GETTING OUR VOICES HEARD

Identifying the best approaches for people with a learning disability to **influence adult safeguarding and associated policy and legislation**

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SAFEGUARDING YOU, SAFEGUARDING ME

In order to exercise equal citizenship, people with a learning disability should have the same opportunities for choice, control, dignity and freedom as

any other


citizen

Table of Contents

Acknowledgements

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Executive Summary

Executive Summary

Introduction

In order to achieve independent living, people with a learning disability should have choice, control, dignity and freedom in the same way as any other citizen. One issue impacting on their experience of independent living is the risk of harm or abuse and the potential for over-protective or under-protective responses to these presenting risks. Within the past decade adult safeguarding policy and legislation has been developed in all four nations within the UK. Influenced by cultural and political contexts, each nation within the UK has different approaches to adult safeguarding.

In developing safeguarding policies and procedures, it is imperative that disabled people themselves have direct influence on these policies. However, the research evidence would suggest that people with a learning disability are often under-represented in policy making processes in general, even when the focus is disability (Irvine, 2017).

Project Aims

This project sought to identify the best approaches to influencing adult safeguarding and associated policies in different contexts across all four nations in the UK. The project concluded with the development of co-produced recommendations. The project aims were as follows:

- To identify the different approaches to exerting influence on adult safeguarding and associated policies and legislation which have been taken by people who have a learning disability and relevant supporting organisations.
- To explore what works in different contexts by looking closely at successful examples where people with a learning disability and relevant supporting organisations have influenced adult safeguarding policies and legislation.
- To make recommendations on approaches to take, identifying barriers and enablers to exerting influence on adult safeguarding and associated policies and legislation.

Methods

The processes employed to address these aims included the completion of semi-structured interviews, focus group meetings, and an online survey. The chosen method for data analysis was exploratory thematic analysis. This research project was set out in five phases and was designed to be inclusive and evolving, with data gathered from one phase informing the next in addressing the project's aims. The five phases of the approach were as follows:

- Phase 1: a desk based review of relevant literature and policy analysis.
- Phase 2: implementing a recruitment and training programme for Peer Researchers to support the co-production of the research.
- Phase 3: semi-structured interviews completed with policy makers/policy advocates/politicians in each nation.
- Phase 4: four in-depth case studies; one case study of the 'best-practice' example of supporting organisations influencing policy in each of the four nations. These were based on focus groups and semi-structured interviews with key stakeholders.
- Phase 5: an online survey completed with relevant supporting organisations and those who have contributed to relevant policy consultations, focused on their views and experiences.

Project Team

The project team consisted of Queen's University, Belfast in partnership with Action for Real Change, NI, Compass Advocacy Network, NI; Praxis Care, NI; Mencap Cyrmu, Wales; Richmond Fellowship, Scotland, and Ann Craft Trust, England. The Queen's University team included three academic staff; Dr Lorna Montgomery (Project Lead), Professor Gavin Davidson and Dr Berni Kelly, along with Lisamarie Wood, a researcher from Praxis Care. This project was based on a participatory disability research design, in that it was co-led by people with lived experience of a learning disability and co-produced in partnership with them. In this process, Leslie-Anne Newton from Association for Real Change (ARC), and Linda McKendry from Compass Advocacy Network (CAN) were also core members of the research team, and facilitated the co-production of the programme. Additionally, three partner organisations from across the UK helped to contextualize the findings for each country, and supported the dissemination of findings. These were: The Richmond Fellowship, Scotland; Mencap Cymru, Wales; and Ann Craft Trust, England.

The project was supported by an Advisory group and a Peer Reference group. It was funded by Disability Research on Independent Living & Learning (DRILL).

Findings and Conclusions

In the first stage of this project we examined the consultation processes in each country collating the responses from individuals who had a learning disability and their supporting organisations, and examining the ways in which safeguarding law and policy was informed by these responses. In so doing it became apparent that across the UK those individuals with a learning disability, and organisations who supported them, raised similar issues in response to the consultations. Issues raised included the need for clarity around definitions, practical difficulties with implementing safeguarding policy, issues relating to capacity and consent, the need for advocacy, and the central importance of negotiating the balance between autonomy and control.

Despite the time and resources given to the consultation process the written responses representing the views of people with a learning disability were limited in number (ranging from a total of 5 responses in NI to 27 in England). Moreover, in terms of impact, a mixed picture was evident. Many issues raised in consultation did appear to impact the final policy and/ or legislation. However, in most jurisdictions, the fundamental aspects of the policy or legislation were already largely written before feedback was sought, arguably limiting the opportunity to shape safeguarding practice.

Policy makers, when interviewed, appeared committed to hearing the voice of people to whom the policy or legislation applied, suggesting that the voice of people with a learning disability was an influential part of the policymaking process and a central source of evidence. Whilst the knowledge of professionals, evaluations of previous policies, and 'frontline' practitioner wisdom was deemed to be useful in finding out what was or wasn't working in practice, it did not provide a full picture of how a policy or law would work. Policy makers consistently agreed that it was important to involve people with a learning disability and supporting organisations in the policymaking process from the outset and throughout the policy making process. The best way to do so appeared to be through face-to-face conversations and discussions which were considered to be more useful than written consultations, with a high value placed on personal stories and experiences.

A case study of the best-practice example of supporting organisations in each of the four nations was completed, identifying important examples of best practice in policy influencing. Similar to the policy maker feedback, all of our case-study organisations advocated for the importance of using people's personal stories and lived experiences. They emphasised that people with a learning disability should be empowered to speak out about their lived experience, interviewees who had a learning disability also suggested that being given a chance to tell their personal stories was often a positive experience for them. Additionally, our case study organisations emphasised the need to work together to build trusting relationships and alliances and have a collective voice on issues of importance.

Finally, to a large extent, our online survey results complemented the results of both our policy maker interviews and our case studies. A high proportion of our respondents told us that their organisations tried to influence government policy, with senior leadership being the most likely to engage in this activity. In order to have an influence, respondents generally engaged consultations, networked with other organisations and provided training. Again, the most useful forms of evidence used to influence policy were personal testimonies and case studies. Encouragingly approximately eighty percent of organisations who responded to our survey perceived their policy influence attempts to be successful, at least to some degree.

In conclusion, our research suggested that people with a learning disability, their families and their supporting organisations were 'powerful actors' (Mayne et al., 2018) in this complex process. However, the research also highlighted that changes were needed in relation to attitudes, values and practical issues which were constraining individuals and groups in their ability to influence policy. In concluding this stage of our project, we have identified a series of co-produced recommendations to assist people with a learning disability to get their voice heard in shaping policies that have a direct impact on their lives.

Recommendations

People with a learning disability are often under-represented in policy making processes. Most people, with or without disabilities, need support to effectively participate in the policy making process. Policy makers should invest time and resources communicating with those people who will be directly affected by the policy. From our research we have identified a series of key recommendations for policy makers and supporting organisations to assist people who have learning disability to get their voice heard in shaping policies that have a direct impact on their lives.

Policymakers

Help people with a learning disability understand the political process

- Initiatives are needed to help people with a learning disability to understand the political process and to empower them to have an influence. An example of this in action is the Welsh Assembly's outreach team who provide workshops on the Welsh Assembly, how to have an influence and on how laws are made.
- People with a learning disability need political representatives to help draw public attention to their policy needs.

Promote meaningful engagement of people with a learning disability at all stages

- Involve people with a learning disability and supporting organisations in the policymaking process from the outset and throughout the policy making process.
- Keep people updated on progress. People with a learning disability often felt that they were asked for their input but not kept informed of the outcomes.
- Avoid repetition of consultations on the same topics and asking the same questions in a short space of time.
- Consider if you have identified and responded reasonably to the views of people with a learning disability.

Ensure communication is meaningful

- Improve the quality of Easy Read documents. Easy Read versions should cover all important information and clearly explain key points.
- Work with experienced supporting organisations and draw on their expertise in how to engage people with a severe learning disability. For example, Mencap 'Involve Me' project which provides a practical guide on how to involve people with Profound and Multiple Learning Disabilities (PMLD) in decision-making and consultation.
- Have realistic timeframes in which co-produced policies can be developed. Send materials at least two weeks in advance to allow time for preparation.
- Face-to-face conversations and discussions are more useful than written consultations.

Utilise different sources of evidence

- Ensure the policy process has been informed by evidence that is high quality and up to date.
- Evidence should include evaluations of previous policies and the experiences of 'frontline' practitioners and people with a learning disability.
- Consider proactive policymaking which makes necessary changes before people come to harm.

Supporting Organisations and People with a learning disability

Build relationships and networks

- Recognise that having an influence takes time as policy and law-making are complex procedures that require the input of a number of people and organisations. You can't change policy by yourself. Work together to build trusting relationships and alliances and have a collective voice on issues of importance.
- Create coalitions with other organisations around a common theme and where possible agree on shared standpoints on these.
- Smaller groups/organisations may find it useful to have an affiliation with a larger organisation, which may have more contacts and resources to help with gaining influence.
- People with a learning disability living in rural areas had fewer opportunities to be involved with supporting organisations than people living in urban areas. Consider rural outreach programmes or the facilitation of smaller groups by large supporting organisations.

Have a clear message utilising different sources of knowledge

- Empower people with a learning disability to share their personal stories and lived experience.
- Use examples of how projects have had positive impact on people's lives and how this learning could be adopted in a policy environment.
- Explain how policies and legislation affect the lives of people with a learning disability. In particular, highlight paternalistic or protectionist practice in relation to safeguarding.
- Referencing official statistics or research can lend weight to your argument.

Design messages to maximise influence, framed for different audiences

- Present respectful and strong, well thought-out arguments that are solution-focused.
- Know your audience and their job role. Tailor information outputs to different audiences, for example, consider using professional, formal language in information given to policymakers.

Engage in policy making processes

- Involvement in campaigns can increase the levels of attention given to policy issues and is a useful way to raise awareness.
- Try to gain membership to policy technical or advisory groups as these are often consulted on policy from the outset and throughout the policymaking process.
- Use windows of opportunity such as the exposure of safeguarding scandals in the media to have your influence. In instances like this, public and political attention is more likely to be focused on the topic, so your input is more likely to be picked up on.
- Appreciate that policy-making is not a linear process but is often complex and dynamic. It may involve trying to influence a lot of different people and overcoming a range of challenges.

Support individuals with a learning disability to contribute

- Provide opportunities for people with a learning disability to experience participation and advocacy in their own lives so they can develop skills which may enable them to engage in influencing policy.

1. Introduction

1. Introduction

In order to exercise equal citizenship, people with a learning disability should have the same opportunities for choice, control, dignity and freedom as any other citizen. However, a major issue impacting on their ability to exercise equal citizenship and to promote independent living is the risk of harm or abuse, with the potential for over-protective responses, or responses which don't fully consider the presenting risks. Since the 1990's there has been a growing awareness that a wide range of adults are at risk of harm from abuse, exploitation or neglect. Adults with a learning disability often experience higher levels of abuse than other adults (Fyson & Kitson, 2010). Moreover, many individuals are placed at greater risk of harm or abuse by the intersectionality of their disability, gender, race or class, creating overlapping systems of discrimination and risk (Shah & Bradbury-Jones, 2018).

Within the past 10-15 years specific adult safeguarding policy and legislation has been developed in all four nations within the UK, articulating the definitions, principles, pathways and scope of adult safeguarding, while promoting public and professional awareness. The continuing evolution of legislation, policy and practice in relation to adult safeguarding is indicative of a growing understanding of the nature and extent of abuse. Influenced by cultural and political contexts, each nation within the UK has different approaches to adult protection. Moreover, variations in approach to safeguarding policy and legislation across the UK are evident, with differences in the definitions of who is an adult at risk, definitions of the terms "abuse" and "harm," and in the range of powers and duties afforded to professionals whose job it is to support people with a learning disability (Montgomery et al., 2015). Arguably, an effective adult safeguarding framework should aim to give people with a learning disability equal access to justice and protection systems, whilst promoting their independence and autonomy.

1.1 What is the research question?

In developing safeguarding policies and procedures, it is imperative that disabled people themselves have a direct influence on these policies. The diversity of needs and abilities encompassed by people with a learning disability must be considered and a one size fits all approach clearly does not respect the human rights of this diverse group (Fyson & Kitson, 2010). However, the research evidence would suggest that people with a learning disability are often under-represented in policy making processes in general, even when the focus is disability (Irvine, 2017).

This project sought to identify the best approaches to influencing adult safeguarding policy in different contexts across all four nations in the UK. It concludes with the development of co-

produced recommendations on approaches to take in order to support their influence on adult safeguarding policy.

1.2 Overview of the report

The report will begin with an outline of our research team and the different roles taken by team members and the methods used to gather and analyse the information provided by participants. A brief review of the literature on policy development will then be presented. This will be followed by a discussion of the main findings. Finally, key recommendations will be presented.

1.2.1 Who was involved in our research?

Project Team: Queen's University acted as lead for this project. The Queen's University team included three academic staff: Dr Lorna Montgomery, Prof Gavin Davidson and Dr Berni Kelly. Lisamarie Wood from Praxis Care was the researcher on the project. Lisamarie jointly conducted all of the data collection with a Peer Researcher. In this process Queen's University partnered with voluntary sector organisations from across the UK. The core partners were Association for Real Change (ARC), Compass Advocacy Network (CAN), and Praxis Care.

Association for Real Change (ARC) is the turn to organisation for the learning disability sector operating across the UK. The NI Director, Leslie-Anne Newton was a member of the core research team, and acted as a delivery partner, facilitating the co-production of the programme with the Telling It Like It Is (TILII) Coordinator. Leslie-Anne also acted as chair of the advisory group.

Compass Advocacy Network (CAN) is a supporting organisation operating in NI, empowering people with a learning disability to self-advocate on a number of issues including sexual health, welfare reform and community planning. Linda McKendry is the Director of Services, and was a member of the core research team and acted as a delivery partner, facilitating the co-production of the programme with CAN members.

Praxis Care assists adults and children with a learning disability to live in appropriate community settings, through offering a holistic range of care and diversional activity. Paul Webb the Research Manager for Praxis Care, facilitated Peer Researchers from Praxis with lived experience of disability to contribute to the training of Peer Researchers for this project, and supported the research process.

Three partner organisations from across the UK were part of the research team and helped to contextualize the findings for each country, supporting the dissemination of findings, co-facilitating a

workshop in each country and providing ongoing advice and support to the project. These were:

Scotland: The Richmond Fellowship Scotland is a charity which supports over 1000 people with a learning disability to live as independently as possible in their own homes and communities. The CEO Austen Smyth was a member of the research team and acted as a delivery partner.

Wales: Mencap Cyrmu is a charity which seeks to improve the lives of people with a learning disability and their families, and fight alongside them for a better future in their own homes and communities. The CEO Wayne Crocker and Sian Davies, Head of Strategic Programmes, were members of the research team acted as delivery partners.

England: Ann Craft Trust (ACT) is a leading authority in safeguarding disabled children and adults from abuse. Through pioneering training, practice reviews and contributing to world-leading research, ACT supports organisations to safeguard disabled children and adults at risk and minimise the risk of harm. The CEO Deborah Kitson was a member of the research team and acted as a delivery partner.

