COUNCIL
FOR DISABLED
CHILDREN

CDC Digest

Winter 2022

Dear all,

I hope you have come into the New Year refreshed and relaxed and ready for the challenge ahead. At CDC the team are as busy as ever as we continue to deliver a support and improvement programme, working with areas across the country.

Given we have now been doing this for a number of years, we have recently been reflecting on our learning. In all the work we do, what is it that underpins positive change? Hopefully it feels the right time to share these reflections with you.

They are a set of key principles and processes:

- The need to understand outcomes. At both an individual and strategic level. These need to be co-produced with all agencies and parents and children, and locally owned with a defined set of indicators that illustrate progress and support development. The local ownership builds strength and credibility and helps the development of a clear vision.
- The development of effective commissioning, which is based on accurate data and analysis of need. This has to reflect families and young people's priorities and should, whenever, possible be joint commissioned.
- These processes can then be embedded in pathways which support the needs of groups of children, for example we work a lot on pathways for children with speech, language and communication needs and for those with neuro-disability. The pathways have to be meaningful for everyone involved, with a clear link back to outcomes.
- We need to support EHCP processes, using CDC e-learning, and building in quality assurance processes and an approach based in need, and producing plans which are meaningful and proportionate.

We have worked with over 50 areas now, each is different but each has needed one or more of the elements above. We know that when we do this we can build workforce confidence and knowledge, help multi-agency communication and collaboration and support the voice of parents and children to be heard.

These are building blocks in terms of effective practice and we expect them to underpin the outcomes of the SEND Review.

We learn so much from working with you and look forward to continuing the partnerships.

Best wishes,

Dame Christine Lenehan

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Postcard from a Virtual Meeting

- Philippa Stobbs

This autumn's meeting of the European Agency for Special Needs and Inclusive Education was significantly focused on European Agency projects on teacher training, professional development and school leadership. These are projects we reviewed at an earlier meeting, while they were under development. As with most of Agency projects, they draw on the policy frameworks, the practices and experiences of member countries. Now that they are written up, published and available on the Agency website, what do they tell us, as we look into the mirror with other European nations?

First, as you'd expect from the European Agency for Special Needs and Inclusive Education, all the work is threaded through with a strong focus on inclusion. The school leadership work re-states the right to inclusive education set out in the UN Convention on the rights of Persons with Disabilities:

A principle that values the well-being of all students, respects their inherent dignity and autonomy, acknowledges individual requirements and ability to effectively be included in and contribute to society.

And, in the European work, the first of three core functions of inclusive school leadership is about setting direction:

Inclusive school leaders have the vision that all learners of any age should receive meaningful, high-quality education in their local community, alongside their friends and peers.

Leadership is described as giving strategic direction, with a focus on the values that underpin inclusive practice, enabling participation, raising achievement, supporting well-being and creating a sense of belonging for all learners, including those most vulnerable to exclusion. An echo from Edward Timpson's review of exclusions?

Schools must be places that are welcoming and respectful, where every child has the opportunity to succeed.

At the teacher level, there are some clear synergies between our teacher standards and the profile of inclusive teachers in the European work. They share strong strands on the effectiveness of lessons and approaches to teaching, but particularly on teachers as reflective practitioners.

This chimes with research based on a meta-analysis of the most effective teaching in inclusive classrooms. A couple of key features that stood out in my reading of this research were: that teachers with a broad and detailed knowledge of the curriculum framework within which they were teaching were better able to understand where children were in their learning, and so were better able to plan next steps for all the children in their class; secondly, that those who were most effective also kept their understanding of the curriculum framework constantly under review with a 'pedagogic community', revising their understanding in the light of what they observed about children's progress. All of this enhanced their ability to be teachers of all learners.

This reads straight in to the messages in the Agency publications that:

effective teachers are teachers of all learners

Our own teacher standards emphasise the importance of high quality teaching as being the most important factor in improving outcomes – this from our Initial Teacher Training Core Content Framework:

The ITT Core Content Framework has been designed in the knowledge that the quality of teaching is the most important factor in improving outcomes for pupils – particularly pupils from disadvantaged backgrounds and those with additional needs. As such, the ITT Core Content Framework is designed to help trainee teachers take their first steps towards becoming expert teachers of the future who can transform the lives all pupils.

Many of the synergies here relate to the professional practices that underpin high quality teaching and are less well pronounced when it comes to setting out the values and direction that are so clearly articulated in the Agency work on school leadership and inclusion. So where are we nationally in terms of setting direction?

Much of the pressure for the SEND Review has been driven by a consideration of the funding frameworks with the report from the National Audit Office saying very clearly that:

The system for supporting pupils with SEND is not, on current trends, financially sustainable.

...it's not unreasonable to point to the financial drivers for the SEND Review: they are significant. But we need to look beyond that to some of the drivers of our values (NAO again):

Pressures – such as incentives for mainstream schools to be less inclusive, increased demand for special school places, growing use of independent schools and reductions in per-pupil funding – are making the system less, rather than more, sustainable.

