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**Executive Summary**

Disability Research on Independent Living and Learning (DRILL) is a new five year UK wide programme, funded by the Big Lottery. DRILL will work in partnership with disabled people, academics and policy makers to build a better evidence base about approaches that enable people to live independently. DRILL is being delivered by a partnership of Disability Rights UK, Disability Wales, Inclusion Scotland and Disability Action.

This report is one of four from each nation on initial engagement with people with disabilities.

Nine Roadshows were held across England to bring together potential stakeholders and give participants a chance to consider the existing research themes. The roadshows have resulted in direct engagement with 340 people through online and offline activity.

The emerging strongest priorities for England are listed below. We are continuing engagement to increase the diversity of involvement and the England National Advisory Group will meet to discuss this report in March.

Our engagement and discussions in the England National Advisory Group (NAG) also raise key questions about what is the most important legacy for DRILL to leave (DPOs better equipped for research and/or mainstream researchers better equipped for co-production with disabled people); the balance between influential, large-scale work and smaller studies; and how to ensure processes and criteria do not advantage larger organisations (see Appendix 1 for key points from the NAG).

The strongest priorities emerging from our engagement activities are as follows:

Influencing public cultures and narratives, potentially including:

* Investigating public attitude research (e.g. trend data) and potentially adding to it (e.g. what influences attitudes/behaviours)
* Evaluating the impact of narratives with disabled people and with intended public audiences – in order to build an evidence base for effectively sharing narratives for greater impact on public discourse and attitudes
* Including public narratives relating to independent living and disabled people’s participation
* Our different identities – exploring inclusive approaches that resonate.

This work would link to more specific work on inclusive cultures and environments:

What makes an inclusive learning environment – and what are the levers to make it happen?

* This could include how schools and colleges enable people with different learning styles to learn and the impact for disabled learners
* What prompts educational bodies to follow legislation/good practice

What makes an inclusive working environment – and what are the levers to make it happen?

* This could include cultures of openness; and effective approaches to creating opportunities for both job entry (eg apprenticeships) and progression
* What prompts employers to follow legislation/good practice

What makes an inclusive local community – and what are the levers to make it happen? Could include:

* Decision-making and disabled people’s role as decision-makers/co-producers of plans, developments – including in context of privatised services. How far does disabled people’s involvement impact on decisions, how?
* How spaces and processes are designed to exclude/include people facing different potential barriers
* What influences decision-makers
* Rural inclusion
* Impact of devolution and localism on disabled people’s participation in decision-making

Peer support:

When, how, for whom and in what form is peer support successful?

* Potentially including learning from sharing stories of the impact of peer support
* Peer support in learning environments, employment (getting in/on), local or wider/distance communities
* Impact on social isolation?
* With cost benefit analysis and learning for scaling up impact

Further priorities emerging from the engagement activities include:

**Cross-cutting themes**

Autonomy:

Enabling autonomy of people at times of transition, for instance going into supported living or when mental capacity is in question

Resilience

What strategies do disabled people use to overcome stigma/discrimination (external and internalised) and how could these be spread?

**Social citizenship**

New service response

How to equip disabled people with skills to use technology to best effect – and get the best blend of technological/human support

Impact of personal budgets with decreasing services

Information

Potential of transparent data to enable disabled people to challenge decisions

**Economic participation**

Improving life chances – reducing school exclusion and bullying, reducing numbers of disabled people who are NEET (and reducing associated reductions in life chances)

**Civic participation**

Leadership

How disabled people are supported to be and develop as leaders

Multiple identities

Addressing multiple, fluid identities. Can we find solidarities?

Participants also noted their concerns about the programme and the challenges that might be faced. The austerity agenda was raised as having a significant and detrimental impact on disabled people. People wanted to ensure that this research would reflect disabled peoples priories and be listened to by policy makers.

There was a concern raised that individuals and smaller organisations may be excluded from the programme. It was noted that extra time would be needed to engage with and build capacity of seldom heard groups.These concerns have been raised as points of reflectionwhen designing the structure and processes of the programme.

