RIP
STARS

Defining quality and rights-based Education, Health and Care Plans (EHCPs) for disabled children and young people

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Disability Research on
Independent Living & Learning

Coventry University

> “It is not just a process. It is a young person’s life now and their future.”

Contents

Foreword

Hello from our research team called **RIP:STARS**.

RIP:STARS stands for **R**esearch **I**nto **P**lans: **S**killed **T**eam with **A**mbition, **R**ights and **S**trength.

We are all disabled young people aged 17 to 25 and we are from Coventry, in the West Midlands of England. Our research project presented here was about looking at the quality of Education, Health and Care Plans (EHCPs) and whether they meet disabled children and young people's rights. We also wanted to find out whether plans prepare disabled children and young people for independent living and help them achieve their dreams for the future. We were funded by **DRILL** (Disability Research on Independent Living and Learning) programme, a five year scheme led by disabled people and funded by **Big Lottery Fund**.

Our project was different or unique because it is research about young disabled people done by young disabled people. We co-led this project with Coventry University researchers, they trained us to do research and we worked as a team. We have been involved in all of the stages of the research process, from coming up with the questions that were asked in the interviews and group discussions to doing the fieldwork with professionals, carers and disabled young people. We have also looked at and analysed the information we collected and have developed recommendations from our research findings. We also worked with Zara Todd, ALLFIE (Alliance for Inclusive Education), Nottinghamshire and Coventry Local Authorities and Grapevine Coventry.

We have also learned about the Social Model of Disability. This means not seeing young people just as a label such as autism or dyslexia, not treating everybody with that condition in the same way, and instead focusing on removing the barriers that restrict us as disabled young people. We have used the Social Model of Disability in our research.

"The Social Model of Disability is a way of viewing the world, developed by disabled people. The model says that people are disabled by barriers in society, not by their impairment or difference. Barriers can be physical, like buildings not having accessible toilets. Or they can be caused by people's attitudes to difference, like assuming disabled people can't do certain things. The social model helps us recognise barriers that make life harder for disabled people. Removing these barriers creates equality and offers disabled people more independence, choice and control[1]."

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[1] Scope (2018) The social model of disability. What is it and why is it important? [online] available from <https://www.scope.org.uk/about-us/our-brand/social-model-of-disability?gclid=EAIaIQobChMI2oW71rD-3QIVDeh3Ch1fEgELEAAYASAAEgIoXPD_BwE> [11 October 2018]

It was important for us to understand the social model to be able to do the research. We wish we had known about the social model when we were younger and are questioning why we were not told. We are angry because we have found that EHCPs are not always carried through correctly. For example, disabled young people are not always involved in their plans and do not get a real say into what is in them. Through our research we have also found out that in reality it is very difficult to make a complaint or change or challenge our EHCPs without a legal process.

This project is also about making our voices heard. ALLFIE and Zara Todd have given us training sessions where we have learnt about our rights under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Before this project we had little information about our rights as young disabled people, but now we have carried out research and learnt about rights and EHCPs, we now have the ammunition to fight back and make changes. Being involved in this research has been all about making our voices heard, speaking up, having the confidence and becoming empowered, as young disabled people.

In this report, you will read about our findings. We have made recommendations for change and these can be found in our **RIP:STARS** EHCP Quality Framework for Professionals. We have gathered and will use all the information from our research project to help and support disabled children and young people with their EHCPs to make sure they have a good plan and they know what it should include. We want to make sure that disabled young people have a real say about what is in their plan. Disabled young people must be told about their options, so that they can be supported in a better way and they can choose what support they want/ need. Often disabled young people and their parents do not know that they have rights as children, and as disabled people. We think this is wrong.

A good plan should include and support a young person's skills, strengths, ambitions and rights. We want to make sure that disabled young people have a real say about what is in their plan – it should be 'Nothing About Us, Without Us'.

The RIP:STARS are:

Ben, Eva, Heidi, Jordan, Tom and Vandana

Acknowledgements:

We especially want to thank the disabled children and young people that told us about their experiences and used their voice to give us messages so that we can make things better for other disabled children and young people. Thank you to all of the parents, carers and professionals that have shared their views. Thank you to Coventry University for the rooms for our meetings. We wish to thank our partner organisations for their support, advice and encouragement – Zara Todd, Tara Flood at ALLFIE, Nottinghamshire Local Authority, Grapevine Coventry and Coventry Local Authority. We would also like to thank DRILL (Disability Research on Independent Living and Learning)/ Big Lottery Fund for funding our research, we couldn’t have done it without them!

Introduction

This project set out to empower disabled young people to research and define what “quality” should be in EHCPs (Education, Health and Care Plan). Here we set out the background context to why this research topic is important. According to government figures the number of pupils with special educational needs (SEN) has increased from 1,244,255 in January 2017 to 1,276,215 in January 2018 (14.6% of pupils). However, only 253,680 pupils have a statement of SEN or an EHCP (2.9% of the total pupil population). The remaining pupils - 1,022,535 are on SEN support (a lower form of support). This is equal to 11.7% of the total pupil population in January 2017[2] .

There is some evidence of the enormous financial and emotional cost of tribunals for local authorities and for parents when things go wrong, so we think it is important to focus on quality and getting it right in the beginning to avoid the need for mediation and tribunals.

An EHCP is a legal document which should provide holistic support for disabled children and those with special educational needs. An EHCP should also prepare disabled young people for independent living, and for having choice and control in their lives.

Being involved in decisions about your life is a **right** yet research evidence indicates that involvement in decision-making and having choice is often denied to disabled children and young people. Few disabled children and young people know their rights or what they can expect from their EHCPs. This research project set out to develop the first quality and rights based framework, based on research evidence and designed by disabled young people, for professionals developing EHCPs. This framework is designed to ensure that EHCPs achieve the best possible outcomes for disabled children and young people now, and for their future lives where choice and control are central.

