Welcome to the summer issue of the CDC Digest

This is a round-up of the latest updates, resources and news stories from the SEND sector that you may have missed over the past few months, if you were lucky enough to get away to warmer climates. I do hope this edition of the digest will be a useful way to dive back into work.

Mental health in schools, inclusive education conferences and reports championing joint commissioning are just a few of the projects that have been keeping the CDC teams busy.

We are also delighted to announce that our membership community is continuing to grow, and we have two new members sharing their impact and future goals in the Shining the Spotlight segment.

This September marks five years since the Children and Families Act 2014 came into force. This feels like the perfect opportunity for us to reflect on the hard work and progress we have made over the last five years.

It is also useful for us to consider the challenges we still face in making sure all children are supported to reach their full potential.

Alongside the usual updates, you can read my thoughts on the last five years, and our vision of what the future could look like. A future we are all working to make a reality.

We are also at the cusp of an exciting move to our new and shiny permanent home in East London. We look forward to hosting you soon once we are settled into the new building. Keep an eye out for more information from us on this in the near future.

Christine Lenihan
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The Children and Families Act: Five Years On

Dame Christine Lenehan, Director of the Council for Disabled Children

The Children and Families Act (CFA) came into force in September 2014, heralding the biggest reforms to Special Educational Needs and Disabilities (SEND) in a generation. At the time, our Director Dame Christine Lenehan said changes would take another generation to embed. As we reach the Act’s anniversary, Christine considers the positives and negatives of the Act’s implementation so far, and sets CDC’s vision for the next five years.

Evolution or revolution?

One or two of you who are blessed with a good memory may recall that at the time the Act came into being, I gave a few thoughts on the new legislation. We can all recognise the significant flaws of the previous system, how it too often let children and their families down and left practitioners facing too many barriers to support them in achieving their best outcomes.

We said then that it would take a generation to embed the legislation. I suggested that the key issue we faced in September 2014 was how to make what we have work for the children, young people and families. So now we reach the Act’s 5th anniversary, I think it is important to reflect on the progress we have made so far.

A few successes

It would be too much to consider here all the incredible work the sector has achieved since 2014, so here are just a few key positive changes the CFA brought about:

1. **Co-production**

I am a firm believer that parents and families are the key to achieving positive change for children and young people. The Act put working together with children, young people and families firmly at its heart. The reforms have also strengthened the voices of children and young people at every level, from individual plans, to joint commissioning, to influencing government policy and practice.
2. **Better understanding**

For many families, their experiences in the previous health system were poor, with many practitioners focusing solely on a child’s condition or their prognosis, without an appreciation of their broader life outcomes. The development of the role of designated medical/clinical officers (DMO/DCO) is making it possible for the needs of children to be better understood at both an individual and a commissioning level. Now, over 90% of local areas have a DMO/DCO and we see, daily, the difference they make.

3. **Information, Advice and Support Services**

CDC is proud to support these services, whose role has been extended, challenged and developed. Their work, not just with parents, but with children and young people directly, has led to tangible change in the outcomes for children and young people. This has been very clear in service user feedback and in the Ofsted/CQC reviews.

**What of the challenges?**

As the Act came into being, I asked if it was possible to introduce new law at a worse time. I would hesitate to dwell on this question, but the timing provided some huge challenges for implementation and sustainability, many of which will be all too familiar to most of you.

**Budget context:** The impact of austerity and savage cuts to local authority budgets have undermined the ability of local areas to work in partnership, innovate and sustain positive change. Together with the challenges to high needs budgets, this has led to a sense of crisis and, if we are not careful, hostility that puts a focus and blame on parents and children for a systemic problem.

**Joint commissioning:** This context has also hindered joint commissioning, which requires flexibility, innovation and trust. Which is all much easier when money is more readily available, as our report *It Takes Leaders to Break Down Siloes* shows. While some areas have shown tremendous leadership to commission joint services effectively, we need strides forward here.

**SEN Support:** A focus on EHC Plans has led to them being seen as the only way of accessing support, with the under-development of SEN Support contributing to this. This has led to real challenges in assuring both schools and parents that children’s needs could and should be met by SEN support.

**Transition confusion:** The introduction of the Care Act at the same time as the Children and Families Act and the lack of focus on the detailed world of post-19 practice, has led to disarray as young people approach adulthood. Many families still describe experiencing a cliff edge of support, often differing for different services.
Leadership: We know the consistency and quality of staffing and knowledge in local authorities around SEND is poor in too many areas.

We are privileged to be facilitating a programme of work to bring positive change in leadership across the country, holding joint ministerial roundtable meetings which complement and feed into the work of the SEND Leadership Board.

So, what do we most want to happen over the next five years?

Reflecting on our progress over the last five years, I still believe that the Children and Families Act represented an evolution, not a revolution. We work tirelessly to bring about positive outcomes for disabled children and those with SEN. For this work to have the most impact I would want to see some key changes.