**National context in relation to disability and policy**

**Policy Context**

As part of wider policy within England, the Localism Act (2011) has sought to devolve power to local governments. This act has seen the running of public services transferred from central government to a range of ‘local’ actors such as voluntary-run community organisations, private companies, and social enterprises. The assumption behind this act is that individuals and communities are in the best position to identify and resolve a range of ‘local’ social problems.

The implementation of this act has also coincided with a government agenda of austerity. This agenda has seen a reduction in state spending and an increased emphasis on free markets. Within this context there have been significant cuts to social care budgets and related supports such as housing and health. Some examples are given below:

**Social Care**

Social care policy in England is increasingly influenced by the philosophy of personalisation or self-directed support. The idea of such support, deriving from the disabled people’s independent living movement, is to give people more control over their lives, giving them the freedom to choose how they would like to spend a given budget, rather than receiving support in a segregated facility. However funding for social care in England is likely to be cut by 50% by 20181. These changes have put an increased emphasis on the need for individuals to buy services which has seen added charges for disabled people and a reduction in the disability eligibility category.

**Housing**

The under occupancy charge, commonly known as the ‘bedroom tax’ has seen a cut in housing benefit for those in council housing, deemed to have one or more spare bedrooms. Disabled people are more likely to be impacted by the ‘bedroom tax’2. Such reductions in housing support have seen people having to move from their home which has wider repercussions for instance in preserving social connections or access to work.

In households where specific adaptations have been made, disabled people were not exempt from this charge meaning either a reduction in income or moving to an unsuitable property (although guidance does encourage local authorities to make indefinite or long-term discretionary housing awards in cases of adapted homes). Only 0.4% of council owned properties have all the accessible features listed in the current Building Regulations3. In the recent spending review £500 million has been allocated by 2019-20 for the Disabled Facilities Grant, which will fund around 85,000 home adaptations that year. This is expected to prevent 8,500 people from needing to go into a care home in 2019-204.

**Welfare Benefits**

Universal Credit was introduced to create a more flexible and simple benefit system that incentivised paid work. However analysis by the Citizen’s Advice Bureau (2015) demonstrated that this system provides poor work incentives for disabled people5. Nearly half a million disabled people have seen a reduction of income since the introduction of Universal Credit and families have reported having to cut back on food or heating as a result of these changes6.

**Employment**

The employment gap between disabled people and non-disabled people is currently 33%7.The government aims to halve this gap by 2020-21. Current policies to support disabled people into work have had little impact: in 2013 Disability Rights UK found only 5% of disabled people on ESA on the Work Programme had found a job, with slightly better but very patchy performance through the Work Choice programme8. In 2015 the Disability Charities Consortium found the Work Programme had still only managed to support 8.5% of those on ESA into work, for whom health and disability is the main barrier to work (22,000 from 256,000).9 . However in the Summer Budget it was announced that three million new apprenticeships will be created by 2020, funded by a levy on large employers. The recent spending review also announced introduction of a new Work and Health Programme, to provide specialist support for claimants with health conditions or disabilities and those unemployed for over 2 years4.

**Partner Organisation Background**

At Disability Rights UK (DR UK) we are disabled people leading change, working for equal participation for all. We are controlled by disabled people and our membership include individual disabled people, organisations led by disabled people and organisations who share our vision. DR UK was formed through a unification of Disability Alliance, Radar and National Centre for Independent Living in 2012.

**Roadshow approach and methodology**

Roadshows took place in each of the nine regions across England. Sessions began with a brief overview of the DRILL programme before a group discussion was facilitated, centring on the main research themes and priorities. Group participants included DPULOs, disabled people, academics and practitioners. An important goal for these engagement groups was to encourage discussion that is solution focussed and understand where research and piloting can make most difference to disabled people. It was felt mixed groups of different backgrounds and expertise would be the best approach to achieve this goal. In total 135 people attended the roadshows, with a further 150 people viewing online, plus 68 people attending our launch event.

