

Dear All,

Welcome to the summer edition of your CDC Digest. The weather is not helping with my underlying belief that it can't possibly be June. We are now well into quarter two of the new financial year and delivery of programmes and initiatives designed to support the implementation of the reforms, and if we blink it'll be September.

As you will be very aware we have been championing disabled children and young people's participation for many years now and so are delighted to include a real focus on participation in this issue of the Digest. There is an update on our Department for Education (DfE) Participation contract which we are delivering in partnership with KIDS. This contract represents the largest ever investment by DfE in disabled children and young people's participation and it is therefore incredibly important that it delivers real and tangible help to local areas and organisations supporting participation.

To ensure it does that we will, as ever, be relying on your support and so would be grateful if you could encourage professionals in your local area to complete the survey to enable us to build up a picture of children and young people's participation nationally and so better target the support we provide.

DfE have not been the only ones to invest in participation and we include an article from NHS England on their Transforming Care grants programme and in particular a project designed to support children and young people with autism.

We have included an overview of all of the DfE contracts designed to support those implementing the SEND reforms. This year there is a real focus on working together across programmes to add value so if you are undertaking a piece of work which you feel would add value to any of the projects or programmes do get in touch.



**Amanda Allard. Assistant
Director: Health, Council for
Disabled Children**

We know that members are always keen to keep abreast of legislative developments and legal precedence so we have an update on the education White Paper and high needs funding proposals and the Children and Social Care Bill and include a synopsis from Barrister Steve Broach on the implications of recent case law.

It would be remiss of me not to draw your attention to the other piece of big news, at least in CDC, which was our Director, Christine's, Damehood. Lest you fear the title has gone to her head Christine has promised to use any additional influence her new title may give her to finally sort out disabled children's access to appropriate continence products and to address the paucity of services for disabled children with mental health needs.

Best wishes,



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What's new?

Ofsted and the Care Quality Commission SEND inspection framework

At the end of April, Ofsted and CQC published their local area SEND inspection framework and guidance for inspectors. Since then, Brighton and Hove, and Bolton were the first two local areas to be inspected under the new local area inspection framework. Early feedback from those areas has confirmed that there is a very strong emphasis in the inspection on the involvement of parents and young people in planning local services, and that the role of Information Advice and Support Services, and Independent Supporters and Parent Carer Forums in supporting their participation is of great interest to inspectors.

CQC also attended a recent event for Designated Medical Officers and Designated Clinical Officers who CDC support as part of our work with NHS England. CQC were very clear that:

- The focus is on health provision for disabled children and young people, and those with SEN, not just those with Education Health and Care plans
- That audit tools which allow local areas to assess their own effectiveness, such as CDC's health implementation tool, are an important way of areas being able to demonstrate robust self-evaluation
- That the timeliness of identification is an important element of the inspection, and that waiting times would be taken into account when considering this.

The first inspection reports are due to be published shortly and will no doubt be scrutinised with great interest by the sector.

First significant judgement on Children and Families Act released by Tribunal

An Upper Tribunal judgement has shed light on what the courts may be likely to decide as education for young people over compulsory school age and when local authorities may need to maintain EHC plans beyond the age of 18. In *Buckinghamshire County Council v SJ* the Upper Tribunal confirmed a number of earlier decisions by the First-Tier Tribunal by finding that:

- Just because attaining further qualifications may not be an option for a young person over the age of 18, it does not mean that they do not require, or would not benefit from, special educational provision;
- Just because further achievements would be small does not mean that they would not be valuable to a young person in their adult life;



- While educational outcomes for a young person over the age of 18 might be achievable through a social care budget, if this is not happening then it may fall to a local authority to maintain an Education health and Care plan to meet these needs instead.

This case also gave further consideration to the issue of mental capacity and when parents can bring a case on a young person's behalf. Please see our [case law updates](#) for details of this important judgement.

Children and Social Work bill – power to relax requirements under social care legislation

The Children and Social Work bill had its second reading in the House of Lords on 14 June. Clause 15 of the Children and Social Work bill gives the Secretary of State an enabling power to exempt a local authority from a requirement under children's social care legislation – with the stated aim of allowing authorities to test new ways of working. These arrangements can be put in place for up to three years, with the potential to extend for a further three years.

The National Children's Bureau, CDC's host organisation, has been briefing Parliament to ensure that children and young people are not placed at risk by these proposals. While we have recognised the value of supporting local authorities to innovate in order to achieve better outcomes for children, there remain concerns about the introduction of measures which could weaken the entitlements of children and families. NCB and CDC will be working with the Department for Education (DfE) to ensure there are proper safeguards in place.

View from the Ground:

CDC Assistant Director leading on Education, Philippa Stobbs, gives us her take on recent news in the sector.



SEN data

In May, the DfE released two publications on children and young people with SEN: one provides the most recent data on [statements and EHC plans](#), as at January 2016; the other draws on a range of data brought together to provide the [annual analysis of SEN data](#). Much of this analysis is based on data from 2015.

We've picked out a few headlines from the data:

- 18.2% of statements that were in place in January 2015 had been transferred to EHC plans by January 2016. This is a start, but still leaves a long way to go.
- In January 2015, there were 32,180 young people with a Learning Difficulty Assessment. By January 2016, 5.5% of these young people were issued with an EHC plan; a further

2.7% were assessed and a decision was made not to issue a plan.

- The SEN analysis shows a decreasing percentage of children with statements and plans being placed in mainstream schools over recent years. This reduced from 57.3% in 2007 to 50.9% in 2015, with an equivalent increase in the percentage of children with statements and plans being placed in special schools. In the 2016 data, it is difficult to see what has happened to this trend and we may not be able to read across to earlier years because of changes in the age-range and type of establishment included in the data.
- The SEN analysis shows a significant drop in appeals to the Tribunal in 2014-2015, after the high of the year before. Relevant to this is the local authority data on mediations: 1,400 mediations were held in 2015 and, of these, 345 were followed by appeals, though more may have followed in 2016.

