COUNCIL FOR DISABLED CHILDREN

CDC Digest

Autumn 2021

Dear all,

As we settle into Autumn I have been in reflective mode. The return to the office after the last very difficult 18 months has made me think about the difficult challenges we face. There is progress. I am really pleased by the work of the NHSE programme on keyworking for children with Autism and/or Learning Disability who are on the edge of in-patient care or who have been admitted. This comes after a lot of work across the sector and, whilst they are a small group of young people, it's good to see them come out of the 'too complex' box and get the attention they need. There is some really good practice coming out of the early sites.

I am also feeling more optimistic about the SEND Review. There is a hard working team across Government looking at the challenging issues involved in achieving better outcomes for children and young people and clarifying accountabilities across the system. I know they are committed to a full engagement and consultation programme and I am hoping you will all want to engage with this over the coming months. I have also had the opportunity for early meetings with Minister Quince and Secretary of State Zahawi and we are working with the cross-sector stakeholder group to prepare for a ministerial round table in November.

One of the issues I feel we have yet to address is the relationships between SEND and poverty and discrimination. We are seeing a lot of evidence linking EHC plans with areas that have high levels of deprivation and I wonder if we make the best policy decisions and practical interventions in understanding what works. I spent a long time managing services in an inner city area and was often asked what "special" interventions would best support the families I worked with. The best would have been decent housing and not having to worry about the bills.

I have also been looking at a number of pieces of evidence which reinforce the fact that, in many places, families from Black and Minority Ethnic communities continue to receive a poorer service than their white peers. Whether this is an over representation in early deaths (see Leder) or delays in accessing diagnostic and support services, there is clearly a long way to go to embed equality. At CDC we are trying to work out ways in which we can highlight the issues and continue to engage the system in a constructive dialogue. Be really good to get your thoughts and ideas on moving this forward: cdc@ncb.org.uk.

Dame Christine Lenehan

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Postcard from Serbia

- Philippa Stobbs

A recent piece of work by the European Agency for Special Needs and Inclusive Education (the Agency) reviews a range of information about the impact of the pandemic on education internationally, across Europe and at a national level. Given that the Agency works by promoting collaborative approaches, sharing practice, policy and research, its role in the pandemic has been, and still is, to identify ways in which European countries *can learn and collaborate to minimise the effects of the current education crisis on vulnerable learners*.

Just a point of clarification: whilst the majority of countries in the Agency are members of the European Union, there are also countries, including Iceland, Norway and Switzerland, who are long-standing members of the Agency, and all four of the UK nations have continued in membership since the UK left the EU.

Back to the report: it recognises that all European countries took measures to ensure the continuity of education during the pandemic. However, across Europe, these measures were sometimes inadequate, with limited guidance on inclusion in education and with school closures increasing pre-existing inequalities. Inequalities affected disadvantaged learners at several levels: ... *up to 32 % of pupils without access to education for several months in some Member States; ... for many learners, this lack of access stemmed from an absence of digital equipment, inadequate digital skills or pre-existing disadvantage; ... even where learners had access to digital education, they still often had to learn without teacher, peer or home support and sometimes in an unstable home environment*. While this particular excerpt is from a report by the European Parliament, it echoes findings from UK studies.

In another European study, from the European Academy of Childhood Disability, there is evidence, from a survey of both families and health practitioners, on the loss of therapies. The report identifies a severe reduction in amount of therapy received, with half of families reporting that they had not have received any therapy at all between March and May 2020; increased levels of stress and anxiety for families and professionals; a significant impact on mental health, again for families and professionals; and an extreme burden being placed upon the (family) caregivers.

Amanda Spielman's commentary on one of the Ofsted reports of last autumn recognised that across all age groups, children with SEND have been seriously affected in both their care and education, as the services that families relied on, particularly speech and language services, were unavailable.

The FFT Education Datalab highlights the differences in school attendance rates (outside the periods of school closure) and the disproportionately low attendance rates for disadvantaged pupils and pupils with SEN. And

in Key Stage 1, the EEF has published further findings from an ongoing study by the National Foundation for Educational Research, examining the impact of Covid-19 related disruption on the attainment of Key Stage 1 pupils. The analysis suggests Year 2 still have significantly lower achievement in both reading and maths than would be expected in normal times, and that the disadvantage gap remains wider than expected.