The methods of analysis is based upon transcriptions of the group discussion. The notes were written verbatim and a coded key word approach was used. This involved reading the engagement group notes thoroughly and assigning a key word to each comment in order to identify categories within the text. The key words assigned were based on the identified research themes (see below: main themes and priorities). The information from each of these categories was then extracted to illustrate the findings generated. Finally, the findings were shared amongst the participants for their feedback to ensure they felt the information captured reflected their views.

**Diversity Objectives**

Data was collected through equality monitoring forms at the end of each roadshow. This enabled people to classify themselves under six categories. As part of the Big Lottery fund grant process, we set out the estimated percentage of people that will benefit from the programme. These percentages are given, alongside the actual results under each equity category for comparison.

|  |  |  |
| --- | --- | --- |
| **Category** | **Actual** | **Estimated** |
| **Gender**MaleFemale  | 35%65% | 48%52% |
| **Disability**Disabled Non-disabled  | 70%30% | 80%20% |
| **Ethnic Background** | 80%1%1%4%2%2% | 87%0.1%2%2.3%1.9%0.7%0.7%1.4% |
| White  | UK |
| Irish |
| Gypsy |
| Any other White background |
| Mixed ethnic background |
| Asian/Asian UK  | Indian |
| Pakistani |
| Bangladeshi |
| Chinese |
| Any other Asian background |
| Black/African/ Caribbean/Black UK  | African | 3% | 3% |
| Caribbean |
| Any other Black/African/Caribbean background |
| Other ethnic group | Arab | 2% | 0.9% |
| Any other ethnic group  |
| **Age**0-2425 -6465+ | 10%80%10% | 19%64%17% |
| **Religion**No ReligionChristianBuddhistHinduJewishMuslimSikhOther religion | 43%32%9%6%0%1%0%6% | 25%59.2%0.4%1.5%0.5%4.8%0.8%7.8% |
| **Sexual Orientation**HeterosexualLesbian/gay man/biseuxal | 87%13% | 98.5%1.5% |
| **Caring responsibilities**WithWithout | 53%62% | 10%90% |

The roadshows engaged with people who had a wide range of impairment experiences, enhancing the depth of feedback we received. Nonetheless in order to further increase access to a diverse range of people, further outreach activities have been undertaken. These activities have focussed on engaging with people with learning disabilities and with young and older disabled people. These activities will continue throughout the life of the programme and will be reviewed to ensure that engagement happens in line with the ethos of the programme.

The National Advisory Group (NAG) for England also includes people with a wide range of impairment experiences such as learning disability, mental health issues, sensory, physical, and long-term health conditions. The group also represents different regions and communities offering coverage of relevant experiences.

**Feedback: Main themes and Priorities**

1. **Cross Cutting**
	1. Autonomy

*Being authors of our own lives and overcoming the barriers to independent living*

The opportunity to make choices was seen as significant to contributing to self-determination and autonomy. Many respondents talked about autonomy around the home and about the need to ensure that this environment was suitable for disabled people. The impact of such interventions could have far-reaching changes including:

* maintaining safety and independence
* the positive health outcomes that are conferred by an accessible home in a satisfactory condition
* an ability to readily engage in community activities due to easy access/egress
* an ability to occupy and use a home in a way that encourages people to visit, hence combating social isolation and loneliness
* facilitating support by informal carers in the home in a more dignified way
* reducing hospital admissions (especially from falls) through prevention services and speeding up hospital discharge should such an admission occur

*(Birmingham Roadshow participant)*

There was reflection amongst some groups about the impact of living in restrictive settings, for example for those with learning disabilities. No one raised this concern from personal experience, however it did come from family members as well as professionals. There was a very clear view that seldom heard groups should benefit from the research. There was a concern that for some the environment in which they live was restricting autonomy, and specific work would be needed to give those people a voice.