The quality framework for professionals provides practical, rights based information to ensure that independent living, and full involvement and preparation for independence, form an integral part of all EHCPs for disabled young people. We have sought to define what choice, control and independent living, really mean for disabled young people.

We have also used the research evidence, views of disabled young people, and our own experiences as disabled young people to develop a disabled young person’s survival guide to EHCPs. This will help them advocate for their rights and for support, which will meet their needs now and as they grow into adulthood, and which will give them more control of their own lives.

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[2](Department for Education (2018) Special educational needs in England: January 2018 [online] available from < https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2018> [11 October 2018]

How we did it/ Methodology

Recruitment of young disabled researchers

Coventry University researchers recruited us to train as researchers and have opportunities to develop skills in activities such as presentations, conference organisation and project delivery. The aim was for disabled young researchers to co-lead all aspects of the research project.

We heard about the project through an advocacy organisation in Coventry called Grapevine. Eight disabled young people began the project, 3 young women and 5 young men, aged between 16 and 24.

Over the next few months training was delivered, mostly at weekends, in the evening and during holidays, as a number of us were at college during the day. We made all decisions about the project together as a team.

Feeling supported

We focused on overcoming any barriers disabled young people might face to leading a research project and adopted a rights based approach to participation to ensure that we were fully supported to take part in all opportunities which were developed during the project.

At the start of the project we all completed an "All about me" booklet, asking for information on what would support us to take part (For example, break out/quiet space, accessible print, personal care needs support).

This support was put in place and regularly reviewed; as our needs changed, and as our confidence grew, some of us needed less support.

We worked together to learn what was working well or needed to change. This project involved a huge commitment from everyone.

We were told at the start that the project would be for 15 months and this did not discourage anyone from remaining involved. We liked the idea of working towards an end goal and doing a piece of work that would be respected, and which we hoped would make a difference to disabled children and young people's lives.

Training as young disabled researchers

It was important to have a plan for each meeting but also to be flexible and adapt to the needs and wishes of the group.

The three key areas that we focused on in training were:

- What is an Education, Health and Care plan?
- What do we mean by rights? What are the UNCRC (United Nations Convention on the Rights of the Child) and UNCRPD?
- What is research and how do we do it ethically and rigorously?

We had little knowledge of what an EHCP is, even though most of us have one, and we had not had very positive experiences of services.

At the start it was important for us to think about ‘What makes a good life?’ Answers to this question included ‘real friendships’, ‘being happy, the happiest you can be’, ‘having a say’, ‘being listened to’, ‘equal opportunities’ ‘love and support’, ‘a place to go, to gather your thoughts, where nothing else matters’.

We then examined example EHCPs from a few local authorities to understand what sections were in a plan, why they were included, what makes a good plan and why we thought that some were better than others.

We learnt about the rights of disabled young people, including the UNCRC and UNCRPD, from a renowned international expert in the field, Zara Todd.

In considering what a researcher does we suggested that researchers explore, they investigate, they discover, they ask questions to find out what is happening. We learnt that there are different types of research and researchers sometimes uncover information or things that some people would not like everyone to know.
The skills needed were to be a good listener, show people respect, make sure that participants consent to taking part and to be able to keep confidentiality.
We were trained in research methods and supported to undertake all stages of research design, data collection, analysis, report writing and development and dissemination of outputs.
The way in which we worked meant we could have individual choice concerning our level of involvement at each stage and it made the research fully accessible, meeting our individual needs and interests.

We identified our interests and skills and we found opportunities to develop these skills further and apply them to new areas to help us with education or employment experiences/opportunities.
For example, we developed skills in project management, commissioning graphic designers, logistical planning, understanding research methods, collecting and analysing data, designing and producing project outputs, organising and delivering events, working with a professional advisory group, attending conferences, taking part in consultations and lobbying and writing blogs.

Fieldwork: Gathering views on EHCPs

Ethical approval

At the beginning of the project we worked on an ethical and safeguarding framework to ensure our research was safe for both us as disabled young researchers, and for our participants (disabled young people, parents/carers and professionals).

We needed to ensure:

- There was informed choice to be involved or withdraw for both young researchers and participants.
- The welfare and safety of us as young disabled researchers.
- Our understanding of ethics, including limits to confidentiality, and ensuring anonymity and safeguarding.

Coventry University approved of our approach to the research and granted us ethical approval. Informed consent of all interview participants was sought and their anonymity and confidentiality fully explained.

Fieldwork

Following intensive training we began fieldwork and gathered our data. We undertook qualitative research and interviewed:

- 15 disabled young participants
- 10 parents/carers
- 17 professionals (multi-disciplinary)

Sample: Young people

The young people we interviewed were from the East Midlands and the North West of England. They were aged between 13 and 25 years.
6 young men and 9 young women took part. Those that declared their ethnic identity were all British (majority White British).
Some young people had physical impairments, some had learning disabilities and some had other needs. In line with working within a social model of disability, rather than ask about impairments we were more interested in their need for support and whether this was being met.

Sample: Parent/carers

Parents and carers were from East and West Midlands. 9 mothers and 1 father took part. The majority were White British and one described themselves as Dual Heritage.
Their children were 8 boys and 5 girls. 6 had experience of special school, 4 of mainstream, 1 had experience of both, 1 did not confirm and 1 was at an independent residential college. Their children had a wide range of impairments and medical conditions; however, we preferred to ask the parents to describe what their child was like.