• Parents and young people must be treated as equal partners and placed at the heart of decision-making.

• We need adequate funding which supports all children, young people and families to reach their full potential. Funding should provide the resources that organisations need, without falling into debt or compromising on other duties.

• SEN support should be strengthened, with practitioners and organisations working together to provide the best support at an early stage. This should complement more specialist services which should be available to schools and colleges wherever children and young people need more support.

• We must identify new measures of success: new metrics to reflect inclusion in schools; parental involvement in the EHC needs assessment process; measures to show how many children contribute to their plan. Our 0-25 SEND Data Dashboard is a step towards gathering meaningful data which can underpin decision making and targeting support.

• CDC is working hard to facilitate good joint commissioning, between agencies and between areas. This must become standard practice in meeting local and area needs, while joint budgets (Education, Health and Social Care) must become fully established for children with complex needs.
How Young People View the Reforms

In the following articles, two young people, Carys and Hannah, talk about their experience of the Children and Families Act. Both are members of FLARE, the national participation programme delivered jointly by CDC and KIDS.

Make your choice - Five Year Anniversary of The Children and Families Act

Carys

Five years ago, The Children and Families Act was passed into law, bringing feelings and wishes to the forefront of all decision-making. It demanded that councils should consider and value wishes of the child/young person and their families, even if that meant changing the way support and services were delivered.

Section 19 of the SEND Code of Practice states that local authorities must consider the wishes and feelings of the young person when making decisions, and the legislation also highlights the importance of youth voice and participation. The Act, effectively, gave us a voice. Brilliant, right?

Yet, many people don’t see how intimidating this voice is. And, when so many young people bravely share their opinions, they often feel like their views have been cast aside or not given the proper respect. But there’s a way to deal with this. Proper feedback systems will enable services to prove they have listened to young people, and show that they have done everything in their power to grant the young person’s wish.

At FLARE and regional KIDS groups, young people are given a voice to speak up when they believe that something is not right. Developing the voice of a young person is so important, so they develop the confidence to tackle any problems that life may throw at them which, in turn, will combat ableism as we see more disabled people in the spotlight, fighting for equality.

Respect is a funny thing. You can respect someone, yet disagree with their opinion. However, from a young age, you’re taught to be silent when expressing an opinion in order to “respect your elders and betters”. This “respect” seems to replace the importance of a young person’s decision, instead helping to silence them and manipulate them into choosing what services or parents may believe to be “the right path”. This power dynamic can be changed, though.
Valuing a young person’s voice will make this power inequality less evident, and will enable a young person to develop trust in you and speak to you honestly.

We’re effectively told:

“Make choices, but don’t make the wrong choice.”
“You have a voice, but we are not going to listen”
“Only you know yourself, but your doctor knows what’s better for you, so, actually, now I think about it... just go with what they say.”

In order to encourage children and young people to speak up, we need to show the benefits of speaking up. You see, in order for the Act to have an even more profound impact on people’s lives, we need to abide by the legislation set out in the Act. Local authorities need to make people feel like their opinion is considered and listened to.

With this Act, however, do we really have a voice?

In my opinion, yes. Or, at least, we should.

Therefore, we must call into question whether The Children and Families Act is enough. Although the SEND Reforms have been a game changer, in effect enforcing youth voice, it is also important that services are willing to listen. As young people, we don’t want false pretences.

Give us a choice if there is truly a choice to make. Lay the facts out in front of us, but don’t lie. So, so importantly, we, as individuals and as a society, must be able to recognise the courage it takes to speak up and add your voice to the conversation.

To children and young people, I say: If your voice goes against what you think others want, speak anyway. There may be reasons for a decision that you don’t quite understand, or the local authorities may not have considered the arguments in your point of view. Nevertheless, by speaking up, you’re only using your human right.

And no matter your choice, speaking up is always right.
My journey through education (so far)

Hannah

In 2014 I turned 17, the same year the Children and Families Act became law. Having suffered meningitis as a one-year-old, my whole life that I remember I have had special educational needs and physical disability. I have suffered epilepsy, I have had numerous hospital stays and health issues.

I spent the first 16 years of my life in education under the old Education Act and since I was 17 I have benefited from the new reforms. I have attended a mainstream school, a mainstream college, a specialist college for students with disabilities, and am now at university studying special educational needs, disability and inclusion. I also, through the EPIC and FLARE groups have had the chance to give my input and views on the development and delivery of the reforms. Because of my direct experiences and advisory role I feel I am in a unique position to reflect on the reforms.

Having always gone to mainstream schools until 16 I always had a full-time Statement of Support which meant I got full-time support at school. I had various ups and downs along the way but by and large I was supported at school. At 16 my senior school only allowed students to stay on to do A-levels. Due to my dyslexia, problems with my short-term memory, and visual issues, I struggled with exams and didn't have the grades to do A-levels there, so had to look at a local mainstream college to do a BTEC.