**Participants suggested research**

What happens to individuals transitioning to supported living who have no informal networks of support e.g. older people living with learning disability whose parents have supported them?

How much choice and control do people with learning disabilities/older people have when in supported living schemes?

Research that attempts to validate the value of housing led interventions in the home such as adaptations.

* 1. Peer Support

*Being able to support each other by sharing our experiences and learning*

The general consensus across all groups was that support from others who had lived experience of disability was more meaningful than traditional services. People who were involved in these engagement activities reported benefits from both sides i.e. individuals receiving support and the people who gave it. Participants thought that challenging the idea that services only require professional expertise could have a meaningful impact in terms of increased wellbeing, but also culture change within more outdated services.

There was a note of caution from some based on two points. 1) Some had experience being supervised by disabled people who they found to be more oppressive as there was a view that “I did it, so you should be able to as well” (Southampton engagement group).There was reflection from the group that being a disabled person does not in itself mean they could provide empathetic support and the correct training and recruitment was needed. 2) Linked to this point, there was a second concern that by promoting peer support we would be inadvertently supporting the austerity agenda and could lead to further under resourced services.

There was a suggestion that peer support was the wrong language, and instead the focus should be on self-help groups as this would capture a wider range of people.

**Participants suggested research**

What does best practice looks like for peer support? What has been beneficial? What hasn’t been beneficial? How can we draw from what hasn’t worked well and learn from this?

There was a suggestion that we could reach out to DPO’s and ask, what are you currently doing to enable people to live fuller lives? Research could be done to highlight good practice and potentially scale some of these programmes up. (See also New Service Response)

Suggested pilot project around formalising peer support for accessing leisure activities.

Research that focuses on user stories to demonstrate the positive impact of peer support.

* 1. Resilience

*Resilience acquired by disabled people as we grow through the experience of loss/adjusting to impairment*

Respondents valued this point because of its focus on the positive. People reported feeling fed up of only ever being seen in a negative light and wanted to be portrayed in terms of their and coping skills.

**Participants suggested research**

What strategies do disabled people use to overcome stigma? How can this be applied in a wider context?

1. **Social citizenship**

A message that came through strongly from participants was their concerns about the impact of austerity on social citizenship. It is worth noting that whist the groups focussed on solutions, the current policy context was seen to be problematic. There was an acknowledgement that research needed to be future proof and fit current trends, however many voiced a concern that you cannot place a monetary value on quality of life.

* 1. Inclusive Communities

*Maximising disabled people’s participation in community life*

In all engagement groups, participants discussed how inclusive communities could be produced. Whist there are many topics that were discussed within this theme, as one participant aptly surmised, this theme can be broadly broken down into two: “attitude and access” (York roadshow participant). In this context access refers to the physical environment and attitude to the social environment.

*Access*

One theme that came up in many engagement group discussions was the idea of designing public places to meet the needs of the diversity of people who want to use them. People discussed being excluded from certain situations due to the way the built environment is designed and managed. The relationship between communities and the built environment was seen to be very complex but there was some understanding that the way in which it is constructed can reproduce and reinforce social norms. There was a mixed picture reported by participants about the way in which local governments regulate the built environment, especially in relation to legislation such as the Equalities Act.

This theme also linked to ideas of sustainability as participants noted that it is often more costly to make changes to facilities at a later stage.

**Participants suggested research**

How do different people’s impairments interact in shared space environments?

Research that documents experiences which draw attention to how spaces are socially constructed to exclude

How do you persuade local governments/ organisations that they need to enact legislation?

How can policies and practices be developed that improve access and therefore quality of life for disabled people living in rural areas?

What are the links between social isolation and built environment/lack of access?

*Attitude*

The wider community’s attitudes towards disability was considered very important by participants. There was a frustration felt by many that there were not enough disabled people who could act as ‘normal’ role models by doing everyday jobs. Many people could not identify disabled people who were visible in their communities or workplaces. This was seen to have a knock on effect on public attitudes as without these interactions the general public are not able to be “disability confident” (Essex Roadshow participant).