Sample: Professional participants and their roles

Professional participants were drawn from a national sample and were located across England.
We interviewed professionals from education, health and social care, service commissioners, practitioners contributing to EHCPs, experts in disabled people rights and equality, strategic policy makers.
These included:

- Head Teacher in special school
- Deputy Head
- SEND Lead
- Special needs teacher
- Autism Lead in special school
- SENCO
- Principal educational psychologist
- Strategic SEND development lead-Integrated Children's' Disability Services
- Special educational needs and disability, information advice and support service officer
- Clinical Lead (health)
- Service Director for Commissioning and Resources
- Manager within ICDS
- Expert in disability equality
- CEO of a Disabled People Led organisation
- DfE representative
- Independent supporter
- ICDS assessment officer
- Children's Disability Social Worker
- CEO of a Disabled Children's Charity.

All (but one) interview and group discussion was facilitated by at least one disabled young researcher and at least one Coventry University researcher. The team analysed the data thematically, looking for similarities and differences, working together to use the data to identify the key messages and recommendations.

Learning has also been a large part of the project. We have all reflected on what it means to research in partnership. We will be writing about our experiences to tell other researchers and sharing them through conference presentations, articles, Tweets and blogs.

For more information about our research and to find all of our outputs please see **ripstars.net**

The following section presents the findings of our research. This report is not meant to highlight what is, or is not working with EHCPs, other reports have focused on this. This research is trying to put a focus on what people think EHCPs could and should be to support disabled children and young people to achieve the best possible life. It is also trying to give a voice to disabled young people who have been given little opportunity to present their views on EHCPs.

This report should be read in combination with the **RIP:STARS EHCP Quality Framework for Professionals**. This framework uses the evidence gathered to set out our key recommendations for good practice in EHCPs.

Key Research Findings

The findings below describe what participants thought should be happening, or be included, to make a **quality** EHCP which would respect the rights of disabled children and young people.

Accessible information for disabled children and young people about EHCPs.

We found that statutory agency professionals often found it difficult to talk about what, and how information should be shared with disabled young people about what an EHCP is, and the process young people would be involved in. Many referred to information being available on their website within their Local Offer, or others focussed on information being provided to parents/carers. Most felt that more work was needed to make disabled young people aware of EHCPs and the Local Offer. Some professionals highlighted the role of SENDIASS (the SEN and Disability Information and Advice Service) in providing this information to disabled young people, although none of the young people interviewed mentioned this service.

Advocates for disabled young people, and disabled young people themselves were very clear that accessible information should be provided to all disabled children and young people:

> "There should be information available to disabled children and young people a long way before the planning process so that they understand what the planning process is about and what it's supposed to achieve...it should set out what the young person's rights are to participate in the planning process and that their wishes and hopes and desires are central to the planning process".
> (Professional)

> "They need to know what an Education, Health and Care Plan is, why they're being suggested to have one, what the process is for getting one, including the timescales that it takes to get one, they should be told what happens after they have one, and how they get the support in that plan, they should be told how they can argue about what's in the plan if they don't like it and where to take complaints if something isn't working".
> (Professional)

> "Sending you a guidance document, 40 pages of densely typed technical stuff isn't going to work... information that enables them and you to take control...."
> (Professional)

> "I think it's really important that people understand that it is a legal document that will be reviewed at least once a year and that people understand what the review process is and what that might lead to".
> (Professional)

Some professionals were also keen to state that without knowing about the process or what an EHCP is then why would disabled young people want:

> "to be involved in writing it and why would you believe that it's going to make any difference in the way people are treated."

Parents also would have liked more information in advance of the process:

> "No, we haven't been given any information about the process at all, so, anything that I know is from my family and from the parents' forum. Everything that I have got so far and there is not much of it, I have had to chase."
> (Parent)

> "I have got some understanding but I'm not sure if I know how the process works."
> (Parent)

Other parents had a better experience:

> "Yes because we did through school and because it was a special school they did it very well, they understood everything in detail."
> (Parent)

Involvement of Disabled Children and Young People in their EHCP

When asked about whether disabled children and young people should be given a "voice" in the EHCP, most professionals stated that this was the ideal, but in reality there was a long way to go to achieving creative, person-centred planning with disabled children and young people.

> "I also think that somewhere in that process needs to be... That one to one contact, and what is difficult about that is we don't have very many resources so we develop processes that meet the outcome of a plan but actually the process can almost appear as if we are not really engaging with the child or young person at the centre of the plan and we need to get better at doing that".
> (Professional)

> "We've moved a bit away from the original concept around all of this which is the old cliché co-production that genuinely any document should be produced together and I do believe that and I think we're a country mile off"
> (Professional)

To achieve a quality person-centred plan, communication with disabled children and young people was highlighted as vital. And for those young people with communication needs, good practice was defined as being flexible in how they contribute their views and having access to someone who can support them to contribute to their plan. Access to independent advocacy was seen as important and information about, and choice to attend meetings about EHCPs was seen by most as a minimum.

However, it was noted that there needed to be an attitude and culture change to achieve full participation of disabled children and young people.

> "I think it's about how you approach the writing of that plan and I think that if you're approaching it as a piece of paper that you must complete, there's a real risk that you just miss the voice of that child or young person out".
> (Professional)

When parents were asked whether their child knew that they had a plan and whether it was written in a way that they could understand responses were mixed:

> "He should be aware that he has one because he is involved in the reviews every year. Whether he does understand the implications would be a different matter, just by the nature of his learning disability. So, I don't suppose he understands that it gets him the help that he needs".
> (Parent)

This seems to suggest that despite efforts by some to include children, the information within a plan is not always made accessible. Very few of the young people we interviewed knew if they had a plan, or if they did have one knew what was in it. Professionals highlighted this as important, especially as so many disabled children and young people are denied opportunities to learn how to be involved in the decision-making from an early age. Equally respecting young people by enabling and supporting them to prepare for meetings in advance was highlighted, as was empowering them to know what options are available. As one professional stated:

> "Show them what their options are because if someone suddenly asks you what you want for dinner when all you've ever had is fish and chips, how do you know there are any other options? How do you know you could have pizza?"
> (Professional)