Peer researchers:

This project was based on a participatory disability research design, in that it was co-led by people with lived experience of learning disability and co-produced in partnership with them. The original idea for this proposal was identified by people with a learning disability involved in ARC (NI) TILII groups. Then, following a structured recruitment and training process, six peer researchers joined the research team and engaged in each of the core stages of the project: data collection, data analysis and dissemination. The peer researchers are as follows:

Ursula Campbell

I have been an advocate for 12 years and have lots of experience representing people with learning disabilities at all levels including in our local government, Stormont. I live independently in the community with my sister Clara, nephew Lucien and my dog Tyson.

I work in Eurospar and have been a member of their team for 10 years. I feel passionately that people with learning disabilities should be treated with equality and am committed to ensuring that I provide a voice for the silent.

Leeanne Gibson

My name is Leeanne Gibson, I am 30 years old and I am concerned about online bullying as I have seen the harm it causes to my friends and people I know. I want to help stop this and I liked meeting and getting to know people during the project. I have enjoyed working together as a team and really hope the project reduces the harm bullying does.

Jadzia Menham

My name is Jadzia Menham I am soon to be 21. I studied media and performing arts. I regularly attend a group project called CAN Pathways in Ballymoney.

I became involved with DRILL when I was informed during a group session in Pathways and was very interested. Knowing we would be raising more awareness around NI about safeguarding people with a learning disability appealed to me. I really enjoyed travelling to different parts of the UK to conduct the interviews. It was amazing, I loved it!

Alex Parkinson

I live in supported living and staff from Triangle help me to live my life to the max. I love spending time with my family and going out with my friends, but I also love hard work. Being a TILII Member has given me confidence. I speak at conferences and workshops and have been told I should be on stage; Billy Connolly has nothing on me. I train staff on how to support people with a learning disability and I am really proud that I am also an RQIA lay assessor. It is important that people with a learning disability have a say about their future. We are experts by experience, we live this life every day and so becoming a peer researcher - finding out if policies that affect our lives have been influenced by us, and making sure, in the future, our views, and opinions are heard was really important to me.

Ethan Redmond

I'm Ethan, 19, I'm currently studying a level 3 Cambridge Technical Extended Diploma in performing Arts which I have a huge passion for!

I became involved in the DRILL peer researcher project to gain some experience and also to have a different perspective of how the law of safeguarding adults is seen across the UK by policy makers/politicians.

Joseph Turnbull

People call me Louie Armstrong, and you would understand why if you heard me sing in Equal Notes Choir. It was really important to me to volunteer at an Oxfam Charity Shop, because it is for such a good cause, also as I have a keen eye for a bargain.

I am an ambassador for the Alzheimer's society and I love being a member of TILII and speaking out for myself and more importantly for others who do not have a voice. Through TILII I have taken part in many projects which have shown my ability to work individually and in a team and I have had a great time working as peer researcher. It was really important to me. I am proud to have been part of such an important project to make sure people with a learning disability actually have an impact on the policies and processes that affect their lives.

Advisory Group: The project was informed at key points by a UK-wide Advisory Group made up of key strategic safeguarding stakeholders, academics, peer researchers and ARC NI. The Advisory Group members were:

- **Ms Leslie-Anne Newton: Advisory Group Chair.** Northern Ireland Director Association for Real Change (ARC).
- **Ms Agnes Lunny:** Chief Executive of Positive Futures, NI, a charitable organisation supporting people with a learning disability.
- **Ms Joyce McKee:** Chair of Northern Ireland Adult Safeguarding Partnership and Regional Adult Safeguarding Office at the Northern Ireland Health and Social Care Board.
- **Professor Jill Manthorpe**: Professor of Social Work at King's College London and Director of the Social Care Workforce Research Unit.
- **Ms Joan Maughan:** Independent Chair, Norfolk Adult Safeguarding Board.
- **Ms Aine Morrison:** Professional Officer of the Office of Social Services, Department of Health, Northern Ireland.
- **Jonathan Murray:** TILII representative. Jonathan says of his involvement: it allows me to meet my friends and take part in important work like training staff and speaking at conferences to make sure people with a learning disability are supported to have their voices heard.
- **Catherine Orr:** TILII representative. Catherine says of her involvement: being a member of TILII is really important to me, speaking out and making sure people like myself with a learning disability, not only have a voice but also understand their human rights so they can make choices about how they live their life.
- **Professor John Williams:** Emeritus Professor Aberystwyth Law School.

Peer Reference Group: The Peer Reference Group consisted of over forty self-advocating adults with a learning disability who live within community and hospital settings. These were pre-existing networks called Telling It Like It Is (TILII), facilitated by Association for Real Change (ARC). Both ARC and Compass Advocacy Network (CAN) supported these self-advocates to engage in project activity, including the design, the implementation (on various levels for individuals) and the dissemination. Louise Hughes is the TILII co-ordinator and provided support and direction in our work with TILII.

1.3 Key terms:

- Policy maker: in this report we use the term policy maker to refer to three different roles. Firstly, a policy maker was someone who gathered information through consultation and research to develop legislation or policy at government level. Secondly, for the purposes of this project, the term policy maker also included policy advocates, who were senior health and social care staff in roles which provided the opportunity to directly influence policy. Thirdly, we included politicians who had opportunity to shape national legislation and policy.

- Supporting Organisation: In this report when we refer to supporting organisations, we include all organisations in the voluntary and community sectors who are supporting people with a learning disability.

- Person with a learning disability. Whilst this is our preferred term, in some places we refer to 'service users', as this was the terminology utilised by some respondents and in some of the documentation reviewed.

- Safeguarding policy and legislation: Safeguarding adults refers to the concept of protecting an adult's right to live in safety, free from abuse, harm and neglect. Policies and legislation have been developed across the UK to provide procedures to guide the management of concerns or allegations in relation to abuse, harm and neglect. As some of this policy and legislation has been developed over ten years ago, we have also asked participants to respond to questions about a range of associated policies and legislation related to adult safeguarding, for example: Mental Capacity Act Code of Practice and the Liberty Protection Safeguards Scheme.

2. Methodology

2. Methodology

The aims of our project were agreed as follows:

- Identifying the different approaches to exerting influence on adult safeguarding legislation and policy (or associated policies) which have been taken by people who have a learning disability and relevant supporting organisations.
- Exploring what works in different contexts by looking closely at successful examples where people with a learning disability and relevant supporting organisations have influenced adult safeguarding policy (or associated policies) and practice.
- Making recommendations on approaches to take and identifying barriers and enablers to exerting influence on adult safeguarding policy (or associated policies) and legislation.

The processes employed to address these aims included the completion of semi-structured interviews, focus group meetings, and an online survey. The chosen method for data analysis was exploratory thematic analysis (Guest et al., 2012). This research project was set out in five phases and was designed to be inclusive and evolving, with data gathered from one phase informing the next in addressing the project's aims. The five phases of the approach are as follows:

- Phase 1: a desk based analysis of relevant literature and policy analysis.
- Phase 2: implementing a structured recruitment and training programme for Peer Researchers to support the co-production of the research.
- Phase 3: semi-structured interviews completed with an identified policy maker/policy advocate/politician in each nation.
- Phase 4: four in-depth case studies; one case study of the 'best-case' example of supporting organisations influencing policy in each of the four nations. These were based on focus groups and semi-structured interviews with key stakeholders.
- Phase 5: an online survey completed with supporting organisations focusing on their views and experiences of influencing adult safeguarding policy (or associated policies) and legislation.

2.1 Phase 1: Desk based analysis of relevant literature and policy

Current safeguarding laws and policies in each region were read and analysed in order to identify the legal and policy framework for safeguarding and to

highlight variations in policy and law across the regions. This included a review of how people at risk were defined, the definitions of abuse and harm, and professional duties and power to intervene. Strategies of policy formation in each region were examined, and the distinct consultation and amendment policy processes explored. Consultation documents were read and the public responses were analysed to identify how individuals and groups responded and in what ways these responses impacted law or policy development.

2.2 Phase 2: Peer researcher recruitment and training

A central aspect of the research was the recruitment and training of Peer Researchers (PR), who had lived experience of learning disability, and who were core members of the research team. Six Peer Researchers were recruited from ARC NI and CAN using a structured recruitment process involving a formal application and interview. This process was supported by a Peer Researcher from a separate DRILL project who used his experience as a Peer Researcher to contribute to the training programme. The training programme was delivered over the course of five half days and focused on: the research process, understanding safeguarding policies, how to influence policy, interviewing and presentation skills, and research ethics. Following training, Peer Researchers accessed ongoing support from the academic researchers and the wider research team as the fieldwork progressed. The Peer Researchers also contributed to core stages of the project (data collection, data analysis and dissemination).

2.3 Phase 3: Semi-structured interviews with a policy maker in each nation

Co-produced, semi-structured interviews were carried out with policymakers from England, Scotland, Wales and Northern Ireland (NI). Interviewees were purposively selected from a range of occupational areas: policy makers, politicians and policy advocates, as outlined in Table 1 below. This variance in occupation allowed the researchers to gain a number of perspectives from those who work in different areas within the policymaking arena. Interviews in Northern Ireland were conducted in person as the research team were located there, with interviews in the other regions carried out by telephone. A set of pre-written, co-produced questions were used to structure the interview, with agreed follow-up questions. Questions sought to explore the ways in which policy was developed, the policy makers' perceptions

of the consultation process, and the factors which most influenced the policy maker (Appendix A). The interviews were conducted by both the academic researcher and the peer researcher, with support staff and Easy Read versions of material made available, as required.

Table1. Policy maker participants

Region (UK)	Number of Interviewees	Occupational Area
Northern Ireland	4	Health and Social Care, Policy Maker
Scotland	1	Policy Maker
England	1	Policy Maker
Wales	2	Politician

2.4 Phase 4: In-depth organisational case studies

A case study of the 'best-case' organisation in each of the four nations was completed. The organisations selected were as follows:

- Mencap, England;
- Positive Futures, Northern Ireland;
- People First, Scotland;
- Learning Disability Wales, Wales.

The organisations were identified as potential best case examples during the preliminary phases of research (Phase 1 and 2), where each organisation was identified as being successful in shaping policy. Each organisation had, to varying degrees: submitted responses to proposed law reforms which were quoted within the Consultation Analysis; been identified in the policymaker interviews as an organisation which was recognised as influencing policy; a reputation for being led by people with a learning disability; and, been involved in campaigns on policy. The academic researcher and peer researcher travelled to meet members of each organisation and conducted a range of focus groups and semi-structured interviews, gaining the views of: key staff members; individuals with a learning disability engaged with the organisation; and family carers. A set of pre-written, co-produced questions and potential 'follow-up' questions, were used to structure the interview (Appendix A). Consideration was given to the ways in which the organisation had co-produced their influencing strategy, and ways in which the organisation sought to influence safeguarding policy and its implementation at national and organisational levels. The impact of devolution and differing policy contexts and structures across the UK was also

considered. The interviews were conducted jointly by the academic researcher and the peer researcher, with support staff and Easy Read versions of material made available to the peer researcher, as required.

2.5 Phase 5: Online survey

An online survey was produced using SurveyMonkey and was sent to supporting organisations who contributed to safeguarding policy consultations (identified in the policy analysis of this project), and in addition disseminated through the Association for Real Change network. ARC operates across the UK, with offices in three of the four countries. Its collective distribution lists include providers of learning disability services; commissioners; policy makers; regulators and individuals supported or their family/carer representatives.

The survey comprised a series of questions designed to capture certain characteristics of the respondents and their views and experiences of influencing adult safeguarding policy and procedures, including barriers and enablers. The survey was sent to over two hundred organisations.

2.6 Data Analysis

All interviews and focus groups were audio recorded, and fully manually transcribed. Data analysis took place in the form of exploratory applied thematic analysis, drawn from the work of Guest et al. (2012), with the help of NVivo software in order to help organise the data in an accessible manner. In addition, descriptive statistics were used to report the results of the online survey, with thematic analysis of the qualitative components.

2.7 Ethics

The project was granted ethical approval by the Research Ethics Committee in the School of Social Sciences, Education and Social Work, Queen's University Belfast. The key ethical considerations for this project were to ensure that that participation was voluntary, that confidentiality was protected and that people were supported if need be.

3. Legal and Policy context

3. Legal and Policy context

Before commencing our research, we sought to explore the legal and policy context as it relates to adult safeguarding, and to review the literature on policy influencing. In so doing we firstly undertook an exploration of the safeguarding legislation and policy in each nation of the UK, a summary of this is presented in the Findings section. Secondly, we completed an overview of the political institutions in the UK with reference to the evidence base for policy development (Appendix B).

3.1 The legislation and policy context

Safeguarding policy and legislation varies across the UK. England and Wales have overarching care laws with safeguarding procedures enshrined within them, Scotland has its own safeguarding-specific law which refers to adult support and protection, whereas Northern Ireland has a safeguarding-specific policy, but no safeguarding legislation.

3.1.1 England

In England, the current legislation used to outline safeguarding practice is The Care Act (2014). This piece of legislation covers a range of care related issues, for example, support for carers, provisions relating to care standards, integrating care and support with health services and safeguarding adults from abuse or neglect (UK Parliament, 2014).

3.1.2 Wales

The Social Services and Well-being (Wales) Act 2014 is the legislation used to frame safeguarding practice in Wales. Its aim is to reform social services law, make provisions to improve the wellbeing outcomes for people who need care and support and for their carers, to make provisions for both co-operation and partnership by public authorities in order to improve the well-being of people, and to put in place a system for complaints relating to care (Welsh Government, 2014).

3.1.3 Scotland

The Adult Support and Protection (Scotland) Act (2007) outlines safeguarding practice in Scotland and is specific to adult support and protection. Its aim is to protect adults from harm; to require the establishment of committees relating to safeguarding adults who are at risk of harm; to amend the law relating to incapable adults; and a number of other related safeguarding provisions (Scottish Parliament, 2007).

3.1.4 Northern Ireland

In the absence of specific legislation, adult safeguarding in Northern Ireland is guided by a framework of generic legislation, policy and procedures. The most recent iteration of the safeguarding policy '*Adult Safeguarding: Prevention and Protection in Partnership*' (DHSSPS, 2015), places a strong emphasis on a preventative agenda. Safeguarding is envisaged in its widest sense, comprising activity which prevents harm from occurring and activity which protects adults at risk where harm has occurred, or is likely to occur. Unlike the remainder of the UK, adult safeguarding in Northern Ireland is delivered within a fully integrated health and social care sector, structured within five geographically distinct Health and Social Care (HSC) Trusts.