This is not intended to send everyone into their own, or even a collective, Slough of Despond, rather to recognise the size and shape of the task that still lies ahead. It is also to recognise that, in the analysis of all the information that went in to the review by the Agency, one of the clearest messages, across Europe, is the intention to *build back better*. Whilst *build back better* may have acquired a bit of a bad name for itself as an empty slogan, in the context of education this is set out as an opportunity to put equality and inclusion at the heart of recovery. There are other positive messages in the review: the need for collaborative approaches is clear; as is the need to share our collective understanding of practice, policy and research.

In the slightly stilted language of the European Parliament, there is also a recognition of what everyone has been through. The Parliament:

Salutes the creativity and resourcefulness shown by education and training institutions, in particular their teaching and educational staff, and by students and parents in adapting to online and distance learning, especially in light of the fast-changing circumstances and uncertain times; salutes, similarly, the positive examples set by citizens, civil society and non-formal education providers in adapting their education practices and developing initiatives that have enabled learning to continue; calls for more efforts to scale up and increase the visibility of effective initiatives, and to promote best practices in all education sectors …

This time last year the bi-annual meeting of the Agency was cancelled, along with many other events that have traditionally relied on face-to-face gatherings. At each of the subsequent meetings we have anticipated that we would meet face-to-face at the next. And each time the next meeting has been convened on Teams. This time, we are more realistic and are planning the second 2021 bi-annual meeting in the virtual world. At least it's quicker getting back to the office when the meeting's over; just a few raised eyebrows when I apologised for being a few minutes late getting back from Belgrade.

I usually sign off by saying Wish you were here but, perhaps more realistically, I should say, *hope we can meet face-to-face again soon.*

Philippa

Liberty Protection Safeguards

System Readiness Tool

As part of CDC's role as Strategic Reform Partner to the DfE, and building on the learning from a series of regional Social Care and SEND learning and development networks and national Designated Social Care Officer (DSCO) Community of Practice events, it was identified that local authority children's social care services needed support to begin or progress on their journey to implementation of the Liberty Protection Safeguards as they apply to children and young people aged 16 and 17.

What is it for?

The purpose of the tool is to support local authorities in ensuring effective implementation of statutory duties in the Mental Capacity (Amendment) Act 2019: Liberty Protection Safeguards (LPS) which come into force in April 2022.

How to use it?

The tool pulls together in one place the key pieces of evidence that a local authority will wish to assure itself on and aims to give a high-level overview of its progress. The questions are divided into 5 of the key areas of a local authority's role in implementing the LPS as they apply to children and young people aged 16 and 17.

It is in 2 parts, the first is focused on strategic planning and engagement including:

- Leadership;
- Identification and Data.

The second is focused on operational planning and implementation including:

- Information and Awareness;
- Assessments and Plans;
- Workforce Development.

This information is presented in an easily accessible "at a glance" RAG review rating system to update the relevant local authority on progress in implementation. It also includes a facility for a follow up audit which enables the responsible local authority officer to demonstrate trends in terms of implementation and flag up any areas which are not moving towards full compliance.

RAG rating scores and trend description options can be chosen from a drop-down menu as can the name of your local authority.

Click here to download the tool.

CDC's Case Law Directory provides an essential update on the latest decisions affecting disabled children and young people and those with SEN. Our series of case law reviews on judgements relating to both special educational needs and disability are compiled by barrister Steve Broach from 39 Essex Chambers. Our digests provide a description of the case, the implications for children young people and their families, and how professionals might need to change their practice as a result of the judgement.

Some of the cases deal with fundamental issues of human rights, such as the recent judgment of the Supreme Court concerning when disabled children are considered to being deprived of their liberty in health and social care placements.

Click here to read our case law updates on deprivation of liberty and parental consent for 16 – 17 year olds.