On leaving school my Statement ceased and, although there were promises of support at college there was nothing legally binding, I was left to struggle. I was the only student that was not allowed to do placements, as there was no one to support me and I felt my time in education was over. Problems with my epilepsy increased and I had major brain surgery and a number of months after that was spent recovering.

During this period of time the SEND reforms came into being. After my surgery, and with the existing support in place, I knew there was no way the local college could support me to achieve my potential. The reforms allowed my parents to apply for me to have an Education, Health and Care plan.
Mine was the first plan independently applied for in Dudley for a student whose statement had ceased. Without the reforms I wouldn’t have been able to do this, my education would have been over. The process allowed mine and my parents’ voices to be heard.

I ended up getting a place at a local specialist college to do Level 3 BTEC. Having always gone to mainstream school I was nervous about going to a specialist college but I can honestly say that this college helped me to achieve my goals. I was allowed to do the course over three years - the slower pace suiting me and helping me build my confidence. I did numerous placements, I became a college ambassador, I even managed to pass my GCSE maths on the fourth attempt, and when I left the college I got the college award that year for an achievement.

I am now back in mainstream education, in my second year at Wolverhampton University. I am enjoying my course, I am enjoying learning. I lived at home for the first year as we are local but I’m trying to increase my independence by living in halls for part of the week this year. Without the SEND reforms and the Education, Health and Care plan, which extends educational support up to 25 years, and listen to my views, this would not have been impossible.

I know there have been issues with the reforms and the delivery of Education, Health and Care plans. For me there were delays and time scales were not met, but I can honestly say the reforms have helped me to achieve my goal of going to university and leading an increasingly more independent life.
We at CDC have had the privilege of creating a wide range of resources, briefings, toolkits and guidance to support children, young people, parents, practitioners and organisations to best serve disabled children. Many of these resources utilise examples of the excellent practice which takes place in local areas. This article highlights just a few of our favourite resources produced over the last five years.

Very early into the reforms, we created a general briefing on Part 3 of the Children and Families Act. This briefing gives an initial introduction to the reforms, and what they meant for children, young people, families and practitioners.

Information, Advice and Support Services (IASS) are a crucial element of the support for children, young people and their families. Our IASS Network work with IAS (also referred to as SENDIAS) services to ensure they have the resources and training to provide high quality information, advice and support to children, young people and their parents in their area. IASSN have produced a huge number of really useful resources.

One of which we are most proud is the Minimum Standards for IAS services. The Minimum Standards set out how each IASS should be operated, and the quality of service they should provide. You can find both the standard and an easy read version here: IASS Minimum Standards and Easy Read Minimum Standards.
**Education, Health and Care (EHC) Plans** can be a fantastic resource to support children and young people.

We created **two linked guides to good practice in EHC Plans**, one for all ages and one focused on transition aged young people from Year 9.

Both guides give good practice examples based on excerpts from real plans provided by IAS services around the country.

As part of the **Making Participation Work programme**, we have developed **a series of Factsheets** on issues related to participation. These are coproduced with children and young people with SEND, in response to issues which are important to them and are raised by professionals during our regional learning events. You can see Factsheets on topics including methods of participation, work experience, developing child centred EHC plans and an exemplar for a participation strategy.

One of the most beneficial outcomes from the reforms was the introduction of the role of **Designated Clinical Officer/Designated Medical Officer (DCO/DMO)**. CDC are proud to have created a wide range of resources, and to host the DCO/DMO forum. The forum supports the sharing of knowledge and peer support across the country. You can find resources and the forum here: [DCO/DMO Resources](#).

Access to up to date, reliable **data on children and young people** is a major challenge across the sector. CDC developed the **0-25 Multi-Agency Data Dashboard** to begin to bring together data relevant to education, health and social care in one place, to aid commissioning. The dashboard is designed to support local areas to understand the needs of children and young people in their area, to measure the work underway and to identify how effective it is.
We know from our work with local areas that measuring success and securing good quality advice for EHC plans remains challenging. We created a suite of audit tools which support local areas to measure their impact and effectiveness on several key areas, including strategic participation, inclusive participation & evaluation. In addition we also developed two resources on securing good quality health and social care advice.

The law evolves and case law creates ongoing, important changes for disabled children and young people. CDC is grateful to be able to work with Barrister Steve Broach from Monckton Chambers, who compiles a Case Law Digest. The digest provides clear, accessible updates on the latest case law changes, and what they mean for local areas and families.

More recently, CDC have published a report on integrating services for disabled children ‘It takes leaders to break down siloes’, you can read more about this and download the report in the article below. There’s also an accompanying parent carer resource: 'Shaping services around your child'.

These are a small selection of our favourite resources from the last five years. These and many more can all be found on our Resource Library.
Recent developments

Joint Commissioning Bulletins

The joint commissioning bulletins are designed to share the learning from discussions around a whole series of issues relating to the SEND reforms and joint commissioning to a broader audience.