3.2 Definitions, Thresholds, Powers and Duties

Variations across the UK are also found in definitions of who is an adult at risk, definitions of the terms 'abuse' and 'harm', and variations in the range of powers and duties afforded to professionals working in this area. In the past ten to fifteen years, each of the four UK countries have defined who they consider to be an adult at risk. In each, the term 'adult at risk' has come to replace the earlier concept of 'vulnerable adult' to shift the emphasis (and by implication responsibility) away from the adult and onto those who pose a risk to the adult (Stewart, 2012). Most countries define abuse broadly, as a violation of an individual's human and civil rights by any other person, acknowledging that this can relate to the physical, sexual, financial, psychological, or social mistreatment of an individual. However, Scotland and Northern Ireland have a threshold based on 'harm', whereas England and Wales narrow their response to 'abuse' or 'neglect'. Likewise, the range of powers accorded by these countries reflects differing approaches to safeguarding. Scotland sees an adult at risk as someone who is over sixteen, unable to safeguard their well-being, property, rights or other interests; who is at risk of harm and who because of disability, mental disorder, illness or physical or mental infirmity are more vulnerable to being harmed than someone not affected (Scottish Parliament, 2007). In contrast, England and Wales define an adult at risk as someone over eighteen who has needs for care and support; is experiencing, or is at risk of abuse or neglect and as a result of those needs is unable to protect himself or herself (UK Parliament, 2014; Welsh Government, 2014). Northern Ireland goes further in this definition, to define an 'adult at risk of harm' as someone over the age of eighteen who may have an increased exposure to harm due to their personal characteristics and/or life circumstances and an 'adult in need of protection' as someone who has the qualities of an adult at risk but who is also unable to protect themselves from the

action or inaction of another person (DHSSPS, DOJ, 2015).

Within the UK, Scotland has the largest range of powers and duties in relation to safeguarding adults, including powers to make inquiries, provide services, carry out visits, conduct interviews and gain access to records. They also hold the power to grant 'Protection Orders' in special circumstances. Wales also has a wide range of duties including those on local authorities to make enquiries and on relevant partner organisations to report suspected abuse, cooperate and provide information. Furthermore, Adult Support and Protection Officers can be given power of entry in order to allow practitioners to speak in private to those suspected of being victims of abuse. However, there is no duty to investigate abuse or harm or power to remove an adult suspected of being a victim of abuse or harm. England has a smaller range of duties; however, it does contain a duty on authorities to investigate. It does not contain any powers to remove a person from their home, and any further intervention in the life of a person at risk must be done so under wider civil laws. Northern Ireland differs from the rest of the UK in that safeguarding information in regards to adults at risk lies mainly within policies. Otherwise, powers and duties are contained in a range of welfare, civil and criminal legislation that protects all citizens.

"So there's a process of getting people up to speed, skilling them up, giving them the confidence to join the conversation, but it really is the only way to do co-production properly because the problems are so difficult and so complicated that you can't compromise solution development because you're patronising somebody"






4. Findings

4. Findings

In this section we will identify the findings of our study, this will be divided into the findings relating to: the policy analysis; the policy maker interviews; the organisational case studies; and the online survey.

4.1 Policy analysis: How safeguarding legislation and policy was developed in each setting

4.1.1 The development of adult safeguarding legislation: England

The Adult Social Care project was announced in the law commissioner's tenth programme of law reform in June 2008. The purpose of the project was to review the laws that were currently in place covering residential and community care and support for carers. The project was divided into three stages; in stage one a scoping review was carried out which delineated the scope of the project, providing an agenda for reform. During stage two, consultations with the public and the government were carried out, and recommendations for reform were made. At stage three, the Law Commission produced a draft bill to implement their final recommendations for reform.

Consultation paper number 192 was published on the 24th of February 2010, and public consultations ran until 1 July 2010. During the public consultation period, the Law Commission attended seventy-two events which spanned the breadth of England and Wales, covering a wide audience, including service users, carers, NHS staff, academics, lawyers, and charities.

The Commission received two hundred and thirty-one written responses to the consultation paper, from a range of different individuals and organisations. Twenty-seven of these responses came from supporting organisations or service users.

Nature of the Responses: Of the responses that came from supporting organisations and service users, eighty-nine percent were from supporting organisations and eleven percent were from service users. Consultation documents did not specify whether service users had a learning disability or whether they were accessing services for another reason. Responses to this consultation were not made publicly available, so a consultation analysis drawn up by the Law Commission was used to uncover how the public responded to these proposals.

How the Consultation Influenced Safeguarding Legislation: It is unclear the extent to which the consultation significantly impacted on the safeguarding components of the Care Act (2014). A number of relatively minor changes were made to language and duties within the Act after the consultation took place. However, it appears that supporting organisations and people with a learning disability were consulted at a relatively late stage of the process when much of the legislation had been established, which appears to have limited the influence of the consultation.

4.1.2 The development of adult safeguarding legislation: Wales

In November 2009, the Deputy Minister for Social Services, Gwenda Thomas (Assembly Member) established the Independent Commission on Social Services. The Commission's main aim was to consider how social services and social care could best meet the needs of Welsh Citizens for the following decade. The findings were published in November 2010 in the report *From Vision to Action* (Independent Commission on Social Services in Wales, 2010). A social work taskforce group was also commissioned and produced a report in December 2010.

Stemming from these reviews, the Government published *Sustainable Social Services for Wales: A Framework for Action* on the 2nd June 2011, setting out the Welsh Government's vision for social services. This paper was followed in March 2012 by a formal Welsh Government consultation on the *Social Services (Wales) Bill* which ran until 1 June 2012. The draft proposals were presented at three consultation events across Wales which were attended by around four hundred people from across both the public and voluntary sectors. In addition, the Wales Council for Voluntary Action hosted a consultation event on behalf of the Welsh Government, which sought the views of workers in the voluntary sector. The Welsh Government also commissioned two organisations, Voices from Care and Cognition to undertake workshops with those whose lives would be impacted by the bill, for example, disabled and looked after children, disabled adults, and carers. Two hundred and seventy-five written responses were received to this consultation. As a result of this, the Social Services and Wellbeing Bill was introduced by Gwenda Thomas (Assembly Member) on 28th Jan 2013. Another public consultation, run by the Health and Social Care Committee was then held on this Bill and these ran from 1st February until 15th March 2013. Eighty-four written responses were received to this consultation, of which seven were supporting organisations or service users.

Nature of the Responses: Of the responses from service users and supporting organisations to the second consultation, fourteen percent were from

individuals identifying as service users and the remaining eighty-six percent were from supporting organisations. A full list of consultees and consultee responses is not available for the first consultation, but responses from some of the consultees have been identified as a result of a freedom of information request sent to the Welsh Government. A consultation summary response document was produced, identifying what consultees generally thought of the proposals provided. A full list of consultees and their responses is available for the second consultation.

How the Consultation Influenced Safeguarding Legislation: The process of developing the Welsh legislation appears to have provided opportunity for the public to exert significant influence over the shape of their social care law, and by extension their safeguarding law. In particular, the use of two separate consultations and the facilitation of workshops organised by Voices from Care and Cognition, appear to have promoted opportunities for public engagement at an early stage of the process. The broad nature of the first consultation document enabled consultees to provide feedback at the developmental stages of legislative reform, with the second consultation focusing to a greater extent on more specific aspects of the legislation. The involvement of the public at a relatively early stage of the project meant that their contribution went towards the framework and ethos of the legislation, rather than in the minor amendments of what was almost complete. However, notably, a number of issues of importance raised by consultees were not addressed: their feedback did not always translate into change.

4.1.3 The development of adult safeguarding legislation: Scotland

The Adult Support and Protection (Scotland) Act (2007) took forward recommendations from the Scottish Law Commission's report on Vulnerable Adults (Scot Law Com No 158, 1997), and those of the Social Work Services Inspectorate and the Mental Welfare Commission as a result of investigations into the Scottish Borders Council. The Adult Support and Protection Bill was created after a lengthy general consultation process including three consultations on the current state of adult care in Scotland.

The first consultation, *Consultation on Vulnerable Adults* was published in 2002 drawing on recommendations from the Scottish Law Commission's Report on Vulnerable Adults (1997) and the Millan Report (Scottish Executive, 2001) which highlighted issues with the current law. Fifty-nine responses were received, two responses being from supporting organisations.

The second consultation paper: *Protecting Vulnerable Adults- Securing Their Safety: A prelegislative consultation paper on the establishment of the list of adults*

unsuitable to work with vulnerable adults, was published in February 2004. The aim of the paper was to create a list of adults who were unsuitable to hold a position which involved caring for vulnerable adults. Eighty-eight responses were received to this consultation, ten from supporting organisations.

Finally, a third consultation paper *Protecting Vulnerable Adults – Securing their Safety: Third consultation paper on the protection of vulnerable adults and related matters* was produced on the 7th of July 2005. The aim of this paper was to seek comments on proposed protection measures for vulnerable adults and people with a learning disability. Responses to this consultation were not available when requested through a Freedom of Information Request to the Scottish Government.

Nature of the Responses: Two supporting organisations responded to the first consultation and ten supporting organisations to the second, no service users responded to either. We do not know if service users' opinions were utilised by supporting organisations in their consultation responses as a full list of responses are not available.
In the first consultation, respondents were asked twenty-seven yes/no questions and given room to expand on their answers. The second consultation asked for comments on the proposals provided, but no specific questions were asked about the proposals. In the third consultation, respondents were asked fourteen questions which varied between an open and closed format.

How the Consultation Influenced Safeguarding Legislation: The use of three consultations in the creation of the Adult Support and Protection (Scotland) Act (2007) seems to have allowed the public to have a substantial say in the development of the safeguarding legislation, as evidenced by the number of changes made since the original consultation was created. However, it is important to note that six years passed between the initial consultation and the passing of the Act. It should also be noted that a limited number of supporting organisations responded to the consultations. Moreover, not all issues raised at consultation were addressed in the final legislation.

4.1.4 The development of adult safeguarding policy: Northern Ireland

Adult Safeguarding: Prevention and Protection in Partnership (2015) was developed as the result of a series of reviews into social care, mental health and capacity legislation in Northern Ireland, alongside a commitment from the Northern Irish Assembly's 'Programme for Government 2011-2015' to introduce measures aimed at improving safeguarding outcomes for children and vulnerable adults.

Based on the findings from the Bamford (Department of Health, 2007) and Donaldson (Donaldson, 2014) reviews and on the responses to the *Who Cares* consultation (DHSSPS, 2012), a draft safeguarding policy was drawn up and made available for consultation in November 2014. Engagement meetings were also held with the Northern Ireland Safeguarding Partnership (NIASP), South Eastern Local Adult Safeguarding Partnership, RQIA, Association for Real Change Northern Ireland (ARC), Telling it Like it is Group (TILII), the Southern Trust FIT4U Group and the Presbyterian Council for Social Witness. Fifty-eight written responses to this consultation were received, with five of these being from supporting organisations.

Nature of the Responses: A full list of consultation responses were not available however use was made of a consultation response summary to distinguish which issues were important to consultees. Of the five supporting organisations or individuals who identified as service users who responded to the consultation, one was an individual who identified as a service user, with the remaining four being supporting organisations.

How the Consultation Influenced Safeguarding Policy: In Northern Ireland, the use of engagement meetings with groups such as NIASP, TILII and Southern Trust FIT4U meant that supporting organisations and people with a learning disability had a say in what was included in the policy, and allowed for discussion and expansion of ideas. However, we do not have access to minutes or the outcomes of the engagement meetings, so cannot comment in depth on the true influence, if any, of these meetings. The consultation on the draft policy also allowed members of the public to advocate for changes to be made, however it may have been difficult to have a significant influence at this stage as the scope of the policy was already mainly defined.

4.1.5 Policy Analysis Summary

On examining the development of safeguarding law and policy alongside the consultation processes in each jurisdiction, a number of similar issues have been raised by consultees. These included the need for clarity around definitions, difficulties with implementing safeguarding policy, issues relating to capacity and consent, the need for advocacy, and the central importance of negotiating the balance between autonomy and control.

Key considerations raised by consultees included concern about the resources available to implement policy/law and the definition of the person at risk. Resource concerns were identified within the context of the economic climate, with the UK being in an era of austerity as a result of the financial crisis of 2007-2008. For this reason, consultees were concerned that new laws would be created but the resources to enact them would not be provided. Concern was expressed that this had the potential to lead to criminalisation of care providers for perceived neglect. The definition of a person at risk was seen as the foundation of safeguarding law or policy, with some definitions being described as over-inclusive, stigmatising or too exclusive. Similarly, the definition of risk or harm to the adult was viewed as essential in providing consistency in practice.

Although many of the considerations of consultees were similar, consultation and law formation processes varied across the UK. In Wales, the public were consulted in two stages, allowing supporting organisations and people with a learning disability to voice their opinions on the proposed law at the beginning of the process and giving them an opportunity to help shape the law and again at the end, allowing for scrutiny of the almost finished product. Despite this, the number of written responses from supporting organisations and service users was low, engagement at the workshops may have made up for these numbers, but we do not have access to what was said at, or the outcomes of these workshops. Similarly, Scotland held multiple consultations on their proposed legislation at the beginning, in the middle on a specific issue within the law, and at the end. Again, this allowed the public to have a say in developing legislation throughout the process. However, the number of responses to consultation from supporting organisations and people with a learning disability was limited. The Northern Ireland consultation process utilised one consultation and also held multiple engagement meetings with supporting organisations, safeguarding groups and people with a learning disability. Again, these engagement meetings helped to get supporting organisations and people with a learning disability involved in the policy making process, however written responses from supporting organisations were low and outcomes from engagement meetings were not available to see what impact they had. The Northern Ireland policy-making process was relatively short from the consultation stage onwards, taking less than a year in comparison with lengthier processes in other regions. This is likely due in part to the differences between policy and law formation processes. Finally, the English consultation process utilised one consultation, with seventy-two engagement events designed to gain interest. This consultation had the largest number of supporting organisation and service user responses, however the responses were not available to read in full, so no comment can be made on these.

On examining the responses by governments/commissions to consultation replies, it would appear that

changes were generally made in a democratic fashion, with the majority opinion taking precedence. If a large number of consultees made the same point about a proposal, it was generally more likely to be amended.

Table 2 gives us an overview of the general issues raised at consultation and how, if at all, they were addressed in the final law or policy.

Table 2. Changes made as a result of consultation in each region

Country	Issues raised at consultation	How these issues were addressed in subsequent legislation or policy
England	Definition of adult at risk unclear.	The definition of adult at risk was altered to reflect that an adult at risk does not need to be in receipt of adult social care services specifically, but that they have needs for care and support, whether or not the local authority is meeting these needs. Significant harm also removed from definition.
	NHS and Police should be required members of safeguarding boards.	The Chief Officer of Police in each local authority area is required to be a member of their adult safeguarding board. Similarly, clinical commissioning groups must be members of the safeguarding board in each area; these are statutory NHS bodies.
	More emphasis required on preventative action, in particular, the phrase 'significant harm' needs to be removed from the definition of an adult at risk.	The phrase significant harm was removed from the definition of an adult at risk. No additional mention of preventative action or preventative measures.
	Need for statutory compulsory or emergency safeguarding powers.	Not included in the final law.
	Worry about lack of resources. Safeguarding boards will need adequate funding to perform to the expected standard.	Resources have been mentioned with regards to budgeting, but no mention was made of extra resources etc.
Wales	Medical model definition of disability needs to be replaced with the social model.	Medical model of disability used in final law.