Council for Disabled Children

Working with Children and Young People

The Council for Disabled Children's Participation team host national conferences designed for practitioner development on a range of participation and co-production related topics. The first conference was delivered on July 6th via Zoom with a range of workshops on offer. On Wednesday 13th October, the second practitioner conference was delivered virtually via Zoom with a range of workshops on participation and co-production, including special educational needs and the early years and learning how HeadStart partnerships have designed and implemented emotional wellbeing and mental health support for children and young people, focusing on details relating to participation and co-production. The team also worked with the Information, Advice and Support Services Network to deliver a workshop around online participation delivery methods for SENDIAS workers.

The Participation team have also been hosting monthly informal coffee mornings, with practitioners coming together in an informal space to share success, challenges and discussion on participation and co-production related topics. To be kept up to date with upcoming Shared Support sessions and Practitioner Conference's, join the Making Ourselves Heard forum or sign up to our newsletter.

FLARE, the young disabled advisors supported by the Council for Disabled Children on behalf of the Department for Education, advise government teams on policies impacting children and young people with special educational needs and disabilities. Over the past few months, FLARE have met with various teams at the Department for Education and have contributed their views and opinions in subsequent policy. Working with teams at this level ensures that children and young people's voices are feeding in directly to policy development. FLARE have also partnered with four external groups to widen the voice of children and young people feeding into the Department for Education. In July, FLARE took part in a Ministerial Roundtable discussion with 5 FLARE members speaking to previous Children and Families Minister, Vicky Ford MP. Opportunities such as Roundtables demonstrate how a high level of engagement between strategic leaders and the experiences of children and young people creates understanding, change, and builds valuable networks between young people's groups and leadership.

Our recently established young people's podcast, Our Turn to Talk, will also be publishing their first podcast in the coming months – it will be posted on the NCB website so keep a look out!

Council for Disabled Children

Updates

Health

The Health team continues to deliver the multi-agency working strand of the Delivering Better Outcomes Together (DBOT) programme, funded by the Department for Education and delivered in partnership with NDTi and Mott Macdonald. Work this year includes large-scale national sharing events (the next one is on 9th February 2022), regional workshops on Health & Social Care Advice for Education, Health and Care Plans (EHCPs) and on Data, and bespoke support to local areas on a range of issues related to strategic multi-agency working. A limited amount of this bespoke support is still available, please contact Philippa at pwatts@ncb.org.uk for more information.

The team is also working with practitioners, senior leaders and parent carers to develop new resources and products, including: e-learning on EHCPs for Child and Adolescent Mental Health Services (CAMHS) practitioners, a toolkit supporting health capacity in schools, tools for outcomes-based data capture, and learning from in-depth outcomes-based commissioning work. The team would like to thank everyone who has contributed to this work so far.

We're also delighted to have recently been appointed Strategic Partner to the NHS England Children & Young People's Learning Disability & Autism Programme; we'll be supporting the national team in different ways to meet their Long-Term Plan deliverables for Learning Disability & Autism, and will share opportunities with our networks as this work progresses. As well as this, over the past few months we have been working closely with Rochdale on a number of projects, including: developing a Joint Strategic Needs Assessment (JSNA) for children and young people with SEND in the area; supporting Rochdale to build their SEND Alliance for a more streamlined workforce where the needs of children and young people are met; as well as supporting them to build their ordinarily available provision for Early Years and all SEND systems (and much more!)

Early Years SEND

The 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, seeking to ensure developing policies are SEN and disability friendly. SEC has submitted responses and position papers to public consultations including, most recently, the call for evidence on Behaviour Management Strategies, the Initial Teacher Training market review and the review of the national funding formula for schools.

The Information, Advice and Support Services Network (IASSN)

IASSN have been concentrating on meeting the training needs of SENDIAS services. In the last two months they have run all three levels of IPSEA legal training and an IPSEA Case Law refresher session, two Tribunal Webinars led by an ex-SENDIAS manager who now works with us as an associate, three sessions of Exclusions Training led by Just for Kids Law, and a New Managers induction session and a New staff induction led by us and our partners. In total we have given 291 staff development face to face places to SENDIASs staff in the last two months. We have also launched, in partnership with the Thomas Pocklington Trust, a new e-training on working with children, young people and families with visual impairments that 50 staff members have signed up to.