White Paper

Towards the end of May CDC [hosted two seminars](#) on the White Paper, “[Educational Excellence Everywhere](#)”. Some of the time was given to debate, which gave us an insight into people’s concerns about the issues that are addressed in the White Paper.

There was both some reassurance and some alarm about the nature of the White Paper, as a document: it seems to be drafted in a very uneven way. Sometimes, for example in relation to initial teacher training (ITT), we know that work has been going on behind the scenes and there is a commitment from the Secretary of State that SEN will be included in ITT. However, in the section on ITT in the White Paper, SEN is not mentioned, though behaviour management is. This looks as if this is a drafting error as SEN is mentioned elsewhere. It is difficult to know how well-developed thinking is in areas where we may not know the back story.

At the seminars people expressed concern about academisation because of the growing number of stories that academies encourage pupils with SEN to ‘go to the school down the road’. The data suggests that there is a difference between converter academies (low on SEN, and on statements and plans) and sponsor-led academies (significantly higher). This may be regarded as a historic issue, in as much as these schools were low on SEN before they became academies, but this doesn’t change the need to address the issue.

There was concern about the ability of local authorities to ensure sufficient school places locally, a duty the White Paper indicates will stay with LAs, if the system gives them no control or influence over local schools. This concern was matched, no, overtaken, by a concern about how LAs could meet their responsibilities to all children with SEN in a fully academised system; this duty to all children with SEN, not just those with a statement or EHC plan, only came in with the Children and Families Act in 2014.



School funding and the relationship with high needs funding was the other big issue that dominated the seminars. At the moment there is flexibility between school funding and high needs funding: the Schools Forum agrees the local formula with the local authority, and where mainstream schools are more inclusive more funding can be provided, either through delegation or 'top-up'; where they are less so, more funding needs to be set aside for special school places.

The proposals for the future are to have a fixed national funding formula for all pupils. High needs funding would be calculated and held separately, with no funding moving between the two blocks.

Delegates expressed clear concerns about the potential for perverse incentives, with schools putting pressure on high needs funding, without the local authority having any means of recovering costs from schools. There was also concern about the potential loss of any sense of collective responsibility for all pupils across a local area and the notion of, essentially, one pot of money with which to meet those responsibilities. DfE is proposing a further round of consultation on funding, so watch this space!

CDC Membership Update

At CDC we know that we are stronger and have a bigger voice if we're together. The CDC membership is a collection of over 200 voluntary or community organisations that represent the various facets of the SEND sector. Membership to CDC is free and open to any voluntary organisation or community interest company who works with or for disabled children and young people with SEN. If you would like to know more about CDC membership, please email Daphne Henderson-Figueroa on dhenderson@ncb.org.uk

Click to
apply
for CDC
membership

Since the last Digest we've had a few new additions to the CDC family. A big welcoming shout out to our new members:

- **Stay Up Late** - Promote full and active social lives for people with learning disabilities by running their volunteer befriending scheme "Gig Buddies" and campaigning to change inflexible support systems.
- **Thomley** - Offer regular days for disabled visitors and their families. They also offer focus days for preschool children, adults, schools, respite groups and the wider community.
- **The Fragile X Society** - Provide information and practical guidance to support and empower individuals and families living with fragile X, and the professionals who support them. The service is provided across the UK through three specialist support workers.

CDC's Projects and Activities

At CDC we provide policy advice, guidance and best practice on SEND across health, education and social care. We also host a number of special interest groups, programmes and national services. Read on to find out what we've been up to and to hear about the exciting work we've been doing:

New audit tool for Clinical Commissioning Groups

CDC and the Department of Health have published a Clinical Commissioning Group (CCG) audit tool which is designed to help CCGs understand their progress in implementing the SEND reforms. As part of the joint inspection process CQC inspectors will regard completion of the audit tool as a positive step and consider it a good evidence base to demonstrate how well local health services understand local need in relation to children and young people with SEND. [Click here to download.](#)

How do you build participation into your work?

As part of our new work on building the participation of disabled children and young people, we are asking professionals who work directly with disabled young people and those with SEN to tell us about how they are doing participation in their local areas. The survey aims to understand young people's participation in strategic decision-making across England. It consists of questions to understand the mechanisms and processes that local areas use to support young people's participation in local decision making processes.

This survey is ideal if you are:

- A professional working directly with disabled young people and those with SEN and have experience in participation
- A professional such as a commissioner or strategic manager across education, health and social care who is involved in developing services or strategic decision-making processes for disabled young people and those with SEN

Fill out the quick survey here: <https://www.surveymonkey.co.uk/r/SENDparticipation>

Not your ordinary workshop: theatre-based Mental Capacity Act training

We're excited to let you know that we've partnered with Face Front Inclusive Theatre to provide you a special training day and performance on the Mental Capacity Act 2005 and supported decision-making. With a mix of interactive sessions and theatre, you will:

- Explore the different experiences of young people and families through an interactive performance by Face



Like what you've read? **Sign up to receive our quarterly digest and monthly newsletters!**

Front Inclusive Theatre, a group of learning disabled artists

- Understand the 5 key principles of the Mental Capacity Act 2005 and how to apply them in practice
- Learn practical person centred approaches for involving young people in decision making, whether or not they have capacity, including use of the 'best interest checklist'

Who should attend:

- Professionals working directly with disabled young people and those with SEN aged 14-25
- Professionals involved in informing, developing and coordinating EHC plans across education, health and social care and across children's and adults' services

There are still tickets left for the following dates:

[4th July - London](#)

[5th July - London](#)

[6th July - Birmingham](#)

[7th July - Manchester](#)

New IASSN service user feedback

During 2015/16 the Information, Advice and Support Service Network (IASSN) carried out a pilot project to evaluate service user feedback from IAS Services across the country. This has enabled them to collate feedback from almost 400 service users over a 3 month period. The results show how highly service users rate IASS (in terms of satisfaction, impartiality and whether support made a difference). This is the first time such data has been collected nationally across a number of different services.



