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Challenging dominant notions of participation and protection through a co-led disabled young researcher study.

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Abstract

In the UK, the Children and Families Act (2014) aims to create one assessment process for children with special educational needs or disability, through Education, Health and Care Plans. It also aims for greater participation from children and young people in decisions about their own lives. Current evidence suggests that children's needs and desires across education, health and social care are not being fully met, partly because adult agendas drive policy, practice and standards of care. Furthermore, little attention is paid to the *way* in which disabled children and young people are included either within decisions about their own support or within research processes. This article presents a research process designed to address these issues. In this project six disabled young people co-led research in which, for the first time, disabled young people had the opportunity define a research agenda which spoke to what 'quality' might look like in planning for their own future and that of other disabled children and young people. This paper presents findings from this process, addressing important ethical issues relevant for policy, practice and research, identified through this rights-based, collaborative way of working in partnership. Three key issues were identified and are explored here. They include firstly, tensions between young people becoming leaders and dominant ideas about safeguarding and child protection; secondly, being empowered through engagement within the project yet restricted in other areas of personal life and, finally, the emotional impact on new researchers of gathering evidence of a continuing lack of autonomy for disabled children and young people. We argue that challenging dominant notions concerning the participation and protection of disabled children is required in order to ensure they access their right to be decision-makers in their own lives, and to being empowered within research processes.

Introduction

Many disabled children and young people face multi-dimensional exclusion, often denied opportunities to be decision-makers in their own lives and mostly excluded from active roles in research (Beresford, 2002). They are rarely seen as actors in their own lives, are frequently involuntary passive recipients of support and services, and treated as research objects, rather than active participants. The dominant discourse is often one of 'being done to' rather than a discourse of 'working with' or disabled children being in a position of control (Franklin and Martin, 2018; Shakespeare and Watson 1998).

The study reported here challenges both notions of disabled children and young people as passive recipients of support and passive research subjects by presenting learning from a co-led disabled young researcher study. At the core of this project was an ideal of empowering disabled young people to be as close to equal partners with academic staff in a research study as possible. Although research *by* children has grown in popularity in recent years (see

for example, Alderson and Morrow, 2011: Lundy et al, 2011 and Bradbury-Jones and Taylor, 2015), there has rarely been discussion of the involvement of disabled young people as co-researchers or research leaders. Rare exceptions to this include Watson et al's study with children with little or no speech (2014) and Liddiard et al's online co-researcher collective (2018). Such attempts to address issues of inequality and power imbalance in a research study with disabled young people are unusual, and thus learning from studies which aim to push boundaries is vital. Barriers are often placed in the way, with many funders and institutions not prepared to see the value of lived experience and/or the potential of disabled young people to become competent co-researchers - often citing risks to the rigour of the research or not being willing to allow a more fluid approach to research design/approach at the outset of a project.   This study, funded by DRILL/Big Lottery, aimed to address these gaps through:

- Training and supporting a group of disabled young people to co-lead, undertake and share research which defines quality and rights based Education, Health and Care Plans (EHCPs).

- Supporting disabled young people to develop a framework and resources to ensure that quality and rights are at the forefront in the development and review of EHCPs.

A co-led research study does not take place in isolation and therefore ideals of empowerment had to be balanced with demands, and rightful obligations, to protect and safeguard the safety and wellbeing of the disabled young researchers. This raised tensions on a number of levels:

1) The balancing act within the research study between the young disabled researchers becoming leaders and decision-makers but subject to imposed institutional and procedural constraints.
2) The young disabled researchers becoming empowered within the project but managing personal experiences in their own life where they have been, and continue to be, afforded few empowerment opportunities and are often subject to many restrictions in the name of protection or due to denial of their rights.
3) Considerations concerning the impact on well-being of the negative research evidence the young researchers gathered. Evidence which starkly highlighted to them entrenched tensions of ableism and over-protection, and the lack of autonomy in the lives of disabled young people generally.

Each of these sets of tensions will be explored through an honest account of how the research team (university academics and disabled young people) managed the situation through continuous dialogue and reflective practice.