Media portrayal of disabled people was raised by nearly all engagement groups and was seen as a barrier to inclusive communities. Participants felt as though the media portrayed disabled people in a one dimensional form and did not contribute to the general public’s understanding of disability.

The education system was seen as an important place to tackle stigma and discrimination. It was suggested that the shaping and role modelling of attitudes towards disability should be a proactive process within schools. Opinion was divided as to whether this should be through targeted interventions within classes such as PSHE, or whether it should be a mainstreamed approach.

It was discussed how the idea of a ‘disability community’ is a misnomer, as in reality there are vast differences across this group. However some reflected that if research around this theme is done right then it has the potential to benefit not only disabled people but other minority or excluded groups, having a wider impact.

**Participants suggested research**

Why does society think differently? Why does it slip backwards? What can we do to embed change? Whose view of progress? What are the social levers that enable change? What could change public attitudes?

What are the factors that create an inclusive learning environment?

What are the factors that create an inclusive working environment?

What aspects of community life do disabled people feel like they can take part in? Why?

Research on the link between media and hate crime, or the link between the media and cultural change.

A pilot programme to create a network where disabled people can share battles and learn from one another.

* 1. New Service Response

*New enablers and models of service to support disabled people to achieve independent living*

Respondents felt that the current language of vulnerability surrounding services for disabled people was problematic and ultimately undermined their status and opportunities. For example participants from the London group noted a difference in the delivery of the Independent Living Fund and Local Authority Community Care packages. Staff from the Independent Living Fund were seen to have a more positive attitude towards disabled people. There was a point of reflection from participants on the framing of disability and the wider impact this may have. For example that the Community Care package focuses on functionality and deficit. New models of service should promote disabled people’s freedoms, rather than curtailing them.

Many respondents talked about technology-based equipment which had helped to facilitate independent living, such as smart phones or tablets. In some cases this technology had helped to normalise aspects of their disability. Respondents said that they would like to understand more about the models that exist, and which ones work in which conditions, as most reported only having access to standardised models. It was felt that social validation assessment would need to be carried out to determine disabled people’s opinions about the impact, applicability and general acceptability of new technology.

Whilst participants wanted to learn more about technology based equipment, the majority of participants were cautious about the idea of technology being a solution to social problems. Participants saw technology presenting an opportunity and a barrier. Whilst these solutions have the potential to create a more inclusive lifestyle, they may also exclude people who do not have certain skills. (See also Information)

It was noted across many groups that ‘new’ models of service may already be happening but just not on a large scale. There was a strong feeling from members of disabled person’s organisations that being user led meant added value to services due to their expertise on independent living. Participants believed that there were plenty of examples of good practice that is both cost effective and offers a meaningful impact. The research could be used to provide an evidence base for these services.

Participants also saw the value in joining up existing services and networks. We were pointed to a programme called [pathfinder](https://www.ageuk.org.uk/cornwall/news-and-campaigns/pioneering-integrated-care-pathway-for-older-people-recognised-by-the-hsj-awards/) which brings together a range of services and personalised support. Participants spoke about services run by a variety of providers that work in a holistic way and in doing so provided more far-reaching benefits.

**Participants suggested research**

Does current framing of disability within policy have a negative impact i.e. cultivating prejudice damaging to the freedom and opportunities of disabled people? What could replace it?

How can we equip disabled people to use services which require certain technological skills?

Recruitment and training of carers/PAs - pilot project to evidence and expand the work DPOs are already doing in this area

Pilot project of a befriending service which connects people over distances.

* 1. Public Services

*How disabled people can be involved in the planning and design of services*

Participants agreed that professionals in control of the planning and design of services should engage with those who use them. Involving disabled people and communities, as opposed to consulting them, is a powerful way to co-create more effective public services and to build strong relationships between public organisations and the communities they serve. There was a strong interest in expanding peer support in this area (see above).

Some participants noted a point of tension concerning the increase in privatisation of public services and questioned how their voices could be heard in this context.

