'LIFE AS WE KNOW IT'

A Participatory Evaluation and Peer Research Project
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EMPOWERMENT THROUGH WORKING IN GENUINE COLLABORATION WITH THE TEAM, AND THE COMMISSIONED EVALUATION ORGANISATIONS

1) Introduction and Overview

The 'Life As We Know It' project was funded by the Life Changes Trust (the Trust) and delivered by Media Education and Briege Nugent (the team). The original intention for the project, which began in December 2019, was to conduct Participatory Evaluations with young people with care experience who are taking part in projects funded by the Trust. The Trust commissioned a range of independent evaluators to review the work of its funded initiatives, and was keen that young people themselves could be part of this evaluative process (e.g. defining research questions, developing creative engagement opportunities and conducting interviews). In late 2019 a group of Peer Researchers were recruited to the 'Life as We Know It' project, with the aim of supporting and informing some of the Trust's commissioned evaluations. This research is not an evaluation of peer research but rather an exploratory study of participatory evaluation and peer research, to understand more and add to a dearth in knowledge around this area.

However, in March 2020, the COVID-19 virus led to a nationwide lockdown in the UK. Due to the impact of the pandemic, both the offer of involvement from the commissioned evaluations and the ability of the peer researchers to participate changed, and what had been envisaged from the outset for this project shifted significantly. Young people from the project have still been able to take part in some aspects of the evaluation work of Trust-funded projects, but this involvement has been more limited than originally envisaged. The Trust and Media Education/Briege Nugent therefore agreed that the 'Life as We Know It' project would adapt and consider two elements:

- the four Peer Researchers' reflections of their own journey as Peer Researchers (primarily through 'in house' arts-based opportunities)
- engagement with Trust-funded Evaluations carried out by Research Scotland and The Lines Between.

All of the participants, regardless of their engagement with the Trust-funded evaluations, were trained as Peer Researchers. The training focused on ethics, exploring the idea of informed consent, confidentiality, their role as a Peer Researcher and the importance of self-care, and they were invited throughout to share their ideas.

This research was underpinned by an ethics of care (Gilligan, 1982), which means in practice that the team considered the barriers and enablers for engagement at each stage and promoted inclusivity, exercising empathy and sensitivity. It was apparent from the very beginning that this approach was shared across the organisations. The vision was to capture the Peer Researchers' journeys and to prioritise:

- creativity - through the Peer Researchers documenting their experience of the Project
- authenticity - as the foundation of their facilitation skills, and
- empowerment through working in genuine collaboration with the team, and the commissioned evaluation organisations.

The project used participatory video methods, Zines (which are self-published booklets), music and creative writing. Their main motivations for joining the project as Peer Researchers were to help create positive changes to the care system, to meet others with similar lived experiences and to share their stories. They have explored these desires through the arts-based opportunities mentioned above.

These reflections did not always align with the 'peer research' remit of the project, so all of the stakeholders have collectively agreed to the wider reflections of the Peer Researchers being given a platform via an online gallery. This gallery can be viewed as a companion piece to the Summary and Full Report into Life As We Know It, and their creative work can be viewed here:

https://artspaces.kunstmatrix.com/en/node/7634697

The remainder of this report, as well as the executive summary, focuses on the findings and learnings from the second element of the project: supporting those with lived experience of the care system to participate in evaluation as Peer Researchers.

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[1] See Section 1.1.1 for reflections on the use of this term.

YOUNG PEOPLE NOT ONLY HAVE A RIGHT TO BE HEARD, BUT THEIR OPINIONS AND VIEWS BRING VALUABLE INSIGHTS AND UNIQUE PERSPECTIVES

1.1 The 'Peer Researcher'

1.1.1 Peer Research vs Participatory Evaluation

In an academic context, the term 'peer research' has a very specific meaning denoting the Peer Researcher being involved in all aspects of the research, from start to end (Lushey, 2017; Cornwall and Jewkes, 1995). Participatory evaluation, on the other hand, is the idea that those who are affected by services are involved in the evaluation in some way, and not necessarily from end to end (Cousins and Earl, 1992). In this project and throughout this report a conscious decision was made to refer to the Peer Researchers as such, despite the reality that not all of the Peer Researchers engaged with the entire process. As will be discussed in more detail in this report, this highlights the value of allowing people to participate on their own terms so it is not a case of their involvement being dichotomously 'all or nothing'. The term 'Peer Researcher' was also what those involved felt most comfortable with and, as will be discussed in more detail in section 3, this title promotes inclusivity.

1.1.2 Including the voices of young people with care experience

The latest figures show that at 31 July 2020, 16,530 children in Scotland were looked after or on the child protection register (Scottish Government, 2021). The First Minister commissioned the Independent Care Review (ICR) in 2017, and this brought to the fore that children and families with experience of the care system do not feel listened to. The ICR presented their findings in 'The Promise' which also set out an ambition for Scotland 'to be the best place in the world to grow up' so that children are 'loved, safe, and respected and realise their full potential' (ICR 2020: 4). A key foundation of this work is the inclusion of the voices of young people and a compassionate, caring, decision-making culture focussed on children and those they trust (ICR: 2020: 9).

YOUNG PEOPLE IN CARE, HOWEVER, COULD BE SAID TO BE TRIPLY SILENCED

At present the Scottish Government are in the process of incorporating the United Nations Convention on the Rights of the Child (UNCRC) into Scots Law. Article 12 of the UNCRC gives the child the right to have their views on self-regarding matters taken seriously and weighted according to the child's maturity (Archard, 2021). Young people not only have a right to be heard, but their opinions and views bring valuable insights and unique perspectives, which is why it is important that they are included in research that affects them.

Young people in care, however, could be said to be triply silenced, because of their age, being in care and often from backgrounds of poverty and trauma. The main challenge to young people being truly heard, which is acknowledged by the ICR, is poverty, which has a pervading negative impact on all aspects of young people's lives (NHS Scotland, 2018). Those in low paid and precarious work, Black and Minority and Ethnic (BME) households, lone parents, private renters and areas of high unemployment and poverty – parts of the population which were often already struggling – have also borne the brunt of the economic and health impact of Covid-19 (Joseph Rowntree Foundation, 2021).