Parents had mixed views about the involvement of their child in their EHCP, and most stated that the involvement of their child could be limited:

"Yes I had a real say in their plan. My child wouldn't have a clue of what is going on. I think it all depends on the understanding of the child. They took into consideration my opinion on the future definitely."
(Parent)

"Even though they listened to my daughter, they asked me questions as well; they knew about her understanding. Its only now at 18 that my daughter knows her disability and she's starting to realise what is actually wrong with her because I have explained in a roundabout way, what she can understand."
(Parent)

Professionals highlighted the importance of separating the young person's views from that of their parents as an issue needing further consideration:

"For children that have got really severe communication difficulties I think it is important that we think about who can be the advocates for those children, and whether the professionals and parents can always be that or whether sometimes there is somebody more independent needed".
(Professional)

"I think sometimes, particularly with some young people, we allow their parents to advocate for them and I think often the parents are advocating their needs rather than the child's needs, so I think there's probably more to be done to balance that out".
(Professional)

"I think we need to do more around advocacy...I think parents, with the best will in the world can be over protective and can also be under ambitious".
(Professional)

Professionals were asked about what they think should happen when young people and their parents disagree about what should be in a plan. Again the need for independent advocacy was seen as a solution:

"I guess that's where advocacy comes in so I hope that advocacy supports a young person to set out why their choices are important and why they want those choices to be supported I guess by families and parents".
(Professional)

Other professionals felt that it was important that parents were supported to understand their child's increasing rights as they grow older and become independent adults.

However, it also appeared that in some cases the involvement of parents was also limited:

> "So we talk a lot about consulting with parents, although often that's done through letters, it's quite bureaucratic, it's not particularly a conversation as such, it's an exchange of bits of paper, and because of that there's not a lot of face to face time with parents or with children and young people".
> (Professional)

It was also highlighted that disabled young people should have the opportunity to see what is in their EHCP before it becomes final and for there to be an opportunity to ask questions and raise issues.

A quality "About Me" Section

With regard to the 'About Me' section of an EHCP (where young people and parents have the opportunity to express their views), professionals highlighted how this can be difficult to write without support, and how often the child's views are missing. However, many expressed the importance of this section to delivering a quality plan and how the quality of this section should be seen as critical.

> "I think that in our quality assurance framework, if that section is not completed sufficiently in the plan Section A, then it is inadequate so it's a clear message saying that you need to have the voice of the child or young person."
> (Professional)

However, not all professionals could report that such attention was given to ensuring a quality "About Me" section.

> "We ask for the child's voice but if it's not there we carry on filling the plan in".
> (Professional)

When specifically asked what should be included in the About Me section, a good plan was seen to contain:

- What I like, what I don't like
- What is important to me e.g: family, social life, friendships and relationships
- Who helps me make decisions
- How I like to receive help from people to make decisions,
- My rights as a young person.
- My aspirations and what you want to achieve in life
- What I need to prepare me for adult life and independent living.

Parents also appreciated the importance of this section in reflecting who their child was and personalising the process:

> "I'm trying to think now back to his plan… it does reflect him because it details all his likes and dislikes; his passions, especially his sports, football".
> (Parent)

> "Well obviously you need to involve them in the writing of it, people need to listen to them which I know doesn't happen a lot, and I don't think you can never put down too much information into such things because the more information, the more knowledge you have, the more you know and the better support the person can get.
> (Parent)

However professionals reported that too often the...

"About Me section becomes one form and then the rest of the EHC plan doesn't relate to this... About Me is seen as the fluffy bit, you write nice things about your future on it but outward planning isn't important".

Or that disabled young people's views are misrepresented:

"The complications come when you've somebody who listens to the young person and then perhaps rewrites what they're saying in a different way not because they want to change something on purpose but they might change the grammar or something which changes the meaning..."

Accessible EHCPs for disabled children and young people

When asked whether disabled children and young people would be able to access and understand the plan that has been written about them, professionals reported that this was an area for massive improvement.

"I feel we've got a long way to go, a long way to go, so the real test is, if a young person could read their plan and at the end of it think, 'I recognise me. I recognise what you're trying to do, and I'm happy with the way I've been involved', the test would be can the child or the young person read it and feel, 'Yes, that's okay, I've been involved'. (Professional)

"I don't think we've ever had any conversations...about if we are going to make some plans available whether we should be doing a young person friendly version that's kind of a plan on a page that tells people, you know, what kind of services they're going to get. I don't think we have, and that's probably something that we should be doing actually". (Professional)

Some professionals spoke of sharing plans via, for example, on-line portals but the accessibility of these for disabled young people was not shared and whether the language used in the EHCP was made accessible.

Other professionals suggested that there should be a named lead person that young people should be able to contact. One professional saw other potential benefits to accessible EHCPs:

> "I personally believe that all Education, Health and Care Plans should be written in language that is accessible to the young person wherever possible and to be honest, if it's accessible to the young person it means it's harder for people to get out of not doing stuff because if it's clear then it's clear to everyone who should be doing what, but also, it should be made so that everyone knows who's responsible for delivering what parts of the plan"

Recognising children and young people's ambitions and strengths

Most participants in the research felt that EHCPs should not just focus on the negatives and needs of disabled children and young people.

Good plans were seen to recognise disabled children and young people's strengths and support them to further develop these. However, some professionals noted how it is often difficult for disabled young people to recognise their strengths when:

> "Here is a person who has been repeatedly told they're not very good, they're not behaving, they have been taken out of their school, how do you start building that young person's self awareness, confidence and resilience and all that".
> (Professional)

Young people were concerned that they were not always treated as a whole person and that there was an over focus on their diagnosis, condition or additional needs:

> "Professionals don't see the individual, the person, they just see your medical condition, like Cerebral Palsy"
> (Young Person)

> "Health professionals work off the medical model"
> (Young Person)

In addition, there was some concern from professionals that if strengths and abilities were highlighted it would lead to loss of provision.