So where do we stand on those values that are so strongly articulated in the European Agency work on all the responsibilities of teachers at different stages in their career: those in initial training, in their early career, in their professional development and as school leaders? Do we have a clear articulation of those values? Is the direction clearly set? And is it the responsibility of the SEND Review or of the wider education system to set this direction?

Like so much else, the last few meetings of the European Agency for Special Needs and Inclusive Education have been hosted in the virtual environment. However, to date, each virtual meeting has still been hosted by one of the member countries, with a welcoming ministerial speech, usually with the national flag, a national emblem or map in the background that confirms which country we are all visiting. This meeting was not hosted in a member country in the same way: our Chair was in Dublin, our Director in Odense in Denmark, each in a different time zone and we were each in our own kitchen, study, bedroom or broom cupboard. So I'm not sure why this was more confusing than pretending that we were all in Belgrade, but it was. It's easier when you know where you are and when you're all in the same place.

Wish you were here

Hope to see you face-to-face soon,

Philippa

Liberty Protection Safeguards

Royal Borough of Greenwich example

Introduction

The Deprivation of Liberty Safeguards (DoLS) were introduced in England and Wales as an amendment to the Mental Capacity Act in 2007. They were intended to provide legal safeguards for individuals who are deprived of their liberty and do not have the capacity to consent. However, the DoLS process applied only to those over the age of 18 who are being deprived of their liberty in care homes and hospital settings. This left a legal grey area for young people aged 16 and 17 in all settings, in spite of the fact that the Mental Capacity Act 2005 applies to all individuals over the age of 16. Consequently, the House of Lords Select Committee on the Mental Capacity Act found that the DoLS system was 'not fit for purpose' and a subsequent review by the Law Commission recommended that DoLS be replaced by the Liberty Protection Safeguards (LPS).

The implementation of the LPS brings many changes, most notably that all settings are now covered and that the safeguards are extended to 16- and 17-year olds. It also brought about the introduction of three responsible bodies to alleviate pressures on local authorities. Under the new system, applications are considered by those responsible for the person's care allowing more appropriate and timely responses.

The Royal Borough of Greenwich has successfully begun this work through a multi-team development programme, as detailed below. Although the LPS are not yet in force, existing case law has made it clear that parental consent is no longer acceptable authorisation of a deprivation of liberty for 16- and 17-year olds and authorisation must be sought from the court of protection. As such the work set out in this learning example is important for current practice as well as future practice in line with the LPS.

Background, aims and objectives

Nationally, there has been growing attention paid to DoLS and MCA for young people under 18 for several years. The work being done by the Royal Borough of Greenwich really began around 18 months ago when they were completing the children's commissioner's data return which was looking for information on issues around confinement and authorisation. Through this it became clear that there wasn't significant oversight of these issues within the LA, despite pockets of good practice. They were also receiving many FOIs in relation to this area of practice and it was evident there was not a sufficient way to track this need.

Additionally, when reviewing cases within Children's Services it emerged that necessary practice around confinement and authorisations had not been fully embedded and there was a need for a full system response to ensure compliance with legislative responsibilities.

Practice was inconsistent across all of children's social care, and this extended beyond SEND services alone.

Therefore, the aims of this project were:

- To embed legally compliant practice around confinement and authorisations across Children's Services
- To increase professional knowledge about legal requirements across teams
- To facilitate adequate and consistent tracking of need

- To increase consistency of practice throughout the LA

Approach

Following on from reviewing practice across the system, the Head of SEND Social Care drafted a paper outlining the areas for development across the system to present to their Director's Management Team (DtvlT). The paper covered the legislative framework to provide the necessary context on core legal responsibilities for decision makers without specialist knowledge of SEND, as well as an update on current practice including gaps and risks to the organisation. By detailing what the authority should be doing in comparison to existing practice, the Head of SEND Social Care was able to highlight the fact that there was a level of risk operationally and organisationally due to the gaps in practice. This helped establish buy in from DtvlT who were able to deliver the message across the system that this area of work was a priority.

DtvlT agreed to the recommendations outlined in the report and a Task and Finish group was established to implement the recommendations made. Task and Finish groups typically rely on sustained involvement from cross-sectional groups of staff from different departments, ranging from senior leaders to frontline operational staff. This approach was chosen because it seemed best able to bring together the right members of staff to enable the full systems change that was needed to meet the aims of the project. The multi-disciplinary group included representation from Children's Social Care, IT, Data/performance team, SEND Assessment and Review, Quality Improvement Team, Legal Services and Adult's Social Care. The DtvlT report was shared directly with this group to provide clarity on the goals they were seeking to achieve and inform the conversations about the necessary tasks to undertake.

The group met for 1.5–2 hours monthly, working through the many recommendations which spanned workforce development; recording; and data, tracking and monitoring. Tasks were taken on one at a time to break up the enormity of the challenge. Within 9 months the Task and Finish Group had successfully implemented all of the recommendations.

Successes

Changes implemented by the task and finish group included a full review and update of Children's Social Care recording to reflect issues of confinement, mental capacity and authorisation. New templates were created as needed, such as a focussed DoLS Legal Planning meeting form, but otherwise updates were made to existing documentation to ensure issues of confinement and capacity were considered across the journey through children's social care.