There are many barriers to capturing the views of young people with experience of care, including because of potential low self-esteem or inherent power imbalances between the researcher and young person. Peer research can be a way of overcoming this (Lushey and Munro, 2015). For example, most young people with care experience (57%) who were surveyed about their experience in a study by Dixon et al. (2019) said they would prefer to be interviewed by someone with care experience. Furthermore, 69% felt that young people should always be involved in projects about issues that affect them (ibid).

Young people from marginalised communities, facing multiple barriers and who have experienced many interventions in their lives, are well versed in the language used to define and describe their situation (Media Education et al. 2020). It might even be true to say that they are 'rehearsed' in their answers. It takes a creative approach, time and trust to reach beyond prepared answers and to find out what they really think. The arts offer a chance for those who are younger, who face multiple barriers, or who simply may find it difficult to vocalise what they think, the use of other mediums to ensure they are heard.

1.2 The Impact of COVID

As a result of the pandemic, at the beginning of the project all communication moved to being digital. Media Education responded quickly, mediating the impact on this project by sourcing Chrome Books, internet access and supporting the Peer Researchers to set up their laptops and use digital platforms. The Peer Researchers were also given an advance in payment as it became quickly apparent that the impact of poverty had worsened as a result of Covid-19. Training was delivered online individually to stress the importance of boundaries and looking after oneself as the 'building blocks' of ethical research. Kvale (1996) describes research using a 'traveller metaphor', a journey whereby knowledge is constructed and negotiated between parties and co-produced. As a research team, it was made clear from the beginning that we are all travelling on this journey together as equals.

Due to the impact of the pandemic, both the offer of involvement from the commissioned evaluations and the ability of the researchers to participate changed and what had been envisaged from the outset shifted significantly. Originally, it had been hoped that through the commissioned evaluations the Peer Researchers would connect with others who have experience of care, for example, through attendance at focus groups. It had also been planned that the Peer Researchers would be brought together to work as a team as well as individually. The reality, however, was that because of the restrictions some of the key components of the original research design were not able to go ahead.

In addition to the offer of the commissioned evaluations changing, the circumstances of the Peer Researchers were also impacted by the pandemic. Two Peer Researchers in particular have faced many challenges over the past year, some of which have been indirectly linked to COVID, with mental health services difficult to engage and employment affected. This unfortunately prevented them from being able to engage with the commissioned evaluations. Through support from the Trust, the decision was made to adapt the original aims of the project to enable more flexibility around how the young people were supported to engage. For some of the Peer Researchers, therefore, the emphasis was more on the use of arts work as a way of continuing to engage those who otherwise were unable to have their voices included.

1.3 Arts-based approaches

The project used participatory video methods and the development of Zines, which are self-published booklets of original or appropriated texts and images, to enable the Peer Researchers to capture their experiences through 'making of' style videos. This platform was a powerful means for the Peer Researchers to capture their personal journeys and understand the role of storytelling as a process of reflection. In the final stages Liam drew on the research skills and use of arts to develop his own topic guides and conducted interviews with his foster family. He then analysed the answers, combining his reflections with images from throughout his life to produce a powerful zine titled 'Home,' which can be viewed on the online gallery.

One Peer Researcher who was unable to engage with the commissioned evaluations was interested in developing his own music, and another Peer Researcher in creative writing. The content created was experimental and creative - with the starting points being 'a self-portrait' leading to subsequently reflective and creative sessions, which act as 'diaries' of their journies. A thematic analysis of the content generated was carried out.

The creative outputs and insights created by the Peer Researchers shows that there is much learning to be gained from working alongside people with lived experience in research, as they have much to say. Over the past year they have grown as individuals, gained confidence and recognise the power of their voice to help promote positive change.

As already stated, their work can be viewed in an online gallery at:

https://artspaces.kunstmatrix.com/en/node/7634697

The next section examines the learning generated from this project, including the value of a participatory evaluation and the arts as a way to make this a meaningful as well as an enjoyable process. The final section provides the conclusion and outlines recommendations, the benefits of peer research and steps to make peer research possible.

2. Reflections and Learning

Introduction and Overview

The following section explores the reflections and learning captured thoughout this project, particularly focussing on the role and value of Peer Research, the value of having an ethics of care and acting inclusively, and the power of the arts as a tool for engagement.

2.1 Role and Value of Peer Research

2.1.1   Value to the Peer Researchers

"It feels good to be listened to and they took what I said on board." (Roxsanne)

From the very beginning of the project all of the participants had been referred to as Peer Researchers. The training focused on ethics, exploring the idea of informed consent, confidentiality, their role as a Peer Researcher and the importance of self-care.

For both Liam and Roxsanne, the experience of engaging with the commissioned evaluations helped them to consolidate their identity as researchers and those with valued voices in what could be viewed as the 'bigger picture.'

For Liam, the experience of taking part in this project has been transformative. He has begun to open up in the reflective and creative sessions about his childhood and reasons for coming into care and was seeking support to deal with past trauma. Through the experience he felt he had gained a greater understanding of who he is and self-acceptance.

"When I took up this work I saw it as a great opportunity to be busy and to understand more about people in care and delve into things...people may have seen things, been through things. People think if you have been in care you are a troublemaker or a troubled child and that is not nice...I feel these experiences are making me aware that life is up to me and I am only going to do the things that I want."

All of the Peer Researchers felt there needs to be opportunities for people growing up in care to be really listened to, no matter what their age and they all valued the arts as being a way for them to articulate what they want to say.

> "PEOPLE THINK IF YOU HAVE BEEN IN CARE YOU ARE A TROUBLEMAKER OR A TROUBLED CHILD AND THAT IS NOT NICE"

> ## "I THINK OPEN QUESTIONS ARE BEST, BECAUSE OTHERWISE IT IS LIKE SAYING I HAVE A FRUIT SHOP BUT ALL I SELL ARE APPLES AND BANANAS"

2.1.2 Value to the Commissioned Evaluations

The Trust always acknowledged that, in terms of the three commissioned evaluations, it would not be possible to utilise the young people in this project as 'pure' Peer Researchers who co-designed the entire research project. However, the Trust recognised the value in young people having the opportunity to be trained in research methods and to bring their lived experience to bear on the activities carried out by the evaluations, and prioritised the involvement of young people in a way that fit both the commissioned evaluations and the Peer Researchers themselves.