IASSN have also launched their new practise and innovation group made up of nine professionals and their young persons' practise and innovation group made up of five young people nationwide. Both groups are designed to monitor and strengthen the work that they do.

National Children's Bureau

Response to the Independent Review of Children's Social Care

NCB's response to the Review's 'Case for Change' demands a focus on what will really transform children's lives for the better.

The Independent Review of Children's Social care is a once in a generation opportunity to transform the children's social care system.

Our vision is a society where babies get the best start in life through high-quality universal services and targeted early help; where inclusive schools value children's wellbeing alongside academic progress; and where young people are enabled to make a confident transition to adulthood, safe from violence on our streets and criminal exploitation. For our most vulnerable children, it is right that the state plays a more active role in this, including taking on parental responsibility where families cannot.

Delivering bold and ambitious change requires cross-government commitment, enabling local leaders to work together with a shared purpose. The voices of children, families and communities must be at the heart of this integrated system. And it means tackling the growing levels of poverty and social inequality that prevent so many children from fulfilling their potential.

Our challenge to The Independent Review of Children's Social Care is to focus on what will really transform children's lives for the better. The Case for Change gives us hope that this will be what the Review grapples with in its next phase.

Click here to read the full response.

Anti-Bullying Alliance

Anti-Bullying Week & Other NEW Resources

It's just over a month to go until Anti-Bullying Week 2021 which is taking place from Monday 15th to Friday 19th November with the theme of 'One Kind Word'. We're pleased to say that at the Anti-Bullying Alliance (ABA) we've created everything you need – entirely FREE of charge – to bring the week and its theme to life in your school/setting.

These free offering include School packs for primary and secondary which comprise of lesson plans, films, cross curricular ideas and assembly plans. We also have an Odd Socks Day pack and competition. This year Odd Socks Day is taking place on Monday 15th November and will include an amazing song from Andy and the Odd Socks which is currently in the making. There is also a resource for parents and carers to help them in having conversations with their children about bullying.

Moreover, we're delighted to be running the Anti-Bullying Week School Staff Award again. Each time a pupil nominates a member of school staff for this award, we will provide them with a certificate to surprise the member of staff with. The winning staff will receive a wonderful trip away courtesy of Radnor Hills. You can also sign up as a supporter of Anti-Bullying Week and receive a certificate. If that's not enough, you can also purchase official merchandise from our online store.

Beyond Anti-Bullying Week, we at ABA have several NEW resources to offer. Notably, with the help of Friends, Families and Travellers we have put together a free online CPD training course titled: Bullying and Gypsy, Roma and Traveller young people. We are also currently taking expressions of interest for our new free whole school anti-bullying programme – United Against Bullying (UAB). It is due to start in early November 2021 and will involve CPD training and lots of tools, support and resources. Find out more and register your interest on our website.

National Children's Bureau

Build Back Childhood

The Build Back Childhood campaign harnesses the support of over 700 organisations demanding that the Chancellor makes a strategic investment in babies, children, young people and families at the autumn Spending Review.

It is the latest action in the high-profile Children at the Heart movement, coordinated by the National Children's Bureau, calling for children to be remembered in spending plans.

We have created a 'case for investment' for how taxpayers' money could be allocated, informed by the views of children and young people themselves, and supported by a wide range of organisations including children's charities, education unions, and community organisations.

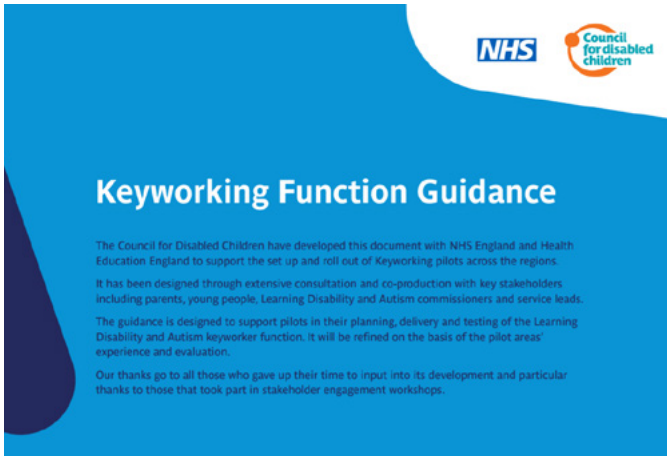
The Spending Review is a turning point. Instead of going back to how things were, this is our chance to look to the future – a future where every child feels safe, secure and supported. This is our chance to Build Back Childhood.

