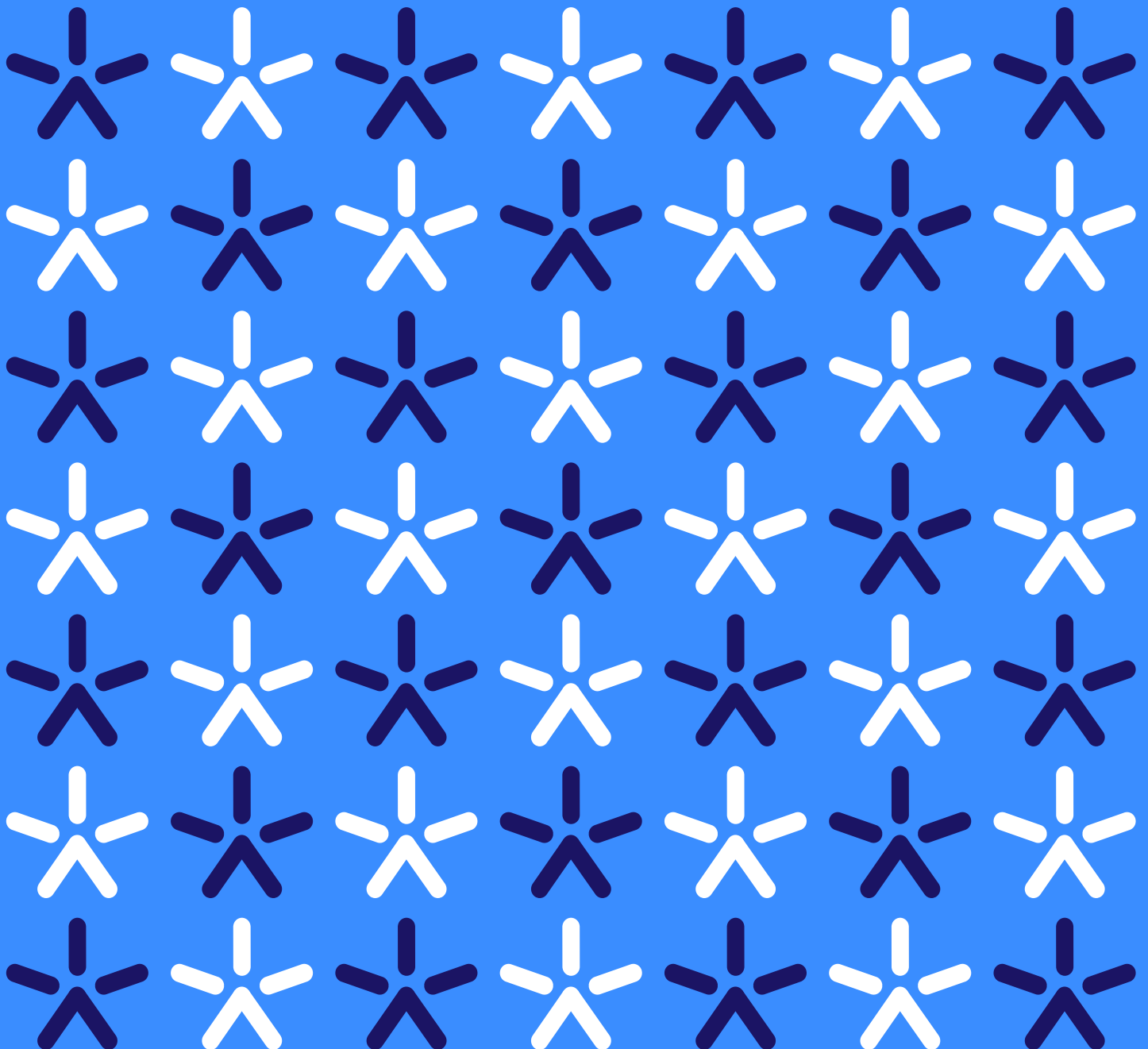


Exploring the education, training and support needs of those who provide care for children and young people with learning disabilities and learning difficulties

Learning from children, young people and their families and those who support them



Foreword

I am delighted to be asked to write the foreword to this important report.

Further to Mencap's 2007 report called '[Death by indifference](#)', which was about 6 people with learning disabilities who should not have died, [Health Education England](#) want to make sure that the staff that work with people that have Intellectual Disabilities have the right skills and values, in the right place at the right time.

The 'Workforce Development for people with Intellectual Disabilities' programme, part of Health Education England (HEE), aims to create a sustainable and secure workforce supply so that people can live a good life.

In line with these aims, all our work at the [Council for Disabled Children](#) (CDC) is influenced by the voices and experience of the children and families we work with and the people who support them.

It has taken a long time for people to understand that children and young people with learning disabilities and difficulties have a voice, even longer to support people to listen to it. Yet we know through all our work with expert patients that when we do listen and when we enable patients to be partners in their care, outcomes can be so much better

An effective workforce of supporters which is able to embrace this, understanding their needs, essential values, and effective approaches to skills development, is key. As such we were really pleased to undertake this work with HEE, which brings the needs of supporters and the voices of young people together.

We began the work in August 2018 identifying young people's groups and the broadest group of supporters including professionals, volunteers, parents and carers, who wanted to take part and bring their expertise and experience to the issue.

The goal of the work was simple, to understand what children and young people need from the workforce in order to reach the best outcomes, and what the workforce of supporters itself needs to do the same.

The young people have a range of learning disabilities and difficulties. They use the health system and need it to function well for them to reach their outcomes. They are also clear that they are experts in their own conditions and want to be actively involved in their treatment and support.

The workforce itself also want it to function well. They want to understand their own learning and be confident about making the right decisions. They were very aware of the need for safeguarding training for example, but also wanted to be equally confident in understanding communication and the social model of disability.

Like everything in 2020, COVID-19 intervened in our world and made us rethink how we needed to communicate and provide support. We have reflected on learning, both positive and negative. The young people rose to the task as we explored the technology that enabled their voices to be heard, and for staff it really did clarify what could be learnt through e-learning and what needed to be face to face.

As this learning shifts our approaches and understanding, and as we embark on the recovery journey from the last year, a clear constant remains. The importance and value of the voice of children and young people is central to the developments in the way their future care and support is delivered. Their voice is also central to the skills and values that their dedicated workforce of supporters need to ensure that they achieve their outcomes no matter what they may be.

Christine Henahan

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About this project

Who was involved?

Health Education England, South East Region

Health Education England (HEE) works nationally and regionally across England to support the high-quality delivery of healthcare and health improvement to the patients and public.

HEE aims to provide the workforce with the right skills and values, in the right place at the right time to better meet the needs and wants of patients. Overseeing workforce planning, education commissioning and provision, to improve both national consistency and standards and local leadership and decisions.

[The Intellectual Disabilities Programme](#), working across the South East Region, supported us to undertake this project

The Council for Disabled Children



**NATIONAL
CHILDREN'S
BUREAU**
Part of the family

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector. Our vision is a society in which disabled children and young people's rights are respected, their aspirations supported and life chances are assured. We have a membership of over 300 voluntary and community organisations and an active network of practitioners that spans education, health and social care.

CDC's role as the strategic reform partner to the Department for Education (DfE) and as part of the Delivering Better Outcomes Together (DBOT) consortium includes workforce development and practice improvement through a range of approaches.

We facilitate national community of practice networks for Designated Medical Officers (DMO) and Designated Clinical Officers (DCO); Designated Social Care Officers (DSCO) for SEND; and special educational needs and disability (SEND) leads in local authorities, as well as delivering strategic workshops and

frontline training to multi-agency practitioners on a wide range of themes in relation to improving outcomes for children and young people.