> "One of our children plays football, loves playing football, he said I go to play football every week so we put that in the plan. It then came to transport and they said no he doesn't need transport because he goes to football every week...who's reading that plan is external and how they interpret what's been put in that, and if it's misinterpreted as an able child when it's actually not...I mean this child was attending a very specialist special needs football club, but because they hadn't said that ..."

When asked about whether EHCPs should support disabled young people to achieve their ambitions, the majority of professionals felt that it should but were not convinced that they always do, and barriers to this were often seen as attitudinal.

> "We're not very good at young people, especially disabled young people, allowing them to have ambitions and dreams in the first place, and most young people have ambitions that don't come true but that doesn't matter".
> (Professional)

A few parents did see the plan as reflecting their child's strengths and ambitions:

> "I actually think everything should be included because everything makes the young person who they are which in my son's case it's in his views and aspirations and it talks about him been sociable and having his football, his computer, what he likes, what we are concerned about, where he has problems; then it has a summaryof his special educational strengths and needs; it talks about him been lively and strong willed (which he is).
> So, on my son's I don't think anything is omitted because it talks about social, educational well-being, communication, interactions; seems to have everything in there."
> (Parent)

However, the few disabled young people who knew about EHCPs felt that plans were not always ambitious for them:

> "Low expectations of what you are capable of doing are brought to the EHCP process"
> (Young Person)

More positively, professionals stated that:

> "In a good plan for me, it's not, it's looking at the now, it's looking at the next and it's looking at long term...
> what they're working towards,

how that's going to be happening, and what they've got to look forward to as well, and also I think looking at long term it's about what choices you want to make, where do you want to go next". (Professional)

Good person-centred planning was seen by most professionals as being the only way to ensure that EHCPs captured and worked towards enabling disabled children and young people to achieve their ambitions.

EHCPs that support Independent Living, Choice and Control

Professionals said that too often ECHPs are not clear enough on what outcomes they are working towards for disabled children and young people, and preparation for adulthood was left too late.

"In my vision of Education, Health and Care Plans I would like to think that the reviews, which start to think about preparation for adulthood are completely changed. They are not dynamic, they are really quite one-dimensional, and they offer platitudes to families in terms of saying, 'Well when you're in Year 11 we'll tell you what your options are', and it's patronising, it's ignorant, it's negative". (Professional)

A good EHCP was said to be one that helped children grow in confidence and prepared young people for adulthood and independent living, and having choice and control in their lives.

"So what does a young person need to live an independent life with or without support and is a life where they have choice and control...What disabled people want is independent living support where we have choice and control over who provides us with that support at a time and in a place that works for us as disabled people". (Professional)

Professionals reported that there was a lot of misunderstanding regarding the social care section of an EHCP and that this was an area for development. Many stated that this section should contain provision to support young people to work towards, for example, independent living, inclusion in the community, access to community groups and services such as youth clubs.

"So, often that section looks very blank and empty but I think that social care, there are a lot of social care issues related to issues around independence and I think social care is much wider... So how is that delivered to a child or young person, it's about in terms of outcomes, it's about preparing for adulthood." (Professional)

"To me, social care is a shared responsibility about doing things in the community, so that you feel life is a little bit better."
(Professional)

"I think social care outcomes are being part of society. I think that's what social care is and it is about friendships and about feeling confident and safe in school and it's about not being bullied and it's about feeling safe going home and not having to worry about those things."
(Professional)

Whilst the narrow perception of what is meant by social care was criticised by a number of professionals, one professional suggested that the section is really about social well-being:

"Because of the way that they happen, they tend to consider issues that social workers have traditionally dealt with, so they've considered whether the child's being cared for properly at home and whether they're safe from abuse. That social section needs to take in a much more wellbeing focus. I think it's almost been labelled wrongly. That's actually probably the section where you need to be covering on things around, you know, leisure and relationships and those kind of things because I think it's become about social care rather than around a wider set of social and wellbeing needs."
(Professional)

Parents spoke of how they would value support, which encourages independence, but often this was denied:

"He desperately wants to be independent but obviously, because of his severe learning delay and he hasn't got the capability to understand certain things, so giving him independence is hard but he has watched his friends do it, so he has the desire to do it. His friends have undergone travel training, he wasn't eligible for it because it wouldn't have taken him off school transport...and of course they are now doing it at college so, what I have asked for him to gain independence around our local town, so he can go to day service on his own, go to his friend's house on his own, there is no flexibility for travel training to be provided locally (only as per college). I have been asking since he was at school, but the funding remit is to get them off school transport."
(Parent)

Friendships and Relationships

Although participants were not specifically asked questions about friends and relationships, recognising the importance of these in EHCPs was mentioned frequently, especially in relation to combatting feelings of isolation:

"If you asked young people what's the biggest thing they would like, it's the idea that they have a social life, have relationships, and things are good for them in that area."
(Professional)

"Often young people with disabilities, it's a generalisation but they can become isolated and you will see references to not necessarily a peer group, but references to low instance of bullying or something like that, I would expect something to be put in place to deal with that".
(Professional)

"Some young people might be very vulnerable and isolated and so they might need some support in being out in the community and making friends".
(Professional)

"A lot of young people with special educational needs are often very isolated and again the plan could help with ideas or provision on local youth clubs, local play facilities and so on, getting help to get them out of the house and mixing with other young people".
(Professional)

Education and educational outcomes

Education and educational outcomes were seen as the dominant focus of most EHCPs, with many participants remarking that because education was the driving force other important areas of disabled children's lives were being neglected. Difficulties in education provision dominated many interviews, with many parents speaking of the difficulties with securing support for their child in mainstream education.