Background

Policy context

EHCPs were introduced in England under the Children and Families Act (2014) which created one assessment of the education, health and social care needs of children with special educational needs or disability leading to an EHCP. The legislation also aimed for greater participation from disabled children and young people in decisions about their own lives. It sought to support them to identify issues that are of importance to them in their EHCP and to be involved in the review of their plan. However, concerns remain that disabled children's needs and desires across education, health and social care are not being fully met within this

new legislative framework, partly because adult agendas drive policy, practice and standards of care in this arena.

Prior to this study, the quality of EHCPs and whether they met the rights of disabled children and young people had not been examined, despite the fact that EHCPs are legal documents and should provide holistic support for disabled children and young people. The plan should also prepare disabled young people for independent living and for having choice and control in their lives. The wider findings from the study are reported elsewhere (www.ripstars.net) the purpose here is to explore the often unreported reflections from working in partnership with disabled young researchers and to share that many of the perceived barriers or concerns to working in inclusive, empowering ways are often unfounded. Through reflective practice and working with values that recognise the strengths and rights of disabled young people, this paper aims to challenge dominant notions of passivity and/or the inability of disabled young people to be involved in decision-making, and produce rigorous research.

Disabled children and participation

Under the United Nations Convention on the Rights of the Child (1989), 'participation' is understood as the right of the child to express their views in matters affecting them and for their views to be taken into account in decision making (Article 12). All children have this right regardless of any impairment or how they might communicate. Participation, involvement, co-design and co-production are all terms that are often used interchangeably to describe in essence a shared decision making process. However, for shared decision making to be meaningful it is important to be explicit about the level or degree of power that a child has in that process. This is to ensure that participation or involvement in decision making refers to more than children merely being present, and enables them to actively influence decision-making by others or to take a lead in making their own decisions (Cavet and Sloper, 2004; Franklin and Sloper, 2006). It is argued that the nature of power sharing with children should be determined by the circumstances and by the wishes of the children taking part (Kirby et al, 2003).

This right to participation is embedded in Article 12 of the UNCRC and in domestic law in England (e.g. Children Act (1989, 2004) and within the Children and Families Act (2014)). Lundy (2007) conceptualised Article 12 outlining four chronological steps to be followed in the realisation of this right:

Space: children must be provided with the opportunity to express their views in a space that is safe and inclusive.

Voice: children must be facilitated to express their voice.

Audience: the view must be listened to.

Influence: the view must be acted upon as appropriate and the reasons for the decision taken must be communicated to the child.

Thirty years after a child's right to involvement in decision making was established in international law, disabled children and young people continue to report that they do not feel listened to and are not involved in key decisions being made about them (Franklin and Martin, 2018). The opportunities for space, voice, audience and influence remain in short supply for this marginalised group. Research indicates that basic rights, such as access to communication and information, are denied to this group, with access to a communication

system/method and access to people who understand a young persons preferred communication method a first consideration for participation (Franklin and Sloper, 2009). Realising a child's right to participate is of particular importance when decisions are taken concerning a disabled child – as they are subject to more surveillance and intervention by services and adults than non-disabled children. Decisions about disabled children's lives are often made by professionals they have not met, and they have little say in aspects of their lives. This has a negative impact on their autonomy and dignity.

Once it is accepted that disabled children and young people should be included in matters affecting their own lives, decisions need to be made about how best to do so. The *way* in which disabled children and young people are included in decisions about their lives has received very little attention (Franklin and Martin, 2018). Disabled children face barriers to being part of groups which are vocal and used to having influence on policy or practice. For disabled children what is understood by 'participation' varies and it is often assumed that asking a child a question equates to participation and will reduce unequal power relations. Consequently, for disabled children who are rarely afforded control in their lives, experience of choice and decision-making can be lacking. This lack of experience can often be interpreted as a sign of incapacity or incompetence to be decision-makers thus creating a cyclical barrier to enacting their right to participation. This is assumption of incapacity is often made of children generally (Alderson, 2007; Lundy et al, 2011), but there is also an added dominant presumption which defines disabled children as lacking the right to a level of autonomy, choice and self-determination or discourses suggesting they are too vulnerable to be decision-makers and therefore in need of protection from risk of harm (Franklin and Sloper, 2006).