In November 2019, CDC were appointed by HEE to support the development of the new NHS England/Improvement Key Working function. Drawing together stakeholder's from across the sector, CDC worked closely with NHSE/I and HEE to help define the function, outline clear parameters and objectives, highlight system requirements and support the commissioning of the pilot sites.

Through the Early Years SEND partnership we are working with five partners and nine English regions to provide significant support on SEN and disability to early years settings and local authorities. CDC is delighted to be working with nasen, I CAN, The Communication Trust, Contact and Dingley's Promise on this programme.

In June 2020, we published Tomorrow's Leaders – A world beyond Disability which was commissioned by the Education Training Foundation (ETF) on behalf of DfE <https://councilfordisabledchildren.org.uk/help-resources/resources/tomorrows-leaders-world-beyond-disability>. This exciting publication profiles the achievements of over 30 inspirational young people who are leading in their communities, with ambition, hard work and dedication to improving society. In addition to the publication we were also able to develop an infographic which sets out the support the young people valued from their experiences in Further Education:

<https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/FE%20Infographic%20-%20FINAL.pdf>

In addition, Making Participation Work is the DfE's national participation programme for special educational needs and disability. Jointly delivered with KIDS we work across England to support professionals and practitioners to deliver effective quality participation. More information can be found online: <https://councilfordisabledchildren.org.uk/our-work/participation/practice/making-participation-work>

Acknowledgements

This report has been made possible by the involvement of several young people's groups across the south of England. The information contained in this report was gained through consultation with children and young people with learning disabilities within a focus group setting.

The focus groups were delivered by both the Council for Disabled Children (CDC) and professionals leading the co-ordination of some of the young people's groups involved.

The materials used to aid discussions with the young people taking part in the focus groups were designed by CDC. All staff delivering focus groups used the same session plan to facilitate discussion with the young people taking part.

We would like to thank the following young people's groups for their time and involvement in this project:

- Ealing Mencap youth group
- Fabulous Youth, Croydon
- KIDS South Young People's Participation Team
- Market Field School, Colchester
- Richard Lander School, Cornwall
- The House Youth project, Cornwall

We also spoke to individual young people who wanted to participate in the evidence-gathering phase of this programme. We are grateful to them for their invaluable input, and their experiences have also been included in this report.

Background and context

What do we mean by learning disabilities, learning difficulties and autism?

Throughout this report, learning disabilities, learning difficulties, and autism are mentioned frequently. Therefore, we want to set out a shared understanding of these, and the differences between the terms.

Mencap share a detailed description of learning disabilities and learning difficulties here: <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>

It states that:

"A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life."

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people."

A learning difficulty is different from a learning disability because a learning difficulty does not affect general intellect. There are various types of learning difficulty, for example, dyslexia, dyspraxia or attention deficit-hyperactivity disorder (ADHD). An individual can have one, or a combination. Both learning disability and learning difficulties can exist on a scale and,

therefore, support would have to be measured by the severity of the learning difficulty.

Autism is a spectrum disorder (ASD). The National Autistic Society (NAS) shares a more detailed description of Autism here: <https://www.autism.org.uk/advice-and-guidance/what-is-autism>

"Autism is a lifelong developmental disability which affects how people communicate and interact with the world."

For example, people with autism may find bright lights or loud noises overwhelming, stressful, or uncomfortable. As a result, they may get anxious or upset about unfamiliar situations. Autism is a spectrum disorder, which means autistic people may have varying support needs. Additionally, one-third of autistic people also have a learning disability.

Importantly, with the right support, most children and young people with learning disabilities, difficulties or autism in the UK will be able to live independent, fulfilling adult lives.

The social model of disability

The focus of this report is to highlight children and young people's voice and experience in their healthcare needs and the role they can have in developing a skilled and responsive workforce. The report raises some of the key issues important to children and young people with learning difficulties and disabilities



This includes discussion about themselves as care receivers, who they want to care for and support them, how that care and support is delivered, and what they think the workforce needs to know in order to do their job properly.

The needs of children and young people with learning disabilities covers a broad spectrum and includes children and young people who require little day to day support, up to and including those who need 24-hour complex care. Their personal experiences are unique but, when it comes to the quality and delivery of care and support, there are common themes that run throughout. This report highlights some of these themes, with suggestions from young people on how to address the challenges. By ensuring that we understand the views of children and young people we can then explore with those who support them the education,

training and support they need to deliver care in that way.

Similarly, the workforce who support children and young people with learning difficulties and disabilities is broad and diverse. Their experiences, training and development needs can differ greatly depending on their setting, their role, their previous training and skills development, and the level of direct engagement with children and young people.

To understand the needs of the whole workforce, we were asked to bring together the broadest range of supporters, not just trained professionals, ensuring we captured the valuable experience of parent carers and voluntary supporters. This approach allowed us to achieve a more comprehensive overview of the sector and the opportunities to improve support for children and young people.



What did we do?

Children and young people

To capture the variety of needs and experiences, we facilitated focus groups across a range of youth settings, bringing together the voice of children and young people aged 11–25 with learning disabilities, who all receive health care and support from a wide range of professionals. We know, as do children and young people, that a number of cohorts, including parents and carers, must be part of the health care and support discussion. However, children and young people feel that their voice is unequal, and if training and service provision is to improve it is this issue that we must address.

To give children and young people an equal opportunity to participate does not mean that they have to participate in exactly the same way as professionals and other adults. To capture the voice and experiences of children and young people with learning disabilities, CDC developed an interactive and visual session that enabled the participants to share their thoughts and experiences at a level comfortable to them. The session plan for the focus groups can be found in Appendix 1.

This report presents the combined findings and key messages arising from six focus groups and discussions with individuals involving 40 children and young people. The focus groups and discussions focused on the participants' experiences of health care and support received from professionals with whom they come into

contact.

The information contained in this report is a summary of specific areas of their support, rather than a comprehensive overview. Key areas of concern for the children and young people were receiving inconsistent care and support from a workforce with a variance in skills, knowledge, competency, relatability (to the care recipient as young individuals), scope of duties and awareness. We discussed these concerns in the context of:

- The range of professionals and other adults providing care and support
- An understanding of who is responsible for particular aspects of care and support, and how these fit together
- When or if treatment is discussed with the care recipient
- The person specification of a good care giver/supporter
- What children and young people think the workforce needs to know

All of the children and young people who participated in the focus groups were passionate about being included in conversations and shaping the quality of care provided to them and other children and young people. They were keen to receive feedback from Health Education England on how their thoughts and views will be used to help develop the workforce.

Supporters

There are a wide range of roles involved in children and young people's lives. Within these roles there is significant variance in duties, responsibilities, skills, knowledge and personal attributes, which contribute to their effectiveness and impact.

As such we designed the interactive sessions to capture:

- the key challenges and opportunities
- the aspects of supporting children and young people which they thought were most crucial
- common aspects of job descriptions
- the person specification of a good supporter
- the types of training they as supporters have accessed
- the types and formats of training which would be most beneficial for other supporters

We facilitated a number of different sessions, one in London and one in Bristol, with a combined total of 23 attendees. We also brought together a group of 24 professionals from the CDC membership, who represent a broad range of voluntary organisations. We also

conducted an online survey to capture further feedback.

All those who were involved in the various sessions were enthusiastic and engaged, and were very keen to share their experiences and learning. They demonstrated strong commitment to supporting children and young people with learning difficulties and disabilities, and spoke of clear motivating factors and benefits of their roles.