Find out more and get involved here.

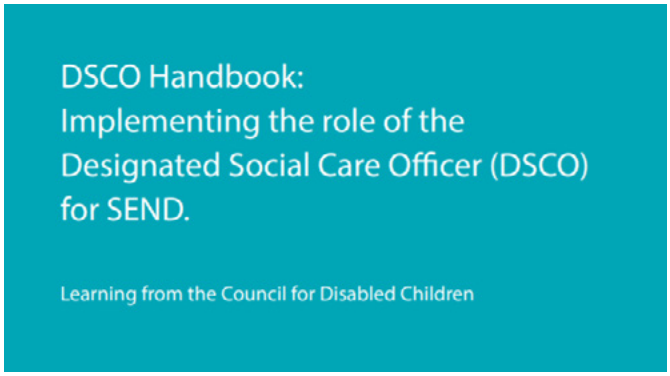
Council for Disabled Children

New Resources from CDC

This Top Tips guide is for all professionals who are involved in supporting disabled children and young people and those with special educational needs, to fully participate in their Education, Health and Care (EHC) plan. This guide aims to raise awareness of the barriers children and young people face when participating in their EHC plan and offer some advice and ideas to help eliminate those barriers. Read the guide here.



The Council for Disabled Children have developed a Workforce Competency Framework and a Keyworking Function Guidance with NHS England and Health Education England to support the set up and roll out of Keyworking pilots across the regions. The guidance is designed to support pilots in their planning, delivery and testing of the Learning Disability and Autism keyworker function. It will be refined on the basis of the pilot areas' experience and evaluation. View here.



CDC have been exploring the ways that local areas have been developing their approaches to ensuring high quality social care input and engagement with the Education, Health and Care needs assessment and planning process, and the wider SEND framework and we have been working to map and develop the DSCO role through the existing online forum and through the development of a national community of practice.

This handbook covers:

- What is a DSCO?
- Development of the DSCO role
- Developing a theory of change
- Job description and person specification

Read it here.

Contact: Keep colds at bay this winter

The flu vaccine is offered every year on the NHS to help prevent people from getting seriously ill from flu.

'At risk', groups including carers, children and medically vulnerable people, are all eligible for a free flu vaccine. And for the first time ever in 2021, older secondary school pupils aged up to 15, including those aged 15 on 31 August 2021, are included in the vaccination programme.

Our health lead Amanda has put together some questions and answers about getting a flu vaccination, to address concerns parents have raised with Contact.

What is the flu vaccination, and why does my child need it?

Flu is caused by a virus that can be a very unpleasant illness for children and lead to serious problems like bronchitis or pneumonia. Children also help to spread flu. The flu season starts in September and runs through the winter.

The flu vaccine is offered every year on the NHS to help prevent people from getting seriously ill from flu. Vaccinating your child protects them and others vulnerable to flu. People with a learning disability are more likely to develop pneumonia if they get flu. Find out more about why we still need to worry about the flu.

Is the flu vaccine effective? I have heard it gives you flu.

Flu vaccines help protect against the main types of flu viruses circulating now, although there is still a chance you might get flu. If you do get flu after vaccination, it is likely to be milder and not last as long.

Having the flu vaccine will stop you spreading flu to others who are more at risk of serious problems from flu. It can take 10 to 14 days for the flu vaccine to work. Flu vaccines do not cause flu.

Is the flu vaccine safe? Does it have side effects?

The flu vaccine is very safe and effective, and most side effects are mild. From the injected vaccine, you may get a slight raised temperature, muscle aches or a sore arm where the needle went it, but these should not last more than a day or two. From the nasal spray vaccine, you may get a runny or blocked nose, decreased appetite, tiredness and headache.