SEND Support for 2016-17

As part of their transition and implementation arrangements, the Government awarded a series of contracts to provide information, advice and support to those affected by the reforms. To help you find what's available to you we've pulled together a menu of support listing all the services, training and advice that is funded this year.

Strategic Reform Partner

CDC will continue to provide support and challenge in its capacity as Strategic Partner to the Department for Education for the SEND reforms, drawing on intelligence from parent carers, children and young people and the voluntary and community sector. More information on our web pages.

Support for Parent Carers



Contact a Family and the National Network of Parent Carer Forums will be ensuring that parents will continue to help shape local provision and get the help they need. This will include a free, national helpline for parents and ongoing support through e-mail and websites.

Independent Support



To support children, young people and families through the transition from SEN Statements to the new Education Health and Care plans the Government launched Independent Support to provide additional help. To find your local Independent Support team visit the Independent Support website.

Delivering Better Outcomes Together Consortium



The consortium is made up of three organisations; Mott MacDonald, NDTi and CDC. Together we deliver a range of flexible and tailored support to help improve understanding, build confidence and support best practice in relation to the reforms to SEND provision.

Supporting local authorities

We provide a range of flexible support to local authorities through a network of 9 regional SEND leads. The regional lead is either an individual local authority or a consortium of local authorities and their partners. They provide intelligence from the ground to highlight areas where further support is needed and provide a route to cascade information back to local authorities.

Preparing for Adulthood



This year Preparing for Adulthood are focusing on identifying and sharing good practice. We will be working with 9 local authorities across the regions, in both rural and urban areas, to develop approaches and support implementation of good practice.

Joint Working

Key to the success of the SEND reforms is ensuring that practitioners across the sectors are working together to share information and collaborate effectively. To support that objective we are providing regions with a combination of network support and one-to-one advice.

Information, Advice and Support



Each local authority hosts an Information, Advice and Support service (formerly called Partner Partnership Services) where children, young people and parent carers can receive impartial and confidential advice. There are 150 IAS services across England offering support.

Local IAS services are supported by the IASS National Network, which is hosted at the Council for Disabled Children. They provide staff employed in IAS services with legal training, one-to-one advice and resources.

You can find out more about the IASS National Network and search for local IAS at www.iassnetwork.org.uk

Specialist Support Contracts

The Department for Education have confirmed funding for the following support for implementing the SEND reforms for 2016-2017:

Supporting dyslexia

www.bdadyslexia.org.uk/

The British Dyslexia Association in partnership with Dyslexia Action, Dyspraxia Foundation, Helen Arkell Dyslexia Centre, Patoss and Manchester Metropolitan University will be working together to promote best practice for those delivering dyslexia support. They will be producing resources & materials for professionals, parents, carers and children and young people with speech and learning difficulties. Video resources for teachers will also be produced and they will further develop and extend BDA Dyslexia Friendly Quality Mark and Literacy Leap award schemes.

Supporting Sensory Impairment

<https://www.natsip.org.uk/>

Natsip will be promoting effective practice and helping improve specialist advice on sensory impairment in EHC assessments and plans. They also aim to harness technology for children and young people with sensory impairments to improve accessibility and outcomes. Over the course of the year they will be developing online resources and training for front line workers and build on existing evidence of sensory impairment EHC plans to provide guidance on best practice examples. They will also be setting up a national advisory group on SI technology.

Supporting the participation of children and young people

<http://councilfordisabledchildren.org.uk/buildingparticipation>

The Council for Disabled Children and KIDS are working in partnership to deliver a programme of activity focused on helping disabled children and young people understand the changes in the law and helping practitioners improve the way they participate with at both the strategic level and in practice. The programme of activity includes regional and national young people's advisory group, 3 national events, a pilot programme working with 3 local authorities and a programme of communication activity to promote understanding of the reforms.

Supporting SENCO's

<https://afaeducation.org>

Achievement for All are working in partnership with Plymouth University to support the national award for SEN co-ordination and review the SEN co-ordination role in the early years and post-16 sectors. The project has three work streams which are:

- Reviewing the effectiveness of the National Award for SEN Co-ordination and leading the forum of current providers of the Award.
- Reviewing the SEN Co-ordination function in the Early Years and post-16 sectors
- Reviewing the possibility of extending the National Award of SEN Co-ordination to providers in the EY and post-16 sectors

Supporting young offenders with SEN

<https://afaeducation.org>

Achievement for All are working together with the Association of Youth Offending Team Managers and Manchester University to support professionals working with or for the youth justice system to bring about a culture and behaviour change around effective joint working.

It will work to build connections between professionals within and beyond the secure estate and run a series of regional and online training events aimed at improving the knowledge, skills and confidence of practitioners working with young offenders with SEN.

Supporting further education

www.et-foundation.co.uk/

The Education and Training Foundation are developing training to support teaching staff as well as practical sessions for practitioners, leaders and governors. They also host an online resource bank with information and advice about dyslexia.

Throughout the programme they will be examining the implications and impact of the reforms on practitioners and leaders and reporting on the impact and effectiveness of the training provision.

Supporting autism

www.autismeducationtrust.org.uk/

The Autism Education Trust have extended their programme of support this year and will be creating four additional training hubs with a special focus on post-16 support. They will launch five new regional networks focusing on a special school and special unit network and a regional local authority strategic network.

They will also be delivering a project to help prevent young people with autism from being excluded from school.

Supporting schools

<http://londonleadershipstrategy.com/>

The London Leadership Strategy aim to build the SEND Review principles into wider school-led school improvement agenda. Alongside work with Regional School Commissioners and Teaching School Council this work will also specifically look at three areas raised by schools as key issues during the last two years of LLS SEND work. These include developing a dedicated SEND programme for classroom teachers, support on how to make effective use of teaching assistants and helping pupils with SEND prepare for adulthood

Supporting speech, language and communication needs

<https://www.thecommunicationtrust.org.uk>

The Communications Trust will be focusing on increasing awareness and understanding of Speech, Language and Communication Needs (SLCN) across the workforce and with national and local policy makers. They will continue to build the evidence base for best practice and support the sectors capacity to respond to the changing landscape. They will be delivering a range of activities including an analysis of workforce development, teacher training, online learning for practitioners, guidance on commissioning as well as continuing their work with local champions and the further education network.

