RIP STARS

A Quality and Rights-Based Framework for Professionals Involved in Education, Health and Care Plans (EHCPs) for Disabled Children and Young People.

EDUCATION NOT SEGREGATION
THE ALLIANCE FOR INCLUSIVE EDUCATION

BIG LOTTERY FUND
NATIONAL LOTTERY FUNDED

drill
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.”

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 looked 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 the **DRILL** (Disability Research on Independent Living and Learning) programme, a five year scheme led by disabled people and funded by the **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 EHCP 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.

Here we present our recommendations for change and we have designed this framework the **RIP:STARS EHCP Quality and Rights Framework for Professionals** to support professionals to think about what EHCPs **should** and **could** look like if they are really going to support disabled children and young people to lead a good life now and in the future. This framework is designed using the evidence we collected via our research and we have drawn upon our own experiences. Information on our research project and the research report can be found at **ripstars.net**

We have gathered and will use all the information from our research project to help and support disabled children and young people with their EHCP 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'**.

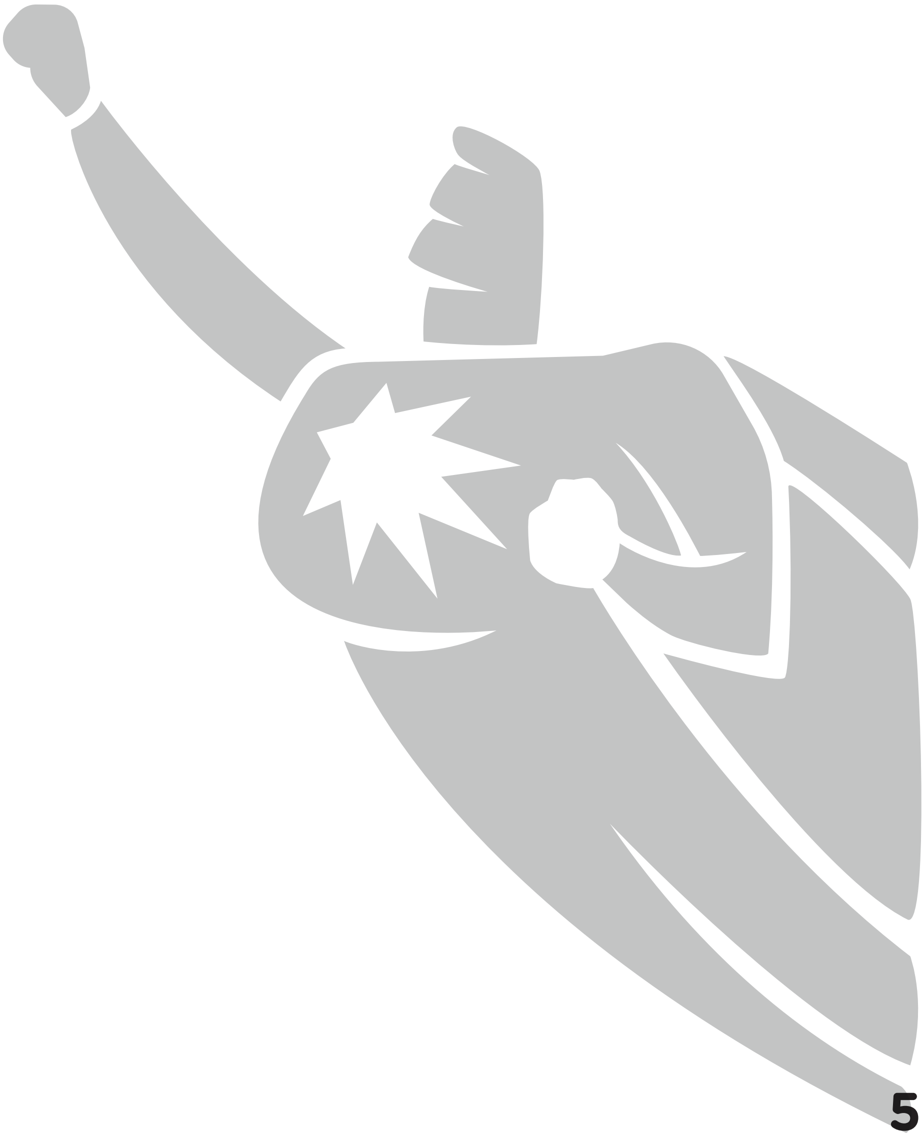
The RIP: Stars are:

Ben, Eva, Heidi, Jordan, Tom and Vandana

Introduction

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.