Throughout the duration of the project and sessions that took place, we made use of graphic facilitation. Our rationale for using graphic facilitators is again linked to the social model, with the focus being on inclusivity and learning. Graphic facilitation is a useful tool to use with a group who may have literacy difficulties, learning difficulties or disabilities. The Learning Disability Network highlight the use of graphic facilitation as a form of best practice for presentations.

The learning from the two supporter sessions is in the illustrations at the end of this report. Key aspects of these illustrations are highlighted throughout this report.



Key findings

Workforce and others with care responsibilities

We asked the children and young people to share who regularly provided care and support to them in some way. The intention of this report is to support the development of the education, training and support needs of the workforce. However, it is important to draw links between the health professionals who provide care and support, and non-professionals who do so. The relationships that should be developed between these two cohorts, as well as the information and resources that need to be shared across the spectrum of carers, means that these considerations should form part of the learning curriculum.

The range of professionals, listed in Table 1, although not exhaustive, will not be a surprise, encompassing a range of services that provide essential and long-term care. As emphasised by the children and young people we spoke to, this makes it all the more important that care is of a high quality with children and young people's needs and wants placed at the centre.

It is the breadth of non-health specific supporters that adds another layer of complexity to joined-up working and quality care. The range

of individuals spans across health, education and social care, as well as including family and friends. It is often these individuals that 'fill the gaps' in care and support that children and young people find lacking in their provision. It is equally important that these individuals feel supported, skilled and qualified to meet the needs of children and young people with learning difficulties and disabilities in their care. The children and young people we spoke to told us that they are more likely – although not exclusively – to trust and speak to people who know them in a non-medical capacity because they are the people who have taken an interest in them as individuals, getting to know their likes, dislikes and how they express themselves. As a result, they feel more comfortable with these people and may use them as 'buffers' or 'filters', testing complaints, concerns and ideas with them first before approaching a professional. This is worth bearing in mind when developing person-centred care approaches.

Professional Healthcare workforce	Others with health and care responsibilities
• Carer	• After school club worker
• Dentist	• Childline
• Doctor (Specialist)	• Football coach
• GP	• Friends
• Mental health nurse	• Grandparents
• Nurses	• Housing Officer
• Occupational Therapist	• Parents
• Optician	• Pets
• Paediatrician	• Receptionist
• Paramedics	• SENCo
• Personal Assistant	• Siblings
• Pharmacist	• Teachers
• Physical Therapist	• Teaching/Learning support assistant
• Psychologist	• Youth worker
• Social Worker	
• Supporters	
• Therapist	

Table 1: List of health carers and supporters

Registered Professionals highlighted issues in finding the best approaches

Supporters who operate in a professional capacity reflected on a generalised lack of skills, knowledge and support systems in place to effectively meet the needs of children and young people with learning disabilities and learning difficulties. It must become a priority to ensure that all Supporters are well equipped and knowledgeable about the specialised and person-centred care and support that they need to provide to children and young people.

One supporter described the process of starting work at a small facility for young adults with complex needs where she had no previous experience or training.

She was acutely aware that at the time she lacked knowledge and confidence in safeguarding, health and safety practices and data protection, in addition to a lack of specialised knowledge in how best to provide care and support for individuals with such complex needs. She also reflected that the organisation was so underfunded that there were no prompt opportunities to access any training or support and identified that she struggled to know how best to work with those she cared for.

Other supporters agreed in this discussion that these are common experiences for professionals in small organisations, which often rely on the skills and experience that practitioners already possess and are ill equipped to meet gaps.

Conversations and Decision Making

Children and young people have told us, where they feel able, that they would like to be more involved in conversations about their care, including treatment options and understanding the impact each may have, as well as the professionals who provide their care. During one discussion a child told us they need someone who "understands about ASD", whilst another young person said it was important that a carer

"knows what makes me calm". Others said that having professionals who can relate to them as young people made them feel valued as people, as well as more relaxed and happier about receiving healthcare.

"Children are not adults with purple brains instead of beige, their brains are just wired differently, they are younger but treat them as humans with respect."

In line with person-centred approaches, some children and young people told us that they were happy with their parent carers' taking the lead on their health and care decisions, but it should be the young person's right to choose who takes the lead, rather than professionals assuming it will be parent carers.

How, when and who to include in conversations:

- Get to know the child/young person and what makes them relaxed and comfortable
- Think about the room/space you are using – is it appropriate for the conversation and will the child/young person be at ease
- Talk to children and young people rather than their parent carers
- Use words that the child/young person understands
- Share information in manageable chunks and take a break if necessary – go at their pace, it is different for everyone
- Give children and young people time to digest the information. You may need to recap at the next appointment
- Young people and parents may disagree on decisions. Be clear on who has the final say and what support and information is available to manage the situation
- Always give young people the choice about decision making – as they get older/grow more confident they may want to take on more decision-making power
- As young people grow their opinions and options may change, always be aware of this
- Always be respectful and considerate

Job Descriptions and Responsibilities

Children and young people with learning disabilities and difficulties often have to access a range of services to support their needs. Often these services are delivered by teams spread across a number of different departments, funded by numerous government budgets, and delivered with each team's specific working pattern.

This makes co-ordinating care a minefield for families, who worry that changing one aspect of the package will have a negative knock-on effect that may be disastrous for the child or young person. The findings from the session with the supporters identified the duties outlined below, which highlights the level of co-ordination needed for families to navigate the health, care and support system for their child. This is compounded by having care and support needs that may not be visible, leading to judgement from professionals and the wider public alike, "[they think] you're not actually hurt and you're just annoying them."

Moreover, attendees also highlighted the importance of appropriate driving, budgeting and financial management, multi-agency working and Disclosure and Barring Service (DBS) clearances, which is a record of a person's criminal convictions and cautions. The DBS works to safeguard vulnerable individuals therefore, no individual can start working with vulnerable children or adults without an employer receiving that person's DBS. Only once the relevant checks have been carried out and the DBS certificate highlights no concerns can that practitioner begin to work with children or vulnerable adults.

The children and young people we have spoken to have told us that they find the ways in which the different services work to be confusing and overly complicated. They are sometimes unsure of who is supposed to be providing specific aspects of their care, and feel uncomfortable or unable to ask. The number one reason children and young people have said prevents them from following up on, what they feel to be, bad care and support is an imbalance of power, followed closely by being worried that their care or support will be removed.

The key day to day duties which supporters deemed to be most important included:

- communication
- personal care (where it is needed)
- supporting the child or young person in activities
- keeping them safe
- medication and health care (where needed)
- empowering the child or young person and helping to build independence

Less frequent but important duties included:

- de-escalation and appropriate restrictive physical intervention where unavoidable
- first aid
- attendance at and support in meetings
- supporting attendance for health appointments

The effectiveness of training available and dissemination of learning

The children and young people raised a number of training needs that could be addressed. There was also some discussion as to how frequently people should have 'top up' training to keep their skills fresh and relevant to the individuals they are caring for.

Communication

The training concern that was raised the most was communication, specifically how professionals communicate with children and young people and their families; with each other, in terms of sharing and recording information across teams and departments; and the methods of communication.

It was suggested that there could be further training on different methods of communication, such as Makaton and sign language, as well as pictorial and assisted technology. Young people felt that too often professionals used unnecessary jargon, or did not take the time to explain what was happening.

Similarly, children and young people said their families often spent too much time co-ordinating care due to a lack of professional communication. Either because key messages had not been passed on, or because systems did not 'talk' to each other and history had to be repeated to each new team. Young people

tell us it is upsetting and frustrating to have to repeatedly focus on the negative aspects of their care needs because information is not shared.