Dominant ideas about safeguarding of disabled children

 The idea that disabled children are passive and dependent, not always capable, needing adult intervention and protection and liable to make inappropriate choices, has led to strong leanings towards over protection of those who are deemed 'vulnerable' (Shakespeare and Watson, 1998). Yet, at the same time, disabled children can be under-protected from very real harm, such as abuse and exploitation (Franklin, Raws and Smeaton, 2015) and this is not always recognised. Engagement with children in decision-making is a firmly established principle in the government's statutory guidance on safeguarding and protecting children (Working Together to Safeguard Children, DfE, 2017). Yet evidence shows that rarely are disabled children involved in conversations about their own safety and welfare or are listened to when they do disclose abuse (Jones et al, 2017). In practice, disabled children's rights to protection and participation are often seen as in opposition, yet they are interlinked and indivisible (UNCRC, 1989). Within research which seeks to address power imbalances and fully facilitate disabled young people's participation, attention to both sets of rights, is required to ensure meaningful, ethical, and safe co-led research with disabled young people.

Methodology

As previously described, it is still very rare for disabled young people to be in positions of power within a research project. This study set out to share all decision-making with the young researchers, aiming for the highest level of participation possible in the circumstances (Shier, 2001; Hart 1992). In practice, three parameters to this were discussed at the outset of the project: decisions had to keep everyone safe and we had to comply with research

ethics; the overall research question had to be answered as this is what we were funded to do; and we had to sensibly use the budget to achieve our goals. These parameters were fully explained, agreed and taken seriously by the young disabled researchers who understood the importance of them. All other decisions were then jointly undertaken.

The research team consisted of Anita Franklin, Geraldine Brady and six disabled young people (aged 16 – 23 years), with research assistant support for part of the project. Together the group had the opportunity to define a research agenda which aimed to address what 'quality' and a rights-based approach might look like in planning for their lives and futures and that of other disabled children and young people.

As all fieldwork was to be undertaken by the young disabled researchers the University team developed a training package to ensure that the group of disabled young people had the knowledge, skills and confidence to be researchers. This involved building on the award-winning collaborative research methodology developed by VIPER (2012) by: introducing them to the research process; understanding issues of ethics, confidentiality, anonymity and safeguarding, designing interview schedules, sampling, how to undertake peer interviews and interviews with parents/carers and professionals, undertake data analysis, report writing, developing policy and practice recommendations and designing an accessible report and practice framework for professionals. In addition the young researchers also wrote think pieces, blogs, co-designed and co-produced all project outputs and associated resources. They also worked with internationally renowned disabled activists, graphic design students, an actor coach and graphic illustrator. This was important in supporting them to establish their individual and group identity; in upskilling them; and giving them the confidence and, in their words, professionalism to be treated as bona fide researchers and respected by the people they wished to research and influence.

The group worked on creating their identity, RIP: STARS (Research into Plans: Skilled Team with Ambition, Rights and Strength) – this was the shared name across all of us – we all became a RIP: STAR. Whilst we developed a strong research identity we were also all very different individuals. In thinking about the identity of particular marginalised groups 'there often exists a misapprehension that people who share the same group identity or label are a homogeneous group. But just as there are differences between insiders and outsiders so there are differences between insiders' (Brady, Brown and Wilson, 2012: 155). While the label of disability was shared there remained differences amongst the group in terms of social background, educational experience, access to resources, gender, ethnicity and age. From the outset we aimed to recognise and acknowledge this diversity and identified the skills and interests of all, finding opportunities to apply skills to the project and to further develop them through the introduction of new opportunities.

Our values were anchored in the social model of disability and the rights of disabled young people to be involved in decision-making as enshrined in the UNCRC and United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006). The social model of disability defines disability as the social restriction placed on people with impairments by society. Thus people are disabled by discrimination, prejudice and by a society that fails to address their needs in terms of social relations and structures, and not as a result of their individual impairment (Oliver, 1996). Beresford (2002) argues that the social exclusion of disabled children continues because authorities locate the "problem" in the disabled child rather than considering external factors such as social, physical and organisational structures that contribute. Although the social model of disability has been critiqued and further

developed (eg. Thomas, 2004), it does provide a helpful framework for considering how the lack of participation of disabled children is shaped by structures and attitudes rather than seeing disabled children through a medicalised lens of being "incapable" or locating "the problem" within. Thus the onus was on the academic team, in partnership with the young researchers, to address any barriers faced by the young disabled researchers to their participation and to the enactment of their rights to be involved at all levels of delivery of the research.