Both Liam and Roxsanne engaged with the organisation Research Scotland, and Liam with the organisation The Lines Between. Time with the research organisations was paid at living wage and Research Scotland also had a certification ceremony at the end. Research Scotland submitted a draft Topic Guide for the Youth Champions Board (Appendix I) and all the Peer Researchers gave their feedback, which was collated and submitted to Research Scotland (Appendix II). The main feedback was that the event could be more fun for the young people (with, for example, an icebreaker included), and the researchers should strive to use more open questions. As Liam reflected:

"I think open questions are best, because otherwise it is like saying I have a fruit shop but all I sell are apples and bananas."

The organisations involved the researchers through a staged process. This was well considered and meant that they had time to build confidence in their role as a researcher. Specifically, they moved from observing an interview, to asking a question, to developing their own question(s) and asking these in the interviews. Both Liam and Roxsanne really enjoyed the experience, and it helped them reaffirm their identity as researchers as they recognised that their input was valued.

Liam asked a specific question of one professional about how they help the 'quiet ones'. This small example shows the value of having someone with lived experience involved, as it is not an obvious question but drawn from Liam's own experience of being the 'quiet one' when he was younger.

In all cases the research organisations felt that the input from the researchers had been really helpful, as it made them think differently about how they ask questions, what questions they ask, and how to make their research as fun as possible.

Research Scotland stated:

"We worked with two people from the Media Education participatory evaluation project. They joined our team as peer researchers, supporting our evaluation of the Champions Board approach alongside a wider team of peer researchers. They each spent around two days working with us (remotely).

Working with peer researchers brought a fresh perspective to many aspects of our evaluation through:

• developing the discussion guides - with young people advising on how it feels to be interviewed, what order questions should come in and what words to use to help people be effectively involved;
• their insight into the topic – young people have provided valuable reflections on the interviews they took part in, demonstrating their understanding and perspective of discussion;
• their media skills – young people developed audio and video content for the interim report; and
• influencing the design of the report - with peer researchers selecting the colour scheme, cover, report style and photos."

The Lines Between also added:

"We have found involving a peer researcher to be a valuable exercise in looking over our draft material, discussing potential sticking points and agreeing on solutions. We've been able to check and correct the tone of our interview guide, and improve the wording of some questions. This led to a better quality of interview, and enabled those being interviewed to feel more at ease. Overall, supporting us to ensure our material is warm, relevant and accessible has been an important contribution."

The wider literature points towards lived experience ensuring that policy making does not fall victim to stereotyping and assumption making (Wright, 2012); and subsequently policies that are realistic and effective (Rogotff et al. 2018 cited in Carlin et al. 2020). Inclusion of lived experience can also lead to innovation, however it requires bravery, not just from those drawing on their stories, but also from those who are listening (Carlin et al. 2020).

2.1.3   Levels of Participation as opposed to 'All or Nothing'

From the outset Media Education and Briege had envisaged the 'Life as we know it' Project, unlike the commissioned evaluations, to be peer research in the purest sense because they would be involved in the design from the very beginning. Although all of the people in this project were adults, and treated as such, Roger Hart's 'Ladder of Youth Participation' offers a useful way of thinking about the different levels or 'rungs' of participation that can be achieved, as can be seen below. The overall project 'Life as we know it' was initiated by the team and therefore the 'adults', but the artistic outputs and key messages have been led by the Peer Researchers and therefore 'rung 7' has been achieved through this project.

8. Young people-initiated. Shared decisions with adults

7. Young people-initiated and directed

6. Adult-initiated. Shared decisions with young people

5. Consulted and informed

4. Assigned but informed

PARTICIPATION

3. Tokenism

2. Decoration

1. Manipulation

NON-PARTICIPATION

Adapted from: HART, R. (1992). Children's participation: From tokenism to citizenship, Florence: UNICEF International Child Development Centre.

The extent of participation is not only about the parameters of engagement or power dynamics, but is also about the interest and capacity of the Peer Researchers themselves. As found in other research, not all of the Peer Researchers wanted to be involved in all aspects of the work (Funk et al. 2013). For example, in the final stages of the analysis there was only one Peer Researcher who wanted to play a role, and preferred to consult and discuss drafts of what was written up, rather than doing the writing up themselves. As also observed by Funk et al. (2013), participation did not mean that the Peer Researchers advanced from one rung to the next in a linear way. Rather, depending on competing demands in their life, the time they could give and their own interests, different 'rungs' were achieved at different stages.

The realities then of doing Peer Research can therefore mean that the 'all or nothing' academic portrayal of Peer Research does not always 'fit' with what is possible or indeed wanted by those involved. It can, in fact, be in direct opposition to what it actually means to be inclusive.

Becoming through doing Peer Research

It is contended that those involved in this project were Peer Researchers, and were referred to as such right from the beginning. They moved quickly after the training to 'doing' and therefore becoming Peer Researchers. Liminality means being 'in between' (Turner, 1964), and this has real resonance with this group, who are in early adulthood. Through this process the Peer Researchers moved from being passive observers to active learners and advocates in their own right. Bearing in mind the context in which they are doing this work and the wider uncertainty in the world around them, these identities of being artists and researchers are very important.

The insights they have brought - as shown by the previous section - are powerful, thought provoking and have the potential to challenge thinking around involving young people with care experience in research and evaluation. The value therefore of peer or participatory research is undeniable, not only as an ethical process that ensures lived experience is heard, but also because having people with lived experience shaping the research agenda allows everyone involved to learn from those who really know. The real value of lived experience lies in its ability to connect people, helping others to understand and emphasising the humanity that binds us all building empathy and hope (Chen et al., 2016; Byrne, 2017 cited in Carlin et al. 2020).