A training programme was developed within the Task and Finish Group as very little was available to buy in. Building a bespoke offer allowed Greenwich to tailor the programme to the specific needs of the workforce and enable discussion and learning across teams. The introduction to MCA and DoLS module was developed and delivered by colleagues in Legal Services, including an inhouse child protection solicitor and barrister. This was made available to all staff in Children's services as the implementation group felt strongly that the goal should be to upskill all staff rather than making this a specialist task. Approximately 150 staff attended this training. A more detailed Mental Capacity Assessment training was developed with an external trainer and opened up to social workers and Team Leaders across the services.

Approximately 50 social workers and Team Leaders attended this. The training programme was joint funded by the relevant social work services, establishing buy in across services. An ongoing, sustainable training programme is being developed now to ensure knowledge and skills are retained in the organisation.

Brilliant Basic tools were also developed for staff to understand DoLS, MCA and local practice around recording and tracking. These were circulated by the Assistant Director of Children's Social Care establishing this as a priority for all services, not just SEND services. This was to recognise that although most cases do come through the SEND team, the safeguards can also apply to children and young people with mental health conditions.

Having reliable data on this cohort was a priority so a recording process was implemented and a report developed to ensure they could pull this data together when needed and analyse trends over time. This included an episode on the recording system with a relevant practice guide on how to record an order.

Tracking and monitoring was going to be key to sustained improvement in this area. A monitoring form was developed to track existing DoLS orders, cases going through the court application process and cases where a DoLS may be required in the future. Within the SEND social care services, this tracking meeting is jointly chaired by the Head of SEND Social Care services and a senior child protection Solicitor. Social Work Team Leaders attend the tracker and bring actions back to their teams as needed. This provides improved leadership oversight on the need within the service.

Challenges

A core challenge has been changing attitudes and perceptions within the workforce. Issues of confinement and authorisation are a new area of practice for many workers in children's services. It is taking time to see changes in practice for staff, particularly those who won't be regularly completing this work. Ensuring all services take ownership for this and maintain good practice around assessing capacity, identifying confinement and seeking necessary authorisation will take time. This is being driven by Head of SEND Social Care Services but requires ongoing buy in from senior leaders and staff across Children's Social Care.

Sustainability of this development work also presents a challenge. Ensuring that as the staff group changes, knowledge and skills on DoLS and MCA are sustained requires an ongoing training and development programme. This is being developed with our social work and training services.

Additionally, having a better grip of need through this implementation work has meant an increase in application for Dols which has a significant impact on capacity within the social work team and legal services. There is also a matter of cost for the applications to court. This is being monitored closely and capacity will be reviewed if increased pressure continues.

Conclusions and next steps

A key lesson learnt from the work undertaken by the Royal Borough of Greenwich is that successful implementation of the changes relies on cross-organisational oversight and buy-in, particularly when you are trying to generate a culture shift. This will require clear messaging from the implementation group to clarify the vision for the future as everyone across the system is learning at the same time. Within Greenwich, they have used a consistent narrative to keep all colleagues on the same page. Namely, that deprivation of liberty is not a negative phrase and it is something that needs to be embedded in daily practice in an appropriate and sustainable way.

It is also important that there is a commitment to ongoing development work and creating a meaningful feedback loop from practitioners and families. For Greenwich, this will involve the Task and Finish Group coming back together to complete a review of practice in a year's time. This will include looking at any unintended consequences from the changes embedded.

In terms of next steps, there is a clear need to extend the scope of the children and young people being focused on. Although the Liberty Protection Safeguards will come into effect when a young person turns 16 there is still a need to consider the needs of younger children, particularly those in a local authority's care. There is also a question over the needs of children who aren't classed as children looked after, many of whom will also be affected by the implementation of LPS. This could include children in residential special schools as well as receiving support in the community through short breaks where they may be deprived of their liberty or have their liberty restricted.

For those local areas who need additional support in beginning their implementation journey, the Council for Disabled Children have developed a LPS system readiness tool designed to pull together in one place the key pieces of evidence that a local authority will wish to assure itself on and give a high-level overview of its progress. Click here to download the tool.

Click here to find out more about our new virtual training 'Decisions, capacity and EHC plans', designed to learn practical, rights based approaches for involving disabled young people and those with SEN in decision-making through an interactive virtual training session.

Council for Disabled Children

3rd Making Participation Work Practitioners Conference 25.01.22

The Council for Disabled Children's Participation team hosted their third national conference designed for practitioner development on a range of participation and co-production related topics. The conference was delivered on January 25th via Zoom with six workshops on offer, it focussed on discussing how SEND youth voice and engagement plays a role in developing quality local area provision.

Workshops held covered a wide range of topics. KIDS hosted a session featuring 'top tips' for feeding back directly from young people and the Chatterboxes discussed their role in improving the Annual Health Check offer for young people with a learning disability. CDC'S Participation team shared how the CDC works with children and young people to support them to develop their voice and speak out to decision makers, which was created and delivered in co-production with young people. The National Children's Bureau's Early Childhood Unit gave an introduction on listening to young children whilst Lambeth Early Action Partnership Community Engagement Team explained the benefits and successes of the 'festival approach' for reaching families and increasing participation. The NCB's Anti-Bullying Alliance ran a workshop on how they have engaged young people by utilising social media.