Very rarely someone may have a serious allergic reaction to the flu vaccines, but this usually happens within minutes and healthcare staff administering the vaccine are trained to deal with this. Many millions of doses have been given in this and other countries. If you have concerns, talk to your GP or child's consultant.

What is in the flu jab?

The nasal spray is Fluenz Tetra contains small amounts of weakened flu virus. The spray contains pork gelatine. If this is unsuitable, speak to your child's nurse or doctor about other options. Children with weakened immune systems or long-term health conditions can have the injectable vaccine instead.

There are several types of injected flu vaccine. None contains live viruses, so they are called inactivated vaccines. You will be offered one that is most effective for you, depending on your age. For adults aged 18 to 64, there are different types, including low-egg and egg-free vaccine. Talk to a GP, practice nurse or pharmacist for more information.

Eligibility

Who is eligible for the flu vaccine?

People eligible for a free flu jab in 2021–22 include:

- All children aged two and three on 31 August 2021.
- All children aged 2–15 (but not 16 years or older) on 31 August 2021.
- Those aged six months to under 50 years in clinical risk groups.
- Pregnant women.
- People aged 50 years and over.
- Unpaid carers.

- People close contacts of people with weakened immune systems.
- Frontline health and adult social care staff including paid carers employed via direct payments.

I am a parent carer. Do I get a free flu jab?

Carers, including parent carers, are eligible for the free flu vaccine if you get Carer's Allowance or are the main carer for an older or disabled person who may be at risk. You can get a free jab if you live with someone who's at high risk from coronavirus .

If you struggle to get registered on the GP carers register, our advice is to politely persist with your GP, reminding them of the NHS eligibility guidance. You can also approach your local pharmacy who can also provide free flu vaccinations to carers and adults with learning disabilities.

Does my child or young person have to have a flu jab?

Having the flu vaccine is voluntary. You need to give permission for your child to have the vaccine, so look out for the consent form in your child's school bag. Young people under 16 years old who understand the pros and cons of the vaccine may be able to give consent themselves.

Young people aged 16 upward are entitled to consent to having the flu vaccine themselves, unless there is 'significant evidence' they cannot. Young people aged over 18 must give consent themselves, unless they cannot. In this situation a trained professional will involve their carer and assess the young person's capacity to make a 'best interests' decision on their behalf.

We recommend using Easy Read information on the flu vaccine or this video to help young people with learning disabilities understand what to expect.

My child has a rare/complex condition. Is it safe for them to have the flu vaccine?

The flu jab is highly recommended for children with rare conditions such as diabetes, cystic fibrosis, muscular dystrophies and primary immunodeficiencies, because they are much more vulnerable to flu complications. There will be very rare exceptions, but if in any doubt, speak to your GP or get advice from your child's consultant If the nasal spray vaccine is not suitable, an injected vaccine can usually be given.

My young person has a learning disability, but they have not been invited for a flu jab yet. What should I do?

If your child is 14 or over, call the practice and check they are on the practice's learning disability register and ask for them to be added. This will trigger invitations for your young person to have a flu vaccine and an Annual Health Check. Even if they are not on the register, they can still have a free flu vaccine at their GP practice. Find out more about the learning disability register and Annual Health Checks.

My son/daughter is autistic, but they do not have a diagnosed learning disability. Can they get a free flu vaccination?

Most school children will be offered the nasal vaccination at school. Younger or older autistic children are also eligible for a free flu vaccination if they have a learning disability or other long-term health condition. For young people not eligible for the free NHS vaccine, you can pay to receive the vaccine at some local and high street pharmacies for under £20.

Getting the vaccine

How will my eligible child or young person receive the vaccination?

Two and three-years olds are eligible for the nasal vaccine delivered at the GP surgery. School age children up to the age of 15 (including those aged 15 on the 31 August 2021) will be offered the vaccine nasal spray. The nasal spray is also available to children aged two to 17 with long-term health conditions. However, if the spray is unsuitable, for example if they have a weakened immune system, they can have the jab instead.