Person-centred care

Person-centred care was frequently mentioned as something children and young people would like more of and felt professionals needed more training in. Some participants have had positive experiences of person-centred care from professionals, and said this has made a huge difference to them, but on the whole the children and young people felt that this was lacking. Some of the older young people we spoke with suggested that young people be involved in the design of person-centred training to make sure it incorporates everything they feel is necessary to put children and young people at the heart of the care provision.

Learning disabilities and difficulties

Our participants wanted this report to note that children and young people with learning disabilities and difficulties may need information shared in different ways, and they may process information differently to others, but they are more than capable understanding their needs and being part of decision making. They felt that people often made them feel different because they did not have the skills and experience to work with them in an appropriate way. However, if more staff were taught to think of the person, rather than the condition, then many problems would be resolved. This is part of understanding and delivering the Social Model of Disability, and we would like to see this approach to disability embedded at the heart of training programmes.



Working with other teams

As already mentioned in previous sections of this report, receiving care across health teams can be difficult, with separate appointments and co-ordination of care too often needed. The young people said they would like to see professionals work together better to limit the amount of time spent receiving treatment, but also so they found it easier to understand what was happening and why. They said they thought the standard of care would improve if teams were able to better work together with delivering care in the community, giving them a wider choice of social opportunities and options of employment and independent living.

Working with non-health carers

As we have already mentioned, children and young people receive a significant amount of their day-to-day care from non-professionals. During our focus groups we discussed what this means for the recipients of care, those delivering it, and the health professionals supporting it. There are outcomes, both positive and negative, of receiving care from non-health professionals, family and friends. What the young people we spoke with are concerned with is that this group of people be able to access training and support when and where they need it. This might be in the form of resources from a range of sources, or non-traditional support, such as e-learning modules and inexpensive face-to-face workshops.

In line with many of these themes, the supporter sessions highlighted the variety in the workforce which supports children and young people is both an asset and a challenge. The range in skills, knowledge and experience can provide a variety of insight and approaches for families, but it can also lead to gaps and weaknesses in the support they receive. It is vital that when training opportunities are developed, disseminated and tested, that this range is considered and accounted for.

Supporters provided a range of information on training, and the variety of programmes and opportunities they had accessed. Feedback showed that training comes in a wide variety of

types, formats and modes, and varied greatly in quality, implementation and effectiveness.

"Opportunities to practice are what embeds training."

How is training accessed?

Attendees had accessed training from a broad range of sources, and identified a large number of potential sources and effective routes of access for future opportunities. Discussions highlighted mixed experiences of online training, webinars and e-learning modules. Whilst virtual training programmes have benefits through being comparatively cheaper than attending face to face training options, their impact and quality can vary significantly.

"Online is very good for safeguarding, health and safety and awareness such as inclusion and equalities. It is also cheap and efficient. Very good for things that need repeating regularly."

The quality of online training was discussed at length, and many supporters had accessed a number of online training opportunities which were poor. They highlighted the importance of e-learning and online training being engaging and interesting throughout, and reflected that many e-learning modules tend to be dry and boring. Discussions also centred on the opportunities to practice or implement strategies and approaches, and online training which prioritises these is greatly preferred.

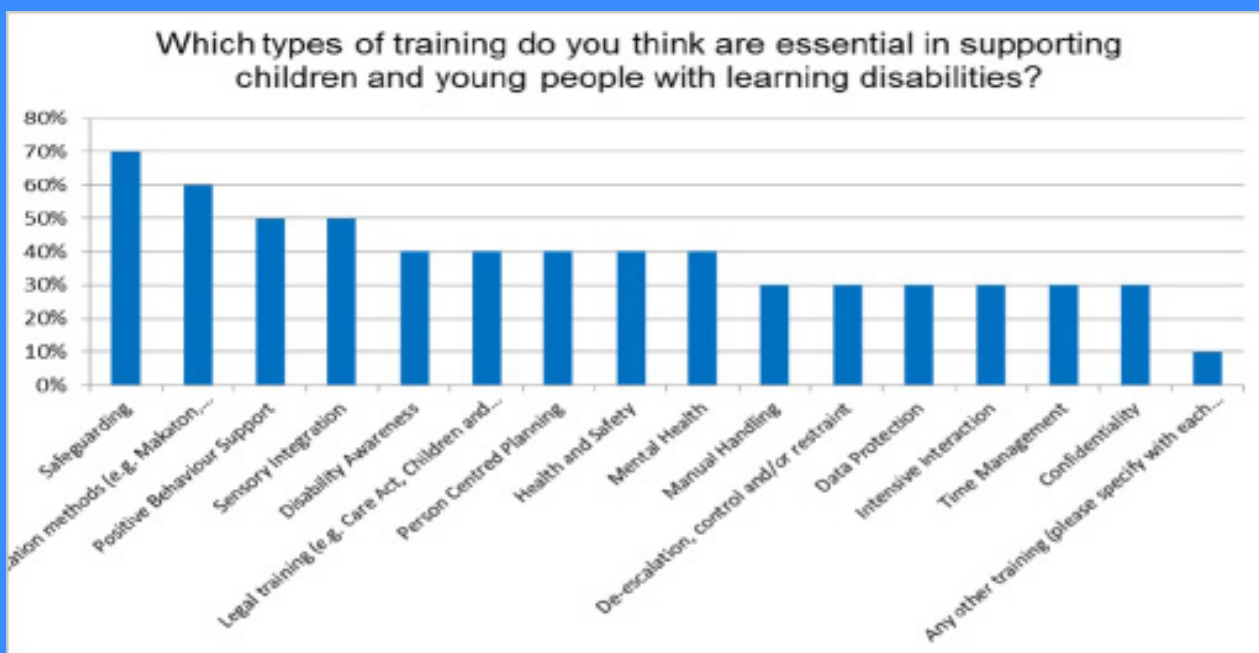
How is learning cascaded?

A key mechanism for small organisations and groups to maximise the impact of training is to cascade knowledge and learning outwards. However, supporters also reflected that there is a need to ensure a sustained level of high-quality delivery and dissemination where learning and knowledge is shared in this manner. There is a substantial risk in drop in quality and the potential positive impact, and whilst this approach can save costs, it needs to be monitored and quality assured.

The most vital and accessed training

The survey drew on the key findings from the sessions, and focused on training specifically. It was designed to capture the types and format of training supporters had accessed in their roles, and which training they believe is essential in supporting children and young people with learning disabilities.