	Need for close multi-agency partnership working. Better collaboration between health and social services.	A section solely on co-ordination and partnership working has been added to the final law, providing guidance on how agencies should work together to safeguard effectively.
	Need for training of staff involved in safeguarding and members of safeguarding boards.	No mention made of training staff involved in safeguarding or of members of safeguarding boards.
	Need for free advocacy and information services.	Provisions for providing free advocacy and information to adults at risk have been made in the final Act.
	Worry about lack of resources; are the funds available to carry out what is expected in the law?	Funding and resources have been mentioned in the Act, but no mention is made of extra funding or resources to meet new requirements.
	Data collection on those accessing services in order to quantify need and understand the demographics of those using services.	No mention made of data collection in the final Act.
Scotland	Need to rethink definition and use of "vulnerable adult" and "significant harm".	"Vulnerable adult" has been replaced with "adult at risk" in the final law and "significant harm" has been removed.
	Stigmatising language- learning disability should not be bracketed within mental illness and the term 'handicapped' is offensive and outdated.	The term 'handicapped' was removed from the final Act but learning disability is still bracketed within mental illness.
	Autonomy and the rights of the adult at risk need to be protected, with access available to independent advocacy.	Access to independent advocacy services for adults who authorities need to safeguard has been mentioned in the final act. Note has also been made of gaining an adult's consent to carry out safeguarding proceedings.
	NHS and Police should have a compulsory role in collaborating with adult protection work.	Cooperation from NHS and Police in Adult Protection enquiries has been written into the final law.
Northern Ireland	Clarity required in the differences between the Adult Protection Social Work Manager (APSWM) and the Designated Adult Protection Officer (DAPO).	The role of APSWM was removed from the final policy as it was viewed as being identical to that of the DAPO.

	Timescale outlines for safeguarding investigations required.	Set timescales for safeguarding enquiries were not advocated for in the policy as it was felt that maintaining flexibility in the process and allowing for professional decision making was important.
	Need to take into account capacity and consent when safeguarding adults at risk.	Reference made to informed consent of adults at risk and provision of accurate and well-communicated information in order to confirm this. Consideration given to capacity, and keeping capacity under regular review, as it can fluctuate over time.
	Need to remove the stigmatising language in the sentence “mental infirmity and impairment of, or disturbance in, the functioning of the mind or brain.”	Phrase removed from the final policy.
	Need for safeguarding legislation	Safeguarding legislation was not created as the DOJ and DHSSPS felt that there was a lack of consensus among some of the leading adult safeguarding boards in Northern Ireland. It was also suggested that the timing of Assembly elections would not allow for a safeguarding Bill to be introduced in the mandate at the time.
	Concern over the lack of resources, particularly in regards to smaller organisations who may not have the resources to implement the policy in its entirety.	Resources not mentioned in final policy.

4.2 Findings: The Perceptions of Policy Makers

A summary of the six key themes arising from the policy maker interviews is given below, these are supported by selected policy maker quotations.

4.2.1 Engagement:

Co-production: The importance of co-production with people with a learning disability was emphasised. Interviewees pointed out that co-production can be a lengthy process, which often involves spending time explaining potential policy reforms in detail, including perhaps very in-depth descriptions of what different policy terms mean. Interviewees generally suggested that co-production in policymaking has progressed in recent years, recalling how policy was created in the past without much involvement of the people who would be affected.

"We didn't really, back in the olden days, really spend a lot of time talking to people and I look back on that now and I think… how did you think that was acceptable, that you didn't actually spend time talking to the people that were going to be using the service?"

It was acknowledged that although improvements have been made in the area of co-production with people with a learning disability, there is a still some way to go until policy is truly co-produced.

Political Engagement: Political power was alluded to in two ways, firstly in how politicians are seen to be vitally important in creating public interest in issues which require law or policy reform; and secondly in how citizens in society can harness their own political power in order to attempt to effect change.

Quality of Engagement:
Policymaker engagement with people with a learning disability was not in itself sufficient, rather it was the quality of the engagement that was deemed to be most important. Interviewees suggested that when they met with people with a learning disability on a face-to-face basis and communicated concepts using specific materials such as Easy Read documents, informants were more likely to understand the topics, engage in the discussion, and put forward useful arguments.

Difficulty Engaging: Difficulties engaging with people with a severe learning disability were noted, with the 'most capable' people most likely to take part in meaningful conversations about policy. One interviewee reported,

"It is…possibly likely where someone has impaired capacity for example, or with a serious disability, or is an older person, is lacking confidence or even is just trying to survive, isn't going to be able to assert their views…in the same way. So, I think as a whole we weren't able to get through to that group as much as we would have liked to."

4.2.2 Sources of Evidence

A variety of evidence was used to inform policy making; including the personal stories and lived experiences of people with a learning disability, consultations, professional knowledge and evidence from other countries.

Personal stories and lived experience: Personal stories from people with a learning disability were seen as useful in helping policymakers decide if a proposal was the right thing to do, with policymakers reporting that in some cases personal stories were integral to the creation of a new law or policy. Personal accounts included stories of 'shocking cases' which helped policy makers understand the consequences for victims of abuse, neglect or harm, whilst positive accounts of the ways in which policy or legislation was utilised to help people to feel safe were also considered important.

One interviewee remarked,

"One of the things I've always been struck with… was about personal journeys and personal experience and the story, the personal journey and the personal story. Because that gives emotion and gives strength and gives belief to everything, and for me, understanding of the impact of something."

It was proposed that formalising the stories of people with a learning disability, for example in official reports and reviews, or referring to personal stories in conjunction with other forms of evidence such as research, was a useful way to have an influence on policymaking. Additionally, many interviewees drew on their own personal and professional experiences when working on relevant policy. Most interviewees had a personal connection to either learning disability or safeguarding issues.

Professional knowledge:

Interviewees often used practitioners' professional knowledge to inform policy, for example by taking advice on what was and was not working in practice. In this context, forms of evidence used included waiting lists, recorded complaints and feedback from service users, doctors or nurses.

Consultation processes:

Consultation was seen as an important source of evidence. Interviewees saw it as 'sensible' to collect the views of people who were likely to be affected by a law or policy and suggested that feedback was taken very seriously. However, issues were raised about consultations including; the quality of feedback, the timing of consultations and the limits of written consultations. Consultation events were

consistently seen as being particularly useful. Interviewees commented on the limits of traditional written consultations, which were generally those where a draft law or policy was sent to consultees who responded in writing. Issues were identified in terms of timing and the quality of responses which were said to be extremely variable. For example, one interviewee commented,

"There were hundreds of responses to that, a huge number of people wrote in but of a very broad kind of degree of quality. Um some people just writing and saying "No, I don't like this" and other people writing in a lot of detail."

Interviewees highlighted that when they are used, consultation documents need to be user friendly. Difficulties were highlighted in ensuring that policy said all it needed to different audiences. Professional staff need policy to have enough detail and guidance to help them to enact it in practice, however this can make it difficult for people with a learning disability to understand.

Timing of consultations

In terms of the timing of consultations, interviewees suggested that they initiated the consultation process when they felt they had something to consult on. One interviewee offered,

"Public consultation is probably a bit later on because you want to target, you want to do the research, you want to gather the learning, you want to get something, you have to get something broadly on paper to be able to consult against and you have to be willing to change that."

Learning from other countries:

A number of interviewees identified using safeguarding policy and practice in other countries as inspiration for policy development; examining how safeguarding policy was approached and learning from triumphs and mistakes in other contexts. However, it was noted that policies cannot simply be translated from one region into another, as they are influenced by the cultural and political contexts of each country.

Lack of research evidence: A lack of research evidence on adult safeguarding was identified and in response, interviewees highlighted that they had to improvise, combining other forms of evidence to make up for the lack of specific safeguarding research evidence and statistics.

4.2.3 Joint Working

Joint working was mentioned frequently by interviewees, highlighting the need for different governmental departments to work together. In particular, Welsh interviewees suggested that the separation of health and social care in Wales was an issue when trying to create

and implement policy, partly because social care was not viewed as being as important as health care. One interviewee suggested,

"You know when people look at health services they say "fantastic, nurses, doctors, brilliant." Then they look at social care and they're like "uh, care support workers," um they haven't got quite the same kudos you know, the same esteem as our nurses do, and lots of that, certainly in Wales is because social care falls under the umbrella of local government, you know the same people that empty your bins and stuff."

4.2.4 Collective Voice and Consensus

Interviewees suggested that supporting organisations and people with a learning disability should try to form coalitions together around common interests, providing a collective voice. Coalitions with members from varying backgrounds such as those with a learning disability, family carers, service providers and professionals, were seen as being extremely powerful in terms of influence. The lack of an organised voice for learning disability was perceived as limiting influence, with an absence of agreement on what needs to change and how.

Moreover, if there was no consensus on a law proposal, policymakers found it difficult to make a decision on whether it should be included in law because of its divisive nature. When speaking about consultations in the interviews, some interviewees referred to the often democratic nature of making sense of consultation responses. In this regard, consensus was referred to a number of times, with agreement from consultees on serious issues being deemed as important. For example, one respondent noted,

"You had a very clear, you know divide there. So in that sort of instance I don't think there was any way that we could have taken that forward given that there was a lack of consensus."

This suggests that in some cases if there was a lack of consensus on a law proposal, policymakers may avoid including it in the law because of its divisive nature. For example, as uncovered in the policy literature, consultees in Northern Ireland were almost evenly divided on whether they wanted to create safeguarding legislation, and this was cited as one of the reasons why a safeguarding policy was created rather than safeguarding law.

However, the same interviewee did suggest that consultation is not always a democratic exercise, that policymakers want to do the right thing and if a consultee puts forward a very salient point that no one else raises, it still holds the potential to lead to a change in the law.

"the more you care,...
the more you understand
the need to do something."
Policy maker

4.2.5 Empowering individuals to get involved

Interviewees felt that people with a learning disability should be prepared and empowered to feedback, critique and get involved in policy conversations. In some cases, engagement with people with a learning disability on policy considerations was not successful because these individuals were giving feedback with limited knowledge of the topic being discussed.

The importance of preparing respondents before the consultation was emphasised. However, conversely, concern was expressed that sometimes people with a learning disability might be too prepared by their organisations, in some cases the person with a learning disability appeared to be putting forward the views of the organisation rather than their own personal views. Moreover, reservations were expressed that some learning disability groups were more influential, and therefore listened to more than others.

Engagement events were deemed to be useful in making policymaking more accessible to people with a learning disability as it was easier to explain concepts through discussion when using tailored materials.

Finally, it was proposed that involvement of people with a learning disability in policy also needed to happen during the implementation period, involving individuals in their own safeguarding once the policy has been completed. In this process, the needs of the individual should be paramount, focusing on what makes them feel safe, rather than prioritising the needs of the organisation.

4.2.6 Barriers to Influencing Policy

Lack of resources and funding:

Lack of resources as an issue in policy and law making was raised a multitude of times by all interviewees, who submitted that the period of austerity which resulted from the economic crash in 2007/2008 was the main reason for the lack of money available to implement policy and law effectively throughout the UK. Policymakers were constrained to a certain extent in what they could include in policies as they were acutely aware that the funding did not exist, but also because they were mindful that anything that may cost extra money was unlikely to be passed by government.

Lack of resources in services, trusts and local authorities was also seen as a barrier to the implementation of safeguarding policy. Interviewees suggested that there was no merit in creating new safeguarding legislation if the law could not be properly implemented due to lack of money. Indeed this could perhaps lead to more safeguarding issues as those in charge of safeguarding adults may struggle as they are, in the words of one respondent,

"Trying to…implement this piece of legislation and there's absolutely no support or resource to allow them to do that."

Social and Political Context: The social and political context was an important factor in policy development including considerations of what will work in the particular social context, what politicians are likely to sign off on, and whether or not the public will be happy with it.

Resistance to Change: Arguably people working within the policy development or safeguarding systems become so accustomed to working in a certain way that it is difficult to break ingrained habits and affect change. New legislation and policies can be an ideal starting point in the journey to altering the way people are safeguarded, but there needs to be a fundamental shift in the way things are done and in the wider environment to ensure that people are effectively safeguarded. In some cases, resistance to change was seen as a risk avoidance strategy, with services trying to avoid risk to such an extent that they were seen as constraining the freedoms of people with a learning disability.

Stigma and Paternalism: Public attitudes to disability and the associated stigma were seen as a barrier to policy influence. This included limitations resulting from overprotective and paternalistic attitudes towards people with learning disability.

Competing Interests: On occasion there were so many groups competing for political and policy attention that it was not possible for all groups to have a voice.

Reactive Policy making:

Interviewees noted that generally policy/law development seemed to follow a 'failure in the system', a 'scandal' or a significant review. It was suggested that a more proactive approach should be taken. For example, one interviewee noted,

"That's the kind of evidence where you say right well we have a big problem here uh and we need to fix it. And so those kind of things which suggest that there is some kind of immediate service level issue um are where we tend to find ourselves focusing because they're where you're going to find something going wrong really quickly."

This theme is common throughout, with interviewees citing high-profile safeguarding cases as events which created momentum for policy changes in their respective countries. Some mentioned that when a serious case was documented in another UK region it gave them pause to think,

"Could that be happening here now?"

4.2.7 Policy Maker Perceptions Summary

As a result of conducting our semi-structured interviews, the perspectives of policy makers, politicians and policy advocates were gathered. Despite geographical and role differences, similar themes were identified, indeed there was some synergy between the issues raised by policy makers and those raised by respondents to the consultation responses.

Policy makers identified that high-profile safeguarding cases tended to create momentum for policy changes, with a more proactive approach to policy development recommended. Moreover, policy makers appeared committed to hearing the voice of people for whom the policy or legislation applied, suggesting that the voice of people with a learning disability was an influential part of the policymaking process and a central source of evidence. Notably, many policy makers also drew on their own personal and professional experiences when working on relevant policy, with many participants identifying a personal connection to either learning disability or safeguarding issues.

4.3 Findings: Learning from best-practice

A case study of the 'best-case' organisation in each of the four nations was completed. The following section will introduce each of the best case study organisations, providing a brief overview of each organisations' history, ethos and organisational structure, whilst also highlighting key learning from that organisation in terms of how the organisations influence policy and legislation. This will be followed by an overview of the collective insights or themes gathered from these four organisations, supported by selected quotations. The four case-study organisations are as follows:

- Mencap, England;
- Positive Futures, Northern Ireland;
- People First, Scotland;
- Learning Disability Wales, Wales.

4.3.1 England: Mencap

Mencap were identified as a best-practice supporting organisation by the research team firstly, because their responses to proposed law reforms were quoted frequently within the Adult Social Care Consultation Analysis, and secondly, as they were identified in our English policymaker interview as a group with policy influence. Two semi-structured interviews and one short focus group were carried out during the visit. One interview was undertaken with two Mencap employees who work on policy and campaigns and the other with two parent carers who came from smaller affiliated organisations. The focus group brought all four interviewees together in a group session to pick up on any unasked questions or unclear answers from earlier in the day.