"We went through a special educational route and we have had the support from them and they've had my back and have been absolutely brilliant. But I have friends/colleagues whose children are in mainstream school and I would like to take a lot of mainstream head teachers and bang their heads together because they seem not to have the slightest comprehension of what is needed just to support an anxious young person through secondary education".
(Parent)

Parents felt that the plan was vitally important in getting their child's educational needs met.

In drawing out from participants what would make a good quality plan to meet the educational needs of disabled children and young people, professionals referred to:

"Clear information about what is described in the law as the presumption for mainstream, so how a young person can be included in mainstream education."
(Professional)

"Support for inclusive education, not just the one to one support but also our teachers and all of the staff in the school getting training to ensure that they are confident to include that young person both in the class room but also outside the class room to support the young person to build relationships with their peers."
(Professional)

"Communication support has been thought about and whether that's British Sign Language or communication support in a different way, but that the young person is involved in thinking about that".
(Professional)

Some professionals were concerned about the lack of ambition in EHCPs for disabled young people's education:

"Don't talk about children not being at school but talk about them not having their educational entitlement, because often with children, especially in secondary..what we think is good for them is ten hours.. so that needs to be challenged within the plan, and sometimes it's hidden and sometimes it appears that because that's what the school say and that's okay."
(Professional)

"I think it needs to consider where someone is and what they're doing but also where they want to go and it needs to consider the support that they need to be in that space and place. And I think it needs to be optimistic about what someone might do, rather than focusing on all the things that they can't do".
(Professional)

Although educational outcomes should be personalised in an EHCP, participants defined their quality in much wider terms than they felt outcomes were currently focused on. For example:

“That they fit the young person rather than the young person fitting in with the system and that’s difficult at the moment because of the way education success is measured really is pretty much determined by exam results and not much else.” (Professional)

“For me education is not all about reading and writing and maths; it’s about an opportunity to be part of the world around you… things like as part of my education I’m going to understand how to make friends.” (Professional)

“In a general way, what are the thing that are going to help you become independent in life… I do think social development skills, making friends, holding on to friends, getting out at the weekends and so on are critical. Another big one I think is also travel. The number of children in special schools, for example, who don’t travel on their own, the minute you can travel on your own, the world opens up.” (Professional)

Health

Many participants that we spoke to had to be prompted to think about health provision within EHCPs. As an example, one professional stated:

“I have to confess, from my personal opinion I don’t think that’s detailed in plans at the moment, it’s very like just access the GP or see the community paediatrician as and when”.

“Health can be a little bit of a difficult one in actually gaining the information from health in the first place and some proper information about what is needed for this young person”. (Professional)

Many professionals and parents raised concerns about the lack of provision for health needs. As an example one professional stated:

“I do have some significant health difficulties on some cases that I work with and sometimes they’re more difficult ones because the funding that comes attached to an EHC plan has to have a special educational need to access one of those and if they have significant healthcare needs but they don’t hit the criteria for continuing care funding or they drop below it after being in it, then there’s no additional funding going into schools to support those pupil’s medical needs and some of these pupils are tube fed, are on morphine constantly, needing significant medical intervention and schools are expected to fund that just on what they would get on any other pupil…”

Yet many people saw the need for this area of the plan to address major concerns around general health and wellbeing, mental health, anxiety, sexual health and the need for support around issues of sexual identity and sex and relationships. Many examples were given where basic needs such as suitable wheelchair provision were not being provided and there was inadequate preparation for transition to adult health services.

> "When somebody talks about low moods and things like that, I would expect to see something, even if it is not a CAMHS service, it's sitting below CAMHS, and expect that in the health section."
> (Professional)

A quality plan would also not contain lots of medical jargon making it inaccessible to the young person and their family. Likewise, quality was defined as good information sharing with the young person and those supporting them particularly around medication, the impact of medication and how to manage it.

Parents said that the process of receiving a medical diagnosis and the on-going support which would be needed could be more streamlined:

> "As you are entering the diagnosis stage, the paediatrician is already aware of the EHC Plans, the questions that are asked are in the same line to what the paediatrician needs to find out, so if it was all going through the same process, then surely that information is valuable."
> (Parent)

Concerns were raised about the accuracy of health information on EHCPs.

> "It should be things that are relevant and factually correct, the amount of times that people write wrong things about certain medical conditions is quite high, so it should be correct and understandable".
> (Professional)

Some professionals and many disabled young people were concerned that EHCPs should not contain just a long list of historical medical information, but they should focus on what was relevant and important to a young person. For example:

> "If you are a young person with epilepsy you need to feel safe at school, you need to understand that somebody meets your needs but also you need to make sure that just because you've got label of epilepsy someone is not saying oh that means they can never go out or go on school trips, we can't do that etc. So for me it's health from the child's point of view in terms of what matters."
> (Professional)

Young people questioned why so much detail of their health condition was needed:

> "Why can't we ask for access needs without having to disclose our medical history?
> Can't an EHCP be on a need to know basis?"

Parents were frustrated that information was not communicated between health professionals and they needed to keep relaying the same information and also emphasise their child's difficulties:

> "So, that information (given to the GP) wasn't properly passed onto the paediatrician before I got there, it would save you to have to go through it all again; So, I went through it all again, then they send you a pack with around 20 different forms and 60 different questions, then you have to go through these and relive the traumatic experiences you have been through with your child until that point...
> you need to demonstrate your child at their worse; you cannot then get the schools that we have been to at least to follow that line of thinking. They are more about this is what your child can do. Unfortunately, paediatricians don't want to know what your child can do, they want to know what your child can't do".
> (Parent)

As with education, personalised health outcomes were seen as important. Quality was seen as not just the management of a health condition but a focus on supporting young people's health so that they can achieve outcomes in other areas such attending school, having a social life, developing skills in self-care and accessing health services independently.