**This theme draws on the themes discussed elsewhere. The main research questions from participants include:**

How do disabled people experience person centred care?

What knowledge and training would councils need to involved disabled people in a meaningful way?

What is going to influence service providers to become more accessible?

Inadequate training of health professionals. What would good professional training look like?

Inadequate training of architects: What would good professional training look like?

How could you educate planners and policy makers about decision making?

How do Local Authorities/disabled people get a voice on design, housing etc. when services are becoming privatised?

Self-advocates with learning disabilities – how do you meaningfully impact housing, and transport?

Transport, particularly in rural settings – how can this be improved to meet the needs of disabled people?

Research to look into the increase in Personal Budgets whilst there are decreased services due to decommissioning. Research to understand the impact on complex disability within this context.

W

* 1. Volunteering

*Benefits of volunteering and activism in overcoming social isolation*

Some engagement group respondents described the benefits of volunteering and the opportunities it opened up to them. For those with acquired impairments the ability to do so greatly facilitated the transition from paid employment. However it was noted that better support was needed for this process. Not all participants said that they were able to volunteer and therefore did not have access to the benefits this can bring.

* 1. Information

*How removing barriers to information, data and statistics to facilitate choice and ability to challenge decisions*

Many disabled people felt that various aspects of their lives could be better if they had access to more tailored information and personalised support. Some participants noted how different ways of communicating are not given the same priority, excluding them from participating in social life. Examples of better information needed include better information about discharge from hospital and ongoing support services, further training opportunities, and support for interviews and during employment.

The lack of sharing information across networks was also seen as a barrier. Whilst it was seen that advances in technology may be able to advance this, participants were wary of the idea that technology can be an answer to social problems. Participants recognised the diversity of experience across the disability community and noted that many do not have the skills of necessary adaptations to access much of the information online.

**Participants suggested research**

Why is technology not open to disabled people?

Information needs to be more accessible – how to make current platforms more accessible?

Communication needs. How can we deliver services that are cost effective and inclusive?

1. **Economic Participation**

3.1 Education

*Benefits of different learning styles for different people*

Respondents discussed preferential learning styles and how, if these were utilised in schools, more disabled children could benefit from learning in a way that maximises their potential. For those who had attended mainstream schools they spoke about how this process, and the human support they had received had been beneficial. However participants noted a disconnect between education and preparedness for independent living.

**Participants suggested research**

Research that focuses on different learning styles and how these could be facilitated in schools.

What structures can be put in place that focuses on young disabled people’s strengths and interests, not on fitting a mould

Strategies for preventing school exclusion and associated life courses. (This was suggested by NAG – see appendix 1)

* 1. Employment

*Enhancing ways into employment for young disabled people*

Across many engagement groups, participants reported concern about the transition to employment. They believed that current government strategy is not effective as there seem to be high numbers of disabled people not in employment. Participants questioned the relationship between employment, wellbeing and aspirations for disabled people. They understood that no work, or work that does not have the right conditions to support people is likely to negatively affect health and welling. It was also questioned by participants whether this prevented disabled people from having high aspirations in the long term.

**Participants suggested research**

How many of those not in education or employment are disabled people and what would work to support them?

What information and guidance is being provided for school leavers?

How could the link between education and employment be strengthened?

What are the levers that make businesses change their practices?

What helps disabled people find meaningful employment?

We are seeing a change in practice from office based work to remote working, in this context how suitable is the home for employment?

* 1. Career Progression

*Approaches to support disabled people to succeed in our chosen careers*

In all engagement groups, participants discussed a variety of factors that either fostered or impeded inclusion within the workplace. Participants questioned how staff could be more open in sharing their experiences of their impairments in the workplace. They also discussed their experiences of work places that did not offer flexibility or understanding in regards to their impairments. There was a sense from participants that the wider systems were not working and were leading to situations where disabled people were doing low jobs skilled jobs when they were much more capable.