History and Ethos

Mencap was first formed in 1946 by Judy Fryd, the mother of a child with a learning disability as a reaction to the exclusion of her child from a mainstream school. Her letter to 'Nursery World' magazine which invited other parents of children with a learning disability to respond, received numerous replies from parents expressing anger at the lack of services available to their children. In 1958, Mencap carried out pioneering research into how the living conditions of children with a learning disability impacted on their progression in a number of areas. In particular, the study showed that one group of children who were relocated from an institutional setting to a 'family-like' setting had improved social, emotional and verbal skills; whereas the group who remained at the institution showed no signs of progress. Since 1958, Mencap has grown significantly as an organisation and today they provide services which support the life choices of people supported, campaign and fund research to fight for a better future and

promote inclusion through their projects and programmes.

Mencap describes itself as “The Voice of Learning Disability” and their vision is “a world where people with a learning disability are valued equally, listened to and included.” (Mencap, 2019). In so doing, they aim to reduce stigma, support friendships and relationships and improve health and employment. Mencap describes its values as inclusive, trustworthy, caring, challenging and positive.

Organisational Structure

The Mencap Trustee Board, made up of the chair of the Royal Mencap Society and up to twelve Trustees, are responsible for the governance of Mencap. Trustees are appointed for a four-year term and can serve two terms in total. At least half of the Trustees have substantial experience of a learning disability in a voluntary, personal or professional capacity and at least one Trustee must be a person with a learning disability. A number of matters are reserved for the Board of Trustees, with the rest being delegated to the Executive Team.

The Executive Team prepares budgets, policy and strategy for consideration and approval by the Trustees, who monitor the implementation of these plans.

Policy Influencing Strategy

Relationship with Parent Carers

Mencap approached policy influence mainly from the viewpoint of parent carers, particularly parents of children with a severe learning disability or behaviours that challenge. These parents were seen as having lived experience and personal stories to tell about how their children have been treated by society and the structures within society; health, social care and educational structures specifically.

The relationship of Mencap with parent carers was viewed as mutually beneficial by both parents and by employees, as Mencap were seen as having important contacts with politicians, policymakers and journalists; whereas parents were seen as having important lived experience and the freedom to speak openly and frankly to politicians and policymakers.

Facilitation of Smaller Organisations

Mencap facilitated other smaller groups and organisations such as the Challenging Behaviour Foundation (CBF) and the Stripped of Human Rights Campaign to influence policy through meetings with politicians and policymakers, responding to consultations and help with campaigns and protests. High-profile campaigns and protests carried out by parent carers affiliated with Mencap have led to policy change in the past and will be used again in the future.

Use of Personal Stories

Emphasis was placed on the importance of personal stories by both parent carers and Mencap employees. Personal stories were seen as a powerful form of evidence which could be used to help policymakers and politicians understand the impact their decisions can have on the lives of people with a learning disability and their parents.

Responding to Consultations

Mencap employees reported that responding to consultations was one of their strategies aimed at influencing policy. They formulated their responses using information provided by people with a learning disability and their families.

Importance of Media Engagement

Mencap employees and parents both highlighted the importance of media in drawing attention to policy campaigns and outlined a number of forms they utilised such as TV, radio, newspaper and social media. Social media was seen as a useful platform for people with a learning disability and families to draw attention to aspects of society that they believe need to change.

Close Government Relationships

Mencap felt that policymakers and politicians were likely to engage with them because of their relationship with Government as a "critical friend" who can be trusted not to leak important information to the press; but who also reserve their right to be critical of policies and laws.

4.3.2 Scotland: People First Scotland

People First Scotland was identified by the research team as a best practice supporting organisation due to the reputation of the organisation being led by people with a learning disability and being involved in campaigns on policy. Five semi-structured interviews with both People First employees and members were carried out, as well as a focus group with the People First Law and Human Rights Group; this group is made up of members with a learning disability and a group facilitator who does not have a learning disability. Two of our interviewees were People First members with a learning disability and the remaining three worked in management roles, as development workers or group facilitators.

History and Ethos

People first Scotland was first formed in 1989 when people with a learning disability who attended their first national conference decided that they wanted their own organisation. From the beginning, the organisation was built on the basis that members make their own decisions and create their own policies. Today People First Scotland functions mainly on the basis of both local and

national groups. Local groups are settings in which members come together to gain skills and confidence, campaign on issues of importance to them and build relationships and support networks. There are currently over one hundred local groups within Scotland. National groups include the Parents Group, the Law and Human Rights Group, and the Supporting Offenders with Learning Disabilities Group. Of particular interest to this piece of research is the Law and Human Rights Group, which is made of up members who want to change how people with a learning disability are treated under the law. They have been involved in campaigns on both the Mental Health (Scotland) Act 2003 and the Adults with Incapacity (Scotland) Act 2000.

People First Scotland describes itself as being controlled by its members who all have a learning disability. Members fight to have rights equal to the rest of society, to have fair access to justice, to have jobs with decent wages and to be free from discrimination and hate crime.

Organisational Structure

People First's Board of Directors is made up entirely of people with a learning disability who are elected by members in each area of Scotland. There are varying numbers of director places in each local area as some have greater numbers of members than others. Directors sit on the Board for three years and then must stand down unless they are voted back on. The board receives advice and support from the company secretary, who does not have a learning disability. People First Scotland also has a number of employees such as national and local development workers, who do not have a learning disability.

Policy Influence Strategy

Empowerment

People First employees suggested their approach to policy influence involved encouraging and empowering people with a learning disability to feel comfortable speaking from their own experience in front of different audiences. It was felt that adopting this method and encouraging others to adopt it was one of the best influences they could have.

Preparation

In order to allow people with a learning disability to be involved meaningfully in the policymaking process, People First asked that policymakers send members meeting papers at least two weeks in advance in order to allow time for preparation. Members required this time to allow them to understand the topic to be discussed and to feel confident that they could have useful input into conversations in a meeting setting. People First saw this preparation as essential and spent a considerable amount of time familiarising members with topics relevant to upcoming meetings.

Collaborative Working with Other Supporting Organisations

People First employees mentioned working together with other supporting organisations to construct consultation responses together on specific topics of interest. In this way, the same perspective is repeated in the responses from a number of organisations. Due to the generally democratic nature of consultations (as highlighted in our policy analysis), the more responses that agree on one specific topic, the more likely they are to be taken on board by policymakers.

Playing to Individual Strengths

One People First employee pointed out that when attempting to influence a policy it is important to have someone involved who has a deep understanding of the policy you are trying to influence. Members were seen as bringing extremely valuable insights to policy discussions through their unique lived experiences; however, working out what may need to change in order to improve policy was viewed as something they may require support on. In this way, People First's approach drew on the strengths of both employees and members, with each input strengthening the other.

Practice Influence

People First aimed to influence not only policy but also practice through their placement scheme for student social workers. This was viewed as a useful way to demonstrate that people with a learning disability should be able to make decisions about their own lives and to perhaps help to change attitudes or approaches to people with a learning disability in the world of social work for the future.

Creating Audience-Specific Materials

Members of People First were responsible for creating a potential framework on rights, will and preference for policymakers and politicians which was presented in a professional manner using formal language. This was then pitched to policymakers as an alternative to guardianship laws that currently exist in Scotland. This was seen as a useful way to engage with policymakers as it was written in "their language" and was seen as gaining respect from policymakers. Equally, the group has produced Easy Read leaflets, posters, games and puzzles on the different laws and the proposed changes in order to inform and involve a wide range of members with a learning disability throughout the organisation and beyond.

4.3.3 Wales: Learning Disability Wales

Learning Disability Wales was chosen as a best-practice supporting organisation by the research team as they responded to Welsh safeguarding consultations and were mentioned a number of times in our Welsh policymaker interviews as having policy influence in Wales. Two semi-structured interviews were undertaken with Learning Disability Wales employees (managerial) along with one focus group carried out with an affiliated People First group (Vale People First). Vale People First members had lived experience of a learning disability and were accompanied by the group facilitator and manager who also took part in the focus group.

History and Ethos

Learning Disability Wales is an umbrella organisation for the learning disability sector and was set up under the All Wales Mental Handicap Strategy of 1983. This strategy was seen as a forward-looking policy created to deliver a range of community services to people with a learning disability and their families. As an extension of this, Learning Disability Wales was set up to be the combined voice of the voluntary sector and to lobby for the closure of long-stay institutions for people with a learning disability. Over the years, Learning Disability Wales has expanded its membership and its scope in terms of what it aims to do for people with a learning disability in Wales. Its current strategy which sets out the organisation's plans for the next five years includes three areas of priority- health and wellbeing (being healthy and happy), education (growing and learning in an inclusive Wales) and employment (being able to contribute to life in Wales).

Learning Disability Wales is built upon a number of core values that are outlined in their most recent strategy. These include the beliefs that people with a learning disability have a right to be valued and respected; be seen, heard and included; work; have friendships and relationships and to have access to meaningful education throughout life. These values are described as being based on the belief that we are all born with equal rights.

Organisational Structure

Learning Disability Wales is led by their Board of Trustees, which sets out their strategic direction and is responsible for its management. The charity strives to achieve a board of Trustees that includes their members, people with a learning disability and members of wider society in general who have an interest in their work. The structure of the board of Trustees consists of two main categories: community of interests and open seats. Community of interests reflect the learning disability world, allowing eleven people representing full member organisations to join as Trustees. Open

seats allow five people from wider society who have an interest in the charity's work to join as a Trustee. There are fourteen seats available for Trustees who serve a two-year term of office. Trustees are elected by full members at an annual general meeting.

The Board of Trustees meets four times a year, Trustees delegate financial responsibility and employment matters to the Finance and Human Resources sub-group that monitors accounts, keeping the Board of Trustees fully informed. Trustees also delegate the day-to-day running of Learning disability Wales to its paid staff team.

Policy Influence Strategy

Sharing Personal Stories

Learning Disability Wales employees expressed that one of the best ways for them to have an influence on policy was by encouraging their members to share their personal stories. This was deemed as useful because it can demonstrate the effect that policies can have on people's lives; whether negative or positive. The organisation particularly highlighted the usefulness of projects that members have been involved in- for example befriending schemes or projects to help young people with the transition period from school to adulthood. In this way they aimed to highlight the difference small projects could make in the lives of people with a learning disability and how they could be replicated in a policy environment.

Engaging with Politics

Employees of Learning Disability Wales indicated that Welsh government is very open, making it relatively simple to organise an informal meeting with a politician or senior civil servant. Citizens can also start online petitions to the National Assembly of Wales; if they receive fifty signatures or more, they will be considered by the Petitions Committee. The Petitions Committee can respond in a number of ways, but may run an inquiry, write to the Welsh government or invite the petition creator to a Committee meeting.

Involvement in Policy Technical Groups

One employee mentioned the importance of Learning Disability Wales' involvement in policy technical groups and sitting on policy evidence committees. The organisation tries to participate in as many of these groups as possible, particularly when policies are being formed to ensure that they are involved from the outset. Similarly, Learning Disability Wales is a member of the Learning Disability Ministerial Advisory Group which was described as a powerful group to hold membership of as it helps in forming relationships with policymakers and politicians.

Close Government Relationship

Learning Disability Wales had a close relationship with the government which they felt was useful when it came to having an influence on policy. This relationship led to their involvement in the creation of a number of policies and laws including the Independent Living Framework, the Loneliness and Isolation Consultation, the Additional Learning Needs Bill and the Social Services and Well-being Act.

Collaboration

Due to the nature of being an umbrella group, Learning Disability Wales was connected with smaller groups and organisations who campaigned and held protests. They also facilitated these smaller groups to respond to consultations on laws and policies, to ensure that the voices of people with a learning disability were being heard. The organisation as a whole aimed to bring together smaller service providers, carer groups, family groups and supporting organisations in order to unite the different voices of learning disability.

4.3.4 Northern Ireland: Positive Futures

Positive Futures was selected as a best-practice supporting organisation by the research team as they responded to the Adult Safeguarding Protection and Prevention in Practice consultation document. They were also identified by one of our policymaker interviewees as an organisation who demonstrated a different approach to the safeguarding of people with a learning disability. Four semi-structured interviews were carried out at Positive Futures; two interviewees were employees involved in organisational safeguarding (interviewed together), another worked within senior leadership and two were people with lived experience of a learning disability who were supported by the organisation. A focus group was also undertaken with the organisation's advisory board which is made up of people with a learning disability.

History and Ethos

Positive Futures was established in 1995 as a response to the lack of individually tailored services available to people with a learning disability in Northern Ireland at the time. The organisation supports people with a learning disability, acquired brain injuries and autistic spectrum conditions in a number of settings including supported living services, peripatetic housing support services, and children and family services. Positive Futures also runs a number of special projects to help people with a learning disability live the lives they want to. One of these is the 'Better Together' project which is designed to bring together adults with a learning disability and volunteers who help them to follow their interests. Volunteers support the person for a

period of up to two years and the project's success in helping people with a learning disability to build confidence in themselves and reach goals that otherwise may have been viewed as unattainable, is highly valued.

Positive Futures' values include always putting the people they support first; challenging the status quo and leading the way; being accountable and realistic; never giving up and proactively seeking out partnerships with other organisations.

Organisational Structure

Positive Futures is both a charity and a company limited by guarantee. Their Trustees are directors of the company (and include a member with lived experience) whilst also being responsible for the governance of the charity. Board meetings take place four times a year and board business is delegated to two sub-committees: Finance and HR; and Operations, Quality, Audit and risk management. These sub-committees meet four times a year in advance of full board meetings.

Positive Futures has an Advisory Board with members all having lived experience of a learning disability, acquired brain injury or an autistic spectrum condition. The advisory board meets four times a year to ensure that people with a learning disability, acquired brain injury or an autistic spectrum condition are facilitated to contribute to the management and governance of Positive Futures. The role of the Board is to:

- Review and consider issues arising from key forums across the organisation, including the Board of Trustees, Directors' meetings etc.
- Ensure that the voice of people with a learning disability, acquired brain injury or an autistic spectrum condition is heard and that their views and opinions genuinely inform and shape the management and governance of the organisation.

The Advisory Board reports directly to the Positive Futures' Board of Trustees and to the Directors Team.

Policy Influence Strategy

Organisational Safeguarding Policy Influence

At Positive Futures, people supported by the organisation were involved in creating their own protection plans and were encouraged to chair their own annual review meetings. Employees reported that they would never create a policy that would directly affect people with a learning disability without involving them in its creation, viewing this inclusion as a form of co-production. In this way, people with a learning disability were involved in their own safeguarding and in the creation of the organisation's safeguarding policy.

“their story... was there in front of me and it was very powerful”.
Policy maker.

Creating New Research Evidence

Members of Positive Futures were involved in research projects aimed at improving the lives of people with a learning disability. These projects were viewed as providing new evidence which could be used to help influence future policies; and as demonstrating the importance of having experts by experience involved in research. For example, one project mentioned by interviewees involved people supported in training the Police Service of Northern Ireland (PSNI) and Public Prosecution Service (PPS) in how to communicate best with people with a learning disability who have been the victims of crime. Projects were also seen as helping to build the confidence of people with a learning disability and supporting them in becoming more involved in wider society.