The conference has received fantastic feedback, including:

"Young people led. Loved it"

"I've come away with more ideas to share with the [young people] I work with"

"Informative and worthwhile"

"Really interesting and picked up useful practice to take back to my service"

The Participation team also have the Youth Voice Matters Children and Young People's SEND Conference on February 23rd. The conference is looking to be very exciting with lots of workshops to choose from, including an introduction into managing money and how to prepare to speak to decision makers.

Ways to stay updated on the Making Participation Work programme:

Sign up to our participation newsletter here

Join the Making Ourselves Heard Forum here

Follow us on Twitter

Council for Disabled Children

Training Event: Navigating Transitions for Disabled Young People

The Council for Disabled Children (CDC) are launching a new range of virtual training for Foster Carers and their Supervising Social Workers, in order to support improved outcomes of children and care leavers with Special Educational Needs and/or Disabilities (SEND).

This training package is designed to provide the knowledge and skills required to navigate the processes of supporting disabled young people transitioning into adulthood, including understanding Education, Health and Care Plans (EHCPs) and staying put arrangements.

The first session will be held on:

Date: Wednesday 9th February 2022

Time: 10:00am to 2:30pm

Cost: £95 per person, including VAT

Sign up here.

Council for Disabled Children

Updates

Health

The Health team have been busy continuing to deliver the multi-agency working strand of the Delivering Better Outcomes Together (DBOT) programme. Recently included in this work was a national webinar for SEND leads and commissioners on the much-debated topic of approaches to sensory support. Planning for our last online national event for this financial year is well underway, and will take place on the 1st March. Further DBOT work has included regional data workshops and bespoke support to local areas.

We also continue our work with Rochdale around mapping their early intervention offer, supporting them to build their ordinarily available provision for Early Years and all SEND systems, as well as supporting them to build a data dashboard. Other work has involved developing tools for outcomes-based data capture, planning focus groups for service managers in health preparing to implement mandatory SEND training in the South East, and developing a resource for professionals on the use of EHCP Hubs.

We have also started delivering our new Learning Disabilities & Autism contracts, looking at current work in different regions around CETRs, with a goal to create e-learning aimed at local authorities.

Early Years SEND

The EYSEND partnership have continued to deliver training sessions to practitioners and parents on a range of topics within the early years, whilst preparing for future events within the next quarter, which you can sign up for here. This includes training in the Equality Act and the duties within the early years and developing the 'ordinarily available provision' in the Local Offer. The partnership also includes direct action learning sets with local authorities to develop their ordinarily available document and support transitions for young children into reception. Early Years SEND Partnership has delivered a range of training events, both face to face and virtually, to support schools in developing their understanding of EHCPs, the Equality Act, preparing for adulthood from the earliest years and developing the 'ordinarily available provision' in the Local Offer.

Special Educational Consortium (SEC)

SEC has held a range of meetings with different divisions in the DfE and with Ofsted, with a big focus on the upcoming SEND review. SEC has met with the lead of the SEND review to discuss their '20 asks' for the SEND review, along with meetings exploring how funding can be used to effectively support children and young people with SEN and disabilities. SEC has prepared responses to public consultations including exploring how local authority school improvements are funded, developing accessible arrangements and exploring Ofsted's role in the online education accreditation scheme.

The Information, Advice and Support Services Network (IASSN)

Since November the IASSN have been focusing on developing and delivering a range of face to face and e-learning courses to meet the needs of Special Educational Needs and Disabilities Information, Advice and Support (SENDIAS) services. IASSN have also developed tools and resources to support SENDIAS services and published their annual data report which gives a national overview of SENDIAS services and can be used as a tool for joint commissioning opportunities locally.

As well as ensuring that IASSN are on target to meet KPI's, goals and outcomes for the year, they have also been talking to service managers at regional meetings, over the E-Forum and individually. The IASSN know that next year will be tough with a reduction in their budget so they need to make sure they get things right by co-producing their work and delivery plan with services as well as with their new Practise and Innovation Board and Children and Young Person's Practise and Innovation Board. The IASSN know that by working with services and other stakeholders, they can make sure they are in the best position to support the incredible work of SENDIAS services next year.

Participation

The National Children's Bureau's network of children and young people have continued to contribute to our work in numerous ways. Two of our FLARE members ran a workshop on Participation and co-production in resource and consultation development with glowing feedback from attendees. Young people from across the various advisory groups helped the Development team to bring the Annual Report to life, you can hear them speak here.

National Children's Bureau

Trauma-Informed Practice in Early Child Development

This report is one of a series of programme 'Insights' which aim to collate and share the learning emerging from A Better Start (ABS) – the ten-year, £215 million programme set-up by The National Lottery Community Fund, the largest funder of community activity in the UK.