The results from the surveys are depicted in the graphs below:





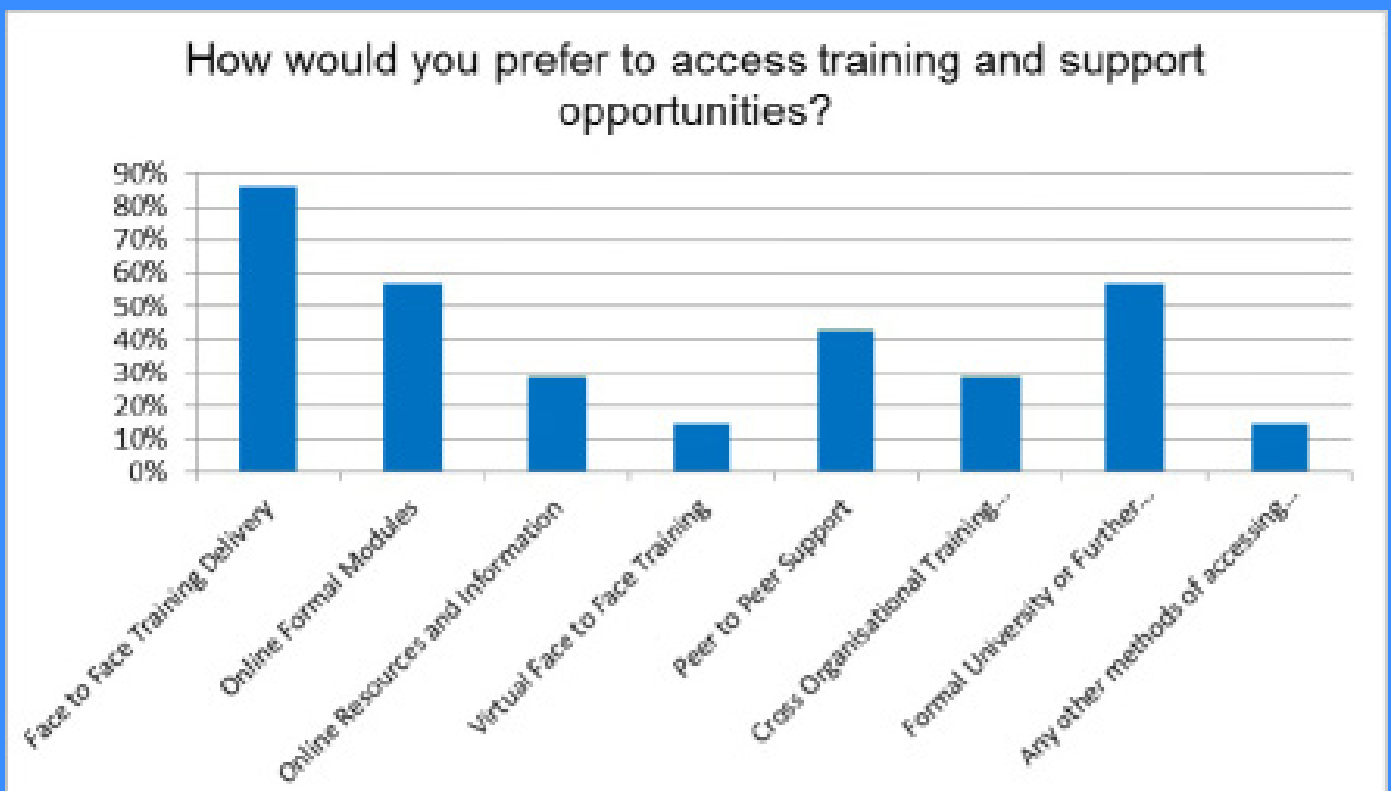
Preferences for training

Interestingly, the data gathered from sessions and in the survey, conveyed that supporters greatly valued the opportunity for face to face training. Comments on this form of training included that it is often more engaging, impactful, interesting and meaningful than virtual or remote delivery. Supporters valued opportunities to engage with children, young people and parents, or to hear feedback about their experiences delivered by trainers if their direct involvement is not possible.

Since the survey was carried out the Coronavirus pandemic has led to an unprecedented change

of culture and practice in the way training and development can be carried out. It will be important to consider the advances and improvements in live, interactive online training, as well as more traditional e-learning, webinars and seminars, to ensure that new approaches and technology that better enable interesting and engaging content leading to effective impact on practice are taken into consideration.

Below is a graph that demonstrates how supporters rated their preference to access training and support opportunities.



Assessment:

Peer support

The importance of peer support and shared learning was raised repeatedly in all the sessions and through the survey. As resources are very limited in many settings, attendees reflected that they often feel that they are 'fire-fighting' in their day to day roles. Opportunities to reflect on their experiences, to identify training needs, and how these might impact on their ability to effectively support children and young people are extremely limited. This is a concern as it is likely to leave individuals feeling ill-equipped to effectively meet the needs of the children and young people that they support and care for. Furthermore, there is a sense that the lack of time to reflect could hinder the development of Supporters, as limited resources means that they are reactive to the demands of their roles and not able to consider long term goals for their own development.

In addition, attendees mentioned that finding opportunities which might meet these training needs is a significant challenge. Supporters value opportunities to network, to gain professional and emotional support, and to share learning, knowledge and expertise with their peers.

Supporters valued opportunities to engage with parent carers in shadowing or coaching when entering into a supporting role with a child or young person. Parent carers, as well as the child or young person themselves, know their child's needs and aspirations best and are able to instruct supporters in optimum approaches to care. This reflects our understanding of the sector and the principles which underpinned the development of our Expert Parent Programme, which trains parents to act as an expert voice and advocate effectively for their children and young people.

CDC's [Expert Parent Programme](#) is designed to empower parents to support and advocate for their children and young people. Developed in 2014, the programme drew on evidence of the positive impact of parent-led training and to train parents of disabled children and young people to become more confident and resilient when engaging with health services.

A core team of lead parent trainers initially delivered 50 training sessions across England for over 450 parent carers. The peer-to-peer, train the trainer approach proved an incredible success. Along with a growing bank of expert parent trainers available to deliver the training locally, we have also developed a series of 'off-the-shelf' online resources and activities, including a series of e-learning modules.

Attendees also identified strong potential for community and voluntary organisations to provide peer support, upskilling and knowledge sharing for supporters and volunteering opportunities for children and young people. Mentoring opportunities were repeatedly identified as necessary and beneficial, and many supporters mentioned this.

There is a clear need and opportunity to establish and sustain peer support networks within the range of supporter communities, which could provide high levels of impact without requiring significant levels of investment. CDC has extensive experience in developing and supporting similar peer support networks community of practice networks, such as our forum for Designated Clinical/Medical Officers (DCO/DMO). This forum provides professionals with a peer learning and support platform, which is highly valued and accessed frequently. The development of robust peer support networks is extremely important for the workforce because it has the potential to increase confidence, improve care and thus deliver better outcomes to the children and young people. In addition, peer support could provide those in a caring role with necessary emotional and practical support, reducing the risk of burn out and breakdown of care arrangements.

Range of roles and feedback

At one supporter session we had two tables who produced very different responses for the various activities. We reflected on this in the session and found one table had more health and professional representatives, whilst the other had more parent carers and strategic roles. There were commonalities between the challenges and opportunities to overcome these. However, when we compared the responses to the training activities these

differed significantly. The table with more health professionals produced a long list of training which is required in NHS settings for nurses, very little of which is related to disability. The other table focused more clearly on skills, knowledge and attributes which they felt were important in supporting children and young people.

Clinical settings

In a hospital setting, clinical staff have a raft of standardised training they must complete within the first six months in post. Very little of this training considers disabilities in any depth. Any additional desirable training on learning disabilities is lower down the priority order and is often overlooked entirely.

In one hospital setting, to overcome the lack of training and awareness around disability and learning disability, specific posts have been created to hold responsibility and knowledge on

these topics. However, these link roles are not usually able to cascade knowledge or training effectively to the wider workforce, given the resource challenges of clinical settings. It is essential that the limitations within clinical settings are addressed to ensure that staff members are adequately skilled to consider the needs of children and young people with learning disabilities and learning difficulties. This is particularly important for the workforce because as trained professionals, parent carers and volunteers may look to clinical staff for advice and even support. Additionally, in order to ensure that there is a holistic approach in the care and support of children with learning disabilities or difficulties, it is crucial that individuals that are involved in their lives are skilled and feel confident to understand specific needs.



Conclusions and recommendations

What do we mean by learning disabilities, learning difficulties and autism?