Children aged six months to two years in the high-risk group for flu will be offered an injected flu vaccine instead, because the spray is not

licensed for under-twos. Young people aged 18 and over who have a learning disability or a long-term condition are also eligible for an injected vaccine. Find out more about who is eligible and more about the children's flu vaccine.

Where can my child or young person have their flu jab?

Babies aged six months to 2 years with a long-term condition will be offered the injected vaccine at the GP surgery. Children aged two to primary school age will be offered the nasal vaccine at their GP surgery.

Primary and secondary school pupils aged up to 15, including those aged 15 on 31 August 2021, will be offered the nasal spray vaccine via school. School aged children with a long-term health condition can ask to receive their vaccine at the GP surgery instead.

Young people aged 18 and over with a learning disability, carers and people or a long-term health condition can receive their flu vaccine at the GP surgery or pharmacy. Home-schooled children should be invited for vaccination by the local healthcare team. If you do not hear from them, ask your child's GP where they should go for vaccination.

My child/young person struggles to attend GP appointments. What can I do?

Families can ask GP surgeries to make reasonable adjustments and provide easy read information to help their young person access the vaccine. See more here on reasonable adjustments and advice from us on making GP surgeries more welcoming for disabled children and their families.

The flu vaccine and Covid-19

Will the flu jab protect me and my child from Covid-19?

The flu vaccine will not prevent you or your loved one from getting coronavirus, so continue taking precautions including regular handwashing. Having both flu and coronavirus diseases (yes, you can have both at the same time) is riskier for your health, so it makes sense to get the flu jab as well as your Covid vaccine. It is safe to have both vaccines at the same time, but don't delay having your flu vaccine if your Covid booster jab is scheduled for later this year.

Is it safe to have the Covid and flu vaccines together?

It is safe to have your flu vaccine and Covid booster at the same time if it is offered. But the NHS have warned people against delaying getting their flu jab now if their COVID vaccine booster is scheduled for later this winter.

Transition Information Network

Blogs

The Council for Disabled Children (CDC) were commissioned by the Education and Training Foundation (ETF) on behalf of the Department for Education, to produce a publication, titled – Tomorrow's Leaders – A world beyond disability. It was published in June 2020 and celebrates the ambitious, inspiring talents and achievements of young disabled people.

Many of the young people who shared their stories in the Tomorrow's Leaders magazine had a lot more they wanted to say about their experiences; the challenges they overcame and who had helped them on their way, so we invited them to develop a series of blogs for the Transition Information Network (TIN).

To get us started Jack Welch has shared his experiences of being part of the Tomorrow's Leaders project steering group and his reflections on life as a disabled young person:

"In a short space of a previous generation, that is the youth of my parents to be more exact, the laws and attitudes in relation to disabled people have changed considerably. Be that he Disability Discrimination Act (now absorbed into the Equality Act) or mainstream popular dramas, like The A-Word (which has its faults), UK society would almost be unrecognisable to disabled people of my generation 20–30 years ago. As these case studies of disabled people advocating for change now though, it would be wrong to assume we have reached any kind of destination, but rather building on the successes of those who have come before us.

Reflecting upon my own past and current experiences, we are still far from lasting solutions for employment, transport accessibility and, hardest of them all, stigma. Yet it is through empowering those young people with the resources and skills that enables them to speak for themselves and not somebody who has 'problems' or 'deficient' in comparison to the wider non-disabled public. As an autistic adult, it would have been hard to conceive the path I took just a decade ago – the act of leaving my house on my own was in itself a hard step taken just to achieve a sense of independence.

For many of us, the efforts to be part of the decision making process or a fair chance of making the same grades in education as our peers have to be greater than those who don't need that extra support. It is not just about 'inspiring' others or being the exception to the rule; rather it is about equity and having the same right of respect and dignity that all of us expect.

The stories you read here will present experiences of overcoming barriers and defying the odds, just so generations after us can live in a society that includes and celebrates all disabled people."

Click here to read the blogs.

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 Little Heroes ASD Support.

How it works?

Little Heroes ASD Support Group is a parent led support group for families of children who are on the autistic spectrum. Helen and Kim met on a professional level when Kim's son Alfie was in the early days of receiving an official diagnosis of autism back in 2011.