The five A Better Start partnerships, based in Blackpool, Bradford, Lambeth, Nottingham and Southend, are working with families so they play an active part in deciding on and designing the services and support they get and ultimately give their babies and very young children the best possible start in life.

These reports reflect on learning on a range of key programme outcome areas in order to inform the work of others in improving outcomes for young children.

This issue is number four in the series, and provides a summary of emerging evidence in the area of childhood trauma and adversity. It shares the learning on how ABS partnerships have embedded an awareness of the impact of adverse childhood experiences (ACEs) within their work, and how they are supporting the development of trauma informed practice, within and outside of their partnerships.

As will be clear from the report, there is a strong bi-directional link between childhood trauma and life adversity, with children living with multiple adversities (such as deprivation) more likely to experience ACEs, and adults living in poverty more likely to have experienced childhood adversity themselves.

Families living in ABS areas are at increased risk of experiencing trauma and its impact. ABS programmes and services have a key role to play, both in addressing existing trauma and preventing further trauma, and have the potential to make a lasting difference.

The report includes:

- Background to this area of practice, including the science of brain development and the impact of trauma on child development.
- Adverse childhood experiences (ACEs) theory and core principles.
- Trauma-Informed Practice (TIP), Implementation models and approaches.
- Trauma-informed practice within the ABS partnerships: overview, case studies, and lessons from ABS.
- Trauma-informed practice examples from across the UK, and lessons learned.

Read the report here. And sign-up to receive the A Better Start newsletter here.

Trauma-informed practice in early child development

Insights from The National Lottery Community Fund's A Better Start Programme

National Children's Bureau

Personalised Care could 'Revolutionise' Mental Health Support for Disadvantaged Children and Young People

Personalised mental health support for disadvantaged children, where help is flexible and tailored to young people's specific needs, improves treatment and responds effectively to individual's lived experiences and challenges.

A series of focus groups, coordinated by the National Children's Bureau, with children, young people, parents and the practitioners who work with them, indicates that personalising care plans, and offering individual budgets to access opportunities to study and build positive relationships can improve a young person's mental health, life chances and wellbeing in ways that clinical services cannot always achieve.

Young people from disadvantaged backgrounds face a range of significant barriers to accessing support. They often lack awareness of the options open to them, and digital poverty can restrict their access to opportunities.

Children said that a flexible and individualised package of support worked best to reduce loneliness and isolation; improve access to education and training, and provide practical help. Personal health budgets and social prescribing approaches enabled them to access items and or experiences which young people from socially deprived backgrounds would otherwise not be able to access. Children and young people particularly value a long-term, trusted relationship with a support worker who can coordinate holistic and integrated care so that their complex and overlapping needs can be met.

Amanda Allard, Assistant Director at the National Children's Bureau, said: "Co-producing mental health support for disadvantaged children and young people, so they have choice, control and flexibility, can revolutionise the impact and outcomes they experience. Children want services that offer continuity in the staff they work with, and provide community-based services where they can discuss their issues in accessible and de-medicalised language. We need support for these new ways of working, so mental health services can respond rapidly and inclusively, with the personalised help that children and families value as soon as problems arise."

'Making a Difference to Young People's Lives Through Personalised care: Mental Health Inequalities and Social Deprivation' is available at: https://www.ncb.org.uk/personalisedcare

All-Party Parliamentary Group for Children Discusses Integrated Care

In December, the All-Party Parliamentary Group for Children (APPGC) met to discuss putting children at the heart of Integrated Care Systems (ICSs), the new structures being established by the forthcoming Health and Care Act that will replace Clinical Commissioning Groups.

Over 130 members of the children's sector joined parents, young people, Government officials and Parliamentarians to discuss the challenges and opportunities offered by the Health and Care Bill – which is currently making its way through Parliament.

The Children and Young People's Health Policy Influencing Group (HPIG), hosted by the Council for Disabled Children and National Children's Bureau, and representing over 70 leading voluntary organisations, Royal Colleges and professional associations, has worked closely with officials and MPs on the Bill.

A number of HPIG's amendments aimed at securing a greater focus for babies, children and young people in the Bill were tabled and, importantly, Edward Argar MP – the Minister for Health and Social Care – gave a commitment to develop "bespoke guidance for Integrated Care Systems on meeting the needs of babies, children and young people".

You can read HPIG's Lords Second Reading briefing on the Bill here.

In a packed agenda at the APPGC, speakers discussed the opportunities for better integration of services and many speakers highlighted how this could impact disabled children and young people in particular:

- Stephen Kingdom, Campaign Manager at the Disabled Children's Partnership, explained why children with SEND are particularly reliant on joined-up care, arguing that we can't allow families to be shunted from pillar to post before having their needs met. He said integrated care needs to focus on funding, accountability and leadership.
- Amanda Allard, Assistant Director at the Council for Disabled Children, echoed the need for data sharing across agencies and stressed that solutions needed to be found for difficulties around governance and accountability related to sharing children's data.
- Edward Argar MP, the Minister for Health and Social Care, restated the importance of multi-agency working – including in relation to housing – and why the needs of children need to be at the heart of integrated care.
- Anna Feuchtwang, Chief Executive of the National Children's Bureau, emphasised: the need to strengthen accountability for ICSs through a national accountability framework; supporting the transition from Clinical Commissioning Groups to ICSs; and improving data and information sharing for children.
- In a video message, parent Leanne discussed her personal experience of what good integrated care looks like. She described how she hid her need for help until a key worker could reach out and help her navigate the mental health system.