Overview of the latest case law

Our series of case law reviews on judgements relating to special educational needs and disability continues with three case law review summaries compiled by barrister [Steve Broach from Monckton Chambers](#). To read the full accounts including advice on what the judgements mean to children, families and local authorities, click on the link at the end of each summary



Case Law Review No. 10: Staffordshire County Council v JM [2016] UKUT 0246 (AAC)

Case overview

This Upper Tribunal decision confirms that school transport is not special educational provision. As such the Tribunal has no jurisdiction to order a local authority to provide school transport. The legal remedy in school transport cases is judicial review.

The Upper Tribunal also held that the duty to provide transport to adult learners only arises if the local authority considers it to be necessary in all the circumstances to fund such transport.

Decision

The dispute in this case arose because the local authority held that it only had to pay for transport for H to her college if they considered it to be necessary. H's family refused to provide the information requested to help the local authority reach this decision on the basis that the request was unnecessary and intrusive.

The First-tier Tribunal ('the Tribunal') had held that H required a carefully graded programme at her college, that provision of that programme required provision of transport to access it and that this amounted to a form of provision for H's special educational needs.

The Upper Tribunal disagreed. Considering a number of authorities under the previous legislation, the Upper Tribunal Judge held that 'it cannot sensibly be argued that a need for home to school transport arises from a "learning difficulty"', this being a requirement of the definition of a special educational need. Nor could home to school transport be classified as a form of special educational provision.

As such the Tribunal lacked jurisdiction to consider transport issues in the appeal or to make any orders requiring transport to be provided. This is because the Tribunal's jurisdiction is limited to matters concerning special educational needs and provision and to the child or young person's placement.

In cases where choice of school or college is in issue, the cost of transport is a matter which the Tribunal may have to take into account in deciding which provision to order. However this was not such a case.

Furthermore local authorities only have a duty to make transport arrangements for adult learners where they consider the arrangements to be necessary in all the circumstances. Although the question of what is 'necessary' is a matter for the local authority, 'in deciding that question they must exercise their judgment judiciously and in good faith'.

As the Tribunal has no jurisdiction over transport issues, the remedy in such cases is judicial review.

What this means for children, young people and families

As the Tribunal will not have jurisdiction to resolve transport disputes, these must be resolved through the local authority's appeals process and if necessary through judicial review. Expert advice on when judicial review may be appropriate will be needed as soon as possible in every case.

Young people aged over 18 can rely on the decision to highlight that there will be a duty to provide them with free transport to college if their local authority accepts that this is necessary in all the circumstances.

Families may want to take advice before refusing to provide information requested by public bodies.

Implications for local authorities and other public bodies

Local authorities will need to ensure that their adult transport policies properly reflect the nature of the adult transport duty, in particular that adult learners will be entitled to free transport if an assessment shows this to be necessary.

Local authorities also need to have effective appeals processes in place given that the Tribunal does not have jurisdiction to consider these disputes, to avoid the need for judicial reviews.

To read the full case law account please go to

<http://councilfordisabledchildren.org.uk/case-law-review-10>



Case Law Review No. 9:

London Borough of Hillingdon v WW [2016] UKUT 0253 (AAC)
Buckinghamshire County Council v SJ [2016] UKUT 0254 (AAC)

Case overview

These two decisions of the Upper Tribunal concerned linked issues as to the proper approach to appeals where the young person lacks or may lack capacity. There were also separate challenges to the reasons given by the First-Tier Tribunal ('the Tribunal') in support of decisions allowing the families' appeals.

In both cases the local authority's appeals were dismissed. The Upper Tribunal gave important guidance on the proper approach to appeals by young people. The decision in the Buckinghamshire case is also important on the meaning of 'education' for young people.

Decision

The Buckinghamshire case concerned an appeal against a decision not to issue an Education, Health and Care Plan ('EHC Plan'). The Hillingdon case involved an appeal against the contents of an EHC Plan, particularly in relation to the school named.

The approach to capacity comes from the Mental Capacity Act 2005 ('MCA 2005'). Under the MCA 2005 capacity is decision-specific and time-specific and there is a principle that 'a person is presumed to have capacity until shown otherwise and then only after all practical steps have been taken without success to help them make a decision'. Importantly, the Upper Tribunal was clear that 'Whether a person has capacity is a matter of fact for the tribunal to decide'.

The Upper Tribunal noted that 'young persons who have capacity are in no different position from anyone else'. They bring the appeal themselves and can 'appoint someone to help and act for them'.

If a young person lacks capacity to bring the appeal, then the right to appeal passes to an 'alternative person'. This is their 'representative' if one exists, being a person appointed by the Court of Protection to make relevant decisions as a Deputy or a person with Power of Attorney. If no 'representative' exists, the 'alternative person' will be the young person's parent.

As noted above, it was accepted that the young person in the Buckinghamshire case lacked capacity to bring his appeal. As such the parents had the right of appeal as the 'alternative person'. The local authority ultimately accepted that there was no error of law in this approach.

In the Hillingdon case, the Upper Tribunal concluded that 'the statutory assumption of capacity was not displaced and the case was properly registered with [the young person]

as appellant.’

In the Buckinghamshire case, the Upper Tribunal Judge also stated that ‘I reject any suggestion that the attainment of qualifications is an essential element of education.’

What this means for children, young people and families

It will be important for families to consider whether the young person has capacity to bring the appeal themselves. This involves applying the four-stage test in section three of the MCA 2005:

- A. Does the young person understand the information relevant to the decision?
- B. Can they retain that information?
- C. Can they use or weigh that information?
- D. Can they communicate the decision?