Six joint commissioning bulletins have been released on the following themes:

1. Identifying the responsible CCG commissioner to support local delivery of the SEND reforms
2. Identifying the responsible commissioners for the core functions of a speech and language therapist, occupational therapist and physiotherapist
3. Applying an outcome based approach to commissioning
4. Promoting personalisation and access to personal budgets
5. Personalisation, development of personal budgets and Integrated Personalised Commissioning
6. Accelerated working group - data and information sharing

Please contact Ryan at rnibloe@ncb.org.uk for further information regarding the joint commissioning bulletins.

SEND Data Bulletin

In response to the lack of robust data available on children and young people with SEND for local services across the country, the Council for Disabled Children has published the first in a series of SEND Data Bulletins designed to share learning and improve data on disabled children and young people.

The CDC Data Bulletins aim to share learning and encourage greater progress on improving data on disabled children and young people. Our intention is for these Bulletins to interest commissioners, policy-makers, and other professionals who are involved in planning and delivering services for disabled children and their families.

The first bulletin was released in July 2019, with the next edition to be published in September 2019. The plan is for these to be released on a quarterly basis.

The first Data Bulletin can be viewed here, which was published in July 2019.

Please contact Anne Pinney, CDC’s Data Champion at CDCdatachampion@ncb.org.uk if you would like to tell us about i) any innovative local developments that others might learn from, as well as ii) any data challenges that you are currently facing which we might be able to find solutions to, or iii) what you would like to learn more about in future bulletins.
Have your say!

As we consider the journey the reforms have been on over the last five years we are keen to hear your views on the experiences, successes and challenges and to get your feedback on future priorities for SEND.

Please take this opportunity to complete our short survey [here](#).

We will share the findings from the survey in the next edition of the CDC Digest.
A Quarterly Update from the Council for Disabled Children

It Takes Leaders to Break Down Siloes: Behind the Report

‘It takes leaders to break down siloes’ is the culmination of a number of years of hard work from the Health team at the Council for Disabled Children around integrating services for disabled children, supported by the True Colours Trust.

The original idea for the study and the field work for this came from Andrew Fellowes who, prior to his current Policy and Public Affairs Manager role at the NSPCC, was working with CDC’s Health team at the time.

Andrew explains below his motivation behind the research that would later form the basis of 'It takes leaders to break down siloes'.

My interest in doing this research came from working with local authorities and clinical commissioning groups and providers across the country on the implementation of the Children and Families Act and NHS reforms, and wanting to understand why and how there was such wide variation in approaches and structures between areas that were subject to the legal requirements and policy framework.

In my work with children and families, the message about the importance of getting joined up services from health, social care and education was reiterated over and over again.

This was echoed in central government’s policy objectives of integration and personal centred services, but it was clear that this was not driving a single approach in local areas.

By carrying out detailed work with three areas I wanted to understand the scope for local areas to make decisions about the structure and delivery of their services, how local authorities and the NHS interpreted their roles and what factors influenced the decisions they made.

I hoped this would help provide some insight and guidance into what made for effective decision making, and how this impacted on outcomes for children and how national government could support, rather than hinder, this.

It was clear from the outset that funding was a very significant driver, every area had made very difficult decisions, but how they made decisions and how they weighed up their impact differed considerably.
Particularly important was how the local authority and NHS developed a joint understanding of how they would work together to achieve specified outcomes, directly informed by children and families.

To be effective this needed to be underpinned by data and operational structures. The absence of these could lead to different services making decisions in isolation that then had knock on impact on the overall provision without a clear sense of how this would impact on children and families.

I was very grateful for the participation of professionals and parents in the three areas, and being so open and frank about their experiences, successes and challenges.

It was impossible not to be stuck by their commitment to doing the best they could for the children and families they worked with.

I would like to thank Amanda Allard and Anna Gardiner for all their support on this work and a special thanks to my travelling companion Harley Young.

Some recommendations from the report:

- National government should rapidly review local funding for SEND children’s services as a response to concerns stated in this report and wider publications, and in the media.

- NHS England must hold CCGs to account in terms of progress towards their set goals, ensuring they give sufficient priority to services for children.

- Senior leadership within national government and NHS England should review and align key priorities across all national programmes impacting this group of children and young people, then align performance measures across programmes.

- The government should ensure that commitments made to ensure that all health and social care staff have training on learning disability and autism adequately covers the children’s workforce and includes education staff so that all professionals know how to support children with SEND.

- CCGs and local authorities should recognise and fund local parent carer forums (PCFs) as a well-established source of expertise.

You can read ‘It takes leaders to break down siloes’ in full [here](#).
There’s an anxiety associated with stumbling around an airport when you’ve just landed and you’re trying to find the right bus to get you to your hotel. This must be universal but, as soon as we’re on our way, the countryside is recognisably Swedish. There are big areas of birch trees, silvery clean, ordered and vertical; and lots of lakes visible from the air, as we came in to land.