Combining Research Evidence with Personal Stories

Positive Futures employees felt it was useful to combine the personal stories of people supported with independent research in order to influence policy. These stories were seen as personalising issues of importance whilst research was seen as further legitimising and backing up these personal experiences with objective evidence.

Networking and Building Relationships

The organisation spent time engaging and networking with policymakers and politicians and believed that this was essential in helping them to understand how policies and laws affect the lives of people with a learning disability. It was argued that in some cases, politicians were not aware of learning disability policy issues and that for this reason, it was important for supporting organisations like Positive Futures to help educate them on these issues. Networking in general was deemed to be important by the organisation. Building relationships with other organisations, different governmental departments and people working in the media was perceived as valuable for future policy influence.

Having Up-To-Date Knowledge

Positive Futures' employees highlighted the importance of remaining up to date with any safeguarding law or policy changes or inquiries in other countries. Reference was made to the Winterbourne review with employees taking learning from the resultant report, translating the findings into the policies of the organisation. It was suggested that learning from safeguarding failures such as those at Winterbourne were considered in the context of Northern Ireland and used to highlight to policymakers what could be done to avoid similar situations in the region in the future.

Similarly, one employee felt it was important to remain informed about what was going on with safeguarding policy in other countries so that they could attempt to predict what issues may arise

in the future and create methods of prevention for these before they arose. They suggested that policy was generally created or reformed as a result of something that had gone wrong and that more effort needed to be put into taking a preventative and proactive approach.

"Civil servants… they are all very well intentioned but they become so far removed from individuals that it's sort of like right, let me help you to draw the thread from that policy down to that person… and I think a way to help the people so high up understand that is to illustrate discussion with story, preferably from the person's mouth".

4.3.5 Overall Insights Generated from the Case Studies

A number of important insights were identified across the case study organisations. These have been summarised in the themes below.

Evidence

Interviewees discussed using a number of forms of evidence to inform their arguments on the need for policy or policy reform.

Personal Stories/Lived Experience

All organisations advocated for the importance of using the personal stories and lived experience of people with a learning disability as evidence of how policies and laws have caused harm to, or improved people's lives. Personal stories were viewed as humanising policy conversations and ensuring that policymakers were aware that whatever law or policy they created would affect real people in their region. One interviewee suggested,

Official Reports from Governments and Organisations

Organisations reported using official reports and formal reviews to inform their influencing strategies. Official reports and recommendations made by professionals were viewed as having a certain level of authority on policy issues and lending weight to the points they were making.

Research

Research presented alongside personal stories and lived experience of people with a learning disability was viewed as adding greater legitimacy to evidence. Independent research was seen as objective, impartial and removed from the campaigning side of policymaking.

Organisations also demonstrated their own involvement in research projects, with people with a learning disability taking on the role of researchers in a number of projects. This was viewed as a way for people with a learning disability to directly contribute to primary research knowledge.

Learning from Other Countries

Organisations evaluated how other countries managed safeguarding and affected change in terms of learning disability safeguarding, and other related issues such as the role of guardianship.

Forms of Influence

Direct forms of influence included campaigning and lobbying; use of media; projects; training professionals; tailoring outputs to different audiences, engaging with politics and consultations.

Campaigning

All organisations were involved in campaigning in some form. Campaigns were seen as useful in keeping public and political attention on an issue, as it was perceived that scandals were usually forgotten quite quickly. Campaigns also helped some individuals in organisations to gain important contacts, for example as one interviewee stated,

"And then of course as I started getting more and more…involved with the campaigns here, um I became more up there with the journalists you know, with the media and all that".

In some cases, smaller groups were supported by larger organisations to hold campaigns and protests.

Media

Organisations reported using multiple forms of media to influence policy such as newspapers, TV, radio, and perhaps most importantly, social media. Social media was seen as a useful way to gain public attention and making use of tools such as online petitions was deemed as potentially very influential. Organisations used the media to promote themselves and the work they do to improve the lives of people with a learning disability. They also raised issues with current law or policy in the media to gain and maintain public and political attention.

Forming working relationships with people in the media was viewed as useful in keeping important issues in the public eye, for example, if smaller organisations were backed by a large charity organisation (who often have media contacts), they were more likely to be approached by journalists.

Projects

Projects were seen as increasing the independence of organisation members and allowing them to participate in things that might not be available to them outside their organisations. Projects were also viewed as improving the social lives of members, helping them to be seen, included and involved in wider society as much as possible. They were also used to demonstrate how more person-centred policies and laws could lead to positive change in the lives of people with a learning disability.

Training Professionals

Organisations recounted times when people with a learning disability had trained professionals on issues that affect them, for example members of one organisation trained the police on how to engage with people with a learning disability who had been the victims of crime.

Tailoring Information Outputs to Different Audiences

Tailoring information outputs to different audiences, for example by using different forms of language, different layouts or sharing the information in different formats was seen as an important influencing strategy. One organisation created a framework about Rights, Will and Preference as a replacement for guardianship. This was done with their organisation's committee (made up of people with a learning disability) and then 'translated' into professional language. One interviewee, when speaking to organisation members recalled,

"I do think that your (the committee members) framework, your booklet… did sway more people than other things. Writing something in their (policymaker's) language that addressed their concerns was a new thing for this organisation because usually we've tried to put things out in an accessible format for all of the members. This time you did it differently, you said we need to write it for the professionals, answering their questions. And I think that had made a difference, I think you got more respect for it because you were able to do that."

Consultations

Given the more distant involvement in specific safeguarding consultations for some organisations, questions were asked about policy influencing generally. All organisations saw consultations as a way to try to influence policy and reported looking out for important consultations that may be of relevance to people with a learning disability. In some cases, workers within organisations said they would formulate consultation responses themselves, but generally if a consultation topic was seen as potentially impacting on the lives of people with a learning disability, organisations expressed that they would involve them in creating a response. Although organisations utilised consultations to try and influence policy, they were unsure about their effectiveness in doing so. Interviewees raised a number of issues with consultations as they currently stand, for example, the cost to organisations, timing, issues with Easy Read, and fatigue.

Organisations responded to consultations with the belief that in some cases their inclusion and by extension, the inclusion of people with a learning disability, was afforded only "lip service". Interviewees frequently mentioned that they were consulted too late in the policymaking process with consultations released when it was too late to have any meaningful input.

Another barrier to influencing consultations raised by organisations was the quality of Easy Read used. While some organisations did suggest that Easy Read quality has improved over the years, others believed it was still not at an acceptable standard. Two organisations suggested that Easy Read often oversimplifies what is in the proposed policy or law and rather than outlining and explaining the contents, will describe how people's lives will be improved. One interviewee argued,

"It's patronising, it doesn't cover the issues, it doesn't ask the issues you know properly, it dumbs down, it dumbs down and it's very patronising I believe".

It was suggested that in order to fully explain a policy document, an Easy Read version needs to be much longer than the original. This idea was based on the reasoning that Easy Read would require a larger font, perhaps more explanatory diagrams and would need to devote more time to explain complex issues. Issues around cost were also highlighted, for example, costs occurred in providing support to complete a written response or on travelling to a consultation event.

Finally, most organisations and members with a learning disability suggested that they were often sent such a large number of written consultations, often on the same subjects, that they had become tired of responding. This appeared to add to the feeling that their views were not being listened to.

Joint Working

Organisations stressed the importance of working with other organisations, professionals and government departments in order to influence policy. Engaging with policymakers in a co-ordinated manner was emphasised as a "collective voice" approach, with one organisation suggesting it is highly important to ensure that organisations share the same message. If groups provided mixed messages, it was believed that policymakers and by extension, the Government would be unlikely to act in order to alter policies and laws. Similarly, some organisations recounted working on consultation responses as a collective with other groups, agreeing what viewpoint they were going to take on certain issues and then going on to create their own separate responses. In this way, more responses were put forward with the same suggestions, strengthening the particular point of view being submitted.

Organisations also suggested that government departments need to work together more effectively, this was particularly salient in the English and Northern Irish context. English interviewees argued that there is a necessity for joint working across children and adults and for cross-government strategies on learning disability. One interviewee reported,

"The support's not there in the community because health and social care are separate. So you know for years everyone's been talking about integrating health and social care and making them work together but it's never really happened."

Moreover, in Northern Ireland interviewees reported that the five Health and Social Care Trusts who oversee social care all have their own interpretations of the safeguarding policy, which can lead to skewed statistics and to people receiving a different safeguarding experience depending on location.

Organisation and Preparation

The importance of preparing people with a learning disability in advance for meetings with policymakers was highlighted. One member with a learning disability stated,

"I think for me it's about um planning with a member of staff who then supports us to make sure we get our voices across uh and listened to."

Organisation and preparation were also discussed in relation to coming to meetings or responding to consultations with strong, well thought-out arguments and being solution-focused rather than simply pointing out problems.

It was also noted that policymakers needed to be better prepared and organised to include people with a learning disability in policy discussions. People with a learning disability need to have access to meeting papers in advance, and advance notice of when meetings will be held. The need for politicians and policymakers to use clearer language and terms was also cited as significant in fostering policy understanding, not only for people with a learning disability, but for the public in general.

Networks, Relationships and Reputation

Interviewees suggested that strong networks and relationships were highly valuable in order to have a real and lasting influence on policy, particularly, media, politician and policymaker contacts. Building relationships with people of influence and having successful working relationships with them could also lead to building a reputation of having useful inputs to policymaking which could be important in securing further contact with the same, and potentially new policymakers. Having a politician involved in your organisation, for instance as a Trustee, was deemed to be a very useful way to gain political attention to learning disability policy concerns.

These relationships were said to have reciprocal value for both supporting organisations and policymakers. It was suggested that not everyone who works in policymaking will have had experience with learning disability policies.

"I think it's really important to help our politicians, because a lot of them don't have a background in social care, they don't understand what it is that we're trying to do, you know in terms of trying to support someone with a learning disability. So I think we have a really important- I think it's very easy to criticise our politicians but I think we should be prepared to put the effort in to be helping them to become more knowledgeable because the more knowledgeable they are, the better they will be at making policies and at making changes."

Organisational networks were also deemed as critical in the lives of interviewees with a learning disability. For some they were important in helping them to form relationships and social networks with other people, and for others they allowed them to build confidence and belief in themselves. These networks were also useful for families and carers. One interviewee with a learning disability reported,

"It's (the organisation) helped me find kinda belief in myself that you can do things that a lot of people thought you couldn't do."

Political Engagement

Organisations outlined the considerable impact being involved in politics can have on policy influence, suggesting a number of ways in which to do so, for example through drawing up petitions for government, creating guidance for government, trying to work with different political groups and having membership of parliamentary committees.

Three of our organisations gave prominence to the creation of petitions, generally online, as a useful way to engage with politics. These could be shared on organisation websites or social media in order to gain attention, and in some cases only required a small number of signatures to be discussed by parliament.

Some politicians in the UK appeared to be more open to engagement from citizens than others. For example, our Welsh organisation indicated that meeting Welsh politicians and civil servants in an informal environment was relatively easy. They also reported that the National assembly in Wales has an outreach team which works with people with disabilities to help explain the inner workings of government, for example by clarifying the difference between parliament and government, introducing them to the different departments and advising them on how to engage with influence.

In general, membership of groups who engage with policy, such as policy advisory groups or evidence committees was deemed very influential by all organisations, as these kinds of groups are often involved in the policy formation process from the outset. In particular, membership of cross-party/all-party policy groups was emphasised as important by interviewees, who believed that engaging with multiple parties would focus more attention on an issue, making change more likely.

Organisational Influence of People with a learning disability

People with a learning disability appeared to have significant influence in our case study organisations. In a number of the organisations, members sat on the board and in some cases boards were made up entirely of people with a learning disability. In others, people with a learning disability had influence on their care and protection, were members of advisory groups and were involved in recruitment of staff. One organisation which had a board made up entirely of people with a learning disability highlighted that they hold meetings without support staff present. These meetings were generally facilitated by a trusted individual who was not involved in a caring role. People with a learning disability reported that they preferred this method as they felt more comfortable discussing issues without their support staff present. This was also seen as a way of raising the independence of members and enabling them to assert themselves without support, a skill which could be transferred to a policy influence environment.

Barriers to Influencing Policy

Stigma

People with a learning disability interviewed in this study felt that some policy makers demonstrated a lack of respect towards them and could be dismissive of their views and opinions. Organisations and people with a learning disability suggested that social stigma and prejudice is still a prevalent issue in society and that this can often feed into policymaking. One possible reason for this enduring stigma pointed out by interviewees was the lack of visibility of people with a learning disability in wider society. Interviewees spoke about the everyday experience of people with a learning disability being seen as less valuable and suggested that in order for there to be real change, society's view of people with a learning disability needs to be altered.

Lack of Accessibility

Lack of accessibility of meetings and consultations was seen as a barrier to policy influence. At times, meetings were not inclusive and some politicians seemed to find it difficult to alter their language to suit a learning disability audience. One interviewee reported,

"Once members are actually at that meeting and maybe the people around the table are using lots of jargon or maybe a lot of long, complicated words… it's difficult then to participate in that meeting um because members are not necessarily sure what's being discussed."

This disproportionately affected people with a severe learning disability and those who lacked capacity. One organisation ran a three-year project aimed at uncovering the best ways to help people with a learning disability to have policy input. The findings showed that involving people with a severe learning disability required getting to know them very well by spending a lot of time with them, being responsive, not making assumptions, being creative and trying out new ways to draw out information.

Political Disruption and Instability

Political instability had a generally negative impact on the ability of organisations to influence policy. Interviewees felt that the uncertainty of Brexit was drawing attention away from social care issues that they felt were urgently important. Moreover, a lack of continuity with and between politicians also caused issues, with roles often changing at inconvenient times. This often meant that while one politician may have held a certain viewpoint on policy reform, the person who took their place may not continue with this line of thinking.

One interviewee highlighted the feeling of disappointment this can cause in people with a learning disability, especially when they have built up a positive working relationship with a politician and start to believe that they are making progress towards policy changes.

"I think she (politician) was somebody who could relate and who could understand where we were coming from um and it was a bit of a disappointment when she had to be moved on to another post."

Resistance to Change and Reactive Policymaking

Organisations suggested that policy is often created or reviewed due to high-profile cases of abuse or neglect, and argued that a greater emphasis needed to be placed on preventing abuse from taking place in the first instance. One interviewee believed that,

"Traditionally what happens is that there's a scandal, there's a sort of, a lot of activity for a short period of time… that service is closed um and then it just carries on as normal."

Organisations also proposed that policy is often not altered because there is a resistance to change in government. It was put forward that this resistance often arose when politicians and policymakers had spent a lot of time and money on a new policy, and were therefore averse to acknowledging any of the negative aspects that people were identifying. One interviewee suggested,

"So there's that sort of inertia of politicians being very proud of what they've done… and there's that sort of resistance to change."

