staffers attended our virtual parliamentary event on 17 June to hear directly from parent carers and disabled young people on their experiences

navigating services, and their views on changing things for the better. We can't thank the phenomenal people that gave up their time and spoke to MPs enough.

Finally, alongside the Sun newspaper, a group of parent carers met the Minister for Children and Families – Will Quince MP – in person to demand a more just and fair system face to face

6 simple questions on SEND

After the event, we shifted focus to helping get as many young people, carers and others involved with the government's reform programme as possible. We heard from many people that the government's own public consultation was long, complicated and hard to understand with 22 lengthy questions.

Working together with parent carer campaigners and charities, we simplified the government's consultation into 6 simple questions on SEND. We shared the responses anonymously with the government on a weekly basis, and facilitated over 1,800 people sharing their thoughts on the future of SEND who otherwise may not have had the chance.

The grand finale

In the last week of the Green Paper, we worked hard to ramp the pressure up, launching an urgent action encouraging people to message the Secretaries of State for both Education and Health and Social Care directly. Over a thousand people took action and demanded no weakening of the rights of disabled children and families from those in power.

Then, on the last day of the paper on Friday 22 July, a group of parent carers and young people supported by the DCP gathered in Westminster to loudly demand a fairer and more accountable SEND system. The group wore boxing gloves and red tape to symbolise the constant battling and bureaucracy in the system, and handed in the thoughts of families with disabled children from the 6 simple questions to the Department for Education.

What's next?

The government will now be taking away all of the responses and feedback they've received, and analysing it to produce an implementation plan by the end of the year, explaining what specific changes to the SEND system they will make.

Until then, the #SENDABetterMessage campaign will continue to provide a platform for the experiences of families with disabled children, loudly shouting that a fairer and more accountable system is needed. A system where the rights of disabled children and families are met.

You can get involved with the campaign by sharing photos and videos as part of our 'online exhibition' on SEND, and by signing up to our campaign network. Go to our website to find out more and get involved.

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 Starlight Children's Foundation.

How it works

Starlight works to promote and support the right to play for children in the healthcare system. We deliver direct services and resources to children and families to make the hospital experience more positive and treatment less traumatic; we create opportunities for social connection for them and their families; and by listening, learning, and sharing knowledge we connect and collaborate with other organisations to work towards systemic change in the provision of play in healthcare settings.

We have recently developed a new policy and public affairs strategy with the overall aim that public policy for children's healthcare fully reflects the importance of play to their health, wellbeing, resilience, and recovery – and that this translates into more and better health play services for more children.

What has been achieved?

In 2021, we reached over 1.2 million children in almost 500 hospitals across the UK. We distributed 4,481 Distraction Boxes and Boost Boxes, and 207 gaming bundles. We welcomed 202 families to the return of our in-person events, whilst still supporting 302 children at home with our virtual parties and resources.

More recently we have been providing support to the Covid vaccination programme, helping to make the process more child-friendly and accessible to more children.

We have convened a regular health play forum to bring together practitioners, researchers, and health service executives to consider how children's health services can better respond to children's needs and rights to play. We are working with NHS officials and practitioner bodies to consider the potential for the role of health play specialist to become a regulated health profession working to nationally recognised and adopted standards for health play services

Next steps

Our vaccine programme support work is being evaluated for wider application and we have launched a new initiative to pilot Starlight-funded Health Play Specialists in healthcare settings across the UK. These new roles will directly support the provision of play for the seriously ill children who need it most. We are also piloting the use of Virtual Reality technology in children's care and treatment.

In the policy sphere we continue to work with the institutions of the NHS to support them to fully respond to the recommendations of the 2021 NICE guidance to ensure:

"easily accessible, age-appropriate play and recreation for children and young people, including to reduce boredom and anxiety while waiting for appointments or interventions" and to *"Reduce the fear and anxiety about pain that may be experienced by babies, children and young people during healthcare interventions by ... using therapeutic play and distraction techniques and creating a calm environment..."*

(NICE Guideline on Babies, children and young people's experience of healthcare, 25 August 2021)

More information

Website: www.starlight.org.uk

Twitter: @starlight_uk

Job Opportunities

Participation Programme Officer

This is an exciting opportunity to join the Participation Team delivering and developing NCB's work on children and young people's engagement and participation. The post holder will take responsibility for the effective delivery of key participation projects including our new NHS England projects focussing on improving key services for children and young people with learning disabilities and autism, as well as supporting other teams across NCB in their consultation activities and contacts with children and young people. Experience of developing and delivering engagement with disabled children and young people and those with special educational needs is a must for this post.

Project Assistant – Participation

This is an exciting opportunity to join the Participation Team supporting NCB's work on children and young people's engagement and participation. The post holder will be the first point of contact for a busy team, supporting effective delivery of key participation projects that put children and young people's voices at the heart of government. This is a varied role that requires attention to detail, the ability to move between tasks at a rapid pace, and skill to make complex information accessible for a range of stakeholders. The majority of the post holder's duties will support the Making Participation Work programme, experience of working with disabled children and young people and those with special educational needs would be an advantage.

Programme Manager – Health and Justice

We're looking for someone with experience of working in the youth justice or health and justice sector, who can jump right into a varied and fast-moving role in NCB's growing health team. In their first month in role, the successful candidate can expect to be project managing; gathering and analysing both qualitative and quantitative data; designing and co-facilitating focus groups and workshops and drafting content for reports. As a key part of the health team, you will be very quickly immersed in a team that delivers a range of programmes and activities related to systems improvement and multiagency working for children and young people. We're looking for someone keen, highly organised and who is happy to learn from, and collaborate with colleagues.

Chair of The School' Wellbeing Partnership

The Schools' Wellbeing Partnership is looking for a leader and influencer who can inspire schools to embed mental health and wellbeing in schools, as well as influence government officials and policy development.

You will support us to achieve our vision, identify and build consensus, work with a variety of stakeholders, and act as an ambassador for the Partnership and our members.

The Cabinet Office Disability Unit – 9 Regional Stakeholder Network (RSN) chairs

The Cabinet Office Disability Unit is recruiting 9 Regional Stakeholder Network (RSN) chairs on behalf of the Minister for Disabled People, Health and Work. They will join an existing stakeholder engagement network that covers 9 regions of England.

RSNs have supported government work throughout the COVID-19 pandemic, and have worked to develop and implement wider disability policy. The RSN's chairs work with networks in their region and the Cabinet Office to continue to ensure the voices of disabled people throughout England are heard and valued in a way that informs policy and strategy.

Previous chairs have made significant changes in their sectors, using their expertise to make good progress for disabled people. They have helped the government improve the lives of disabled people and remove many obstacles and barriers they can face.

Yet there is still more that can be done to improve the lives of disabled people. The new chairs will continue the work to tackle issues faced by many disabled people through an ongoing dialogue with the government.

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

INFORMATION, ADVICE & SUPPORT SERVICES NETWORK

MAKING OURSELVES HEARD

SPECIAL EDUCATIONAL CONSORTIUM

TRANSITION INFORMATION NETWORK

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

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NATIONAL CHILDREN'S BUREAU

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