It’s the bi-annual meeting of the European Agency for Special Needs and Inclusive Education, the host government is Sweden and the meeting is in Stockholm.

It’s good to talk to people across Europe about the successes and challenges encountered in seeking to improve education for children and young people with SEN and disabilities. Representatives across Europe are passionate about what they are doing, and there’s a creative energy in the discussion groups.

There are some big caveats though: one of the most important is recognising that the policy export/import business is not just not a good idea, it is a really bad idea. Something that worked well in Sweden or Germany cannot simply be imported to another country and expected to work as it did in the Swedish or German context.

Rather, it is a careful study of what enabled something to work in one context that can help others to understand their own context better and, potentially, to understand how to achieve something similar that takes account of that different context.
With this in mind, I hesitated to think that a new report from the European Agency, on Financing Policies in Inclusive Education Systems (FPIES), might read across into the current call for evidence in England on the financial arrangements for pupils with SEN (call for evidence closes 31 July).

The Agency report is based on research in six different countries across Europe, practical exchange visits and support from Ramon Llull University in Barcelona. If we avoid the simplistic import/export approach, can we learn anything from this report?

Only the Final Summary Report was available at the meeting, so this is headlines, but a strong theme emerges. Throughout the report there is a clear emphasis on finance systems as a tool for promoting and ensuring inclusive education systems that provide quality educational opportunities for all learners. So, in the English context, how keen are we on an inclusive education system that provides quality educational opportunities for all learners?

In the context of rising exclusions, rising placements in special schools, rising use of alternative provision, and rising numbers of children with SEN being home educated, are there signs of inclusive policy intentions?

Well, at least three: Damian Hinds speech of last July, which I’ve quoted before, in which he made the clear statement, “Every school is a school for pupils with SEND; and every teacher is a teacher of SEND pupils”. Then, for the second sign, fast forward to earlier this year when Ofsted’s revised inspection framework talked about inclusive systems.

For the third example, look at, or listen to, if you prefer, Nadhim Zahawi’s throwaway remark at the end of a fairly unsatisfactory session in front of the Education Select Committee. The Minister concluded by saying, “All I would say, Chairman, is for any educational leader you cannot call yourself world-class as a leader if you are not inclusive”.

Let’s look at the DfE’s call for evidence on the financial arrangements through this lens: do the financial arrangements promote and ensure an inclusive education system that provides quality educational opportunities for all learners?

Let’s design and then, as a country, let’s find the funding for a more inclusive system that provides quality education opportunities for all learners.

Wish you were here!

Philippa
A Community of Schools Focused on Good Mental Health

It is starting to be accepted that wellbeing and good mental health should be a strategic priority embedded into the culture and ethos of every school. But are things moving fast enough asks our Assistant Director for Health, Amanda Allard.

It’s starting to be accepted that wellbeing and good mental health should be a strategic priority embedded into the culture and ethos of every school. But are things moving fast enough? Research evidence is clear about both the negative impact that poor mental health has on children’s learning and the positive contribution that a well-coordinated whole school approach can make.

One well-conducted review in the US summarised research on 207 social and emotional interventions, and suggested that schools with effective wellbeing programmes showed an 11 per cent improvement in achievement tests, a 25 per cent improvement in social and emotional skills, and a 10 per cent decrease in classroom misbehaviour, anxiety and depression.

In this context, Ofsted recently launched the new Schools Inspection Framework. Reducing the focus on exam performance, and the separation of ‘behaviours and attitudes’ and ‘personal development’ have been broadly welcomed as helping to improve mental health and value the contribution of all children.

However, we know that schools that involve the whole school community in developing a culture of wellbeing see the greatest benefits for children, young people and staff. So it was disappointing to see that despite recognising these benefits, Ofsted did not include or recommend a whole school approach to mental health and wellbeing within its inspection framework, nor incentivise or recognise schools for implementing this way of working.

There is some hope that this was less a rejection of the benefits of the approach and more an implementation issue. After all, you can’t start marking schools down for not doing something that takes effort and time to implement if you haven’t given fair warning that this is your intention. Ofsted would be out of step with other developments if this wasn’t their longer term plan.
New commitments to improving mental health and wellbeing support for children and young people in schools bring us closer to having the support our pupils deserve in place.

National initiatives such as the government’s ‘Transforming children and young people’s mental health provision’ could, with its emphasis on prevention and early intervention at school, mark an important milestone in how children access mental health support. Similarly, the statutory Relationships and Sex Education and Health Education and the NHS Long-term plan all aim to significantly improve the understanding of mental health issues and access to support. The convergence of these initiatives provides both opportunities and challenges for schools on the frontline of this change agenda. For example, the role of the Designated Senior Lead and Mental Health Support teams must eventually form part of a whole school approach. How do we support schools to take this forward?

For a start we need to get better at learning from other schools that are leading the way. Staff from the National Children’s Bureau were recently lucky enough to visit a London school that has gone from being in special measures to good / outstanding in some areas within three years.