2.2 Value of Ethics of Care and Inclusivity

Overcoming barriers and promoting enablers to engagement

An ethics of care and inclusion has underpinned this project. From the outset the team thought through ways to overcome practical barriers the Peer Researchers may face to engaging, such as sourcing their equipment and giving them a monthly 'wage' so they can budget their finances accordingly.

The team also thought through potential enablers, particularly for the recruitment stage, which included making the interview process informal and covering the costs of having someone to accompany the individual. This opportunity was advertised widely among trusted networks and the deadline for applications was extended. This proved to be important, as otherwise two of the Peer Researchers would not have applied within the original time frame, and all five who applied were recruited. Recruitment for the project proved to be a challenge. Much of this was due to the impact of Covid-19, but it may also be linked to young people with experience of care lacking confidence in putting themselves forward for such opportunities. As this approach remains rare, it may also be that they do not recognise the potential value this sort of work can bring.

Had this project been run as it had been hoped, with face to face contact at the heart, the importance of thinking through practicalities and making engagement accessible at each stage would have been central, and is worth bearing in mind for future projects.

The Peer Researchers received a living wage and their video content (and the planning and reflection around their experience) can secure a certificate in 'Access to Media' from Media Education, which is accredited by Edinburgh College and can be used as an access point for students experiencing barriers to further education.

Communicating with trusted support networks

All four Peer Researchers had a key worker, which has been especially important throughout the difficult lockdown periods. The rationale to this approach was to ensure that the Peer Researchers had appropriate local support networks already in place. There were points at which the team were concerned about a Peer Researcher and contacted their key worker, who in turn offered direct support and feedback. Key workers will also be able to support the Peer Researchers to maximise the learning from the experience and bring some of their new skills back into communities once the project has finished.

Regular Contact and Personal Planning

The team completed the NHS online training on trauma. In the postponement period of the project, the team kept in touch with the Peer Researchers, and the project moved from being about bringing a team together to providing an individual tailored engagement plan. This stronger emphasis on regular personalised communication set out to build confidence and clarity both over each Peer Researcher's role in the evaluations, as well as their own personal development goals and support needs.

> # ALL FOUR PEER RESEARCHERS HAD A KEY WORKER, WHICH HAS BEEN ESPECIALLY IMPORTANT THROUGHOUT THE DIFFICULT LOCKDOWN PERIODS

Communicating the way the person wants to communicate

The team learned small but thoughtful ways of ensuring that the digital communication replicated face to face contact. For example, in the same way as if a group face to face meeting was held, a member of the team was always the last one on the call to give people a chance to hang back and have a chat on their own, should they want it. Both Chloe and Jordan communicated mostly using WhatsApp or by email rather than using digital platforms and this 'worked' for them. Overall, the team have felt that face-to-face contact is best to establish relationships, however the changes to digital or phone communication have had benefits too that are also important to document. Namely, the Peer Researchers have learned new skills and as the model moved from being about doing groupwork to instead providing tailored pathways, as a result individual hopes, aspirations and interests were specifically understood and met.

Inclusivity and flexibility

The pandemic exacerbated the challenges people faced and for some of the Peer Researchers the circumstances in their lives lead to them having to cancel things last minute and this raised concerns about their engagement with the commissioned evaluations. The team, supported by the Funder, decided to provide more 'in house' opportunities for Peer Researchers to contribute through creative writing and music. Originally the research with the commissioned evaluations should also have included Matter of Focus, who are evaluating the impact of the Advisory Group, a group of people with experience of care who advise the Trust and co-design projects and initiatives. However, engagement with Matter of Focus was not possible, as the Peer Researcher who had been identified ended their engagement after the training. In our experience, being inclusive means being flexible and open to change with the approach and the needs of both organisations and individuals.

THE PANDEMIC EXACERBATED THE CHALLENGES PEOPLE FACED

THE EXTENT OF FINANCIAL AND EMOTIONAL INSECURITIES WAS EVIDENT EVEN BEFORE COVID-19 HIT

2.2.1 The Complexity of Need

The extent of financial and emotional insecurities was evident even before Covid-19 hit, and at the recruitment stage it was noted that it wasn't necessarily age related. The younger Peer Researchers who still had statutory support in place tended to be in a better position than those who were older and had officially left care. For example, one older Peer Researcher requested £10 to cover heating and food costs over the weekend when their social worker was off. We helped the individual and requested a three-way dialogue with their social worker after the weekend, with the social worker reminding the individual and notifying ourselves of the emergency procedures in place via the duty social worker. The mutual discussion on the situation strengthened the social worker's existing case to put a designated support worker in place for the individual to manage their tenancy.

This level of need was greater than what was initially anticipated, and this is an indication of how this group have been especially adversely affected by the pandemic, often without a safety net of organic networks as well as the wider challenges of living in poverty. Some of the Peer Researchers reported that the creative and reflective sessions they had with the team were sometimes they only contact they had with another person on a given day. However, the importance of care and ethics of care is also about being realistic about the team's role, and of not taking ownership of the role of others, particularly as we may not be in the Peer Researchers' lives after this project ends. The Key Workers were all aware of the project and with the consent of the Peer Researchers when issues arose we contacted them so that support was provided.

LEARNING SKILLS AND HAVING EXPERIENCES THAT HAVE THE POTENTIAL TO 'REFRAME' INDIVIDUAL IDENTITY

2.2.2 Establishing Relationships and Boundaries

All of the Peer Researchers struggle with anxiety and felt there was not enough awareness of the impact this has on individuals preventing them from participating in activities and research. One of the benefits of moving towards digital communication was that more regular contact was normalised and as a result the Peer Researchers built good relationships with the team and even began to open up about the past.