You can find a full write-up of the event, as well as some of the useful resources discussed, on our website here.

More information about the All-Party Parliamentary Group for Children's far-reaching work can be found here.

Childhood Bereavement Network Survey

Help us reach bereaved children & young people – so their voices can be heard

Bereavement is a tricky subject to talk about. We don't talk about it often, and many people feel awkward discussing death, dying and bereavement. Many people feel uncomfortable and often don't know what to say. Many people may have had their own experiences, and talking about it means remembering something they find painful or sad.

The UK Commission on Bereavement thinks it's really important that we do talk about it. We know that more children and young people have been bereaved in the United Kingdom due to the pandemic. The Commission really wants to find out what works for them, and what doesn't. Have a look at these three surveys that will allow the Commission to listen to bereaved children and young people:

- One for bereaved children aged 5 – 12, to complete with their parents (we think this would take about 10 mins to complete)
- One for bereaved children aged 13 – 15 (again, this should take about 10 mins to complete)
- One for bereaved young people aged 16 and 17 years (this is a slightly longer survey, and would take about 25 minutes to complete)

There is full information about safeguarding, confidentiality and the use of data before you start any of the surveys, along with support information from places ready to listen to any concerns a bereaved child or young person might have. **The surveys close on 20 February 2022**.

If you are aware of a bereaved child or young person who is ready to talk about their experience, please consider signposting them to these surveys. This is a brilliant chance for bereaved children and young people to shape the future of bereavement support. They can choose to complete the survey – it's completely up to them. Thank you so much!

Contact

Families with disabled children left financially devastated by pandemic, new study from Contact reveals.

Many families with disabled children are still living with the financial fallout from the pandemic. Almost half of families with disabled children reported a devastating drop in household income of £48 a week – or £2,500 a year. And that's before the Universal Credit £20 uplift ended in October 2021. These are the findings of Contact's Counting the Costs 2021 survey, the charity's flagship survey and research report about the finances of families with disabled children.

"I found myself having to battle to get the smallest bit of support during this time. I was registered homeless for nine months while I applied for council housing, home schooled my twins who both have high-level needs, and juggled caring for my daughter who needs constant supervision while my son was in hospital with a post-operative brain injury."

Joanne, mum of 14-year-old twins

Two-thirds of parent carers forced to give up work

Contact surveyed almost 3,000 UK families with disabled children to find that:

- Nearly two-thirds (61%) of parent carers said that their caring responsibilities mean they or their partner had given up paid work, on average losing £21,270 from their family income.
- In the last 12 months, almost a third of parent carers have gone without heating (30%) and food for themselves (37%). Half have gone without toys, presents and computer equipment for their children.
- 55% of respondents were shielding during lockdown. As a consequence of shielding, 30% report they got into debt or borrowed money, 15% got behind with mortgage payments, 10% used a foodbank for the first time and 7% lost their job.
- Nearly a quarter (23%) of respondents claim Universal Credit and 40% of those said they are worse off since claiming, despite assurances from government that no one would be worse off.
- 92% of parent carers say going without affects their own health and a third (34%) saying it affects the health of their child.
- Almost one in five say they have increased care commitments due to the pandemic that will impact their ability to earn money in the future.

Download Contact's full Counting the Costs 2021 report [PDF].

"Parent carers felt abandoned during the pandemic, filling the gaps not only with home education, but nursing and physiotherapy too. Financial difficulties combined with a lack of support have taken their toll. We must turn the tide and have a benefits and support system that genuinely values carers."