Children and young people with learning difficulties and disabilities want and need to be more involved in their health and care support. From our conversations with the children and young people who contributed to this report, the main message is that at the moment, they do not feel that they are given an equal say in their support. In addition, they do not feel that they are regarded as being useful, and indeed necessary, to workforce development. The Information, Advice and Support Service Network is hosted by CDC and they have worked with young people to create an opportunity for them to advise services on ways to support disabled children and young people as well as planning and co-delivering training sessions across England. The young people involved share their own experiences, for example living with autism and dyspraxia, to improve professional practice. You can read more about this and other similar work in Tomorrow's Leaders: A world beyond disability which was commissioned by the Education and Training Foundation (ETF) <https://councilfordisabledchildren.org.uk/help-resources/resources/tomorrows-leaders-world-beyond-disability>.

The lack of choice surrounding support for health and care needs means that children and young people are often supported by people who do not share their interests, may not fully understand their health and communication support needs, and do not show them due respect and consideration. In some cases, particularly involving personal care, the lack of choice leaves children and young people feeling embarrassed and ashamed. By being included in workforce training and development children and young people with learning difficulties and disabilities hope that they will support the sector to grow and become more skilled, supporting the public to view health and care as a desirable career path for more young people beginning their careers.

Children and young people made clear that decision-making is a skill that needs to be

learnt over time, and is valuable to their sense of independence. Children and young people know that learning decision-making skills can influence how others view and interact with them. Whilst they also said they value support from family and friends to help them make decisions, they do not always want these supporters to make the choices for them, but rather help them to understand the options available, and the consequences of their choices.

Below are the key workforce development recommendations based on the feedback we have received from the focus group participants.

Core training for supporters:

- Social Model of Disability training – all healthcare professionals and organisations should be familiar with the model, participating in training to understand how their role supports Disabled individuals to be equal, including in decision making.
- Safeguarding – both generalised and specialised for children and young people with learning difficulties and disabilities. This should also be regularly refreshed.
- Disability awareness
- Communication
- Behaviour support
- Professional training and qualifications (where appropriate) – e.g. first aid, health and safety

Supporters highlighted several key aspects to ensure that training is effective, engaging and leads to positive impact for children and young people:

- Training should involve interaction and opportunities to practice or implement strategies
- Training which is presented as compulsory is often deemed to be less engaging. The benefits and meaningful difference which will be made by attending training should always be made clear.
- Where training is provided online or through e-learning, it should be reviewed to ensure that it is interesting and keeps the user's attention and interest throughout. Supporters

were clear that often e-learning and virtual training can become tiresome and boring.

- Networking and peer learning opportunities are vital. Develop co-ordinated approaches that allows professionals from across teams to share information in a confidential, timely and efficient way, thus limiting the amount of time needed for the patient to co-ordinate and receive treatment.

Making use of community resources and building in co-production at all levels.

Supporters greatly valued interactions with children and young people and parent carers as part of training. Their coproduction and co-facilitation should be prioritised wherever possible.

- Include children and young people with learning difficulties and disabilities in the co-production and co-delivery of training for the workforce.
- Include children and young people with learning difficulties and disabilities in the co-production of person-centred tools.
- Make training accessible so that children and young people with learning difficulties and disabilities are fully informed and included in those sessions, where applicable, and feel safe and confident to share their experiences and recommendations.
- Develop and support relationship building between the health and care workforce and non-health and care professionals who also provide necessary support, that fosters mutual respect and creates information and resource sharing opportunities.
- Create opportunities for those who know the care receiver best, including family, to be part of training opportunities to share their own experiences.
- Involve children and young people with learning difficulties and disabilities in decisions about their care from an early age, supporting them to understand the consequences of decisions, and when and how they would prefer others to advocate on their behalf.
- Establish a peer support network
- Explore utilising connections to large

organisations and corporations who may be able to provide places on generic professional training e.g. health and safety

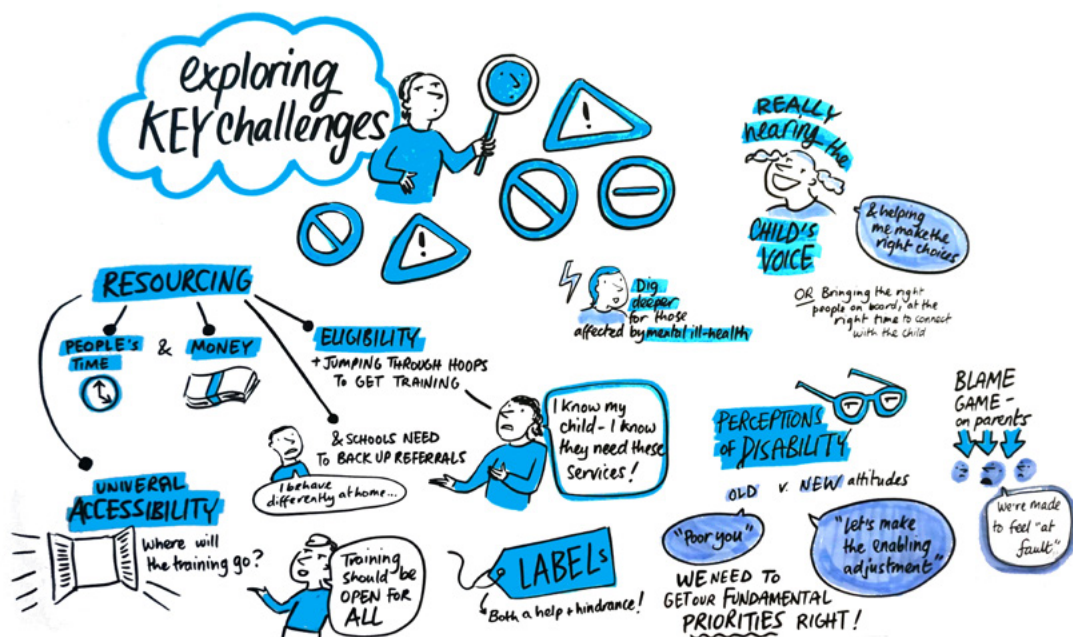
- Identify existing training packages and opportunities which are easily accessible by the workforce, and signpost to these in addition to providing targeted or bespoke programmes. This would be most effective if it formed part of a resource hub or directory which included related tools, information and resources.
- Promote the coproduction and co-facilitation of training with children, young people and parents wherever possible.

Challenges

CDC has welcomed the opportunity to work with Health Education England (south region) on Skills for Support, particularly in championing the voice of children and young people with learning difficulties and disabilities. As with all engagement with seldom heard groups of children and young people, there are unique challenges that occur when supporting these particular cohorts to be heard.

Whilst there has been recent improvement in attitudes towards people with learning difficulties and disabilities the stigma of this 'label', and general attitudes towards these particular groups of people, means that many children and young people with learning difficulties and disabilities often miss out on accessing real participation opportunities alongside others their age. Or where decision-making and voice work is delivered they may be offered a diluted option to engage. The outcome is that children and young people with learning difficulties and disabilities do not have the opportunity to develop participation skills on par with their peers. The impact of this is that when participation opportunities do happen the children and young people are not adequately prepared, or may find the process overwhelming or confusing.