Although the above formed our value base and theoretical underpinning, as professionals, we also had the responsibility to consider the ethical implications of this approach. Others such as Bradbury-Jones and Taylor (2015) have considered some of the challenges and solutions in co-researching with children. However given the additional discriminatory barriers experienced by disabled children, a focus on this group is much needed. Both the training of young researchers and the delivery of the research necessarily involved engagement in thinking through tensions between the right to participate and the right to be protected and safeguarded from harm, in daily life and in the research setting and process.

Ethical and practical issues considered within the context of empowerment and safeguarding of disabled young researchers in the study

1) Becoming leaders/decision-makers and complying with safeguarding procedures

One of the tensions throughout the project was the balance between the young disabled researchers becoming leaders/decision-makers but subject to imposed institutional/procedural constraints and in particular our duty of care to keep the young researchers safe when attending training meetings, fieldwork visits and conferences. Although we endeavoured to reduce power imbalances between the academic staff and young people wherever possible, the need for intrusive questions about medical details, medications, and parent notification in the name of safeguarding had the potential to change the dynamic of the group, and undo our desires to create as much equality of power as possible.

In interactions with university colleagues and organisers of meetings and conferences the starting point for interaction with the group was often, 'what are their conditions? What disability do they have?' and judgements about "how disabled are they?" We were keen not to label young people and resisted describing any individual in terms of conditions or diagnoses, in keeping with the social model of disability. It became apparent that this was not usual and a social model of disability was not well known about. Davis and Watson (2001) found that disabled children are often not recognised as children first, in discourses on childhood and on disability, with an over-focus on their impairment which can lead to them being 'othered', regarded as different from the normative concept of 'the child'.

In order to address some legitimate need for information and as an alternative to objectifying assessments we created 'About Me' documents which were about the young person, sharing what we needed to know to keep them safe. This included their likes and dislikes and how we could make the sessions, interviews and conferences accessible in terms of meeting their needs. Importantly information was only asked for on a 'need to know' basis. The group agreed that this was more empowering than their previous experiences of their personal information being managed. It enabled us to accommodate preferences for

expression of views and ensure young researchers were as comfortable as possible participating in each session or activity. An additional consequence was that, over time the young disabled researchers became adept themselves at challenging those that wished to define them by an impairment label.

Inevitably, university risk assessment forms also needed to be completed as part of research ethics procedure. We ensured that any 'risk' described was always contextualised, based on a situation or circumstance, rather than appearing to be located within an individual young person themselves and without reference to notions of any inherent 'vulnerability'. Whilst all of the young researchers were 16 or over, and we did not require parental consent, we asked permission from the young researchers to contact their parents if we needed to (for example, when activity required an overnight stay). It was their choice whether to allow any contact, apart from in the event of an emergency. This was a choice that had been denied for some previously. Disabled young people are familiar with parents making decisions and choices on their behalf. Our alternative approach signified our attention to power disparities between the young person and their parent, and the young person and the researcher. Where possible we communicated only with the young person, respecting their autonomy.

Safeguarding the well-being of the young people within the training and research process involved the question of what would happen when the project was over. Managing expectations; thinking about the end at the beginning; planning an exit strategy and process for closure; and not over-promising were key to the success of this project. It was crucial for the RIP: Stars group that we (as academic researchers) provided some structure to the process, notwithstanding the need for flexibility or potential for new directions led by them. The group needed to trust that we knew what we were doing, had belief in them and it was crucial that we all trusted each other.

Towards the close of the project, whilst reflecting on the research journey of our group and preparing to share with others issues encountered (including through writing this paper, informed by the group of six), we were interested to know at what point of the 15 month project the young people trusted the researchers. The first response to our question of when did you trust us was '*When you were human*'. In unpicking what was meant by this we learnt that young people needed to know who they were talking to, know about us, things about us and our lives that we were willing to share. They compared us to some other professionals that they had encountered in their lives and whilst they understood that professionals are busy people, which may have implications for building personal relationships, they stated appreciating us '*not being emotionless*'. Feeling that they were able to trust the researchers was particularly important for the young people that had often been disappointed by adults.

We built in time to talk and listen, opportunities for each to talk separately to one of the team if they wanted to, especially about difficulties outside of the project. This was possible as there were usually three researchers and six young people, the sessions were between 2.5 (evening) and 5 hours (weekend) and we met over 30 times. We had all been involved in previous research projects where such matters were not as well considered and had learnt from experience that taking a genuinely co-creative, participatory approach with children and young people involves time, consistency and adequate resourcing.