Helen assisted the family in her formal role of autism specialist portage worker for the local council and together they experienced the ups and downs of the "autism rollercoaster". When Alfie began at the local specialist school Helen and Kim decided they would like to create a small support network for families with children of similar ages – this would be the monthly coffee morning sessions at Summercourt Children Centre, Westcliff-on-Sea and officially began back in October 2012.

Little Heroes is now a registered charity and continues to bring more and more families together. We provide support and assistance for families within Southend-on-Sea and the surrounding areas.

Little Heroes provide a drop-in service for parents and families of children with autism on a regular weekly basis. During term time these are at least once a week and are within the local community. Little Heroes offer activities throughout the school holidays and provide suitable events for families whilst offering them the chance to socialise with other likewise families whilst receiving advice and support from one another, as well as potentially creating new friendships within a circle of support.

What has been achieved?

Little Heroes has many achievements in supporting families:

- Little Heroes was named as one of Southend's Mayor Borton's chosen charities of the year in July 2021.
- Little Heroes run a successful dads club, supporting fathers of children with Autistic Spectrum Disorder.
- Little Heroes provided 150 families with 'Thinking of you' support packages which included children's activities, food parcels and tablets with 12 months internet access during lockdown and a further 60 'refuel pamper packs'.
- Little Heroes secured funding from A Better Start Southend to deliver virtual activities during the pandemic including circus and sensory workshops and music therapy.

Next Steps

Little Heroes are focussing their efforts on fundraising because the challenge of the pandemic in 2020 has had a knock-on effect to

2021. They now have a regular monthly lotto know as 100 Club – for just £2 per number per month you can have the opportunity to win one of 3 cash prizes – 1st prize £50, 2nd prize £20 and 3rd prize £10. Even better, for the draw that takes place in the month of December these prizes are doubled! That's either £100, £40 or £20 that could be won for £2.

If you would like to take part then please make contact as a very limited amount of numbers are still available. Alternatively, if you have any suggestions for fundraising or would like to fundraise on behalf of the charity then please email littleheroes.asd@gmail.com.

Website: www.littleheroesasd.co.uk

Email: littleheroes.asd@gmail.com

Twitter: @LittleHeroesASD

CDC Staff

In a new feature for the CDC Digest we wanted to shine a spotlight on some of the lovely people who work at CDC and make lots of great things happen. Meet our newest member of staff, Joe Fautley!

Hello! My name is Joe Fautley and I'm truly honoured to be working for CDC. I joined last week as Project Assistant in the Health Team at CDC. I'm really enjoying being involved in the team's exciting work. I am currently working on different tasks including writing up summaries of notes from the team's recent workshops on advice for Education, Health and Care Plans (EHCPs). I am recording overall examples of local good practice, challenges and key asks for change that were discussed and identified by professionals in health and social care across all the regions in England.

I am an MA graduate with lived experience of Autism and Dyspraxia. Over many years, I have been involved in various projects which enable children and young people with SEND to have a voice in decision making and make a positive impact on society. As an Autistic person myself, I'm featured with other inspiring Autistic people in a video for the NHS to raise awareness of the Autism Spectrum. The video was published this year for Autism Awareness Week and has already received over 4,000 views on YouTube. You can watch this video on the link here.

I have also created an individual short video published by the NHS in which I talk openly about my personal experiences living on the Autism Spectrum. It's currently received over 2,000 views on YouTube. You can watch my video on the link here.

About the digest

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

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

About CDC

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

Find out more

councilfordisabledchildren.org.uk

facebook.com/councilfordisabledchildren

@CDC_tweets

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

INFORMATION, ADVICE & SUPPORT PROGRAMME

INFORMATION, ADVICE & SUPPORT SERVICES NETWORK

MAKING OURSELVES HEARD

SPECIAL EDUCATIONAL CONSORTIUM

TRANSITION INFORMATION NETWORK

COUNCIL FOR DISABLED CHILDREN
Part of the family

COUNCIL FOR DISABLED CHILDREN

United for disabled children

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

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

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NATIONAL CHILDREN'S BUREAU

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.