More generally, whilst children and young people with learning difficulties and disabilities are themselves seldom heard it is even more difficult for some members of this group than others. In particular, children and young people from a BAME heritage, or with complex learning and/or communication needs face additional



barriers to participation. These challenges may include:

- Lack of awareness of opportunities to engage – cultural communities may be isolated from the wider community and not aware of services on offer.
- Cultural barriers – Where opportunities are present, cultural barriers may exist, or appear to exist. For example, where English is a second language for some families, producing information materials only in English sends a message that the opportunity is inaccessible for them.
- Increased exposure to poverty – The Joseph Rowntree Foundation's 2007 report Poverty rates among ethnic groups in Great Britain says "The income poverty rate varies substantially between ethnic groups: Bangladeshis (65%), Pakistanis (55%) and black Africans (45%) have the highest rates..."¹ Using data from the UK Data Service's Households Below Average Income 1994/94-2017/18², the Joseph Rowntree Foundation cites in 2017/18 the poverty rate for a person

in a family with a person with a disability was 30%³. The higher risk of poverty the more likely it is that a child or young person will not access participation opportunities.

Similarly, children and young people living in less urban and rural areas may also find it difficult to engage in participation opportunities. There is less participation, extra curricula, and social engagement provision in these areas, which leads to an increase in social exclusion and lack of opportunity to share valuable experiences all three levels of participation⁴. Where provision does exist in less urban and rural areas lack of regular and reliable transport may be an additional challenge to participation. Children and young people have previously told us that the lack of reliable transport available to them impacts their ability to attend groups on a regular basis, or means they are reliant on adults being available to drop them off and pick them up. This lack of opportunity means professionals and organisations often miss out on hearing these unique and important perspectives, and children and young people themselves continue to miss out on being heard.

1 The Joseph Rowntree Foundation's 2007 report Poverty rates among ethnic groups in Great Britain - <https://www.jrf.org.uk/report/poverty-rates-among-ethnic-groups-great-britain>

2 UK Data Service's Households Below Average Income 1994/94-2017/18: <https://beta.ukdataservice.ac.uk/datacatalogue/studies/study?id=5828&type=Data%20cataloguehttps://discover.ukdataservice.ac.uk/catalogue/?sn=5828&type=Data%20catalogue#!/details>

3 Poverty rates in a family with a disabled person: <https://www.jrf.org.uk/data/poverty-rates-families-disabled-person>

4 Further information on the three levels of participation can be found in the Making Participation Work factsheet: Methods and Levels of Participation - <https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/Factsheet%20%231%20Methods%20and%20Levels.pdf>

Next steps

The challenges outlined above mean professionals must do more to actively seek the thoughts, views and experiences of seldom heard children and young people, understanding that this active exploration must take into consideration the additional challenges many children and young people face. There is no quick fix to this problem and it must be tackled by multiple approaches.

Considerations must include:

- The ways in which children and young people with learning disabilities are empowered to make decisions and be active participants in their lives.
- Taking participation out of traditional settings and into communities.
- Using creative technologies, resources and tools to support participation.
- Working with existing support networks to engage with children and young people who face additional challenges.
- Extending the timeframe of participation projects for some groups of children and young people to help them develop the necessary tools to effectively engage and share their experiences.

As a result of the learning from this project:

- CDC would like to see a commitment from Health Education England, and other organisations responsible for developing the workforce, to further engage with those children and young people with learning disabilities and difficulties they are directly supporting to better understand how they can continue to effectively build the skills and values of those supporting them. As part of the Making Participation Work programme the Council for Disabled Children has produced a series of participation factsheets that would support Health Education England to consider how to work in participation and co-production with children and young people. The factsheets are free to access online at: <https://councilfordisabledchildren.org.uk/help-resources/resources/making-participation-work-factsheets>.
- CDC would recommend the co-development of a consistent, accessible core training framework for all those in direct support roles, including volunteers, parents and carers, across a range of themes, as set out on page 24 of this report.
- For those carers providing support outside of a formalised professional role CDC recommends establishing peer communities of support. CDC use a variety of approaches to facilitate and sustain professional communities of practice, by running regular events, sharing information and enabling open conversations, similar approaches could be used in these peer support communities.
- Create opportunities to engage with parents and carers in shadowing or coaching when entering a direct supporting role with a child or young person. Parents and carers, as well as the child or young person themselves, know their child's needs and aspirations best and can instruct supporters in optimum approaches to care.

Appendix 1 – focus group session plan

	Activity	Outline	Materials	Time
	Introduction	<ul style="list-style-type: none"> • Introduce ourselves • Ask the young people to introduce themselves • Explain why we are here <ul style="list-style-type: none"> • Who are HEE + what do they do (?) • Why we want their views – they are the experts • What we are going to do today • Make sure they are aware they can opt out at any time • Anonymity • What will happen to their views? How will they receive feedback? 		<ul style="list-style-type: none"> • Note: Tailor the timings to meet the needs of your group
The members of the children's workforce that children and young people with health conditions come into contact with	The different people in my life	<p>Option 1 – individual activity</p> <ul style="list-style-type: none"> • Children and young people are given a 'target' card • They write / draw on the card a picture of themselves <ul style="list-style-type: none"> • Me and my family • Other adults in my life / other people who help me • OR – young people can point / choose pre-prepared cards which have names of different workers on • Young people to develop their own 'map' <p>Option 2 – group activity</p> <ul style="list-style-type: none"> • Place large sheet of paper on the wall with symbols of children and young people – 'People in My Life' • Ask the young people to say which adults they have in their life • Use pre-prepared cards as prompts • Write on the sheet / get young people to stick the prompt cards on the sheet • OR – ask yp to write draw some people in their lives then stick on the wall sheet <p>Group discussion – group 'workers' into categories</p> <p>Link this discussion / number of professionals in their lives to the importance of asking children and young people what they want from their workforce</p>	<ul style="list-style-type: none"> • A4 card and pens • Some pre-prepared cards with a symbol for 'me' in the middle • Pre-prepared cards with different workers on as prompts • Prepared wall sheet • Pre-prepared cards with symbols of different workers 	

	Activity	Outline	Materials	Time
Existing / desired skills and knowledge of the workforce	Good/bad worker	<ul style="list-style-type: none"> • Draw around 2 young people on 2 large pieces of paper (or pre-prepared) • 1 – good/perfect worker • 2 – bad / worst worker • Starting with good worker – <ul style="list-style-type: none"> • Ask the young people what their perfect worker would be like <ul style="list-style-type: none"> • What do they need to do (skills) • What do they need to know (knowledge) • What should they be like (values) • They can write/draw/choose pre-prepared word cards • Are the workers in their lives like this? • What makes some workers better than others? • Bad/worst worker <ul style="list-style-type: none"> • As above • What would the worst worker be like • How could they helped/made to be a better worker? 	<ul style="list-style-type: none"> • Pre-prepared symbols cards re: skills knowledge and values • Pre-prepared sheets with outline of a person 	
	Rating exercise	<ul style="list-style-type: none"> • Pre-prepared sheets to stick around the room on a wall <ul style="list-style-type: none"> • Questions based on skills/ themes from the day/ themes from HEE • Give the young people green stickers. Ask them to put a green sticker on the statements which they think their workers are good at • Give them red stickers and put these on the ones their workers are not good at / don't do • Give them a star and ask them to stick this on the statement they think is the most important • Is there anything missing?! 	<ul style="list-style-type: none"> • Pre-prepared statement cards with symbols • Green, red, and star stickers 	

SKILLS FOR SUPPORT

MONDAY
21st JAN.
2019
LONDON



Sharing Experiences

of working with children + young people with learning disabilities

CHILDREN + YOUNG PEOPLE: INSPIRATIONAL POSITIVE PEOPLE!

WHAT ARE YOUR EXPERIENCES?

UMBRELLA BODY FOR THE SECURE
ADVISE + INFLUENCE GOVERNMENT

LEAVING FUTURE PRACTISE

ALL YOUR EXPERIENCES ARE VALUED
HOW HAVE NEARINGS AFFECTED YOUR WORK?