It was also apparent that there was a need for the team to also be aware of boundary setting, particularly as for most of the Peer Researchers, this was the first time they were interacting with an organisation where the dynamic was not about them directly receiving support. Part of the creativity of the process was not just about building technical skills to produce media but also the social and emotional learning generated. This was about learning skills and having experiences that have the potential to 'reframe' individual identity on their own terms and "re-see" who they are, building affirmation. Unlike the support organisations the Peer Researchers were engaging with, this project supported them to channel their lived and living experience in the way they wanted to. The notes of the conversation with one Peer Researcher and a member of team illustrate this well:

> "We had discussed what a 'call anytime' offer to Peer Researchers actually means - we do need to observe some difference between work colleague as opposed to friend or family access. We want to be as open and welcoming as possible.

I reassured them that there wouldn't have been a problem with calling Media Education. I went on to talk about the importance of the project as a learning process for them to understand about work and the experience of working with colleagues and what expectations this entails. I said that I am always happy to talk about work and happy to get back to them about that. For other issues we talked about the support networks they have in place and that they're a more appropriate route as they know their personal circumstances much better. I said that the difference would be as follows: I am feeling a little fed up and lonely - I call a friend or family member. If I'm feeling a little fed up and lonely and can't talk to a friend or family member I might just call a work colleague and talk about something to do with work which might also help me feel less lonely or fed up. I said that I was happy to receive a work related call even if his primary motivation was just to have a wee chat.

This brought home to me the potential for the Peer Researchers to be actually very isolated and to have no close and trusting relationships with friends or family leading to them wanting that from this kind of work based situation where perhaps the standards of interrelationship are much more exacting and therapeutic because of the nature of the working practice and ethos that we adhere to. Their reaction to that is to recognise that their need for trusting companionship is not necessarily being met through their existing relationships and that therefore they find it very tempting to try to bridge that gap in terms of the role and to treat work colleagues more as friends."

As far as possible therefore interactions with the Peer Researchers were purposeful and contributed towards the project. The Peer Researcher in this case responded extremely well to boundary setting and understood their role as being different to their interactions with their key worker, and has grown in confidence as a result.

2.2.3 Beyond Anonymity and Protecting the Story Teller

The Peer Researchers understand that it is their choice to tell people their story and understand the limits of confidentiality. Right from the beginning Jordan wanted to be named in the report, feeling that his voice was stronger if he was heard and seen. Liam, Chloe and Roxsanne initially had spoken about using a pseudonym, but when they reviewed the analysis of the key messages they recognised how proud they were of what has been written and created, and wanted to be known. It has been emphasised throughout that the Peer Researcher's participation dictated by what they are comfortable with and respecting their decision if they choose not to take part anymore. All of the notes from the creative and reflective sessions were shared with the Peer Researchers so that they could amend or change anything before it was included in the analysis. For the final stage in the writing of the creative report the Peer Researchers were invited to review all aspects, and to amend or change anything they felt. An event has also been held bringing the Peer Researchers together to 'walk through' the report and agree the final version.

THE PEER RESEARCHERS UNDERSTAND THAT IT IS THEIR CHOICE TO TELL PEOPLE THEIR STORY AND UNDERSTAND THE LIMITS OF CONFIDENTIALITY

2.3 Creativity and Innovation Overcoming (some) Challenges

Digital Inclusion

When Covid-19 and lockdown happened the team were committed so that the project in some form would go ahead. Media Education responded quickly as already discussed, recognising the need to move all of the interaction to being through digital means and for the Peer Researchers to be 'connected'. As already discussed, Media Education used the budget to purchase Computer equipment and data for those needing it, and the Creative Facilitator assisted with 'unboxing', digital literacy and practice with the shared drive and remote communication tools. For the Peer Researchers, this kit enhanced their access to other opportunities, such as writing college applications and being able to attend college classes remotely.

Mental Health and Relationships

The team were also very concerned about the impact of the pandemic on people's mental health and relationships. We had weekly calls with the Peer Researchers in preparation of and throughout the training, and communicating as a team regularly to action any issues as they arose.

As already discussed, the face-to-face interaction, training, residentials and planned activities were no longer able to happen. In response, the team redesigned the content of all the training to be delivered one to one. Media Education also found innovative ways to help the Peer Researchers create content, by for example providing each with a selfie-stick and tripod to record footage of their everyday lives contributing towards their self-portraits and diaries.

"SOMETIMES KIDS DON'T HAVE THE WORDS TO SAY WHAT THEY WANT"

2.3.1 Arts as a Tool for Articulating Stories and Amplifying Voices

"Sometimes kids don't have the words to say what they want." (Liam)

"I am writing down some lyrics and I put 'em to a beat, finally I am better I am back up on my feet." (Jordan Lee, 'What It Do')

"I like creative writing so getting it down on paper helps me." (Chloe)

Overcoming Anxiety

As already related, all dealt with anxiety and felt this was a particular issue for young people in care, potentially stemming from past trauma. Using arts, the Peer Researchers reflected that they could take the time they need, work at their own pace and use the medium(s) they preferred to shape the messages they wanted to make. Over time and with positive affirmation, their confidence grew.

It's fun

All felt that making films, Zines, creative writing and music was fun and the process was as important and meaningful to them as the output. In the participative evaluations all of the Peer Researchers' input highlighted that interviews or focus groups should be made as fun as possible. The key message was that although these are serious issues, professionals can't forget that for the young people they are engaging with 'having a laugh' is really important and will help young people to feel comfortable, want to be a part of the process and 'open up'.

Amplifying Voices

The arts can be a useful vehicle for unlocking stories, and the mediums and how people connect to them are a sort of magic. For Chloe it was writing, Liam used images and analogies, Roxsanne, spoken word and Jordan rapping and music. Liam spoke in the sessions about how using the arts helped him to 'get out of his head.'

All of the Peer Researchers recognised that it is also important how their story is used. The creative work has provided a trusted platform from which the Peer Researchers experienced feeling ownership and strong personal development through their reflective practice. Using the arts they developed their own boundaries, built confidence, self esteem and gained recognition. The artistic outputs provide professionals information, which is shaped by lived experience and provides an interpretive focus for those engaging with the Peer Researcher. It means that they (the viewer, professional etc.) have to bring their experience to bear - not in terms of judgement but of interpretive understanding. The focus on the arts elements (which cannot be wrong - only interpreted) is that they provide a more nuanced and neutral setting for further exploration.

