Introduction

The ImaYDiT research project- Imagining young disabled people's transitions in a time of major societal change

The 'ImaYDiT' research project was organised by a user-led organisation (ULO), in partnership with a university and children's social services. The project ran from July 2017 to December 2018. The principles underpinning the project reflect wider ideas of disability rights. As stated by the ULO: "This project is about life not services. It is about what disabled young people can do and not what they can't do". The overall aim of the project was to support disabled young people to explore and re-imagine their transitions into adulthood. The main research question was:

"In the context of major societal change, how do disabled young people imagine their transitions into 'adult life'?"

The project sought to understand how disabled young people can be supported to become the next generation aware of their rights, with high expectations for their future, confident of their own place within their communities, positive about what they can bring to them and able to establish meaningful and independent adult lives.

In addition, the project sought to use and develop co-production methodology with disabled young people at the centre to identify barriers and facilitators that are meaningful to participants and disabled young people more widely. Goodley and Runswick-Cole (2012) call for researchers to decolonise research relations by avoiding othering, not repeat academic-based and top-down research practices but working closely with members of marginalised groups. In the ImaYDiT project, peer researchers co-designed and delivered the research, and were involved in disseminating its findings through their report, social media and stakeholder workshops. We highlight where we saw peer researchers becoming change makers and conclude that co-production with disabled young people is both possible and vital to create meaningful voice and new opportunities. We consider peer research as ‘work’; work that needs to be recognised as being distinct from the legacy of exploitation institutionalised as ‘volunteering’.

Re-imagining the lives of disabled young people and their futures

The thinking that informed our project emphasises disabled young people as having productive lives and futures (Curran and Runswick-Cole 2013, 2014; Runswick-Cole et al. 2018; Curran et al. 2018). Slater (2013) is critical of youth studies that present young people as passive consumers, objects of services, or as deviant, disruptive and dangerous and points out that disabled young people are rarely included in such studies. The gendered, able-bodied myth of adults as being autonomous, independent and rational should, she argues, be vigorously resisted and re-imagined. Researchers need to adopt a ‘critically young’ positionality, to be reflexive about normalcy, celebrate full, multiple living intersectional identities to influence service provision, social media and everyday cultures (Slater 2013:189). In policy, there is a growing agenda around child rights which presents young people as citizens (UN Committee on the Rights of the Child 1989). However, in England, disabled young people continue to be discussed through the lens of ‘needs’ rather than ‘rights’ (Sayers 2018; Wells 2017). Despite legal frameworks for transition planning, the inadequacy of support and the stressful processes involved for young people and their parents and carers continue to be major concerns (Broach et al. 2016). The assets-based approach adopted for this project, recognises this adverse context and disabled young people’s capacity to re-imagine their own futures.

In a rapidly changing society there is a potential to achieve aspirations, explore new possibilities and find innovative ways of supporting disabled young people's futures. A large body of recent academic and popular literature draws attention to the prospects offered by new forms of automation, connectivity, working patterns, social mixing and cultural diversity (see for example: Bessant 2018; Frase 2016; Harari 2018; Hermann et al. 2018; Srnicek and Williams 2016). Whilst these works are almost invariably counterpoised with dystopian directions, these visions point toward a radical re-configuration of disability over the course of the 21st century. However most of this futurological thought shows little evidence of directly engaging with the worldviews of disabled young people on the subject of the probable, the possible, and the preferable. It follows that voices of disabled young people need to be at the centre of research; that there is ongoing ethical interrogation over the lifespan of the research and active resistance to the potential for normalcy to shape many aspects of the research. Accessible research methods are key to meaningful involvement of disabled young people, but are not enough. Research needs to be based on questions that really matter to disabled young people. Links between the young and adult disability activism are an exciting prospect for a new generation of disabled young people ready to define their futures, and in this project two disabled advocates from the ULO had a role in encouraging the voice of the peer researchers from that perspective.

Methodology

Using qualitative research design principles, we sought to employ a co-production methodology from the outset and through to the end points of the project. At the centre of the research we adapted the knowledge café approach (Brown 2001) to generate, validate and promote knowledge created by disabled young people about their hopes and dreams and re-imagine their transitions into adulthood and life. The five key principles of the methodology are to create a hospitable space, explore questions that matter, connect diverse people and perspectives, listen together for patterns, insights and deeper questions, make collective knowledge visible to the group (Brown 2001:4).