In many cases it will be necessary for an assessment of capacity to be undertaken by an appropriate professional, for example a medical professional or a psychologist. Young people with capacity to appeal must bring the appeal themselves but can appoint someone to act as their representative (in the advocacy sense).

If the assessment shows that the young person lacks capacity, the appeal must be brought by the ‘alternative person’, either a ‘representative’, most likely a health and welfare Deputy, or by a parent if there is no ‘representative’. The alternative person can act on their own or appoint a representative (in the advocacy sense).

Capacity issues should be resolved as early as possible in the appeal process. Advice should be sought on the facts of individual cases.

The Buckinghamshire case also shows that the meaning of ‘education’ for young people must not be narrowly defined as linked to attainment of qualifications.

Implications for local authorities and other public bodies

Local authorities must be alert to the question of whether young people have capacity to make decisions in relation to EHC Plans and subsequent appeals to the Tribunal. Where appeals are issued, local authorities have an obligation to bring any issues in relation to capacity to the attention of the Tribunal and to assist with obtaining any necessary evidence to resolve these issues.

Local authorities should not adopt a narrow approach to education for young people over compulsory school age and in particular must not limit EHC Plans only to those young people who may be able to attain qualifications.

To read the full case law account please go to

<http://councilfordisabledchildren.org.uk/case-law-review-9>

Case Law Review No. 11

Kent County Council v M, K (by her guardian) [2016] EWFC 28

Case overview

A local authority was held to have breached a child's right to family life and right to a fair trial under the Human Rights Act 1998 following failures in relation to assessment and care planning and the failure to issue care proceedings. Damages of £17,500 were awarded to the child. This suggests that serious failures in assessment and care planning by local authorities in relation to disabled children may also result in human rights breaches.

Decision

The Court had to consider firstly whether a care order should be made for K and secondly whether her human rights had been breached. The Court decided it was necessary to make a care order for K, endorsing the plan for her to remain in long term foster care.

The human rights claim concerned failure to assess K, failure to meet her needs and failure to issue court proceedings. The Judge held that 'the failures by the local authority to properly assess and then support K's needs and to delay issuing legal proceedings for over three years were actions that were unjustified and incompatible with K's article 6 and 8 rights'.

The Judge gave a long list of reasons as to why the local authority had breached K's human rights. These included:

- The failure by the local authority to conduct or update K's core assessment for three years.
- The failure to secure appropriate mental health assessments and/ or therapeutic support for K.
- The repeated failure to seek legal advice to secure K's position through issuing proceedings.

This led to a finding of four breaches of K's human rights:

1. Failure to properly assess K from March 2012 until July 2015
2. Failure to implement a care plan that met K's needs from March 2012 to July 2015
3. As a result of (1) and (2), failure to provide K with a proper opportunity to secure a suitable long term placement and a settled and secure home life.
4. Failure to issue proceedings in a timely manner.

Taking account of the impact on K, the Judge decided that an award of £17,500 to K in damages under the Human Rights Act 1998 was necessary to afford K 'just satisfaction'.

What this means for children, young people and families

This judgment makes clear that serious breaches by local authorities of their obligations under the Children Act 1989 can result in human rights breaches. This can lead to significant damages being awarded by the courts. This may apply where there has been significant delay and / or failure to act in cases involving disabled children.

It is however important to keep in mind that the assessment and care planning failures in K's case lasted for over three years and had a seriously detrimental impact on her welfare. Less significant failures will be unlikely to result in a human rights breach. Advice will be needed on the facts of any specific case.

Implications for local authorities and other public bodies

Local authorities will be reminded by this judgment that one of the consequences of breach of statutory duties owed to children and families may be a successful claim for damages under the Human Rights Act 1998.

The judgment also specifically emphasises that if section 20 of the Children Act 1989 is being used instead of care proceedings for a child, this must be kept under careful review with active consideration given at all times as to whether proceedings should be issued.

To read the full case law account please go to

<http://councilfordisabledchildren.org.uk/case-law-review-11>

These updates are intended to provide general information about recent decisions of the courts and Upper Tribunal which are relevant to disabled children, young people, families and professionals. It cannot and does not provide advice in relation to individual cases. Where legal issues arise specialist legal advice should be taken in relation to the particular case.

Member Focus:

How the Children's Sleep Charity are tackling sleep deprivation in children with autism

By Vicki Dawson, CEO of [The Children's Sleep Charity](#)



The Children's Sleep Charity tell us about their current project aiming to support families of children with autism to get a good night's sleep.

"Sleep deprivation can lead families into crisis. Insufficient amounts of sleep impacts on the physical, emotional and mental health not only of the children with autism but also their parents and siblings. It is vital that families receive appropriate support."

The Children's Sleep Charity was set up in 2012 and aims to support families to get a good night's sleep. I founded the charity after experiencing first-hand the impact of sleep deprivation as a mother. My professional background prior to establishing the charity is as a specialist teacher working with children with SEND.

The charity is now well established as one of the leading providers of training in sleep across the country, and delivers a range of services including training professionals, sleep clinics and producing resources. Since its launch the charity has been inundated with requests for support from families of children with additional needs. A behavioural approach to sleep is adopted where qualified sleep practitioners work in partnership with the parents/carers in order to establish why sleep issues may occur and identify appropriate strategies for them to implement.

It quickly became apparent that a significant number of enquiries that were being received were around children with autism. Consultation with both professionals and parents led the charity to identify that there is a huge gap in this area of support which must be addressed to ensure children are able to sleep well and meet their full potential. Research suggests that over 80% of children on the autistic spectrum will experience a sleep issue.

There are a range of reasons why children on the autistic spectrum may have sleep issues and that a behavioural approach to sleep can support significant improvements in the majority of cases. The lack of support for families around sleep issues is worrying and so when we secured NHS England funding for this pilot project we were delighted.

In January 2016, the charity received funding to pilot a project across Herefordshire, Gloucestershire and Worcestershire aimed at supporting families of children with autism to get a better night's sleep. The project involved developing a specialist workshop for families to receive key information around sleep and autism alongside professionals. A steering group of parents was established to advise on the materials used. In addition to the workshop the families were offered follow up support from an experienced sleep

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practitioner as they implemented any changes.