Feeling Part of Something Bigger - I Matter

Liam spoke about feeling part of the team, and when he was being linked back up with one of the male artists he described this as 'the boys being back in town'. In terms of wider input, all recognised their potential to be advocates for change. The arts provided a platform for them to do this. In the following film created by Jordan, he described using music as a way for him to reflect on his life and called for staff working in the care sector to genuinely care. To view Jordan's film, a powerful message highlighting the benefits of listening to those who have 'been there' and learning from their experience, you can go to the online gallery or use the following link:

https://vimeo.com/551873996/976ab9c713

THE ARTS CAN BE A USEFUL VEHICLE FOR UNLOCKING STORIES, AND THE MEDIUMS AND HOW PEOPLE CONNECT TO THEM ARE A SORT OF MAGIC

Conclusion and Recommendations

Ethics of Care and Inclusion

At the very beginning of this report it was stated that young people in care could be said to be triply silenced, because of their age, being in care and often from backgrounds of poverty and trauma. The 'Life As We Know It' Project had two main elements, firstly the Peer Researchers' reflections of their own journeys throughout their engagement and how this connects to the trajectory of their lives; secondly, to make sure the voices of those with lived experience were represented within the Trust-funded evaluations. This research has been underpinned by an ethics of care and inclusion, prioritising creativity, authenticity and empowerment.

From the outset this project was advertised through trusted networks and the recruitment process informal, with practicalities and barriers mitigated against, but even then there were very few people who came forward, and this may be indicative of the lack of confidence generally within this group. All of the Peer Researchers were trained in ethics, their role, boundaries and the importance of self-care. The level of need presented by the Peer Researchers was greater than anticipated and heightened during the pandemic, but keeping close contact, being aware of boundaries and limitations, and working alongside trusted networks worked well. The team responded quickly to ensure all of the Peer Researchers were able to connect digitally and the focus shifted from being about the team being brought together, to instead delivering individualised pathways of support. The challenges some of the Peer Researchers faced meant that at times they were not able to engage as had been hoped. In response the team supported by the Trust changed the approach to be less about engagement with the commissioned evaluations, to offering instead more 'in house' options, so that they could tell their story. The Life Changes Trust as a funder has prioritised promoting inclusivity and being flexible.

Value

As well as being an ethical and 'nice thing' to do, this project has shown that involving those with lived experience has real benefits to research enquiry. This practice helps to flatten power disparities between those doing research and those being researched, leads to the creation of thoughtful research tools, enhances engagement, increases levels of reflection and inspires innovative thinking. For funders, it increases the likelihood of getting in-depth, meaningful insights and learning. For the Peer Researchers themselves, when properly supported, it can be an opportunity to not only learn new skills but also can facilitate their understanding of their own journey and create a new identity as a 'researcher'.

This research has brought to the fore that peer research - in the academic sense of individuals being involved at every stage - fails to take account of the realities of people's lives and that not everyone wants to be involved in every stage. Instead, we argue that peer research should be about what the individual chooses to be involved in, moving away from the unhelpful binary of engagement having to be 'all or nothing.'

INVOLVING THOSE WITH LIVED EXPERIENCE HAS REAL BENEFITS TO RESEARCH ENQUIRY

Power of Arts

This project worked with young adults who on the face of it are articulate and able to say what they want. However, they reported that this is difficult, and using films, Zines, writing and music has enabled them more easily to tell the story they want to tell, reflecting on where change needs to happen. For example, one Peer Researcher felt that taking photographs and using metaphors to relate how he felt as a result of his experience was just as powerful and got the point across, but was not as personally painful as verbally telling his story. The messages able to be delivered through these mediums also can mirror the complexity of feelings.

It is not a new finding that the arts can help people to express themselves, have intrinsic as well as extrinsic benefits, can be adapted to different age groups and interests, and is fun too. Yet, in terms of supporting people with lived experience to have a voice in policy making, this method of engagement is underutilised. The arts offer a way to meaningfully engage with people so that they can move from being passive recipients of policy to active participants in design. This would require participation to be facilitated by skilled practitioners who understand the barriers faced and working alongside agencies to ensure adequate support is in place throughout.

People with lived experience of care are not 'hard to reach' and systems are not impenetrable. In the current context of the whole of Scotland working to 'Keep the 'Promise' there appears to be a genuine desire to make policy inclusive, and although not a panacea for overcoming all the many issues people face to have their voice heard as outlined, the arts undoubtedly offers some creative ways to make this possible.

Beyond Anonymity and Protecting the Storyteller

Throughout this project the team have been concerned about protecting the storyteller and supporting them to understand the limits of confidentiality. All of the Peer Researchers have opted to 'go public', recognising the power of their voices and experiences in being able to impact positive change. In earlier reflections it was felt that the title of this project 'Life As We Know It' may be misplaced, because this project did not bring the Peer Researchers together as had been envisaged. However, this is 'Life As We Know It', because all of the Peer Researchers strongly identify as people who have experience of being in care and the desire to change the system. This project has been about valuing their lived experience and its role in participatory evaluation, making space for their work and reflections to be valued and respected.

USE CREATIVE APPROACHES TO SUPPORT BROAD AND INCLUSIVE ENGAGEMENT WITH PEOPLE WITH LIVED EXPERIENCE

Recommendations

- Adopt an ethics of care, inclusive flexible approach to the concept of peer research as opposed to being "all or nothing". Create a variety of opportunities to be involved and meet people where they are (Section 2.2).

- Design evaluations to be as fun as possible (Section 2.1.2)!

- Ensure there is sufficient time for Peer Researchers to settle, discover their own sense of the role, make authentic connections to peers and colleagues and understand appropriate boundaries (Section 2.2.2).

- Be aware of the Peer Researchers' wider context and consider what safeguards should be in place prior to starting the work. This may include trauma-awareness training for staff or agreeing procedures for supporting Peer Researchers with potentially triggering topics. (Section 2.2)

- Be realistic about your role as professionals or researchers and clear about the boundaries of the relationships with Peer Researchers.
Where appropriate, discuss those boundaries with the Peer Researchers (Section 2.2).