Staff from the ULO invited disabled young people through a variety of their networks in one local authority area to become peer researchers. The main Easy Read recruitment advert started with the message “Calling All Young Disabled People. Would you like to be part of research looking at what your future has in store for you?” and explained the contribution, support and contacts. This went out through the highly active ULO’s social media network, and to over 90 practitioners, volunteers and activists on the ULO’s contacts database. However, we relied on in-person visits to activities, individual meetings, and phone/video calls over a twelve-week period to communicate the idea directly with individuals. Sixteen people expressed an interest and, after further dialogue, 11 took part in a series of meetings with research team. Over the course of the work, two of the 11 individuals stood down from the peer research. At the meetings, we developed the basic research idea, incorporated the interests of individuals, practised knowledge café research methods and sought to build a sense of shared group identity. Two disabled advocates provided encouragement to the peer researchers and began to support their own life interests as they also became members of the ULO.

The research obtained ethical approval from the university ethics committee. Peer researchers were provided with easy-read and verbal information about the project, and asked to provide written consent to take part. This was reviewed over the course of the project and they had the opportunity to withdraw at any time. The peer researchers received university certificates of peer research training, expenses and vouchers.

Research participants were also provided with easy-read written and verbal information about the research and asked to provide written consent to take part. Names used here are fictitious and consent was given for photos published here.

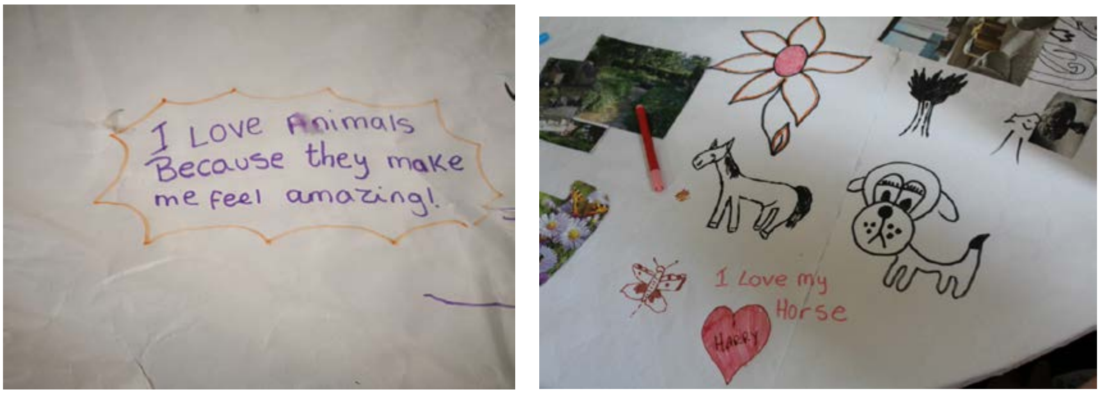
The research group ran knowledge café events through a college and youth club with 57 disabled young people. At these events we used a variety of approaches to stimulate ideas and discussion based around the question: “What does a good life look like to you?” This was supplemented with a similar question: “What are your hopes and dreams? Think big. Think bold”. The approaches included the use of a series of video clips highlighting social change and innovation, photo-voice activities, interactive cartoon capture, table cloth art and trigger questions on particular areas of life. All members of the research group made notes and took photographs during the knowledge café events.

Figure 1: Photographic images illustrating aspects of the research methods

Photo voice activities:

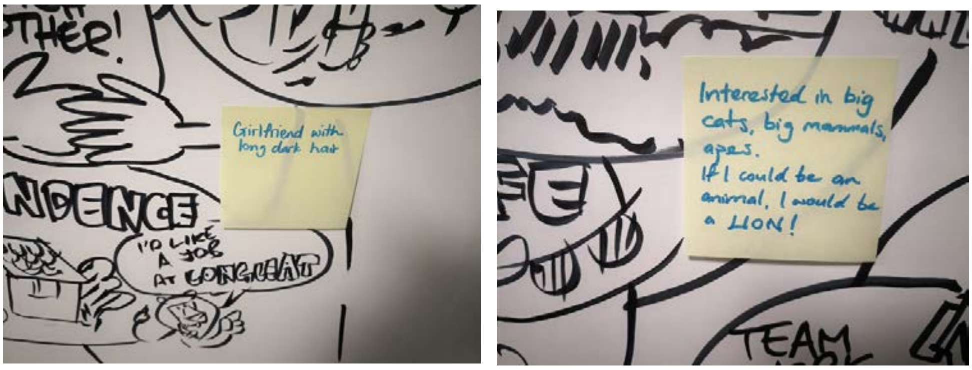
Interactive cartoon capture:

Table cloth art:



Wrap of messages captured by the cartoonist:

Record of young people's ideas and comments on the cartoon illustration:



Girlfriend with long dark hair

Interested in big cats, big mammals, apes.
If I could be an animal, I would be a LION!

Over the course of the research, there were points of reflection with the peer researchers, the steering group, and within sub-groups. We used these reflection meetings to start identifying themes from the fieldwork. With these ideas, the university researchers made use of NVivo to formally analyse the data collected across the course of the research process. Following Braun and Clarke's (2006) constructionist approach to thematic analysis, we examined the data and then considered, with reference to wider literature, the ways in which events, meanings and experiences that surround the lives of disabled young people correspond to discourses operating within society.

In the final phase of the research four peer researchers visited a university home robotics and transport automation research laboratory. The purpose was to offer the peer researchers the opportunity to see and try out new technologies that are part of the rapidly changing society. This came towards the end of the project that that it might further inspire or facilitate their hopes and dreams rather than reflect a narrow impairment-based view of technology in terms of aides and adaptations. Given the knowledge café principles of experience-based knowledge making we were keen for the peer researchers to have formed their ideas first and also to be invited to share their ideas with the team there as experts by experience in the role of peer researchers.

The university researchers then checked and firmed up these findings with the peer researchers and ULO staff. Peer researchers took lead roles in several sessions identifying key messages, setting out the research process, findings and lessons in a jointly produced project report (ImaYDiT Report 2018). While the key messages resonate closely with the thematic analysis we see them as a further step in co-production clearly refining expectations and aspirations for future. Interestingly as the project progressed, the wider research group shifted from the term ‘user researcher’ (in the research bid) to ‘peer researcher’ (recruitment onwards) and finally in the last stage of analysis and dissemination the term ‘change maker’ was used towards the group becoming a co-production group with the ULO into the future.

The findings reported in this paper reflect a more extended version intended for audiences of peer review research, and we discuss how the voice of the peer researchers challenged and developed the thinking about voice itself. In keeping with generative research, the use of literature is considered as part of the methodology developed in response to the themes and key messages making links to other co-produced research as an extension of ‘voice’ more internationally though without making universal decontextualized knowledge claims.

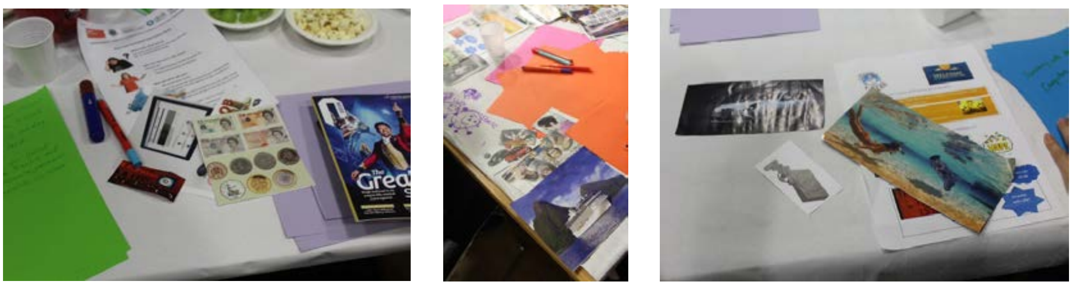
Findings

Developing and naming themes

This section sets out the main themes arising from the research. The findings here are clustered around four major themes:

1. Giving love
2. Being responsible
3. Freedom and happiness
4. Have a strong sense of self and togetherness

Figure 2: Examples of café table tops



We then report on the wider learning from the perspectives of peer researchers and the wider messages that they took away from the research.