Being clear about what was possible over the course of the project also seemed to aid relationship building. Although we were confident that there would be a number of 'added

value' opportunities arising through our networks of contacts we were nevertheless careful to under-promise and over-deliver. We found, as O'Kane (2008) also did, that having the space to take part on their own terms increased young people's involvement in taking on new challenges and their sense of ownership of the project. It was made clear at the outset that each aspect of the project was open to re-negotiation and potential changes of focus and direction – within constraints/boundaries imposed by the budget, which was set by the funder.

2) Empowering disabled young people whilst managing disempowering experiences

Early on in the project the young researchers were introduced to the social model of disability and the notion of disabled children's rights. It was fundamental to the research approach being adopted, that all members of the team knew what the differences between a medical model and social model of disability were and how the model impacts on views of disability. However, all of these took place within a context where we were aware of the differing experiences of the group, and the impact that this had on their need for training and support. As the young people became empowered within the project, we developed trust with each other and shared more personal experiences. Subsequently tensions became evident between young researchers experience of becoming empowered within the project but managing personal experiences in their own life where they have been, and continue to be, afforded few empowerment opportunities. They also shared how they were often subject to many restrictions in the name of protection or due to a denial of their rights.

Equally, the research evidence that they gathered highlighted to them high levels of entrenched ableism and the lack of autonomy in the lives of disabled young people generally. Concerns were raised by the academic researchers regarding the impact of the negative research evidence on their well-being and whether it was right to expose young people to this. Yet we were also conscious that it was also their right to be informed about and aware of the issue. At an early steering group meeting the potential consequences of involving children and young people in addressing issues of injustice which they, themselves may face was discussed. Our partners (a disabled people-led organisation and disability activist) also had experience of working with children who had become angry or upset at the injustices experienced by themselves and those in a similar position. Raising awareness of oppression and discrimination through research can raise difficult emotions (Brady and Brown, 2013). These emotions manifested variously in our young researchers. One young man's anger about injustice was evident; in one session he was raising his voice, pacing around, talking about the unfairness and coming to the realisation, which he had always felt, that he should not have had the poor treatment that he had experienced across a number of schools and from a range of professionals who should have provided support.

In a further example, another young man began to challenge his parents and his college lecturers once he knew that he had rights under the UNCRPD. He asked more questions than usual and wanted to know about his own EHCP and to be more fully involved in any decisions which were being taken about his life. As a result of participation in the project he was no longer willing to passively accept a lesser role in discussions about his life.

A young woman who was generally very quiet did not show any outward signs of being distressed by what was discussed during the sessions, however, when asked to lead a collaborative article to be published in the Alliance for Inclusive Education's 'Inclusion Now' magazine (2018) she was able to freely express how she felt:

'*We have also learned about the social model of disability…..we now feel angry because through our research we have found out that in reality we cannot make a complaint or change our EHCP without a legal process. We are also angry because we have found that EHCP's are not always carried through correctly. Disabled young people are not always involved in their plans and do not get a real say into what is in them*' (p3).

In discussion with the group, some young people said that they had always spoken out and known when they or others were not being treated fairly but had previously been told that they were in the wrong: '*I nearly got kicked out of college for speaking out*'. In this case the young man was asking for support at college which was denied, he was unable to start his preferred course and told us '*I feel cheated out of my life*' because he was excluded from being able to make his own decision.

We raised the question, which other researchers have considered, of whether involvement in the project had raised expectations about how much power disabled young people could and should have when, in reality, this is not always available to them. He and the group strongly felt '*if you never give them hope then how can they achieve their best?*' They appreciated that through the project they had been given hope, they said that we had never given them guarantees but also not simply said no, that things were not possible. In other areas of life promises had often been made and then not kept, leaving the young people feeling let down, disappointed and sometimes angry. Anger, however, was not always regarded as a negative emotion as it meant that young people were passionate and motivated to speak up. The effect of anger needed to be managed…'*angry that the world is like that and you want to make it better*'.