The project aimed to work with 50 parents and 50 practitioners, however due to the high demand these numbers were exceeded. Sleep practitioner, Helen Rutherford, carried out the work with families and says *"We used evaluation methods to indicate parental mood pre and post workshop attendance and recorded that over 90% of parents experienced a positive shift in mood. Families were able to share experiences and this helped, I think, to reduce some feelings of isolation that they may have previously experienced."*

The workshop explores how pre-bedtime activity impacts on sleep quality and research shows that the light emitted from screens such as televisions, mobile phones and computers can interfere with melatonin production. Switching screens off in the hour leading up to bedtime can be an important step towards getting a better night's sleep.

The key focus of the workshop is around every child being an individual, and therefore it is important to unpick why the sleep issues may be occurring and to then select appropriate strategies to help support the child. Training is given around understanding the structure of sleep, keeping sleep diaries and interpreting results, sensory issues and their impact on sleep, helpful supper time snacks as well as creating appropriate bedroom environments.



Parental feedback on the project has been incredibly positive, highlighting the importance of this piece of work:

"We are doing brilliantly with the programme, it has worked! We are all a bit calmer for sure."

"We are so happy with how it's worked out. Our son is much happier in himself too, he is having an easier time in school now that he isn't as tired"

The charity are currently exploring funding opportunities in order to roll this programme out across the country. For further information please contact Kim at

info@thechildrenssleepcharity.org.uk

Doing some innovative work at the moment? We'd love to hear from you! CDC are always on the lookout for great examples of how fellow organisations are working in the SEND sector and we're always keen to shout about your achievements.

If you fancy speaking at a CDC Members Meeting or would like to be featured in an article in the Digest then please do get in touch. Contact Daphne Henderson-Figueroa on dhenderson@ncb.org.uk

Spotlight on Siblings



by Monica McCaffrey, Chief Executive, Sibs
and Clare Kassa, Partnership Development Manager, Family Fund

With their expertise in the field, CDC members [Family Fund](#) and [Sibs](#) give us an in-depth look at why siblings of disabled children and young people still have fewer choices and opportunities than their peers.



Siblings face barriers to wellbeing and learning

Floyd (above, on the left) is one of over half a million siblings of disabled children in the UK. Siblings often enjoy positive and enriching relationships with their disabled brothers and sisters. They also play a huge role in their social lives, in supporting with their care, in advocating for them, and in helping them develop new skills. However, the experience of being a sibling of a disabled child today can have a significant impact on siblings' wellbeing and education. [Floyds' story](#) illustrates missing out on opportunities, having disrupted sleep and being different from peers.

The joint research review between Sibs and the University of Warwick [Children and adolescents who are the siblings of children with intellectual disabilities or autism- Research evidence, Sibs, 2013](#) highlighted that siblings of disabled children were at increased risk for problems with wellbeing and education themselves, especially siblings who were caregiving and siblings whose brothers and sisters had high levels of behavioural problems.

A picture of sibling life in the UK today

Family Fund, which provides grants to families of disabled children, piloted a project giving direct grants to siblings as a small token of recognition of the important part they play in their families. Family Fund carried out a research study with the University of Portsmouth on the impact of these grants on siblings as well as more about the life experience of siblings. The report [Do Siblings Matter Too?, Family Fund, 2015](#), contains very powerful responses

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from siblings. Many talked and showed in photographs the isolation they experience, their worries, and the impact disability has on their daily lives. Siblings shared that they experienced aggression and violence and many were sleep deprived which affected their own potential at school. Many siblings had emotional needs that were overlooked because of the needs of their disabled brother or sister.

'I have moved upstairs now because it was disturbing my night's sleep with the night staff going up and down the stairs (and the ambulance staff when called out)...we are meant to get six nights a week but they keep messing it up and we get about three or four nights.'

Sibling with a sister with a disability that causes her to stop breathing

Siblings are doubly vulnerable to cuts to service provision

Local authority services for siblings in their own right are no longer a priority for commissioners as they were ten years ago, and siblings are experiencing the practical and emotional impact of reduced support for families of disabled children. Mental health support through Child and Adolescent Mental Health Services has also become more difficult for siblings to access. The report [Life to the Full: Care and Support in the UK for Disabled Children and Children with Life-Limiting and Life-Threatening Conditions, Demos, 2015](#) recommends that sibling support is one of the key areas that charities and funders focus on.

Are siblings lost in other agendas?

Policy and practice around the needs of siblings of disabled children to date have been within the disabled children and young carers' agendas. But the needs of siblings also need a place within the mainstream children's agenda, especially education. The focus on siblings as young carers misses the vitally important fact that many siblings do not provide care yet still have fewer choices and opportunities than their peers and experience problems with their wellbeing and progress at school. Whilst every sibling has the potential to become a young carer during their childhood, care is just one of the many [barriers to wellbeing and learning that siblings face](#).

'Having a disabled 7 year old sis is really hard for me because I always feel bad when I go out on residential trips with school or I stay at my friends house. I feel like this coz she can't do what I do. I always worry about her when I'm at school as well and I think it affects my learning. This is bad especially as I have SATS in two weeks.'

YoungSibs chat

Not just a childhood issue

The impact on siblings continues into adulthood, often for a lifetime. As siblings become young adults they increasingly worry about their role in the future care and support of their disabled brothers and sisters. Cuts to adult social care, lack of engagement of service providers with siblings, and poor implementation of the Mental Capacity Act are making

the life choices for adult siblings harder than ever. The experiences of adult siblings today are explored in [Guardian Social Care Network: Charity highlights role of siblings in supporting adults with a disability](#).

Key recommendations

1. Acknowledge the role siblings play in the lives of their disabled brothers and sisters.
2. Identify siblings in school as a vulnerable group and provide sibling support interventions in schools.
3. Recognise that sibling harm is a safeguarding issue and that it should be addressed within mainstream children's safeguarding procedures.