> "It might be that someone might be a diabetic..it's about at what point does that diabetes impact on them getting into school and how can we make sure that that doesn't stop them from doing that...because health professionals tend to look at just the health care plan and how can we make their health better and not thinking a bit further on about making it so they can get to school. So I think we've got a lot of work to do around getting them to think differently"
> (Professional)

Accountability - Making sure what is in the EHCP is delivered

Professionals thought that EHCPs are often not specific and are open to interpretation, and it is not always made clear who is responsible for making sure the plan is delivered.

"In theory the education, health and care plan is legally binding but so often parents of young people and young adults are letting us know that it doesn't happen... almost everything in that plan is the responsibility of a whole group of people so you want it to be a group effort. It doesn't feel like a group effort now."
(Professional)

Following through what is stated on the plan was not always straight forward in practice, particularly if they are not seen as a live, legal document:

"Plans are no good at all if they are bits of paper and you put them in a drawer and a year later we say oh yeah... they've to be an active document, and if it says we are going to support the young person to do this then you have to have a plan to do it."
(Professional)

It was also reported that much depends on the practice around the use and maintenance of the plan, and that it is important to keep it updated and allow for change.

"We (the Local Authority) cannot micro manage the lives of, nor should we, of every child or young person with a plan. The plan is the route map, the plan should describe the journey and if it's well written, all of the steps on the journey. The school or the education provider, when it picks up that plan and agrees to offer a place is legally committing to providing what is written in that plan and in the vast majority of cases, it works reasonably well but the other thing of course you have to appreciate is, people change.
So what is described in the plan in January 2018, by August 2018 may not be relevant or may have moved, particularly for very small children."
(Professional)

Young people recognised that provision and resources were not always forthcoming without being asked for, requested and at times demanded:

"My mum campaigned, fought, until I was 16 then I had to take it over, that's when I realised the barriers, it was then down to me"
(Young Person)

Professionals stated that at any point a review can be called, it is not necessary to wait for the annual review if something is felt not to be working. Making the plan clear and specific was seen to enable parents, children and young people and professionals to see if an aspect is not being delivered or a target met. One young person asked:

> "Is the reason the EHCP is left vague because the Local Authority don't want to give you X amount of sessions and provide?"

> "Why do we have to have enough fight to fight just to get what we need"

Accessible complaints and appeals processes

Everyone agreed that disabled children and young people and their families should legally have information about the complaints and appeals processes, how to access it and where they might find support. Many professionals stated that this information was on their Local Offer.

> "I think by giving them the knowledge and understanding about how the plan is put together that sometimes gives them the power to then be able to challenge any decisions that have been made, with some support, hopefully, from our service if we're involved... There's a document available from the SENDIASS website that talks you through the process of how to appeal."
> (Professional)

> "I think people should be made aware of the complaint process before they even start embarking on a plan process because in my experience the rollout of EHC plans has not gone as smoothly as people would have liked and therefore there are a lot of people that are waiting a very long time to get plans. If you don't know how to complain before starting the process, there's no point complaining at the end going 'I had to wait for six months for a plan when it's meant to happen within sixteen weeks."
> (Professional)

> "We think that there should be clear information about what a young person can do if they don't like what the plan says, i.e. how they can appeal against what's in the plan and then clear information about what the young person can do if the content of the plan isn't realised, i.e. what happens in the plan isn't delivered".
> (Professional)

One finding around the appeals process which many parents and professionals were not aware of is that health or social care issues or deficiencies cannot be addressed unless there is also an issue with educational provision:

“Right, so at the moment they’ve never been allowed to address it, they can only go to tribunal if there’s a problem with the education side of the plan. However, there’s a new pilot that’s come out and it’s called a single route redress, and basically it’s a national pilot that started on the 3rd April where if there is an issue with health or social care they can raise it, but they have to still have identified an education issue. So that’s the initial way of trying to address that health isn’t reflected within a plan, but equally before the final sign off I think a family carer or young person should be able to say before it’s signed off.. Unfortunately, because it’s about meeting special educational needs, which is a battle for us health professionals, because that’s why I have a lot of trouble in panels, like well I know it’s about education but, all these other factors actually will impact on that ultimately. So it is a big battle”. (Professional)

Respecting the Rights of Disabled Children and Young People

All people have rights, yet many professionals seemed nervous when we asked about rights in EHCPs. Overall, most professionals, parents and young people had not thought about disabled children and young people’s rights. Most young people we interviewed did not know about their rights. However, most people thought that EHCPs should respect disabled children and young people’s rights, but they are currently not doing this.

“the SEND framework focuses on needs and medical diagnosis and all the things that disempower young people”

“I think the system as the way that it’s been set up doesn’t have- it doesn’t feel like it has children’s rights at the heart of it. At the moment it feels much more like a desk based exercise than it does in terms of agencies improving the nature of the young person’s relationship with all the agencies and actually improving care in all cases”. (Professional)

Many felt that that it was not EHCPs per se that were the obstacle to doing it, but that people at the moment were not thinking of rights and wider policies and practices were impacting on disabled children’s rights. Examples were given of schools adopting zero tolerance to misbehaviour and not making appropriate adjustments.

"I don't think it's the EHC Plans that are necessarily the problem, I think it's the culture in the system".
(Professional)

However, when participants were presented with a list of rights as defined under the United Nations Convention on the Rights of Persons with Disabilities, no one did not think that they were not important or that they should not be respected.