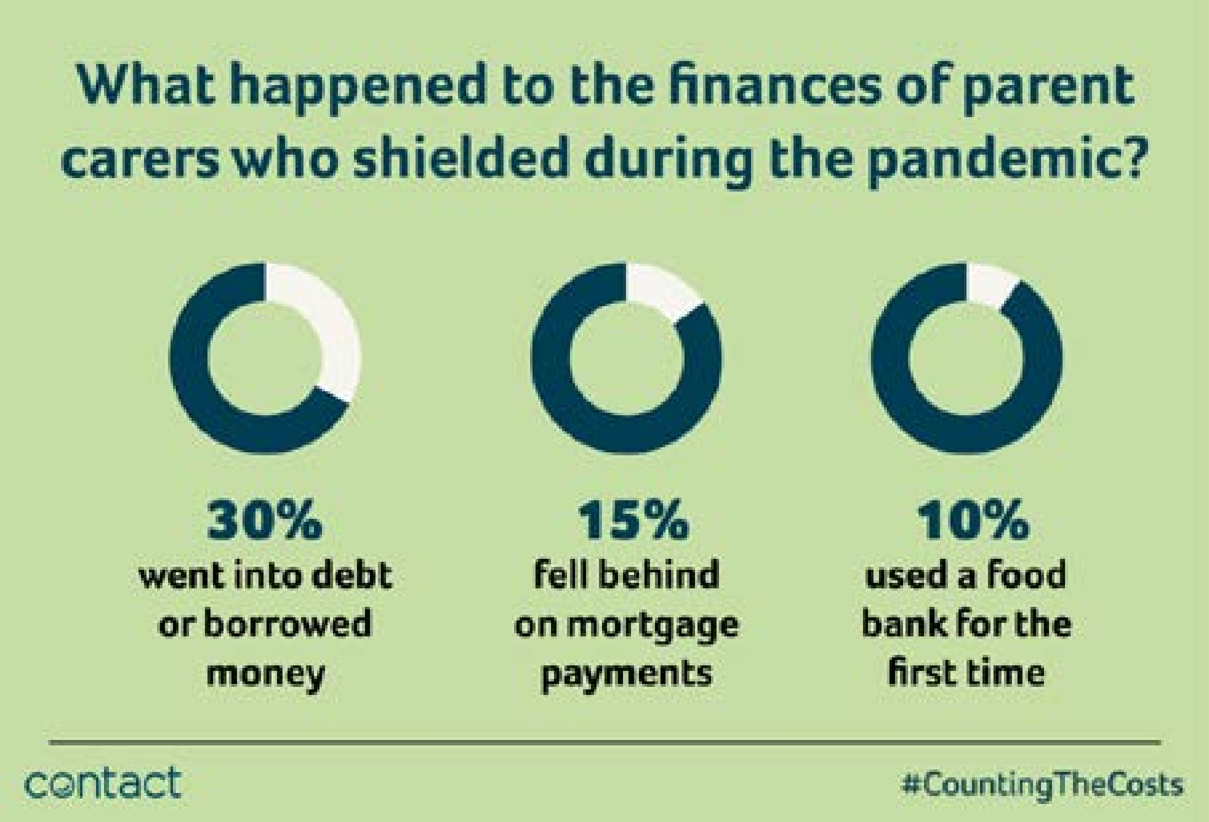
Amanda Batten, chief executive at Contact

As a result Contact is calling for:

- An increase in Carer's Allowance and child disability payments under Universal Credit.
- Energy companies to introduce a special tariff for households with sick and disabled children due to the rising bills facing families this winter.

The government to invest in specialist independent advice services, to help families with disabled children claim what they are entitled to.

Join Contact's Counting the Costs campaign to call for a benefits and support system that genuinely values carers. Email this template letter to your MP demanding change.



Special Needs Jungle

Special Needs Jungle is establishing a panel on Race and SEND, called the SNJ Intersectionality Panel. We're currently recruiting panel members from parents and SEND practitioners who are from relevant communities to look at how discrimination, misunderstanding of culture (or both) negatively affect children and families when trying to access the right SEND support.

Initially, we're looking to gather experiences of families to input into the SEND Review, so this is an urgent piece of work. We have created a survey here, that is now open.

The panel is led by SNJ's Associate Editor, Marguerite Haye, a former head teacher and parent of a disabled young woman, and Mala Thapar, also parent of a disabled child. Marguerite and Mala both understand these issues intimately and have previously written an article on SNJ about the problems faced.

SNJ firmly believes that all disabled children, regardless of their background, should be offered the help they need to thrive. We hope that by facilitating this Intersectionality Panel we can highlight issues, raise awareness and influence positive change. We aim to produce guidance on working with disabled children from diverse backgrounds.

Please pass this survey link to your relevant members, and if you have someone within your organisation that you feel could make a positive contribution to the panel, please email team@specialneedsjungle.com.

Disabled Children's Partnership

#CountDisabledChildrenIn – the new Disabled Children's Partnership campaign

Aidan Smith – the Campaign Officer at the Disabled Children's Partnership – gives an overview of their latest campaign and outlines how you can get involved.

For too long disabled children and families have had their human rights undermined. At the Disabled Children's Partnership – a coalition of 100 organisations (including the CDC) that campaigns with parents, young people and others – we passionately believe that every family with a disabled child has a right to the proper level of health and care support.

So every child can develop alongside their peers, and achieve the same opportunities. So every parent can have a break from caring, and pursue other opportunities if they wish.

But sadly, our research shows that too many disabled young people and families simply are not getting the support they deserve. **We are campaigning for local councils to do better.**

What is the #CountDisabledChildrenIn campaign?

#CountDisabledChildrenIn was developed with parent carers, and forms part of our wider #GiveItBack campaign highlighting the underfunding of disabled children's services.

In Spring 2022, local councils in England will be deciding their budgets for 2022–23, including how much to spend on disabled children's social care services. The campaign calls on councillors in England to prioritise disabled children in their plans and invest in the social care services that disabled children and families have a right to in order to live a good quality of life, and right years of injustice.

Our research

Our pandemic research has exposed that **nearly three quarters of disabled children have seen their progress managing their conditions regress** in the pandemic as services were further diverted and cut, with many parent carers facing huge levels of mental health problems and exhaustion.