Theme 1: "Giving love"

The young people spoke about their various relationships where they expressed their bonds of affection towards their family, pets, towards each other, and more widely. For example, one participant wrote *"Love needs to spread across the world. Love someone that you love."* Loving was often expressed in the active sense of 'giving' rather than 'receiving' love. The opportunity to give love to others was expressed in relation to sharing lives with others, forming intimate relationships and setting up a family.

Vignette on "Giving Love": what a good life meant for Jane

During the photo selection activity, Sarah chose the picture of a family as most important out of her three images.

Regarding a photograph of two adults and three children.

Researcher A: "What have you chosen here? Can I ask you?"

Jane: "I chose this. It's a family. I want to have children. They make me happy."

Researcher A: "Yes. I see it looks like a family…so you'd like to have a family?"

Jane: "Yes – that's what I want! [proud, pleased smile, hand on photo].

Researcher A: "So you'd like to have children – like here in the picture?"

Jane: "No. I don't mind…like any children…I don't mind" [indicated that it did not matter whether the family is as the one in the photograph].

The young people took care in selecting their photographs, in displaying them and in feeding back their idea to the graphic illustrator. Some participants were not immediately forthcoming about their choices during the image selection activity. A young man chose photographs of a smartphone, a television and a pair of rings. Smiling throughout the exercise, he held the image of the pair of rings in his hand, out of sight of the researchers. When the graphic illustrator asked about his choice of photographs, the young man's female friend relayed that he had chosen a picture of a pair of "wedding rings".

Using the table cloth as a drawing surface another participant chose to make a picture of her friends, mothers and pets, captured within one bubble and with a heart at the top.

Theme 2: "Being responsible"

The young people identified active and productive roles where they had ownership and agency in the type of relationships they wished to form in their adult lives. The areas of responsibility were very varied and included many aspects of life. One aspect of responsibility concerned developing kinship and household relationships. Strong aspirations included the desire to become a parent, look after children and to build a family. Some knowledge café participants were very open about these ideas from the outset and had strong goals in life.

Vignette on “Being responsible”: Rick’s café table

Rick was very positive and happy to show a researcher his photos. With the photo selection activity, he said he knew very quickly what photos he wanted to choose:

Peer researcher B: “You’ve got pictures of cars?”

Rick: “Yes. I’m going to take my driving test…”

Peer researcher B: “…to drive?”

Rick: “Yes. I’m going to drive [relaxed/cool hand gestures driving around]…so I can drive to work and with my mates…like drive all about from my home” [hand gesture like ‘that would be nice’]. I’m going to pass my test”

Peer researcher B: “So you chose these pictures – why these ones specially?”

Rick: [pointing to a picture of a car on the open road] “…Look. Look, that looks nice…there [pointing to the forest surroundings].”

Rick shared a similar interest with other young men on his café table who had chosen images of cars, new technologies and property. James in the same group talked about his selection of photos of houses: *“Sometime in future, in perhaps a year or two, to I’d like to go travelling. But when I get back I want to focus on getting employment, buy a house and settle down and start a family” (James).*

An area that was a focus for some café tables concerned looking after pets. On one café table a group of three participants drew a picture of a ‘home’ with rabbits, horses, cats and dogs, along with carrots, grass and tins of pet food. The group talked about the importance of caring for animals properly. This was also talked about as a two-way relationship: pets need care, but also bond and connect in ways that others might not do so. These roles included the preparedness to take the risks associated with the responsibilities of pet ownership, such as exercise, bathing, healthcare and taking out insurance.

Ideas of other life responsibilities were conveyed including finding employment, managing money, running a car and owning a home:

> Neil: “I want to work. I want to work at [a safari park]. I would like to work at a funfair or maybe work chain-sawing trees.”
>
> Sarah: “I want to have my own house and live independently with my current partner and have fun with my friends.”

The way in which these were talked about by the young people in their assumed capacity and with confidence.