"All of those rights are important and they all need to be acknowledged within a plan and with different levels of emphasis depending on how old you are".
(Professional)

When examining the list of rights professionals made a number of comments about how important they are to disabled children and young people's lives and wanted to emphasis certain rights:

"I think access to communication is key, right from the outset... The thing I hate most on reports, is "the child cannot communicate their needs" and I have seen this again and again, I think that's a fundamental breach of rights."
(Professional)

"So for me some of this is about the recognition of rights to be who you are and be proud of who you are and not have to be anything else, and to feel safe in who you are."
(Professional)

"I think privacy and involvement in decision-making are really important because I think one of the problems with the system is that you can become a number on a form and you stop having the right to be private".
(Professional)

"I go back to that idea of educational entitlement, entitlement to learning because what we find and it has been through the tribunals but you have some people saying, that young person can't learn anymore, and the tribunal says actually they can learn but it's because you're trying to frame it in way of levels of attainment and measures of attainment rather than learning some of these things, learning about understanding money, gaining independence, access the information, so you can help somebody to access information".
(Professional)

"The right to be busy and have a busy day, to me is really important".
(Professional)

Some professionals thought that there should be more attention to rights within EHCPs:

"A rights statement, probably in the plan itself, and to be very clear about how the plan meets those needs, and it's not a massive job, is it, to say- given everything that we've said, how is a young person going to access, you know, or how is the right to access communication, you know, enacted in this plan? So it seems to me, to have a statement of rights at the end that covers off these things or at least make sure that they are well covered in the plan would be a really good idea."
(Professional)

"Yes. I think they're all really-really important, and they all link, because for a young person to progress after school and into further education, into life, all of these things matter…
it's probably not made explicit that they are in the plans, so I think that's really important, I think it needs to be highlighted. All of these rights need to be highlighted, and maybe there needs to be separate sections so it's clear, and outcomes need to be revolved around these rights."
(Professional)

Disabled people however, pointed to the need for a change in attitude and culture to achieve a rights based approach to support for disabled children and young people.

"I'll tell you why it doesn't work because the language the professionals use is very excluding and it's very medicalised. Professionals really want to talk about us whether we're zero to twenty five or we're beyond that, in a very medical model of disability approach. They want to place us in certain boxes that work for them… because I want to be able to talk about me and my life and my impairment in a way that works for me and I want to talk about the support that I get in a way that works for me and that's the only way, I believe, that we will have choice and control over that support, when we can take the conversation away from that medicalised conversation to one that focuses on me as a human being first."
(Professional)

Others called for revisiting the principles underlying the development of EHCPs and saw the issue as one of training and workforce development, to encourage a move away from a more tick box approach:

"We need to do more workforce development with the workforce. I think we have to go back to the idea that this process in terms of the EHC plans was supposed to be less confrontational and I think as local authorities have got less and less money more and more confrontation is going to develop within…

> the system and that doesn't make anything person centred. So I think we need to go back and look at the principles behind it. So workforce development, looking at the principles and not seeing it as a way of churning out a plan on a piece of paper."
> (Professional)

> "I think that it needs proper communication with young people as part of the process, and we need to move to the system a culture where it isn't about people swapping bits of paper in order to make a new bit of paper, that actually it's about a dialogue around young people's needs, how they're going to be met, what the future looks like and how that's going to be good."
> (Professional)

Parents found it difficult to name the rights that disabled children have, and they too did not think that EHCPs currently focus on rights:

> "They are more about showing what a disabled young person needs, help them to be equal within society. I know of quite a few young people who have had plans rejected because they are not 'severe' enough and yet they are being let down by society because nobody is fighting for their need".
> (Parent)

When shown a list of rights, parents commented that they were all important. However, in their responses to questions they tended to focus much more on explaining how they were fighting hard to get the needs of their child met rather than their rights respected. It appeared that having their child's rights respected seemed a long way off when the fight for services had been hard.

One professional commented that the word 'rights' is loaded and sounds confrontational, "I want my rights, I'm not getting my rights", which may lead to professionals backing away. Their preference was for talking about young people having their voices heard. However, having your voice heard is only one part of having your rights met.

Conclusion

What makes a good quality rights based EHCP ?

> **"It's about making sure that the plan lives" (Professional)**

We wanted to find out what would make a good quality EHCP for disabled children and young people. Many people we interviewed had experienced poor plans, where plans have been produced but the content and the process are not what would be considered to be quality. Perhaps most importantly, the rights and views of disabled children and young people are rarely at the forefront in planning. However, many people showed us that there were possibilities to make the process work well for disabled children and young people if barriers to this were removed. So given that an EHCP could be beneficial for disabled children and their families, what are the key elements which make a good plan?

- Focus on inclusion
- Very clear support for decision-making
- Young person focused outcomes
- Aspirational
- Accessible to parent and child
- Clearly written
- Preparing for adulthood
- Creative and dynamic
- Person-centred
- Accountability and quality control
- Multi-agency involvement
- Accurate information
- Not medicalised
- Specified timeline
- Meets child's holistic needs
- Personalised
- Creates a pathway to independent living
- Support put in place to achieve outcomes
- Outcomes that can be measured and reviewed
- Co-production with disabled children and young people

> "The best plan in the world would be a support for a young person and an ally. That a young person has a plan that they're comfortable with and is supporting them to do what they want to do in life to the point where they don't even notice that it's there, a bit like an invisibility cloak, where it exists and it protects them but they don't need to know it word by word in order to benefit from its existence". (Professional)

Final thoughts

We hope that this research contributes to wider debates and demands for service improvement in the UK for disabled children and young people. We hope that our disabled young person-led quality and rights framework for EHCPs, and our outputs to increase awareness of rights, disabled young people, their families and professionals will feel empowered and encouraged not to accept the limitations of services and will together consider what the present lives and futures of disabled children and young people could and should look like.

By disseminating this report and the quality framework nationally we aim to influence local authorities and policy makers to consider quality and rights in the development and review of disabled young people's EHCPs, always ensuring that they are focused on what disabled young people have defined as important to them.

This co-led participatory project has empowered us as disabled young people to challenge policy and practice development at a national level. This project is about changing attitudes and practice nationally to ensure there is quality, rather than tokenism, in EHCPs for disabled children and young people.
As one young person stated in a discussion group:

> **"Remember, we are human beings,**
> **not a problem to be solved"**
> **(Young person).**

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