This 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 children and young people. We have sought to define what choice, control and independent living really mean for disabled young people. We hope that this framework will be used by professionals to examine their current ways of working with disabled children and young people and reflect on how this **could and should** be better.



Principles for Person Centred Practice

Respecting disabled children and young people

Our research showed that often attitudes towards disabled children and young people needed to change. As a basic starting point for developing and delivering Education, Health and Care Plans, professionals should:

- Read the EHCPs before attending meetings about them.
- Not talk about disabled young people, but should talk to them.
- Share information about disabled young people with them and in accessible ways.
- Respect disabled children and young people's rights.
- Make an effort to learn more about the disabled young people they work for.
- Listen to disabled children and young people and involve them in decisions about their plan and the support they need.
- Not make it a fight for disabled young people and their families to get an EHCP assessment, and an EHCP that provides the support they need.
- Be polite.
- Value us equally.

Disabled children and young people should be given accessible information at the start of the EHCP planning process

They should know:

- What an EHCP is trying to achieve.
- Why they are being suggested for an EHCP.
- How they are going to be involved in the process.
- The timetable.
- What will happen afterwards.
- What is in their plan.
- When it is going to be reviewed.

NOTE: It is no good just putting this in the Local Offer as this is not accessible to disabled children and young people.
WE DO NOT KNOW WHAT A LOCAL OFFER IS!

NOTHING ABOUT US WITHOUT US!

EHCPs should be developed in a person-centred way and co-produced with disabled young people

Disabled children & young people should:

- Be able to express their views in any way they chose.
- Have access to someone who understands their communication method.
- Have access to an independent advocate if needed.
- Be included in their plan from an early age so that they can learn how to be involved in decision-making and learn choice and control in their lives.
- Be given a choice about attending meetings and be fully prepared and supported to attend them.
- Have the opportunity to see their EHCP before it is signed off, and they should be given opportunities to ask questions and raise concerns.

Disabled young people and their parents might not always agree, but young peoples views should be respected.

"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)

Principles for Ensuring Quality EHCPs

A quality 'About Me' section

This section should always include a disabled child and young person's view and this should be distinguishable from their parents view.

CHECKLIST FOR PRACTICE	YES
• Have disabled young people's views been accurately recorded and checked with them?	☐
• Is this section reflected in the rest of the plan and support put in place to achieve the outcomes identified in here?	☐
• Has the development of this section of the plan empowered children and young people, supported them to express their views and be involved in decisions being made about their care?	☐
• Has this section focused just on the negatives, has the child's strengths been recognised and support put in place to further develop these?	☐

NOTE: The information in this section should not be seen as separate, disabled children and young people's views should inform the whole plan.

A good 'About Me' Section should include:

- What I like, what I don't like.
- What is important to me e.g family, friends, social life, relationships, learning new things.
- Who and what helps me to make decisions.
- How I like to receive help.
- How I want my rights to be respected.
- My aspirations and what I want to achieve in life.
- What I need to prepare me for adult life and independent living.

“We ask for the child’s voice but if it’s not there we carry on filling the plan in”.
(Professional)

If a plan is written about me I should know what is in it.

EHCPs should be made accessible for disabled children and young people. They should be in easyread language.

Disabled children and young people should have:

- Information on why they have been given support and what support they should be receiving.
- Information on why decisions have been made about them.
- A named person who they can contact about their EHCP.