Theme 3: “Freedom and happiness”

The theme of “freedom and happiness” covers a set of very clearly and strongly expressed ideas from most knowledge cafe participants. In many instances, young people started by communicating their current enthusiasms and passions. They then set out their desire to pursue these further, more deeply and without constraints. This area of discussion included a lot of laughter, excitement and pleasure as participants exchanged and developed their ideas. While participants often enjoyed being openly fantastical and imaginative around these ideas, there was also a strong sense that some individuals had confident and bold ambitions.

Vignette on “Freedom and happiness”: Bryony’s owl

Bryony spoke quietly and after some thought. She put her pictures in a specific order and was very clear about the story she wanted to tell the group and cartoonist.

Photograph 1: An owl

Photograph 3: A couple watching the sunset outside a tent

Photograph 2: A house

Bryony: "This is an owl leaving the nest. It's flying to freedom. I have someone special to go on holiday with and to share special moments in life. We're watching the sunset. And here's the home we can go back [to]"

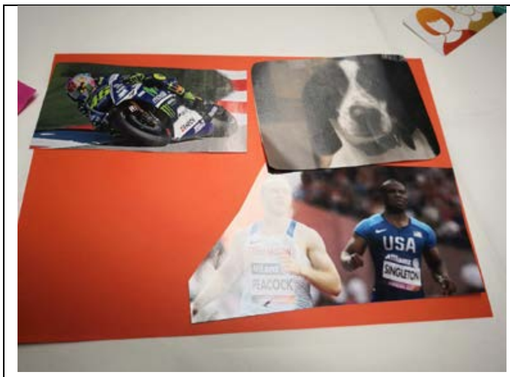
The cartoonist drew a picture of an owl as illustrated above.

How freedom might be achieved was expressed in a wide variety of ways. John told a peer researcher that *"I'll need money first before I can to get a Mini, compact and reliable car that can take me places."* By contrast, Jake chose photographs of countryside and natural scenery. Jake said he liked the outdoors, telling the peer researcher that *"You can live happily without money, as you can live in the wild and hunt for your food"*. Jake said that his most important photograph showed a group of people outdoors. This showed how with '*teamwork'* he could '*have fun with family and friends'*, 'see different places', and '*go around the world'*.

Theme 4: "Know yourself - and your togetherness with others"

A theme cutting across the knowledge cafes concerned doing things that are both personally important and also reflect their connections with other people. Young people highlighted interests, skills and achievements such as playing music, making art, or playing sports. As well as being a source of pleasure in themselves, they could help develop friendships and connections with family. Much of this theme linked to topics around belonging and being part of a community.

Vignette on a strong sense of self and togetherness: Simon and Clive



Simon was talkative with the other participants and peer researchers. In the photo selection activity, he had selected a dog, a sportsman running, and racing motorbike. He said he had chosen these images because they all show things that show typical things that he and his family do. His family take part in athletics, they like walking their dog, and members of the family are enthusiastic bikers.

Amongst some of the images that Clive selected was a caravan and a Doctor Who phone booth. Clive did not talk about his choices, but his friend said to the cartoonist that Clive really loved watching Doctor Who and going on holiday by sea with friends and family.

Checking themes and creating messages

Following the knowledge café fieldwork, the research group met to review the information collected. The peer researchers talked about their own responses to the research trigger questions and what they learnt from the knowledge cafes. There was wide range of ideas that came out of the knowledge cafes. The group agreed that some of these did not fit into the themes presented above. There are a number of alternative ways to group the material, particularly given the diversity of data collection activities, contexts and participants.

The visit to a university robotics laboratory for peer researchers came after the knowledge cafes having established a broad view of a good life and future. The aim was for peer researchers to experience and reflect on demonstrations of technologies such as robotic personal assistance, home automation devices, telecare, virtual reality communication, and autonomous vehicles from that perspective. The peer researchers felt that the new technologies might help them lead lives in the way that they wished, and remove their reliance on others. For example, a house robot personal assistant *'felt safe - like a friend - and [could help people] not feel lonely'* (Abbie), a driverless car could *'after I finished work at the weekend, I could programme it to pick up friends and [we could go out and] celebrate'* (Rian). The technologies showed possibilities for future freedoms from reliance on carers and limited resources, but the peer researchers also had some concerns about 'spying' and remote control by others. It is notable that new technologies did not feature very strongly in either the knowledge café data, or in the aspirations of the peer researchers themselves. For example, one peer researcher hoped to become a carer for older people. Even after the robotic laboratory visit, showing kindness, being responsible, and helping people were more important than working with new home support technologies. The technological aspect of a rapidly changing society was not discussed separately or as fantastically futuristic (which it may have done if it was an expert led event at the start of the project), but was linked with the peer researchers existing use of and skills in IT and their existing aspirations and is therefore discussed in terms of the overall themes drawn from the project.