**Participants suggested research**

Many disabled people have hidden challenges in employment– what can be done to make this more open and accepted in the workplace?

What does a good work place look like?

Research into the interaction of disability and anxiety and how this may be a barrier into higher positions.

How can barriers to career progression be overcome?

How can you create a culture change which sees whole office support rather than relying on one person (i.e. a mentor or manager)

* 1. Peer Support for Employment

*Potential of peer support to enable disabled people to take charge of our careers*

Participants believed that support from peers at work would give them the confidence to be assertive and ask for reasonable adjustments. However acknowledged that this would also require the right systems of management in place.

 **Participants suggested research**

What type of peer support is effective to get into work and progress in work?

1. **Civic Participation**
	1. Active Participation

*The contribution disabled people make to society*

Many respondents talked about not knowing anyone in their community or local networks who could meaningfully influence change in political and public life. They discussed the barriers in entering this process themselves and the frustration in how many of the places where they were invited to participate felt tokenistic.

Despite these negative experiences this theme was seen as very important to many as there was a belief that civic participation would enable disabled people to take part in a way that was “the same as everybody else” (Derby participant), rather than through services where they would be seen as different from other people. The importance of this research was noted as an opportunity in itself for people to have a voice

People discussed requiring support to engage in civic society and noted how useful peer support could be in this area. However the longer term challenge of addressing broader structural barriers such as inaccessible buildings, transportation and technologies was also noted. The media was also seen as a barrier to active participation as there is a perception that disabled people do not offer valuable contributions to public life. Despite these observation, participants noted people within their community who defy such perceptions and suggested that these people could be promoted within the research.

**Participants suggested research**

Why does extra needs mean financial penalisation? In this context where there are financial barriers to participation, does it negatively affect disabled people aspirations?

Research on process of devolution/localism and impact this has had on participation of disabled people

How many disabled people are making decisions at government level?

Disabled people in clinical commissioning groups – does their involvement impact how decisions get made? Do they have real power?

What will make decision makers implement change on disability?

* 1. Enabling Leadership

*The effectiveness of programmes designed to enable disabled people to take up leadership positions*

There was concern from some participants that the leadership of disabled people in Disabled People’s Organisations is declining and that some organisations are no longer truly representative of disabled people. There was particular concern about the lack for young disabled people joining these organisation.

* 1. Multiple Identities

*The interaction of gender, age, sexual orientation, ethnicity, victim identity with disability and public attitudes*

Whilst some participants were strong advocates for the social model of disability and its associated language, others found this to be an inadequate way of representing their situation. There were also those who would prefer to disassociate completely with the disability label. From these discussions it was suggested that research needs to move beyond simplistic categories as this can serve to perpetuate oppressive ideas about disability. It was felt that how people choose to identify needs to be acknowledged by the researcher.

It was raised in a number of engagement groups that the research should not be impairment specific as this appears to be in line with the medical model. Instead, when common issues are identified every effort should be made to explore these across impairment groups.

The way in which different forms of discrimination interact with each other was discussed across most groups. In particular these multiple identities were considered in relation to the austerity policy with concern for people who will “fall through the net” (Southampton participant). Participants wanted to understand what this means in practice for people as these experiences seem invisible within mainstream narrative.

 **Participants suggested research**

How can the disability community be unified and brought together for social change?

How do people identify? Can we find solidarities?

**Critical feedback and Challenges**

Participants strongly felt the impact of austerity and concerns were consistently raised that this research may become used to advance this agenda.

Participants wanted to ensure that this research would be future proof and projects emerging will communicated in a way that will be listened to no matter the political climate. Whilst people wanted to use this as an opportunity to ensure their stories were heard, concerns were raised that qualitative approaches would not be valued. Support to produce quantitative research would be needed.

There was a concern raised from individuals that the setup of the programme would mean that organisations would take preference and individuals who were not affiliated with such organisations would be excluded. Many disabled people’s organisations also had experience of losing out when bidding against larger charities and wanted reassurances that this programme would not have the same exclusionary standards.