Our response to the emergence of these feelings and emotions was to make time for discussion about how, during interviews, such feelings could be channelled into challenging the EHCP decision-maker participants in appropriate and socially acceptable ways. We talked about asking poignant questions, using our research evidence to state a case, not relying too heavily on personal experience but also still feeling able to talk about lived experience. Yet, we were aware that we were attempting to carefully manage the young researcher reactions, to our action of introducing the idea of rights and the social model of disability.

3) The emotional impact on disabled young people of co-leading research

Evaluating the impact of the research is important and will consider societal change, improvement in the lives of the wider group of children, young people and parents and influence on policy over time. The impact of engagement in this research and fieldwork on the young people involved is more difficult to measure as it was only one part of their lives, changes and development over the previous 15 months. Yet, when asked, the RIP: Stars were able to say directly how they felt they had benefited from participating in the project. One young person said:

'*That is easy. Think about it. What would I have done if I had not done this project? Woken up in dread every day, thinking about college, saying I don't know why I'm here…I was shy, scared, sad, angry and I developed, as a person, because of this*'.

Another young man gave an example of how he had made a complaint when he was unable to access his computer account at college for some time, saying that he was now more aware of what he was able and entitled to do '*when things go wrong*' and that he would not have said anything or raised the issue before his involvement in the project.

The RIP: Stars identified what they regarded as the key personal and group successes of the project. Predominantly this centred on the fact that they had co-led the project and had been involved in decision-making throughout the process – they identified that they had planned, developed and delivered the project at all stages. Of equal importance was the development of their own knowledge particularly concerning their rights and gaining a more empowering perspective of disability through utilising a social model approach. This was an approach which they could identify with, which motivated them, and which they could use as a framework for understanding how their research could impact on policy and practice. Successes also centred on the impact they felt their work was making through numerous dissemination events, contributing to other policy and practice development opportunities which came their way as people within the sector learned of their work. On a personal level they spoke of gaining skills, confidence, friendships and being proud of themselves.

However, with dedication to the project and stories of positive impact in the lives of the young people involved also came accounts of the emotional impact of the huge responsibility to improve the lives of participants. One young person told the group that if the project had failed '*I would have been in tears every day, with the burden of the other voices we'd heard we had got to make it work*'.

This sombre revelation caused us to question whether it is even appropriate for researchers and research involvement to put that 'burden' on disabled or any young person. The group felt that no, it would not be right for individual young people to be burdened but this is where team work is important, as the burden is shared across the team. With the responsibility to make a difference also came hope and a sense of possibility – '*we can edit the future now, for young people*'.

Discussion

Drawing on examples from the *RIP:Stars* DRILL funded project, this paper has argued that disabled children and young people have a right to be included in research about their lives and the lives of other disabled children and young people. When researchers commit to young people having a right to be heard, taking part in decisions, and influencing action, the ways in which this happens may be unconventional. For example, the act of sharing power and control during the process can appear to be taking risks around the safety of young people and can challenge procedures and practice that operate to reinforce the vulnerability and dependence of disabled children. However, this is highly necessary, otherwise medicalised and objectifying ideas which often categorise, 'other' and limit possibilities will be perpetuated. Researchers and indeed practitioners and policymakers need to ensure that any participation of disabled children and young people in decision-making about their lives is not limited by narrow assumptions of their abilities. Young people involved in this project did not want to be defined solely in terms of their impairment. In fact at the start of the project a minority rejected being regarded as disabled or having additional needs as this had always been a marker of difference and been experienced negatively. By the close of the project they had a different view, claiming their disabled identity, their rights and being able to challenge assumptions by others of individual deficit. As identified by them, this change was facilitated by an understanding of their rights and a more empowering view of disability through working within a social model of disability. This study enabled the young researchers to use their skills, their voice and undertake leadership roles of which they were all capable but all of which had been previously denied to them in their lives, especially within education. Utilising this framework could easily be undertaken in practice settings,

supporting the involvement of disabled children in decisions about their own lives, mirroring the research process.

Throughout this project, as academic researchers, we wanted to motivate, encourage, raise aspirations yet not raise hopes unrealistically. Providing disabled young people with the opportunity to co-lead a research project over 15 months necessitated finding a balance between the constraints of, at times, rigid procedures and supporting young people to lead. The following is an example of how one young man thinks this worked out:

'Before I started this project I had no voice to make a change but being on this project has changed my life and will change everyone else's life. Especially the University team have helped me to be confident in speaking. I'm really proud of this project, and of myself, and the group. We have all worked really hard, we've committed 110%, we've never missed a meeting, we are now work colleagues'.