It was also notable, that the subject of transition services for young disabled people was almost entirely absent in the knowledge cafés and peer researcher meetings. This absence is reflected in the priorities identified by the peer researchers. Towards the later stages of the project the peer researchers talked about the main messages and actions they felt should come from the research. The peer researchers agreed that they should be:

(1) "Don't call us 'Disabled young people' – we are just young people with the same hopes and dreams for the future as anyone else."

(2) “Support us to change the world! We want to contribute to making the world a better place.”

(3) “We want the chance to make our own choices, do things for ourselves and decide on our future.”

(4) “We want a chance to find where we belong. Everyone has a place where they feel they belong.”

(5) “We want to be part of loving families, to have the chance to get married and have kids.”

The peer researchers felt that these were messages that they needed to keep in their own minds as well as to communicate to local and national government, employers, local training and welfare agencies, families, and friends. These messages were presented through dissemination events with a range of audiences, new individuals joined the peer researchers and, with the UOL’s support, the group are planning events and further projects.

Discussion

In this section we first consider the main themes in the context of other academic work on the social and personal ideals of disabled young people. We then discuss the presence - and absence - of ideas about technological change, utopian/dystopian narratives, and alternative ways of framing the future.

The themes, Giving Love, Being Responsible, Freedom and Happiness and a Strong Sense of Self and Togetherness interlink and together present the participants’ view of ‘a good life’ and hopes and dreams for the future. ‘Giving Love’ and ‘Being Responsible’ convey actions, performances, generating future opportunities. A number of research studies undertaken with disabled young people echo having family and friends as an aspiration (Slater 2013; Foley 2012), but in the ImaYDiT project, illustrations of Giving Love were expressed as expectations as part of their active identity. Such confidence clearly contrasts with policy and professional literature in which disabled young people are rarely portrayed as *being* siblings, sons, daughters, friends, as actively generating and performing their relationships (Curran 2010), or, as forming families in their adulthood. Being Responsible was also expressed as if a given right to do with enjoyment and life satisfaction, having a home, employment and opportunities for freedom and happiness. This version of Being Responsible differs to the neo-liberal discourse of 'individual responsibility' in which disabled young people have reported a sense of pressure to self-manage as part of becoming 'adult' to avoid the stigma associated with seeking support while continuing to experience exclusion and bullying (McLaughlin et al. (2017). Within the rights discourse, adulthood is not seen in terms of independence from support but about freedom to participate. Sandland's (2017) promotes the United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006): that all need support to be free and autonomous. This shift from a focus on individual decision making to one of 'supported decision making' in which all can participate, demands that 'childhood' be understood like 'disability'; as a set of practices that create barriers and that discriminate. He therefore proposes a 'social model of childhood'. It follows that intimacy and opportunity for relationship are also viewed as a matter of citizenship (Curran et al. 2017).

Freedom and Happiness was the strongest theme in terms of generating ideas about an exciting future. Participants shared their cultural icons, their love of the outdoors, and the many activities that they knew about. We could say it was a reflection of youth as ‘consumer’, alternatively disabled young people were not talking from a position of excluded ‘other’; they knew about the music icons, mobile phone apps for taxis, cult movies and so on. They were communing together over their era as if very much part of a contemporary community. This notion of full community life is reflected in Quintana and Ortuzar’s (2018) view of leisure as being about challenge and satisfaction key to all areas of identity and community. In their study, leisure was highly valued for socialisation, solidarity, relaxation, personal development and recreation. Further accessibility and equal opportunities were sought for leisure to be regarded as a human right. Participation across all areas of life is seen as central from the rights perspectives (Carroll et al. 2018), though for disabled children and young people participation is often conflated with wellbeing and therapy. The enjoyable things in life like play, leisure, music are appropriated by professionals for therapeutic outcomes (Goodley and Runswick-Cole 2010). Similarly Murphy and McFerran (2016) review of studies on music and disabled young people with intellectual impairment found the medical model framework dominated with goals around their development with rare inclusion of the views of disabled young people or perspectives that challenge the therapeutic paradigm.