- Provide appropriate support and connect with others who play a supportive role in the lives of the Peer Researchers. People with lived experience should be supported throughout and beyond the project and have a clear path for their own journey going forward (Section 2.2).

- Use creative approaches (e.g. visual arts, music, creative writing) to support broad and inclusive engagement with people with lived experience (Sections 1.3 and 2.3.1).
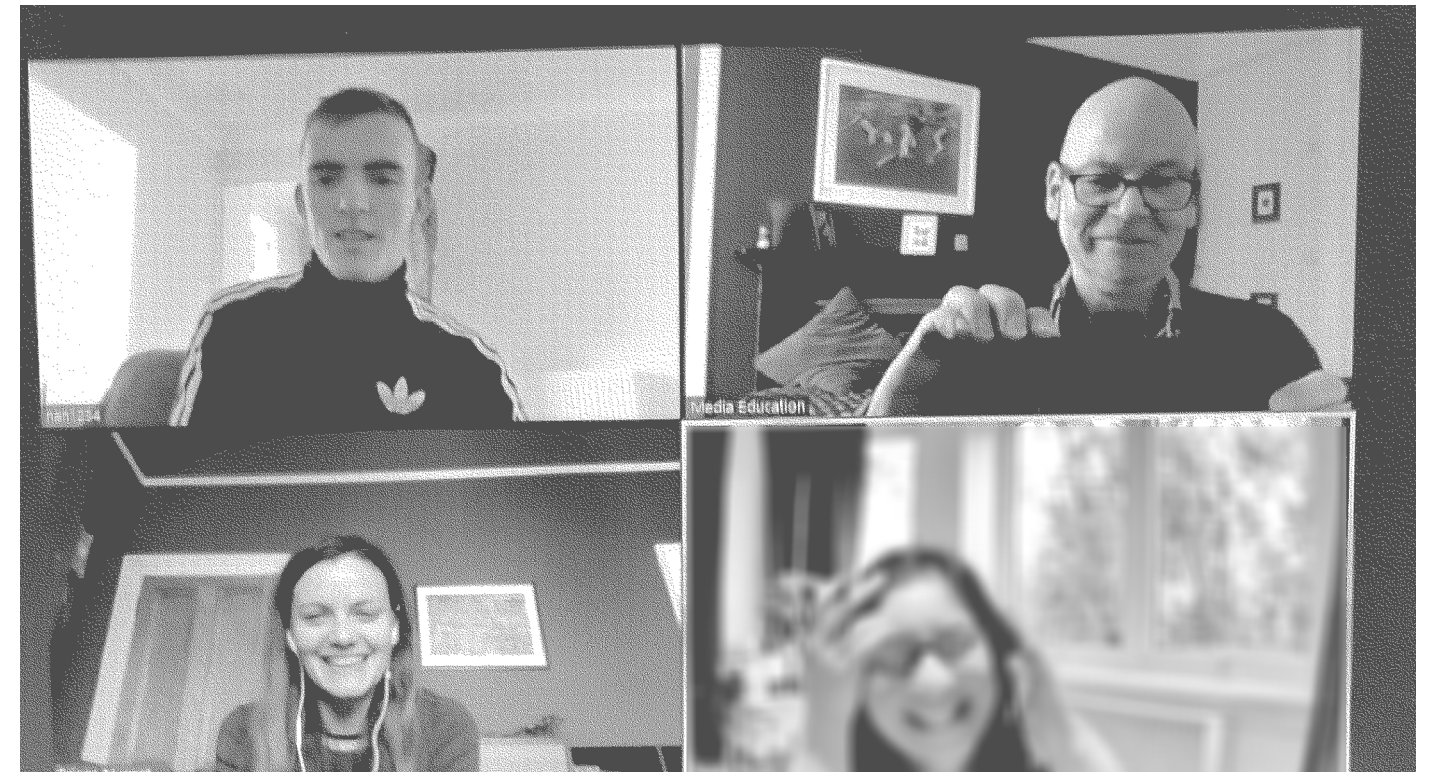
Benefits of Peer Research

The involvement of Peer Researchers can:

- Lead to a more engaging experience for the interviewees, allowing them to feel more at ease due to the tone and content of the questions. This in turn can lead to higher quality interviews, which contributes to higher quality data and learning.

- Help inform the creation of ethical and well-considered research tools, analysis and 'real life' thoughtful recommendations.

- Focus the researcher more on the needs of their participants, spurring them to more carefully consider how they engage, what they are asking, and how they are asking it.

- Make it more likely that the interviewees' practical needs are well considered; for example, barriers to engagement may be more easily identified.

- Increase the level of insight and meaningfulness of analysis, through more thoughtful reflection and the opportunity to 'sense-check your analysis – even if the Peer Researchers are not directly involved in the original analysis themselves.

- Benefit the Peer Researchers themselves, supporting them on a journey from being passive observers to active learners and advocates in their own right.

Steps to Enable Peer Research

Budgeting

- Budget appropriately for the level and types of Peer Researcher engagement anticipated.

- Give Peer Researchers a monthly wage - at least at living wage - so they can budget and have clear expectations of time they should give.

Enabling Factors/Scaffolding

- Recruit for positions through trusted networks and establish a good flow of communication.

- Be realistic and clear about levels of involvement and responsibilities of Peer Researchers. Follow through on what you said you were going to do at each stage, and do not over-promise.

- Address potential barriers to engagement; for example, travel expenses, access to devices, or childcare.

- Refer to and treat Peer Researchers as colleagues throughout.

- Provide training to establish both the importance of ethical research and the fact that Peer Researchers are employed as experts with lived experience. There should be no pressure on them to ever tell their story, but instead to draw on their experience to help inform the research.

- Bring trauma awareness to this work, recognising that engagement may be triggering for Peer Researchers and work alongside trusted networks to think through what other support can be offered.

- Use the arts as a way of helping people to engage, share their views, learn new skills and have fun.

Relationships

- Be prepared to really listen to what the Peer Researchers have to say and take their advice on board.