POSITIVES

CHALLENGES

FIRST THOUGHTS

LET'S DEVELOP & LEARN FROM PARENTS AS A FIGHT FOR SERVICES!

CHALLENGES OF OUR ROLES

- New environment - lots of questions!
- PERSON x LEAD RECRUITMENT SUPPORT
- MONEY - reduced funding - large areas cover
- HELPING PARENTS TO RELAY NEXT POINT IN HOSPITAL
- Multi-tasking all children need SIGHT
- TRANSITIONING TO ADULTHOOD - HARD THEY GO (TO A PARTIAL)
- HEAVY HEADED PERSONAL WORK: I HAVE SOMETIMES I DON'T HAVE THEIR NEEDS
- YOU NEED A PASSION FOR THIS WORK!

THE CHILDREN & YOUNG PEOPLE!

The JOY of working with them by helping them INDEPENDENCE

going from places: changing lives

Small things make a big difference

WE'RE EMPATHETIC SO DON'T WANT TO PUT THE BURDEN BACK ON THE FAMILY!

ALSO NEED TO BE CLEAR ON BOUNDARIES

WE NEED LOTS OF KNOWLEDGE (IN YOURS) IN ORDER TO SUPPORT MY SON

REDUCE THE STRESS OF A PARENT DYING OR FALLS ILL

GOOD TRAINING

RECEIVING + ACCESSING INFORMATION
PLANNING + MEETING NEEDS OF YOUNG PEOPLE DAY TO DAY V SHORT BREAKS

GOOD TRAINING SO YOU CAN SUPPORT THE INDIVIDUAL

MENTAL HEALTH FOR YOUNG PEOPLE
PARTICULAR COMMUNICATIVE SKILLS
NEEDS-SPECIFIC SUPPORT
GENERIC DISABILITY AWARENESS/SAFE-GROUNDING
PRACTICAL TRAINING

MODULAR TRAINING
Better links between mainstream & special schools

CHILDREN & YOUNG PEOPLE

SUPPORTED DECISION MAKING FOR RISK MANAGEMENT

INTERACTIVE INTERACTION for non-verbal

SOURCE

PLEASE FEED BACK IF YOU KNOW OTHER ORGANISATIONS THAT WANT A SIMILAR SESSION

ASKING YOUNG PEOPLE "WHAT DO YOU WANT?!"

I've got ASPIRESERS & I've got EXPERTISE

I'm depending them & I'm training these people

I want my career to look like this!

EXPLORING KEY CHALLENGES

PRESENT INFO DIFFERENTLY?

USE different ways to capture the spirit

I could think!

I CHOOSE what I share (DATA PROTECTION) KEEP IN MIND

BUT WHO DOES IT?

VERY COMMON: "YOU ARE JUST A PARENT"

WITHOUT WE NEED A PROCESS OF SUPPORT AT HOME

BE CREATIVE + OPEN-MINDED GIVING OPTIONS

WE'RE EMPATHETIC SO DON'T WANT TO PUT THE BURDEN BACK ON THE FAMILY!

ALSO NEED TO BE CLEAR ON BOUNDARIES

WE NEED LOTS OF KNOWLEDGE (IN YOURS) IN ORDER TO SUPPORT MY SON

SOMETHING IN THE STRUCTURE NEEDS TO CHANGE

eg HAVE A MANAGER

BUT COSTS MONEY - SO NEEDS TO MANAGE A GROUP

REDUCE THE STRESS OF A PARENT DYING OR FALLS ILL

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PLANNING + MEETING NEEDS OF YOUNG PEOPLE DAY TO DAY V SHORT BREAKS

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THE IDEAL SUPPORTER

RELIABILITY
COMMITTED
PROACTIVE & FUN
POSITIVE ENERGY
FLEXIBLE!
HAPPY FRIENDLY
REFLECTIVE
CHANGE WITH THE INDIVIDUAL (UNDERSTANDING THEM) ONLY SEE THEM!
SOLUTIONS FOCUSED
SUPPORTER
LOVE & RESPECT - not pity!
CHECK TICKING INTERVIEWABLE
DISINTERESTED/LACK OF COMMITMENT
I'm just "going through the motions"

THE "COULD DO BETTER" SUPPORTER

It's a challenge getting the right person for the job - with the particular skills...

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THE "COULD DO BETTER" SUPPORTER

It's a challenge getting the right person for the job - with the particular skills...

IF MONEY TIME + TRAINING WERE NO OBJECT...?

What would make it BETTER?

A COMPLETE CHANGE! IN CULTURE! AS PARENTS WE'RE FIGHTING ALWAYS

SHARING THE PARENT LEARNING FROM THE PARENT

RELATIONSHIP BUILDING

CONSIDER INTO TIME & TRANSITION PERIOD

AN HONEST PROFILE WITH SKILLS QUALIFICATIONS & QUALIFIERS FOR THE CHILDREN

CREATE AN APP

TO MATCH PEOPLE

TO KNOW THE PEOPLE

THANK YOU FOR COMING!

PLEASE FEED BACK IF YOU KNOW OTHER ORGANISATIONS THAT WANT A SIMILAR SESSION

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PEER SUPPORT

- one to one
- A CAREER NETWORK
- facebook

SKILLS

- HAVING THE BESPOKE SKILLS
- ACCESS TO PRACTICAL TRAINING
- POSITIVE BEHAVIOUR SUPPORT
- GENERAL DISABILITY AWARENESS

A CAMPAIGN/AWARENESS RAISING

- GET TO KNOW A DISABLED PERSON
- ACCESS how can I help a family with a disabled child?
- EMPLOYERS' ATTITUDES (to disability confidence)

RECRUITMENT

- ENGAGE WITH UNIS + use for volunteers
- APPROACH CHARITIES - DONE OF EDINBURGH
- DON'T ALWAYS HAVE TO BE A SPECIALIST - COULD BE A PEER/BOOK PERSON
- FAMILIARITY - PEOPLE GROWING AND WORKING TOGETHER

What training & support has been most useful?

MENTAL HEALTH FOR YOUNG PEOPLE
PARTICULAR COMMUNICATIVE SKILLS
NEEDS-SPECIFIC SUPPORT
GENERIC DISABILITY AWARENESS/SAFE-GROUNDING
PRACTICAL TRAINING

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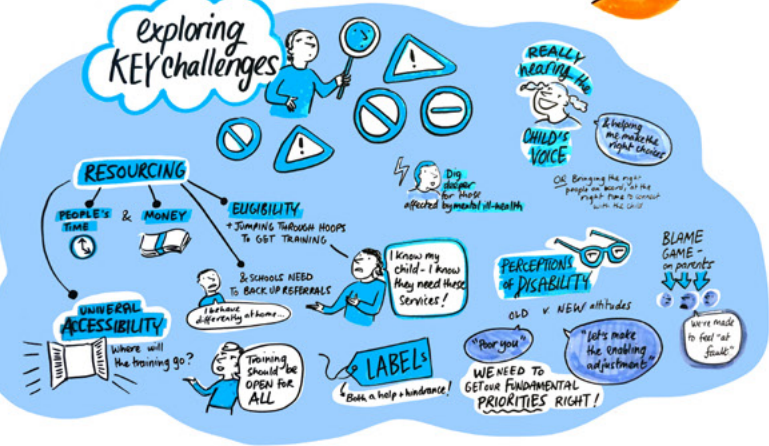
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United for disabled children

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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Part of the family

NATIONAL CHILDREN'S BUREAU

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