This was largely by re-focusing the school’s central aim as promoting wellbeing. The transformation involved using limited resources to recruit a full-time, fully trained child counsellor to focus solely on pupils’ wellbeing with no other teaching responsibilities. You can read more about Lessness Heath’s extraordinary journey here.

To help schools learn from each other, the Partnership for Wellbeing and Mental Health in Schools has launched a national online Schools Forum, which provides a platform for schools and education providers to share practice and learning examples as they develop whole school approaches to improving mental health and emotional wellbeing for pupils.

The Schools Forum will help to create an evidence base of what works, driving and inspiring change so schools can create an enriching educational environment that is conducive to a good level of mental health and wellbeing support for every pupil.

We want all schools to sign up, regardless of where they are in the journey, to learn from, encourage and support each other to develop and embed your own whole school approach.

We think school leaders are best placed to support other school leaders in implementing this vital change in how we support children and young people’s mental health. We hope others will join our growing community so many more schools are ready when Ofsted catches up.

Amanda Allard coordinates the Partnership for Wellbeing and Mental Health in Schools, part of the National Children’s Bureau.
Shining the Spotlight

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 two new members.

How it works

The Essex Family Forum is a parent/carer forum. The Forum is a well-informed, connected and empowered community of families that includes disabled children and young people up to the age of 25 and/or those with special educational needs.

Essex is a large, diverse county and we have a responsibility to ensure that we can reach a cross representation of the SEND (special educational needs and disabilities) population throughout the geographical spread of the county. We do this through our Family Champion Model.

Family Champions are Parents and Carers that represent the lived experiences of families. They attend well established local groups, coffee mornings or could simply be someone that represents a handful of parents meeting at the school gates or their kitchen table sharing their experiences.

Our Family Champions ensure each parent/carer’s voice is heard by adding their comments onto the Forum’s Graffiti Wall. We ask that the comments highlight what is working well and what is not working well within their local areas.
These views are collated and we feed back to the organisations we work in partnership with.

Essex Family Forum works in partnership with specialist organisations, our local authority and health commissioners aiming for quality outcomes that meet the needs of all our families.

We are also part of the Eastern Region and National Network of Parent Carer Forums.

What has been achieved?

Essex Family Forum were proud to be commissioned by Essex County Council to host 17 Parental Engagement Workshops across Essex.

The workshops were run in conjunction with Essex County Council’s consultation “Developing a Strategy for SEND in Essex”. The workshops generated over 1000 comments across 30 themes on SEN provision within Essex, which we presented to Essex County Council.
Essex Family Forum hopes to be involved with Essex County Council on their vision going forward and will work co-productively with the necessary agencies to achieve the goals that are set.

Essex Family Forum also hosted its second successful AGM. The event was well attended by families and professionals across Essex, with stalls such as Essex Short Breaks, The Children’s Society and Essex County Council. Speakers included representatives from the Multi Schools Council and National Network of Parent Carer Forums along with Rachel Wright, author of ‘The Skies I’m Under’.

We also represent families’ views in several of the region’s Strategic SEND Working Groups, SENDIASS Strategic group, Preparing for Adulthood Strategic Group. We are also working closely with the Local Authority to create a parent and child friendly SEN transport guide, along with videos and communication stories to aid passengers and their families amongst other projects.

**Next steps**

As we look to the future, we are committed to increasing the number of trained Family Champions to further representation of the SEND families within Essex.

Furthermore, we hope to continue to build upon the relationships we have developed with our local authority and health commissioners and continue to represent and contribute our families’ views to the SEND services within Essex.

Essex Family Forum will be issuing a more comprehensive report to Parents/Carers in the autumn term which will also be shared with Essex County Council, Clinical Commissioning Groups and Social Care.

Hello@essexfamilyforum.org

https://essexfamilyforum.

You can also find us on Facebook
How it works

Soundabout’s mission is that everyone with a severe or profound learning disability can access music as a means of communication. We use music to empower and unlock the potential of people with profound and multiple learning disabilities (PMLD), and train teachers, parents and carers to do the same.

Soundabout works across the UK, running specialist group music making sessions in schools and community settings, individual family sessions in the home, and training sessions at schools, colleges and other educational institutions.

Our practice is built around the use of intensive interaction with music, and underpinned by Sounds of Intent – an assessment framework for the musical abilities of children and young people of all abilities (Read more on our website [here](#)).

What has been achieved?

Soundabout’s recent research report “Sounds of Intent In The Early Years” revealed how targeted music sessions for children in the early years in areas of high deprivation can close the gap in terms of meeting their age related expectations, especially for children with complex needs.
We were delighted when Tracy Brabin MP, Shadow Minister for the Early Years, recently asked a question in Parliament about plans for music provision in the early years citing our report.

Soundabout recently launched Oxford’s first inclusive choir, which we run on a monthly basis, and has really taken off. The purpose of the choir is to build a community around Soundabout’s families, bring people together and remove the barriers to participating in a choir for people with learning disabilities. Earlier this year the BBC released a film about one of our members - a young man called Sam with Down’s Syndrome, and the moment he stepped up to do a solo.