"It's (the organisation) helped me find kinda belief in myself that you can do things that a lot of people thought you couldn't do."
Organisation member

4.3.6 Summary of Case Study Findings

A number of important insights were gathered as a result of our case study interviews and focus groups with supporting organisations within the four nations of the UK. Organisations and members with a learning disability felt that the most useful sources of evidence they could utilise were the personal stories and experiences of people with a learning disability. These were viewed as humanising policy discussions and demonstrating the impact policies can have on the lives of real people.

Organisations used the media (including social media), projects, public campaigns and consultations as forms of influence and as ways in which to share the personal stories of people with a learning disability, all of which they believed worked to varying degrees. In particular, consultations were seen as a useful form of influence, however issues with the quality of Easy Read and the timing of consultations were raised as potential barriers to influence.

Other barriers to policy influence raised by people with a learning disability and supporting organisations were the lack of accessibility of meetings with policymakers and politicians, the stigmatisation of people with a learning disability in society, resistance to change in the social care system and political instability as a result of events such as Brexit or the collapse of the Northern Irish Assembly.

4.4 Findings: Online Survey

An online survey was produced using SurveyMonkey and was sent to supporting organisations who contributed to safeguarding policy consultations in the four nations of the UK (identified in the policy analysis of this project), and in addition it was disseminated through the Association for Real Change network.

The survey comprised a series of questions designed to capture certain characteristics of the respondents and their views and experiences of influencing adult safeguarding policy and procedures, including barriers and enablers. The survey was sent to over two hundred organisations and received forty-three responses. The survey results are presented below.

4.4.1 Respondent Characteristics

The majority of the organisations who responded to our survey provided services in Northern Ireland and Scotland. Of the total number of responses, 24 out of 43 respondents worked at care provider organisations, with the remaining 19 working in either research, in advocacy and community groups, in local government or at NGOs.

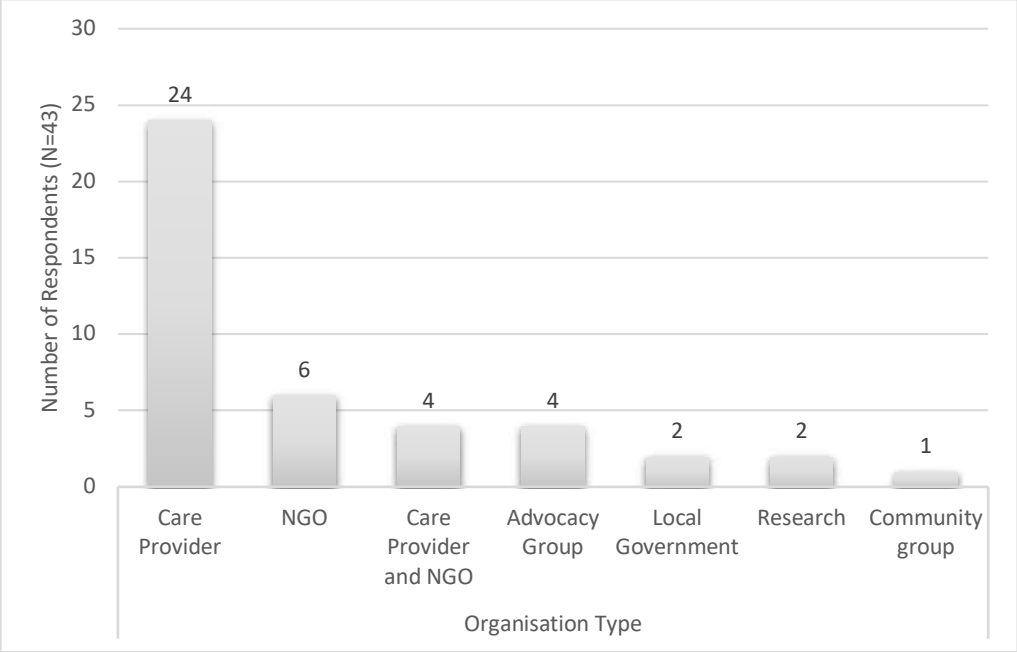

Figure 1. Number of respondents by type of organisation.

Of our 43 respondents, 31 worked in managerial, higher managerial or directorial positions in their organisations.

4.4.2 Survey Results

Decision-making Involvement of People with a learning disability

As highlighted in Figure 2 below, 23 out of 43 respondents stated that people with a learning disability were involved in decision-making at their organisation, 14 said they were not, and the remaining respondents answered 'other'. Some of the 'other' responses stated that the respondents try as much as possible to involve people with a learning disability, that they include them if and when available, and that they are included if policies will have a direct impact on their lives.

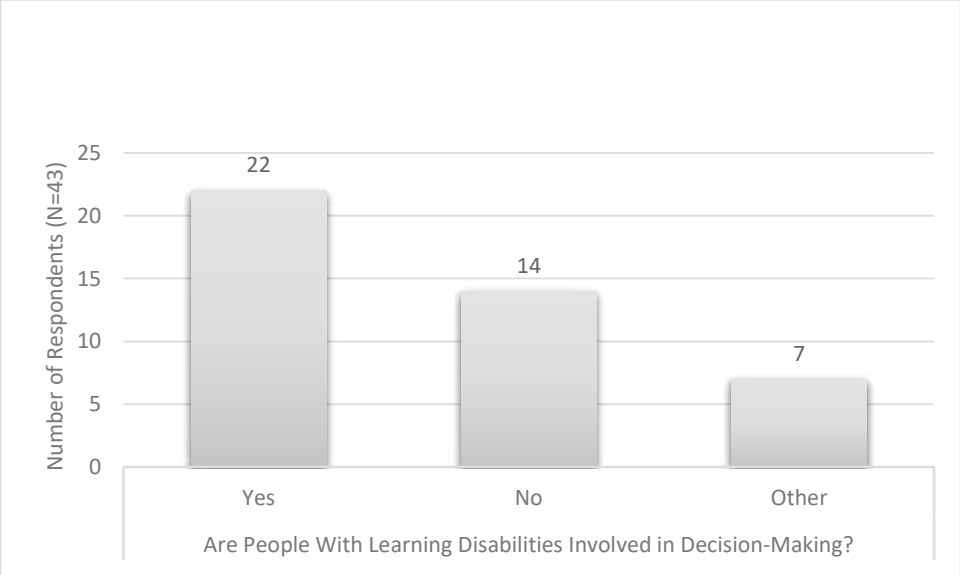

Figure 2. Extent to which people with learning disabilities involved in organisational decision making.

Respondents reported that people with a learning disability were involved in policy discussions mainly through the use of advisory groups, focus groups or questionnaires.

Policy Areas Focused on

Organisations decided which policy areas or issues to focus on by keeping up to date with changes in legislation, by looking at issues that were being publicly highlighted, and by examining issues that currently affected their organisation and

the people supported by their organisation. Four respondents suggested that policy areas focused on were service user led.

Policy Influence

As demonstrated in Figure 3, most respondents reported that their organisations seek to influence government policy somewhat, with 18 out of 43 falling within this category. Twelve respondents said they seek to influence very little, with 11 choosing 'to a great extent'. Only two respondents said that their organisation does not seek to influence government policy at all.

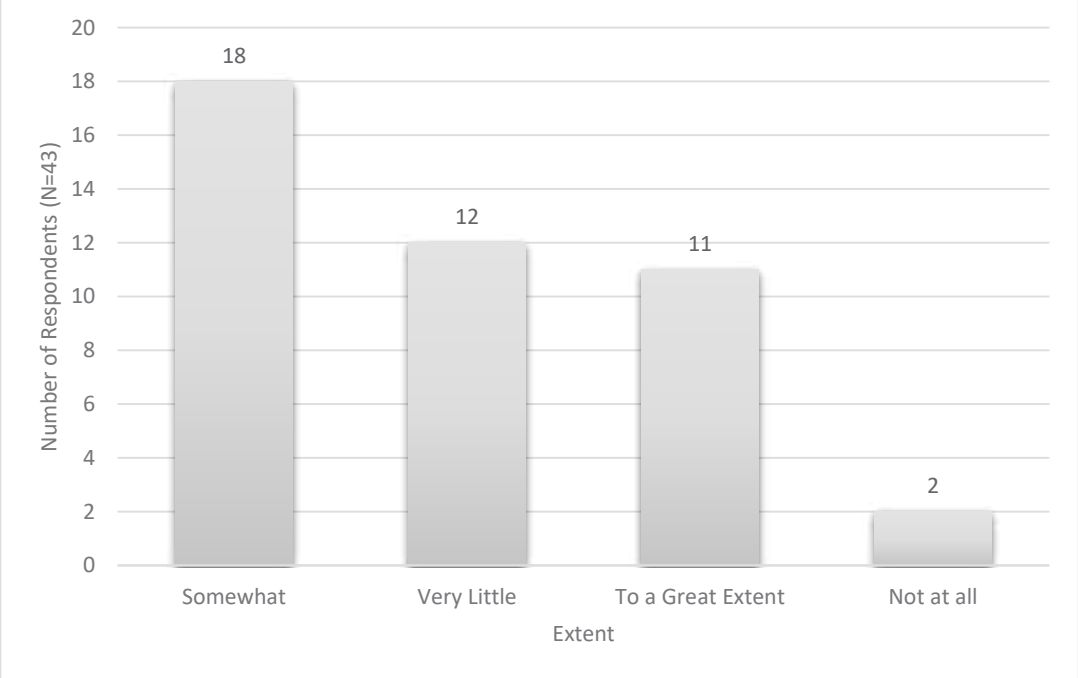

Figure 3. Extent to Which Respondents' Organisation Seeks to Influence Government Policy

Success of Policy Influence

Of the 43 respondents asked to rate the success of their organisation in influencing safeguarding policy, 34 thought they had been successful to some extent. Nine respondents felt that they had not been successful in influencing policy. We are unable to tell from these figures whether this was because they tried to influence safeguarding policy and it was unsuccessful, or because they did not try to influence safeguarding policy.

Who is Involved in Policy Influence?

Twenty-six out of 43 respondents reported that senior leadership were involved in trying to influence safeguarding policy in their organisation. Fourteen people said that everyone in their organisation was involved in attempting to influence policy and 12 people said that people with a learning disability were involved. This was a multiple choice question and respondents were encouraged to 'tick all that apply'.

When asked what their organisations do to influence policy, most respondents said that they networked with other organisations, provided training and responded to consultations.

Forms of Evidence Used

Respondents were asked to choose which forms of evidence they thought were most useful when attempting to influence policy and were enabled to choose multiple options. Results (in Figure 4 below) show that personal testimonies and case studies were deemed the most effective forms of evidence to use when seeking to influence policy.

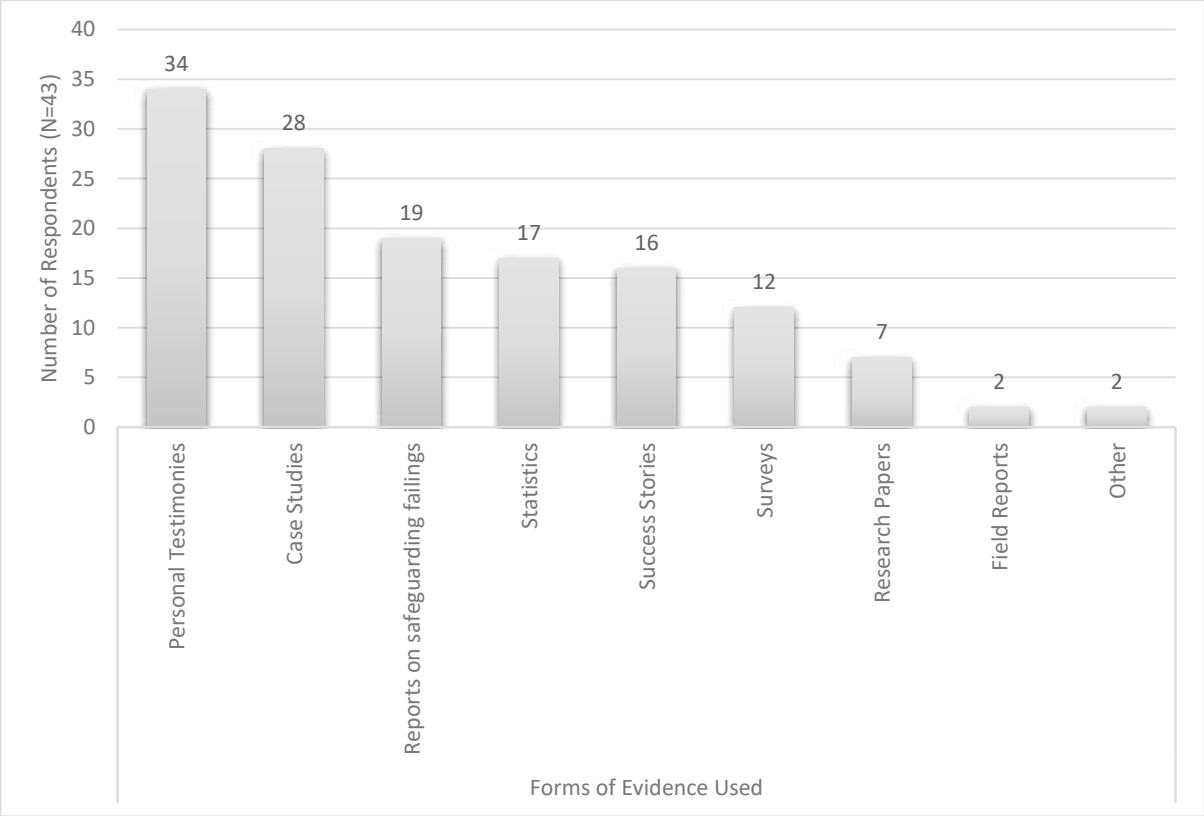

Figure 4. Types of evidence considered most effective when seeking to influence policy.

Examples of Policy Influence

When asked if they could provide an example of when their organisation's activities had a definite influence on policy, 16 respondents answered that they could not. Six respondents answered that the question was not applicable, but the remaining 21 respondents felt that their organisations had had influence, citing examples such as user involvement, changes to government guidance, changes in format of safeguarding documentation and having helped to inspire the Self-Directed Support Act (2013) in Scotland.

Barriers to Policy Influence

Respondents answered that the three most important barriers to influencing policy were staff and members not having sufficient capacity, staff not having enough time and not having enough knowledge about policy processes.

4.4.3 Online Survey Summary

Our survey results complemented the results of both our policy maker interviews and our case studies. A high proportion of our respondents told us that their organisations tried to influence government policy, with senior leadership being the most likely to engage in this activity. In order to have an influence, members generally responded to consultations, networked with other organisations and provided training. Respondents found that the most useful forms of evidence were personal testimonies and case studies, followed by official reports and statistics. Around eighty percent of respondents felt that their policy influence attempts had been successful to some degree and cited examples that emphasised engagement of people with a learning disability, changes in proposed policies and helping to develop laws. Respondents saw the main barriers to policy influence as being related to lack of time of staff and lack of knowledge of staff and members of policy processes.