A further concern raised was around reaching seldom heard groups.It was acknowledged that time was needed to reach and build relationships with certain groups. For example people with complex needs who face multiple barriers. Or BME or older people who may not consider themselves as disabled people, may not be the language within their culture to identify in this way.

We received feedback that the setup of our workshops were not as accessible as they could be for people with learning disabilities. Following this feedback we will be running further engagement specifically for people with learning disabilities in the New Year.

We received request for the reimbursement of travel expenses from a number of potential participants. Unfortunately as this was not in the budget we were unable to facilitate this which excluded certain people attending. This was particularly apparent in Darlington and Cornwall. In order to ensure that those who could not afford to come were still able to contribute we have been actively engaging with people in other ways. Most notably through streaming the roadshows lives as well as through direct contact with those interested in contributing.

**Progression towards measuring:**

* **Outcome 1 - Disabled people have increased knowledge about key issues and new evidence of what works, enabling them to achieve independent living and fulfil their potential**

*The proportion of disabled people who feel they are more knowledgeable about key issues and evidence of what works to assist independent living. 85% of disabled people engaged feel they have increased knowledge of key issues and understanding of approaches to independent living*

We initially trialled a feedback form to measure this outcome but received negative feedback. Of those who filled out this form they rated themselves between a 7 and 9, with no change. Participants did not understand the relevance of these forms from further verbal feedback people explained that they would expect to go to a more specialist event for this.

Following this feedback we instead trialled a feedback form with the following statements:

*I know more about the DRILL programme*. 33% Strongly agreed. 46% Agreed. 13% neither agreed or disagreed. 6% disagreed.

*I feel I have understood the proposed research themes* 25% strongly agreed. 44% agreed. 30% neither agreed or disagreed.

*I feel I have been able to share my insights and these were listened to* 26% strongly agreed. 60% agreed. 6 % neither agreed or disagreed. 6% disagree.

*I feel like I can be involved with the programme as it continues* 38% strongly agreed. 37% agreed. 25% neither disagreed or agreed.

* **Outcome 4 -Disabled people are empowered and have directly influenced decisions about services that affect them**

*The number of disabled people that have directly contributed to the project through the dedicated website, promotional activities and roadshow events 10,000 disabled people have contributed to the project*

The England Roadshows have so far resulted in direct engagement with 340 people through online and offline activity. Where people have been unable to attend the roadshows we have engaged with them through other means such as through email and phone calls. We have also been able to generate a strong online community around the roadshows with 150 people streaming the events live. We also have a mailing list of over 100 disabled people who have signed as contributors to the programme.

In addition to the roadshows the DRILL England launch event was attended by 68 people from the disability community. In order to continue the outreach from the roadshows and to spark further conversation we launched the DRILL England Twitter account which now has over 1000 followers and is generating on average 8500 impressions a month.

The above statements also show a generally positive response from people about the quality of engagement with over 70% strongly agreeing or agreeing with each statement.

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**Appendix 1**

**England National Advisory Group. Key points made**

DRILL legacy: important to decide on the balance between DPOs being equipped for future research; and mainstream researchers working more fully in co-production

Process: importance of enabling DPOs to bid – brokering partnerships, capacity building, setting criteria and processes so larger organisations (not disabled-led) are not advantaged

Piloting: prospecting and evaluating existing good practice, not just starting anew

Influence: need to decide balance between large mixed method or quantitative studies (influential with government) and smaller studies manageable by small DPOs. Vital for the programme to share learning and embed change/good practice

Research themes:

Public attitudes and behaviours. Framing of debate. What would generate public understanding/support for independent living?

New cost benefit analysis on value of investing in independent living

Specifics including: social isolation and approaches to overcoming it; approaches to improving life chances – reducing school exclusion and bullying, reducing numbers of disabled people who are NEET (and reducing associated reductions in life chances)

Research focus on perpetrators of discrimination/exclusion – not just on disabled people ourselves