Earlier this year we also launched our #ShareTheLove campaign which raises awareness of the importance of music as a form of communication especially for people with complex needs. It involved some of the world’s top composers including John Rutter and Dame Evelyn Glennie - please take a look here.

Next steps

We are currently able to reach 2,000 people directly through our work, but we are aiming to double our reach over the coming three years. We are doing this by working strategically with music education hubs to help them deliver inclusive music provision for children with PMLD in their area.

In addition, we are in the first year of Building Bridges, a new three year project funded by Youth Music and Global’s Make Some Noise. This will see our music practitioners working directly with individual families to help them strengthen communication with their young children in the early years, and when they are ready to leave school or college.
The charity is currently working to develop online and hard copy resources to help families to continue to make music with their child between practitioner visits.

Alongside this, we are working to grow our successful Oxford-based Soundabout Inclusive Choir and to establish similar choirs in regions across England.

Finally, the charity’s Sounds Wild sessions combine music and nature to inspire and instil a sense of wonder and appreciation of the natural environment for pupils with special needs. We encourage and provide opportunities for creating child-led multi-sensory music making experiences in outdoor environments. We are working to secure the funding to be able to deliver these sessions more widely across England.

www.soundabout.org.uk
@soundaboutuk
@soundaboutuk
@soundabout.uk
My Future Choices is a magazine for disabled young people, their families and people who support them. In this issue we have the latest news and stories from young people on campaigning, sport, school exams and much more!

On the Water: Rowing with a Disability

Sebastian Johnson

My name is Sebastian Johnson and I am 16 years old. I’d like to tell you how adaptive rowing – that’s rowing for those with disabilities – has enabled me to compete in regattas and indoor rowing championships. I have a visual impairment and left side weakness following a brain injury when I was a baby. Ball sports are hard for me and this left me feeling rather left out at primary school when my friends were football mad. I am very active and love being outside so I was keen to find a club sport I could enjoy and feel part of a team.

I live in Oxford where rowing is very popular so I thought I would give it a try. As my confidence on the water grew I wanted to meet other rowers with disabilities and find more opportunities to compete, so British Rowing put us in touch with Bruce Lynn, the Adaptive Rowing Coach at Marlow Rowing Club. I would really recommend adaptive rowing to anyone with a disability - it’s a great feeling racing along on the water and being part of a club. Adaptive rowing is growing fast and I am proud to be part of it.
10 Top Tips for Surviving and Achieving in School

Hannah Louise

My name is Hannah Louise and I have just finished Sixth form and my 13 years in school. In this long period I have learnt that there are many ups and downs that come with school life, especially as a student with a disability. I wanted to share my top tips for overcoming challenges and achieving in school even with the added challenges of disabilities or SENs.

1. Develop resilience
2. Talk to people!
3. Your view is important!
4. Ask for help
5. Change is going to happen!
6. You are the expert!
7. Be realistic!
8. Be patient
9. You can achieve
10. Your disability doesn’t define you!

The Importance of Social and Educational Inclusion in the Mainstream System

Joe Wastell

When I was five years old I had encephalitis. When I recovered I lost my ability to walk and talk, I also lost my ability to read and write. Soon after returning to my mainstream school, I got moved to a SEN school. Half way through my education I joined a mainstream scout group and went to several jamboree camps.

I am an active member of my local political party and I am hoping to stand in the 2019 local elections. I don’t think any of this would have been possible without the initial confidence of being a scout and being given the opportunity to be included in the mainstream system.

DOWNLOAD MY FUTURE CHOICES HERE
Update from the Participation Team

Children and Young People’s Conference on Film
In April, the participation team delivered the second national Children and Young People’s conference with the charity KIDS. Co-produced with young people, and for young people, this event gave young people with SEND the opportunity to have their voice heard! You can watch the full video here.

Updated Resources
The participation team have been busy updating their hub of handy resources for young people and professionals to help involve children and young people in the decision making process.

Participation Webinars
- 🔄 Breaking Barriers
- 🔄 Support during Inspections
- 🔄 Social Media

The Council for Disabled Children and KIDS, as part of the Making Participation Work programme, are hosting a series of webinars where professionals and young people discuss how to improve participation methods of children and young people with Special Educational Needs and disabilities (SEND).

These webinars are intended for practitioners and professionals at all levels who wish to improve their participation skills, and better understand how to meaningfully include children and young people in decision making.

Participation Audit Tool
Evidence and develop your participation practice and outcomes.

The Participation Audit Tool is an essential resource for statutory and voluntary agencies, across health, education and social care to evidence and develop their participation practice and outcomes.
University of Warwick Lecture provides overview of literature on behaviours that challenge

Prof. Richard Hastings of Warwick University has produced a comprehensive overview of the research evidence surrounding services for people with learning disabilities and/or autism with behaviours that challenge. This lecture was a key element within workshops facilitated by the Council for Disabled Children and NHS England Transforming Care Midlands in June 2019. It supported discussions to support local areas aiming to reduce inpatient admissions and improve services for children and young people with learning disabilities and/or autism.