About Sibs

Sibs is the UK charity for siblings of disabled children and adults.

Current work:

Providing information and workshops for [parents on supporting siblings](#)

Running [YoungSibs](#), an online support service for young siblings

Developing resources for school staff to use to support [siblings in schools](#) and working with schools to identify which of their pupils are siblings

Developing a network of [support groups across the UK for adult siblings](#) of people with life-long learning disability or autism

About Family Fund

Family Fund provides grants to families raising disabled or seriously ill children, across the UK. These grants are for essential items such as furniture, clothing, kitchen appliances, computers/tablets and family breaks. The work of Family Fund extends beyond grants, to ensure that families also receive timely and appropriate information and signposting to relevant support agencies. Family Fund continues to explore ways of supporting the whole family, including siblings.

Would you like your project featured in the next Digest? We'd love to hear from you! For more details on how to get involved please email Daphne on dhenderson@ncb.org.uk

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Increasing participation:

Empowering children and young people with autism to have a stronger say in their lives



By Siobhan Gorry, Strategic Case Manager (North) Children and Young People's work stream, NHS England

As part of their Transforming Care for Children and Young People with learning disabilities and/or autism work stream, NHS England recently funded a range of grant projects to support children, young people and their families. One of those projects was a programme of work designed to support children and young people with autism.

The project aims to help young people:

- be actively and meaningfully involved in processes about improving their life
- be aware of who they are and what they need to make life better
- have the confidence to actively participate in their care and treatment.

Inclusion North, in partnership with Autism in Mind Sunderland People First and Spectrum enterprises set up a programme called "All about Me". This programme of six sessions set out to 'promote emotional resilience and confidence and develop self-advocacy and communication skills to enable young people on the autism spectrum to have more choice and a stronger say in their own lives'.

The sessions, co-facilitated by a neuro-atypical and a neuro-typical facilitator worked to achieve these goals by individually identifying with participants supportive behaviours. This included: reducing social isolation, preventing 'meltdown', and developing routines which enhance good mental health and the confidence to speak up about those needs and issues.

The training course was underpinned with autism specific activities which encouraged self-reflection, challenged avoidance behaviours, and encouraged realistic goal setting and the development of coping strategies.

The sessions were evaluated throughout the course based on feedback from the young people, their carers/supporters, facilitators and independent external observations in order to assess whether the following outcomes were met by the end of the course:

- That young people and their carers/supporters feel that they have developed in relation to their autism understanding, self-confidence, self-awareness, communication and self-advocacy skills.
- That the young people feel more equipped at the end of the course to communicate their needs to others and in particular to those they are less familiar with,
- That the young people and their carers/supporters feel that they or the young people they support are better equipped to advocate for themselves at the end of the course and are able to give examples of this.
- Success was measured by the participants and supporters verbal feedback both in groups and as individuals throughout the course and by sample independent observations of a number of sessions throughout the course, with particular focus on the beginning, middle and end.

The young people gave feedback in several ways throughout the duration of the course, through one to one and group discussion with the facilitators and independent evaluator, by completing evaluation forms, through video diaries and via the observations and feedback of their carers / supporters. Examples of participant feedback which clearly demonstrates the real value of this programme for young people with autism includes the following:

Carer of Joanne (not her real name) said: “Joanne is the youngest but she has got a lot out of the course, she is now tolerating things such as eating the food provided rather than bringing her own which sounds small but is so massive for her with her extreme anxieties about germs”

Joanne reported “I am seeing myself much better in terms of self-esteem now than I was at the start of the course”

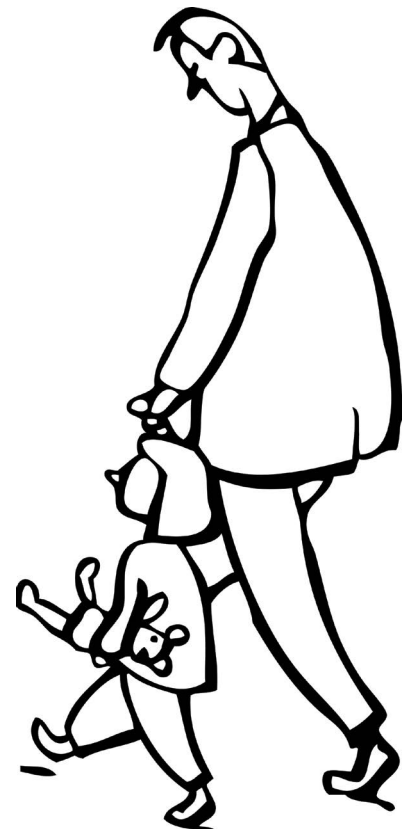
Simon felt he had also been able to self-reflect whilst on the course, that at times he tries to ‘provoke reaction’ in his mother when at home, he was now trying to work on reducing this. (Mum attended the course with him).

Daniel (not real name) spent week one sitting behind a chair as he was so anxious about being with new people. By week six, Daniel was sitting with the group and contributing to activities/discussion.

Aisha (not real name) has met the goal she had set to see her GP independently about a health concern and tell the GP that she has autism at start of consultation, this is a huge step for her.

Overall, the sessions helped the young people to learn how to become more self-aware, understand how their autism affects them, and to be able to present the way they are feeling to others before they reach a state of panic, 'meltdown' or depression. These steps are arguably the starting point for empowering young people to take control and ownership of their lives, and to give them the tools and confidence to be active participants in creating opportunities for young people to participate in planning and decision making for their lives.