Recognise our ambitions and strengths

Don’t just focus on the negatives, recognise our strengths and support us to develop them. **AND DO NOT USE OUR STRENGTHS AGAINST US AS AN INDICATION THAT WE DO NOT NEED SUPPORT**... understand why and how we are able to do some things and not others.

DON’T just focus on medical conditions or a diagnosis. These might be why we need support but they do not completely define us.

Be ambitious for us as we have ambitions. We do not want plans to set low expectations for us.

Using person-centred planning enables us to express our strengths and ambitions as well as what we need support with.

“Professionals don’t see the individual, the person, they just see your medical condition, like Cerebral Palsy”
(Young Person)

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

Supporting Independent Living, Choice and Control

EHCPs should support disabled children and young people:

- To access their community and support inclusion in youth services, sport, arts, drama and other activities that are important to them.
- To feel safe and know where they can go for help.
- To develop skills in decision-making so that they can learn to make choices and take control of their lives.
- Early in preparing for adulthood.

Do EHCPs in your local authority have clear outcomes to support disabled children and young people to lead independent lives with choice and control?

Friendships and Relationships:

Do your EHCPs recognise the importance of friendships and relationships in disabled children and young people’s lives?

Are disabled young people in your local authority isolated? Do your EHCPs address this?

Do they support young people to develop and keep friendships?

Education and educational outcomes

EHCPs should be supporting:

- The inclusion of disabled children and young people in mainstream education.
- The inclusion of disabled children and young people in school both within and outside the classroom.
- The ambitions of disabled children and young people – and not just in terms of academic qualifications.
- Disabled young people to lead independent lives.

EHCPs should look at disabled children and young people's holistic health needs – Not just their impairment.

Our health includes physical, mental and sexual health needs. It should not just be about management of a condition but should support disabled young people to achieve outcomes in other areas of their lives.

EHCPs should not contain lots of medical jargon and a long medical history – only include relevant and important information.

Make sure EHCPs contain correct health information – no mistakes.

MEDICATION

Disabled young people should be given full information about the medication they are taking, why it is being recommended, how it might help, how they should manage it and the impact of it. They should also be given information on how this is being stored and administered in school.

> **"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?"**

Accountability - Making sure what is in the EHCP is delivered

CHECKLIST FOR PRACTICE	YES
• Are your EHCPs clear and specific so that they are not open to interpretation?	☐
• Do they make it clear who is responsible for doing what and by when?	☐
• Is there a mechanism in place to check if they are working – waiting for a yearly review is too long?	☐
• Are your plans drifting? Can you really be sure that young people are getting the support that is identified in their plan?	☐
• Are disabled young people given accessible, understandable information about the complaints and appeals process, how to access it, where they might find support and the timelines?	☐

Principles for Rights Focused EHCPs

Respecting the Rights of Disabled Children and Young People

All people have rights and all of the above is about respecting the rights of disabled children and young people. The following provides a checklist of rights under the United Nations Convention on the Rights of Persons with Disabilities. The UK has ratified this convention. We challenge you to think about rights, and tell us if we, as disabled children and young people, should not have our rights to these respected.

As a checklist of quality, do EHCPs in your area respect disabled children and young peoples rights to:

	YES
• Access to communication?	☐
• Accessible information on the Local Offer and EHCPs?	☐
• Express their views on all matters affecting them?	☐
• Support to enable them to be involved in decision-making?	☐
• Receive the support identified in their EHCP?	☐
• Have their support regularly reviewed?	☐
• Be included in mainstream education and social activities, with all necessary support?	☐
• Health information and services that meets all their health needs?	☐
• Be part of their community and have a social life?	☐
• Support to prepare for leading independent lives?	☐
• Choice?	☐
• Feel safe?	☐
• Have ambitions?	☐

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

Contact information

If you would like to find out more about our research project, please contact:

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Please use the following to reference this framework:
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For further information about the research upon which this framework has been based please see - RIP:STARS., Franklin, Anita., Brady, Geraldine and Durell, Shirley (2018) Defining Quality and Rights-Based Education, Health and Care Plans (EHCPs) for disabled children and young people. Coventry, Coventry University.

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