The presentation presents an overview of the existing literature around behaviours that challenge, and stresses the importance of the following themes:

- The importance of a shared understanding to underpin all services for people with learning disabilities and/or autism
- Research evidence around anti-psychotic medication
- The significance of staff training elements in designing services

You can watch the video of Prof. Hastings’ lecture here.
Welcome Back From the Summer Break
This is what’s been going on in the sector...

In the news

Researchers call for more guidance on tackling the bullying of students with SEND

Researchers are calling for guidelines for tackling disability-related bullying to be revised by the Department for Education, after a study found frustration with the way the problem is tackled within schools. The report recommends a minimum inclusion standard for disability awareness in the personal, social, health and economic (PSHE) education curriculum.

Ignorance of disability issues among schoolchildren, even those with special educational needs (SEN), is revealed in the report drawn from 11 focus groups with children aged 12 to 14, with and without special needs. It found widespread frustration among pupils with SEN in both mainstream and special schools at the failure of teachers and school leaders to deal with bullying and to promote inclusive classroom environments. The DfE said that between September 2016 and March 2020 it was providing £2.8m of funding to anti-bullying organisations to support schools, including the Anti-Bullying Alliance which has a particular focus on SEND in some of its programmes.

Read the full article here

New children's minister

The new children’s minister has been announced as Kemi Badenoch, who will take up the post responsible for children’s social care.

Read more about the new minister and the reshuffle here.
New resources and guides

AUTISM & DENTAL CARE
A Guide for Their Oral Treatment

A Guide For Dental Patients with Autism

Going to the dentist can be a cause for anxiety for most of us, but it’s a very different feeling for those with autism.

These dental experts have put together their tips and techniques to help patients and caregivers prepare for upcoming dental visits. Contents include:

- The importance of a shared understanding to underpin all services for people with learning disabilities and/or autism
- The significance of staff training elements in designing services
- The development of service models

Download the guide [here](#)

Overshadowed: The mental health needs of children and young people with learning disabilities

All children and young people deserve the best possible outcomes and start in life. Those with learning disabilities are likely to need additional support in various aspects of their lives including how to enjoy good mental health.

However, young people with learning disabilities continue to face challenges. Studies suggest that it is the wider risk factors that these young people and families experience, rather than their learning disability, that contributes to poorer mental health.

This report from the Children and Young People’s Mental Health Coalition explores these factors combining insight from young people (aged 11 to 25), families, professionals and research. Read the full report [here](#).
Preparing for adulthood: The role of social workers

This guide from the Social Care Institute for Excellence looks at what social workers need to do to help young people with learning disabilities prepare for adulthood (transition).

Download and read the guide [here](#).

Conferences

2020 International Respite (Short Break) Conference

The 2020 International Respite (Short Break) Conference will be in Madison, Wisconsin, United States (U.S.) from June 16th-19th, 2020. This conference will provide a space to advance knowledge and understanding of respite by learning from and with international leaders in the field of respite, and is intended for everyone who provides, uses, or needs respite/short break services.

It is also for policy makers and program administrators who want to understand or better support the respite/short break needs of family caregivers, and individuals who receive respite care across all ages.

Call for presentations

There is an open call for presentations from family caregivers, individuals who receive respite care, researchers, and caregiving professionals.

[Find out more here.](#)
Campaigns

Fire It Up

The Department for Education’s apprenticeships campaign ‘Fire It Up’ is once again live. It is already showing positive results since its launch in January, with a 10% increase in young people’s consideration of apprenticeships.

The campaign continues to target broad audiences such as young people, parents etc. but will also focus on those audiences that contribute to widening participation in apprenticeships such as those with learning difficulties or disabilities. The adverts will appear on TV, cinema, out of home poster sites, digital and social media.

How to support:

1. Share your apprenticeship case studies for potential PR opportunities with Apprenticeships.CAMPAIGN@education.gov.uk

2. Signpost to www.apprenticeships.gov.uk from your website to ensure people are receiving the most up-to-date information on apprenticeships

3. Post your apprenticeship stories on your social channels including including assets from our campaign toolkit and the relevant handles/hashtags: @FireItUp_Apps #FireItUp. The campaigns team will be promoting across their channels as well.

4. Post your apprenticeship vacancies on www.findanapprenticeship.service.gov.uk. This is a free service and receives over half a million visitors per month.
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 councilfordisabledchildren.org.uk/about/subscribe-newsletter 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

www.councilfordisabledchildren.org.uk
www.facebook.com/councilfordisabledchildren
@CDC_tweets
www.linkedin.com/company/council-for-disabled-children

...or contact us on cdc@ncb.org.uk or 020 7843