Freedom of information requests revealed that local authorities and the NHS struggled to meet legal targets for providing services – creating a large backlog in services and a timebomb in unmet need:

- 40% of local authorities cut respite care for families – despite the prevalence of relationship breakdown and social isolation in parents.
- Over half of local authorities have failed to meet their targets for providing vital Education, Health and Care plan assessments

Infuriatingly, COVID-19 simply upturned and further scorched a landscape of support that was already in dire need of investment and reform. Our economic analysis with the charity Scope already revealed that there is a **£2.1 billion funding gap in disabled children's health and care services** in 2019/20.

Public support for disabled children and families

To coincide with our campaign, we commissioned a poll of 2,000 adults in the UK about their views on disabled children's health and care services.

- Only 18% thought that disabled children and families got the right support from councils and the NHS.
- Whilst 73% said that the delays disabled children and families have experienced to health and care services in the pandemic were unacceptable.

The results clearly show the public think disabled children and families deserve better

support, and that they currently are not getting it.

With these new polling figures, combined with our other research, the argument is overwhelming for local and national government to do better.

What are we calling for?

At Rishi Sunak's 2021 Autumn Budget, no dedicated health and care support for disabled children and families was announced. However, a total of £4.8 billion in additional government funding for local councils was released.

As councils plan their budgets, we are asking them to use some of this money to invest in disabled children's health and care, correct years of underfunding, and give every family the support they are entitled to.

Finances will be tight, but this is a huge opportunity to right years of injustices, and make long-term savings for the future as expensive medical procedures are prevented through better early intervention, and more parent carers have the opportunity to enter employment.

How can I get involved?

We are asking parent carers, professionals, and anyone who is any ally and wants to stand up to social injustice to take our quick and easy online action to email their local council leader, ahead of when local councils set their budgets in Spring 2022. You can take action here. **Please join us, and call on your local council to #CountDisabledChildrenIn.**

You can follow the Disabled Children's Partnership on Twitter at @DCPCampaign, or on Instagram and Facebook at @DisabledChildrensPartnership. Visit their website here for more information on their research, and other campaigns.

Aidan Smith – the Campaign Officer at the Disabled Children's Partnership

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 **Raising Youth**.

How it works?

Raising Youth was originally established as a community group in July 2019 to spread awareness of services available to young individuals and signpost where necessary. Raising Youth began to grow towards providing their own services that you see today and as a result was registered as a Community Interest Company in April 2020 before converting to a Charitable Incorporated Organisation in October 2021.

Raising Youth provide services to support individuals aged 0–19 years and 20–25 years for those with Special Educational Needs and Disabilities (SEND) or Mental Health (MH) conditions. Their services cover a wide range of topics ranging from Mental Health, Employment, Education & Daily Life.

Raising Youth is ran completely by volunteers both behind the scenes and frontline.

What has been achieved?

Raising Youth has many achievements:

- Raising Youth launched their Skills for Life Programme. The programme is designed for young people with SEND to prepare for adulthood and independent living. The programme aims to teach young people in key areas such as: cooking and nutrition; cleaning and hygiene; washing and other domestic chores; accessing health and social care services; managing personal relationships; accessing the community and travelling (public transport); looking for and accessing work and post-18 education.
- In October 2021 Raising Youths' newly launched Skills for Life Programme received funding from the National Lottery Community Fund. The funding was used to ensure high quality resources for service users and to help promote the service to reach even more young people.
- Raising Youth hosted a celebration evening to reward their fantastic volunteers for their hard work over the past two years.

Next Steps

Raising Youth are currently looking for individuals to join their Trustee Board to govern and steer their work to success. If you are passionate about what they do and about changing the lives of children and young people, they would love to hear from you!

Website: www.raisingyouth.co.uk

Email: enquiries@raisingyouth.co.uk

Twitter: **@RaisingYouthSE**

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. Meet Sorrel Norwood, our senior project officer in Social Care.

Hello! My name is Sorrel Norwood and I joined the Social Care team at the Council for Disabled Children six months ago as the Senior Project Officer. Since I've started, I've been getting to grips with the many different important contracts that the Social Care team delivers with support from internal and external colleagues. A core part of my role is to provide project management support and ensure we are meeting all of our objectives across contracts. Recently this has included attending contract management meetings with key partners like the DfE, preparing for end of year reports and mapping all of our upcoming delivery for the next 3 months.

I am passionate about ensuring all children and young people have the right to a happy and healthy childhood and I've been lucky to work in this sector for some time. Before I joined CDC, I was leading youth participation projects for young carers and children living in care. I also have experience of running a pan-London youth empowerment programme for young carers and young people with life-long or life-limiting conditions.

These experiences working directly with children and young people have shaped my practice and strengthened my understanding that for meaningful change to occur, all frontline professionals across the sector must work together in the interest of children and young people. I'm grateful to be working in an organisation which is firmly committed to listening to the voices of children and young people, empowering professionals, and leading on creating change.

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,
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PROGRAMME

INFORMATION,
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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

London: 23 Mentmore Terrace, London, E8 3PN

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NATIONAL CHILDREN'S BUREAU

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