The young researchers expressed frustration, anger and sadness about being kept in the dark and not having known about their rights as disabled persons before starting the project. The research led them to argue that children and young people need to know this information from an early age. Their passion for focusing on influencing social change came from direct, lived experience of inequality and injustice, particularly within education. Many of their painful life experiences were linked with their school or college educational experience and often a lack of support. As one young man said in a final reflection session on what being involved in the project had meant to the RIP: Stars:

'Growing up in education I have been ignored or moved to one side. I have been neglected by staff, support has been taken away and growing up I have always wanted to make a change for the better for children so I did everything I could to support them in lessons, an unpaid teacher, risking my exams to help someone in a wheelchair because the staff would not help. And being able now to actually make a change for the future to make so many children's lives better and getting my voice heard is amazing and if I wasn't here now I wonder what I would have spent all of this time doing because I feel like this was the best way to spend it'.

Although the emotional impact on qualitative researchers of fieldwork relating to sensitive issues has been much discussed (Letherby, 2003: Mannay, 2018), less discussion has taken place around the emotional impact and labour of disabled young researchers. Having created an inclusive space where personal and sometimes quite traumatic experiences were shared the impact of the stories heard stayed with some young people and gave them resolve to make a difference. It is thus important that researchers and funders who wish to work in empowering ways with disabled children allow time and a space of support and safety, to reflect on this together.

'When you first start off (a co-led research project) most disabled children will have their stories and if they have had a past like mine will want to make a change. Some children will think that they can't do it or they are not as good as someone else. You need to remind them that it doesn't matter who you are or what you have in your background if you want to make a change to children's lives then you are welcome in the room to do it'.

Taken the points raised above together, engaging in raising critical consciousness and introducing (disabled young) people to their membership of an oppressed group needs to be approached carefully (Freire, 1973). It is unethical practice to raise such emotions and not provide an outlet for young people to be able to express their voice. The opportunity to be

heard and to make a difference is crucially important in the validation of the experience. Given the considerable emphasis placed on creating change by the young researchers, it is vital that attention to dissemination and achieving impact is seen as an integral part of any research and not just an "add on". When considering the impact of research on policy and on practice consideration also needs to be given to the impact on those who are becoming researchers, particularly when they are part of a marginalised group. In investing in the aims of the project the young researchers felt a responsibility for its success, they would have felt accountable and a sense of failure had the research findings and recommendations not been listened to or acknowledged as important. Working with disability activists - and one of the academic team having a background in policy, practice development and lobbying - has supported the young people to achieve their goals in this area. The research report and framework developed to aid professional practice has also been widely welcomed by professionals and parents and carers.

Most recently, the RIP:Stars presented their evidence to a government cross-party Parliamentary Inquiry into Special Educational Needs and Disability (SEND) provision in England. Following this UK Members of Parliament have been widely citing and quoting their words. There is evidence that the impact of this research is beginning to make a significant contribution to the on-going debates around Special Educational Needs and Disability (unpublished).

Conclusion:

Attention to the process of research as well as the outcome or outputs is essential when aiming to influence social change and research in an ethical and socially responsible way particularly when researching with (young) people understood to be marginalised (Brady, Brown and Wilson, 2012; Brady and Brown 2013; Mannay, 2018). Participatory research methods are often equated with the enabling of the exercise of agency, as children and young people become involved in the construction of knowledge about themselves. Gallacher and Gallacher state that researchers, in acting in socially just ways, must be honest and open about what they aim to achieve through engaging young people. Most importantly they need to address the 'messy contingencies of research encounters' (2005:8). Throughout our thirty plus working meetings with the young researchers we were required on several occasions to address and prioritise such messiness. Our loose plan did not always go to plan as each step was open to discussion and joint decision-making which shaped the direction, often in more creative ways. As Larkins et al (2015) have argued, much children's rights framed research lacks critique, this paper has engaged with the challenges of rights led co-research to challenge dominant ideas about participation, inclusion and protection relating to disabled children and young people. Change is required to the cultural context of how their lives are currently perceived, including the development of a rights-based framework against which to ensure quality within the new assessment framework and development of subsequent Education, Health and Care Plans (EHCPs), and young people's meaningful inclusion in research about the lived experience of disabled young people.

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