The conversations illustrating a Strong Sense of Self and Togetherness did not reflect a discourse of individualism or a disability activist identity and the peer researchers’ analysis presented identity as about being ‘young people’ with common hopes and dreams. On reflection we might have been more pro-active around sharing the normalcy and identity debate that exists within the disability movement. In Ginsburg and Rapp’s study (2013) they discuss a range of innovative transition projects as ‘cultural innovation’ in which disabled young people who ‘come out’ as disabled, create peer advocacy and activism in afterschool and post school places, which is a very different approach to that taken within this project. On the other hand, the ‘ordinariness’ and peer researchers’ call for ‘sameness’ might reflect the successes of activism in a time of social change. As Midjo and Aune (2018) put it, “Today’s young adults with intellectual disabilities represent a generation that has grown up in a historical period that pays great attention to rights and independent living and may as such have expectations for living an ordinary life” (p.35).

Running through the themes from this study, has been the place (or not) of technological change in young disabled people’s perceptions of their future. Much of what the peer researchers and participants wanted to communicate had little to do with new technologies. That which did mirrored the utopian-dystopian narrative split identified in other critical disability studies research. Futuristic ‘innovations’ routinely promise improved assistive technologies for disabled young people (e.g. Brodersen and Lindegaard 2013) that bring possibilities for greater social participation and citizenship. This image obtains weight where it is also argued that disabled young people should have opportunities for co-creation, design and customisation, for example in the case of mobile technology (Darcy et al. 2016). If not empowered, it follows that disabled young people will be presented with a technologically driven dystopian future that produces surveillance, new dependencies, erosions of privacy, and removal from ‘real’ offline lives (Gale and Bolzan 2016; Brodersen and Lindegaard 2013). This utopian/dystopian dichotomy has been challenged by feminist disabled philosophers, such as Rice et al**.** (2017), who call for a re-thinking ‘the future’ by ‘cripping time’ and exposing ‘the future perfect’ in which disabled people’s futures are cast into doubt if not into dystopia. They uproot the normative theories of time that set out a past of nation building, Western progress and ‘the life course’ from childhood to hetero, autonomous, adulthood as ‘the future perfect’. Rice et al. argue to disband these normative notions of the future in favour of a ‘dis-utopia’ – a cripping, re-ordering, reclaiming, and talking back. A multidirectional, plural, relational, affective, irreverent, interplay of past and future in present living becomes possible**,** and re-imagining of liveable futures becomes a generative narrative. From this perspective we can see the views of those involved in the ImaYDiT project, not as having ‘ordinary’ expectations innocent of disability politics, but as having a generative narrative about futures with multiple directions, as continuing conversations without end. Futurity, where identity formation is an open, multiple process of ‘becoming’ is a clear shift from stage-based transition to ‘the future’ (Worth 2009; Nguyen 2018). The focus can then become one of conversation, forming networks and creating opportunities to explore identify and how the past and future interplay in the present. The challenge is perhaps to refuse ‘the future perfect’ and focus on freedom for many ways living.

Conclusions

In this study we asked young disabled people to imagine their futures in a rapidly changing world. Service-based narratives, concerned with transition support and care arrangements, were almost invisible in the hopes and dreams expressed by project participants and peer researchers. Ideas of loving, responsibility, freedom, happiness, selfhood, and togetherness were leading themes that went beyond immediate next steps in life and connected to bigger ideals about the future. The rapid pace of social change – particularly with respect to technological innovation – was sometimes a matter of interest and possibility, but it was as one of many factors that might enable the quality of life issues highlighted in the main themes and messages. The research re-affirms the importance of framing and methodology in shaping knowledge and understanding. In this case, the assets-based framework and co-production approach helped generate a filled-out and aspirational vision of how disabled young people see their futures. This form of dialogical research has a role in checking back dominant needs-based narratives and putting a new politics of possibility to the foreground.

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Declaration of interest statement

None

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