- Strive to achieve the upper rungs on the participation ladder, and ideally support the Peer Researchers to take on ownership of the project.[2]

- Be flexible, presenting different stages of involvement as choices.

- Recognise the benefits of bringing people together that have shared experience.

- Be empathetic and responsive to change, prioritising inclusivity.

- End contact sensitively, firstly ensuring that outputs are fully agreed and engagement is reduced incrementally, ideally with further opportunities outlined. Peer Researcher involvement should be viewed as a stepping-stone to the next destination, not the end of a journey.

RECOGNISE THE BENEFITS OF BRINGING PEOPLE TOGETHER THAT HAVE SHARED EXPERIENCE

[2] https://organizingengagement.org/models/ladder-of-childrens-participation/

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Appendix I:

Early draft discussion guide: detailed
Young Champions Boards participants

Timing: 60 minutes
Methods: Tailored to different age groups as appropriate

Before we start

* All participants will already have the Participant Information Leaflet
* All participants will be asked to review and sign the consent form (with help if needed)
* All participants will receive their incentive before the discussion begins (so that they can withdraw at any time)

Introduction (5 mins)

* I'm x from Research Scotland. We are a research company.
* This work is for the Life Changes Trust
* It is an evaluation of the Champions Board approach – not individual Boards
* We will do a report which includes your views – quotes, examples, stories
* We will make sure you have the chance to get a copy of the reports we do, through your Champions Board lead
* Everything will be reported completely anonymously. We won't tell anyone who took part or who said what.
* Taking part is completely voluntary. You don't need to answer any question if you don't want to. You can withdraw or stop at any time. You don't need to tell us why
* The discussion will be informal, relaxed and hopefully interesting and fun
* Does anyone have any questions before we start?
* To get started, can you just let us know your name

Your involvement (10 mins)

1. I've never taken part in a Champions Board before. But I've read a bit about the interesting work you have done here. Can you work in small groups for 5 minutes to decide what to tell me so I understand a bit more about what kind of things you have done through the Champions Board?

(Large paper and post its available for people to draw/ note down things if they want to)

2. Can you tell me what it feels like to be involved in the Champions Board?

Experiences of taking part (10 mins)

3. Do you feel:

* able to get involved in a way that suits you? (very, quite, not very, not at all)
* able to express what matters to you? (very, quite, not very, not at all)
* listened to? (very, quite, not very, not at all)
* respected? (very, quite, not very, not at all)

This can be done using a link on an ipad or on participants phones – set up so everyone can see the anonymous results. Or it can be done using sticky dots with the questions on paper stuck up onto the wall.

4. Informal group discussion about responses. Probe why participants answered in that way and examples of when this happened.

What has changed for you? (15 mins)

5. Can you think about how you feel now, and how you felt before being involved in the Champions Board, about these nine statements.

1. I feel confident to try new things (1 = low, 5 – high)
2. I feel confident speaking to people
3. I feel good about myself
4. I believe I can achieve my goals
5. I enjoy learning new things
6. I am happy with my friendships
7. I work well with adults
8. I am active in my community
9. I can be a leader in my community

These statements can be tailored for each Champions Board to fit with its own intended outcomes.

Participants use green stickers to rate how they feel now. And red stickers to (try to) rate how they felt before being involved in the Champions Board.

6. Informal group discussion about responses. Probe on what makes you feel this? Can you give me an example?

Bringing about change (10 mins)

We want to know what difference you feel you have had on the organisations involved in the Champions Board – like how they provide services, how they make decisions and how they involve young people.

7.   What do you think organisations are doing differently because of the Champions Board? (Open question in buzz groups)

Probe – Do you feel that these changes happened because of your engagement with the Champions Board?

8.   I read that the Champions Board had been involved in making these changes: (tailor for each Board).

What difference (if any) do you think these made for young people with care experience?

Wider involvement (5 mins)

9.   Have you been to any events with other Champions Boards? Or connected with other Champions Boards in any way (probe: National Network activity)?

Follow up: What did you think of this? How did it help? What difference did it make?

Thank you (5 mins)

Thank you for taking part. We'll make sure you hear about what we found through feeding back to the Champions Board lead for your area.

There are other opportunities to stay involved too:

* If you want, we could develop a short case study on your experience. This could be written or video. It could be anonymous (if written) or not anonymous, depending on your preferences. You would be able to approve the case study, edit/ change it, design what it looks like, or choose not to use it.
* We want young people to be involved in doing this research. If you are interested in helping out, we can work with you to gather the experiences of more young people at your Board.

Note: There will be a clear consent process for and separate form for each situation.

Appendix II

Feedback on Research Scotland Topic Guide

'Before we start' felt it:
- would be good to explain more about the project and what is in the consent form as young people will be unlikely to read this and too scared to ask questions, and especially where the information is going. 'If you have an adult handing you a form, you just sign these things.'
- Also good to know more about the research organisation and the work that they do.
- Good that the incentive is at the start so that if people don't feel comfortable they can just leave.

Intro:
- It would be good to have an icebreaker, rather than just tell me your name.

Q.1 – Good idea to start with groups and to help people feel involved. Many people who have been in care have anxiety issues so this is a good way to help people to overcome that.

Q2. Good, chance to discuss.

Q.3 Good idea to get people to begin to open up and also Q.4 so that they have a chance to discuss further.

Q.5 Not clear that the questions being asked are about whether the Champions Group had an impact or not. Maybe better to ask:

How far do you agree with these statements:

Being involved in the Champions Group has made me feel more:
1. Confident to try new things
2. Confident to speak to people
3. Good about myself
4. Believe I can achieve my goals
5. Enjoy learning new things
6. Work well with adults
7. Active in my community
8. That I can be a leader in my community

Felt that the question about friends should be changed, so that instead it is that I think more carefully about whom to be friends with

All the other sections felt to work well, apart from at the end where it would be good to get more information about what the feedback has been generally, and given those who are participating a chance to give their views about what has been taken away.

A Participatory Evaluation and Peer Research Project
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Chloe Williams, Shaun Glowa, Iain Shaw