For more information about the NHS England Transforming Care project please go to www.england.nhs.uk/learningdisabilities/camhs or email England.camhsLD@nhs.net



Resources

Young people in Youth Custody: A practice guide

This practice guide is aimed at those working to improve outcomes for young offenders who have or may have special educational needs. [Click to download.](#)

FAQs on social care and the SEND reforms

Barrister Steve Broach has prepared advice for social care professionals in relation to the SEND reforms. It sets out a number of frequently asked questions that have arisen through CDC's transforming culture and practice in children's social care assessment programme as well as feedback from our social care training. [Click to download.](#)

Organisations Who Provide SEND Support

Developed through the IASSN-led SEND Information Organisations Group (SENDIOG) this [info sheet](#) provides details of organisations who provide FREE advice and support (such as phonelines, emails and direct support) on a range of matters relating to SEN and disability in England. The document includes impairment specific support, and support available which children, young people, parents and/or professionals can access.

Identifying the social needs of disabled children and young people as part of EHC assessments and plans

Drawing from their work with local authorities and their partners, CDC has developed this briefing to help those coordinating EHC assessments and plans to have the confidence to gather information which will provide accurate social care advice, particularly where a young person is not known to a social work team. [To download click here.](#)

The role of Independent Reviewing Officers in EHC assessments and plans

Following discussion with Independent Reviewing Officers (IRO), social workers and other local authority staff, this briefing was developed to help IROs in carrying out their role in respect of disabled children and young people and those with SEN. It focuses, in particular, on education, health and care (EHC) needs assessments and plans made under the Children and Families Act 2014. [Click here to download.](#)



CCG Audit Tool: SEND reform implementation

CDC has developed this tool (which can be found [here](#)) to help CCGs understand and develop their progress in implementing the SEND reforms. It will be useful to support areas in the preparation for joint Ofsted/CQC Joint Area SEND inspections.

New edition of resource magazine from Contact a Family

Connected, a magazine for families with disabled children and all who work with them is out now. Packed with stories from parents, this edition's theme celebrates the vital support families give each other. Sign up for an email alert [here](#).

Down syndrome: good practice guidelines for education

This report, published by the UK All Party Parliamentary Group on Down Syndrome, offers guidelines on education for children and young people with Down syndrome aged from birth to 25 years. [Click here to download](#).

Disability Rights Handbook

The handbook is a good guide to disability benefits and independent living. It provides clearly written, in-depth information on the entire benefits and independent living system.

[Available to purchase here](#).

Supporting deaf young people through transition (England)

This resource is for professionals supporting deaf young people in England through transition when they leave school or college – this includes deaf young people with and without an Education, Health and Care (EHC) Plan. [Click to download](#).

Schools, Pupils and their Characteristics: January 2016

DfE have released a [range of data and information on schools](#) collected in the January 2016 school census, it includes Special Educational Needs (SEN) provision and type.

Early Intervention Project

The British Dyslexia Association and Springboard for Children have produced a series of resources for parents and teachers to improve the learning literacy of primary school children. Included is a whole school policy for supporting children with literacy difficulties.

[Click to view](#).

Making it Personal: A guide for education local authorities

This guidance has been written to assist local authorities (LAs), schools and other educational settings, in becoming more familiar with how personal budgets are being used, and how they might be used, as part of the change from statements to Education, Health and Care plans. [Click to download](#).



Making it REAL: SEND reforms fact sheet

Ideal for those working in early years, the National Children's Bureau have produced a fact sheet on the SEND reforms as part of their Making it REAL project. It gives an overview of the reforms, looking at what's new and what's changed in practice. [Click to download.](#)

NatSIP: Sensory Impairments and the reforms

NatSIP have produced an extensive range of guides on EHC plans and work force development as part of their DfE funded programme of support. [Click for more information.](#)

Training and Events

It's My Life! Decisions, capacity and EHC plans

The Transition Information Network in association with Face Front Inclusive theatre have announced new training opportunities in London, Birmingham and Manchester. If you are a professional working in education, health and social care and wish to learn about the principles of the Mental Capacity Act 2005 and supported decision making for young people with EHC plans, this training is for you! Click below to book tickets:

[4th July - London](#)

[London 5th July](#)

[Birmingham 6th July](#)

[Manchester 7th July](#)

Benefits training course

This course gives a basic overview of the current benefits system. It is aimed at professionals who work in advice or advocacy who need to know more about - or need a refresher on - changes to welfare benefits and social security. To attend, please email training@disabilityrightsuk.org

Early Years Pupil Premium: Innovation & Impact'

This event brings together well-renowned early years experts, practitioners, managers and senior leaders in primary schools to offer a range of deliverable, evidence-based, practical approaches. It's designed to support professionals in developing their understanding of how best the Early Years Pupil Premium can be put to work. [Click for information and tickets.](#)

Free CPD course for teachers and educational practitioners

Focus on SEND is a free course aiming to help teachers and educational practitioners working across the 0-25 years age range to develop high quality practice in order to better meet the needs of their learners with SEND. The offer of training for Primary and Secondary school teachers is now freely available to access. To reflect the intentions of the SEND Code of Practice, and following testing and expert review by colleagues working in these settings, they will be launching training for Early Years and the Post 16 sectors later in May.

Mental Health Conference for 2016

The new strategy for mental health services in England, The Five Year Forward View for Mental Health, sets out 59 recommendations that promise to shake up all aspects of mental health care. At this conference learn how the report's recommendations will be hardwired into how care is commissioned, funded, delivered and inspected across the whole of the NHS and wider public sector. For more information [click here.](#)

Bespoke training from CDC

We deliver training to help practitioners and services for children, young people and families on a range of current issues. Our training combines sensible guidance on all the latest legislation with practical advice and solutions for delivering good outcomes for children and young people.

All of our training can be delivered on request to your organisation either on site or at our offices in London. To find out more about the following training please contact 020 7843 1900 or email cdc@ncb.org.uk for a quote or click on the link to see the full training programme: <http://www.councilfordisabledchildren.org.uk/what-we-do/training>



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.

You can **download the latest issues from the CDC website**.

If you would like to be added to the list to receive this digest, email **cdc@ncb.org.uk** with 'Subscribe to CDC Digest' in the subject line.

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**, **Preparing for Adulthood**, and the **Independent Support** programme.

The Council for the Disabled Children is part of the National Children's Bureau



Find out more



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