5. Discussion

5. Discussion

Pearson and Trevisan (2015) have outlined the history of disability activism in the UK since the 1960s. In the 1960s the focus of activism was on the social and economic exclusion of disabled people. This developed through the 1970s to 1990s when the emphasis moved to civil rights, anti-discrimination legislation, power and direct payments for independent living. Since 2010, the public spending cuts involved in austerity have created additional barriers to social and economic inclusion and there has also been a growing awareness that a wide range of adults are at risk of harm from abuse, exploitation or neglect. Alongside this realisation, the intrinsic ethical concerns in balancing the autonomy of disabled people and the need for State protection has come to the fore.

Approaches to keeping safe are a central concern in promoting independent living, as adults with a learning disability often experience higher levels of abuse than other adults, including other individuals in receipt of social care services (Fyson & Kitson, 2010). Determining the extent of abuse is difficult, in part because abuse often goes unreported, however, figures from Adult Safeguarding Boards across the UK indicate that people with a learning disability are subject to disproportionately high levels of mistreatment. For example, in 2015/16, fifty-five adults in every ten thousand of the population of Northern Ireland were referred for suspected abuse and thirty-two percent of these referrals were in relation to adults with a learning disability (NI Adult Safeguarding Partnership Annual Report 2015/16).

Arguably, an effective adult safeguarding framework should aim to give people with a learning disability equal access to justice and protection systems while fostering their safety, autonomy, independence, social inclusion and confidence. Devolved governments across the UK have divergent views about appropriate governmental roles and responsibilities vis à vis those of their disabled citizens. There are concerns about overly interventionist responses to low levels of abuse that may result in further trauma to the adult concerned. Conversely, minimalistic responses to serious cases can result in significant trauma for disabled people which have, on occasion, led to death. Ultimately, there is the need to balance autonomy with intervention, in the context of an individual's decision making capacity. Debate continues as to how best to achieve this balance.

Policies and practice in respect of adult safeguarding are evolving. Safeguarding policies are developed in the context of general health and social care services, policing, community and public awareness strategies which also help to address the oppression, exploitation or discrimination of disabled adults. However, it is imperative that individuals with a learning

disability should have a say in how these are developed. This is particularly more pertinent in light of the positive developments in other aspects of service delivery. The status afforded to users of services as 'experts by experience' has empowered individuals to gain some control of their care whilst providing opportunities to contribute to service development (Social Care Institute for Excellence (SCIE), 2011). Co-production initiatives are gaining momentum. Partnerships with service users are utilised to create changes in the way health and social care systems are designed, planned, commissioned and delivered.

There is already extensive literature around the policy making process, presenting an understanding of political systems and the process of policy development (e.g. Cairney and Weible, 2017), alongside reviews of the role of evidence in policy making, and effective strategies for influencing policy (e.g. Mayne et al., 2018).

For example, Involve (2018) have identified the main stages in the policy making cycle as: political vision; policy formation; policy proposals; decision making; and implementation. Strategies to inform and influence policy development include those developed by Cairney and Kwiatkowski (2017) who present a three step strategy to communicating with policy makers:

- "Understand your audience. To help tailor your approach to the cognitive processes present in human beings, synthesise evidence concisely to minimise its cognitive burden, and 'frame' your conclusions rather than expecting evidence to speak for itself.
- Identify the right time to exploit 'windows of opportunity'. 'Timing' can refer to the right time to influence an individual, depending on their current way of thinking, or to act while the political conditions are just right.
- Engage with real world policymaking rather than waiting for a 'rational' and orderly process to appear. To present evidence during mythical stages of a 'policy cycle' may be misguided, and to 'speak truth to power' without establishing trust in networks and an open culture in organisations may be counterproductive." (Cairney and Kwiatkowski, 2017:2).

Mayne et al. (2018) have distilled their analysis of how to inform and influence policy into four key points: "(1) learn how policymaking works, (2) design evidence to maximise its influence on specific audiences, (3) design and use additional influencing strategies such as insider persuasion or outsider pressure, and adapt the presentation of evidence and influencing strategies to the changing context, and (4) embrace trial and error." (Mayne et al., 2018:2).

However, there should be additional considerations for policy development when the focus is on disability. The research evidence would suggest that people with a learning disability are often under-represented in policy making

processes in general, even when the focus is disability (Irvine, 2017). Most people, with or without disabilities, need support to effectively participate in the policy process.

The findings from this study identified the perspectives of both policy makers and those who have sought to influence adult safeguarding policy, on how to increase the influence of people with learning disability on policy development. We will here review the key learning from each group.

5.1 The impact of Consultation Processes: The story so far

In the first stage of this project we examined the consultation processes in each jurisdiction, collating the responses from individuals who have a learning disability and their supporting organisations, and examining the ways in which developing safeguarding law and policy was informed by these responses. In so doing it became apparent that across the UK those individuals with a learning disability, and organisations who supported them, raised similar issues in response to the consultations. Issues raised included the need for clarity around definitions, difficulties with implementing safeguarding policy, issues relating to capacity and consent, the need for advocacy, and the central importance of negotiating the balance between autonomy and control.

More specifically, four key issues were consistently raised by consultees:

1. Definitions of who and why people need to be safeguarded. The definition of a person at risk was seen as the foundation of safeguarding law or policy; concern was raised that definitions could be over-inclusive, stigmatising or too exclusive. Similarly, the definitions of 'abuse', 'harm' or 'risk' were critiqued.
2. Approaches to consultation. Consultation processes need greater consideration of accessibility, time and resources to facilitate planning and preparation with people with a learning disability. Public engagement events seemed to work better than written responses to consultations.
3. Impact of consultation and engagement. Whilst many agencies and individuals made considerable effort to respond to consultations and participate in engagement events, the impact of sharing the views and experiences of people with a learning disability on safeguarding policy developments was less clear. Timely and transparent processes are required to demonstrate how the input from people with a learning disability impacted on safeguarding policy.
4. The implementation of safeguarding policy/law. Resource concerns were identified within the context of the current

economic climate of austerity. For this reason, consultees highlighted that new laws would be created but the resources to enact them may not be provided. There were also concerns about the slow pace of change and the negative impact of resistance to change.

The ways in which governments sought the views of citizens with a learning disability about policies and legislation that impacted them differed across the UK. Variations were found in the number and timing of consultations and public engagement events. A correlation between the number of face-to-face engagement events and the number of responses was identified. Consultations at the beginning, middle and end of the policy or legislation development process were favoured, as this allowed supporting organisations and people with a learning disability to voice their opinions on the proposed law at the beginning of the process, giving them an opportunity to help shape the law, and again at the end, allowing for scrutiny of the almost finished product.

The written responses to consultation representing the views of people with a learning disability were limited in number (ranging from a total of five responses from supporting organisations in Northern Ireland to twenty-seven supporting organisation or service user responses in England). Engagement at the workshops may have made up for these numbers, but we do not have access to what was said at, or the outcomes of these workshops, to determine their value.

Finally, Table 2 in the Findings Chapter identified those issues that were raised by the consultation process and identified the ways in which these issues were or were not addressed in the subsequent safeguarding policy or legislation. In terms of impact, a mixed picture was evident. Many issues raised in consultation did appear to impact the final policy and/or legislation. However, in most jurisdictions, the fundamental aspects of the policy or legislation were already largely written before feedback was sought, arguably limiting the opportunity to shape safeguarding practice.

5.1.1 Learning from policy makers

The perspectives of policy makers, politicians and policy advocates were gathered. Despite geographical and role differences, similar themes were identified. These included: the strengths and challenges of engaging with people with a learning disability, the need for high quality evidence provided by respondents with real-life experiences, and the challenges of policy development. There was some synergy between the issues raised by policy makers and those raised by respondents to the consultation responses. For example, all groups identified that high-profile safeguarding cases tended to create momentum for policy changes, with a more proactive

approach to policy development recommended.

Generally, policy makers appeared committed to hearing the voice of people for whom the policy or legislation applied, suggesting that the voice of the service user was an influential part of the policymaking process and a central source of evidence. As identified in other studies (Mayne et al., 2018), whilst the knowledge of professionals, evaluations of previous policies, and 'frontline' practitioner wisdom was deemed to be useful in finding out what was or wasn't working in practice, it did not provide a full picture of how a policy or law would work. Policy makers consistently agreed that it was important to involve people with a learning disability and supporting organisations in the policymaking process from the outset and throughout the policy making process. The best way to do so appeared to be through face-to-face conversations and discussions which were consistently considered to be more useful than written consultations. Questions around when and how best to engage service users were identified by all policy makers. A high value was placed on personal stories and experiences, presenting a "simple and persuasive story" (Mayne et al., 2018:2). Personal accounts of safeguarding issues helped policymakers decide if a proposal was the 'right thing to do', and was often identified as integral to the creation of a new law or policy.

Notably, many policy makers also drew on their own personal and professional experiences when working on relevant policy, with many participants identifying a personal connection to either learning disability or safeguarding issues.

5.1.2 Learning from the case studies

A case study of the best-case example in each of the four nations was completed. The use of exemplar case studies of organisations that have been successful in policy influencing has been identified as an effective approach to learning in this area (Mayne et al., 2018). We selected a best-case example in each of the four nations (Mencap, England; Positive Futures, Northern Ireland; People First, Scotland; and Learning Disability Wales, Wales). To various degrees, each of these organisations had people with a learning disability in leadership roles within their organisation. Moreover, we were impressed by the level of organisation and preparation of their members who acted as respondents in this research.

A number of important insights were collected as a result of the case study interviews and focus groups. Many of the themes mirrored the issues which were considered important by the policy makers. For example: all organisations advocated for the importance of using people's personal stories and lived experiences, including evidence of how policies and laws had caused harm in people's lives or had improved lives. Respondents who had a learning disability suggested that being given a chance to tell

“Personal stories were seen as humanising policy, ensuring that policymakers were alert to the impact they had on real people and their wider networks.”

their personal story was often a positive experience for them. As Mayne et al. (2018), suggest, “The messenger is as important as the message” (Mayne et al., 2018:7). Personal stories were seen as humanising policy, ensuring that policymakers were alert to the impact they had on real people and their wider networks, as identified in other contexts (Hillier & Wood, 2003).

Additionally, both policy makers and organisations highlighted the need for collaboration in policy development; an identified need to work together to build ongoing trusting relationships and alliances and to have a collective voice on issues of importance. Coalitions are important; with an encouragement for organisations to consider coalitions around a common theme and where possible agree on shared standpoints on core issues. Within this context, smaller organisations may find it useful to have an affiliation with a larger organisation, and rural outreach programmes may be needed for people with a learning disability living in rural areas.

5.1.3 Learning from the online survey

To a large extent, our survey results complemented the results of both our policy maker interviews and our case studies. A high proportion of our respondents told us that their organisations tried to influence government policy, with senior leadership being the most likely to engage in this activity. In order to have an influence, respondents responded to consultations, networked with other organisations and provided training, for example, on how to make information Easy Read, and on how people can better engage with people with a learning disability. Similarly, the most influential forms of evidence were seen as personal testimonies and case studies, followed by official reports and statistics. Encouragingly approximately eighty percent of organisations who responded to the survey perceived their policy influence techniques as successful, at least to some degree.

There was a high level of synergy across the different groups from which we gathered evidence. These have been summarised to identify the following barriers and enablers to policy influencing.

5.1.4 Barriers to Getting our Voices Heard

Lack of resources or funding

Policymakers were both constrained and enabled by the wider political and socioeconomic systems. In the current climate of austerity, any recommendation that would cost extra money to implement was deemed to be unlikely to be passed by government. This significantly influenced policy makers’ ability to include measures identified in the consultation process. Additionally,

supporting organisations expressed concerns that safeguarding legislation and policy would be created but the resources to enact them would not be provided.

Lack of time and limited knowledge

Some respondents indicated that one barrier to policy influence related to lack of staff time and limited knowledge of policy processes amongst staff and members. Moreover, there is a need to expand knowledge of policy making processes and strategic ways to influence policy which can build the capacity and confidence of people with a learning disability, allowing them to exert influence on safeguarding policy.

Social and political context

Consultation responses to potential policy and legislation developments generally reflect societal and professional attitudes which change over time. Recommendations were likely to be shaped by societal attitudes. Thus when creating policy, policymakers noted there were a number of considerations to make such as what would work in the particular social context, what politicians were likely to sign off on, and what the public would be happy with.

Resistance to Change

Staff within the Health, Social Care and Criminal Justice systems were seen to be accustomed to working in certain ways, with perceived difficulties in affecting change. In some cases, resistance to change was seen as a risk avoidance strategy, with services trying to avoid risk to such an extent that in some cases, they were seen as constraining the freedoms of service users.

Stigma and paternalism

Public attitudes and the influence of stigma towards people with a learning disability impacted on their ability to have their voice heard. Moreover, overprotective and paternalistic views towards people with learning disability limited their ability to have an influence on policy.

5.1.5 Enablers to Getting our Voices Heard

Face to face consultations

Face to face consultations were seen as most influential for supporting organisations and people with a learning disability. Optimal consultations appeared to occur at the beginning, middle and end of the policy making process; and engaged respondents who were prepared and supported to address the key issues.

Accessible and timely resources

Optimal engagement through written responses was based on consultation documents which were disseminated

widely across supporting organisations, presented in Easy Read format with Easy Read questions for consultation, and with a realistic timescale for preparation and response.

Collaboration across agencies

Coalitions with other organisations around a common theme are encouraged. An agreement on shared standpoints where possible, provide a stronger voice. In particular, the opportunity for smaller organisations to have an affiliation with a larger organisation, which may have more contacts and resources to help with gaining influence, was seen as useful. However, it is also important to allow consideration of different experiences and to be inclusive and responsive to the unique views of members of smaller organisations in various localities.

Personal stories

Personal stories were seen as a powerful form of evidence which could be used to help policymakers and politicians understand the impact their decisions can have on the lives of people with a learning disability and their families and carers.

Mayne et al. (2018) suggest that “simple and persuasive stories” provide an important source of information in this “highly crowded environment”. (Mayne et al., 2018:2).

Co-produced Research

Research that seeks to capture the views and experiences of people with a learning disability in relation to safeguarding policy and processes is a key source of evidence (Department of Health, 2018; Liddiard et al., 2019). In particular, research that is co-produced with people with a learning disability offers useful insights into their safeguarding priorities and also helps to build the capacity of collaborating people with a learning disability to engage in research as another mechanism for influencing policy.

6. Recommendations

6. Recommendations

People with a learning disability are often under-represented in policy making processes. Most people, with or without disabilities, need support to effectively participate in the policy making process. Policy makers should invest time and resources communicating with those people who will be directly affected by the policy. From our research we have identified a series of key recommendations for policy makers and supporting organisations to assist people who have a learning disability to get their voice heard in shaping policies that have a direct impact on their lives.

Policymakers

Help people with a learning disability understand the political process

- Initiatives are needed to help people with a learning disability to understand the political process and to empower them to have an influence. An example of this in action is the Welsh Assembly's outreach team who provide workshops on the Welsh Assembly, how to have an influence and on how laws are made.
- People with a learning disability need political representatives to help draw public attention to their policy needs.

Promote meaningful engagement of people with a learning disability at all stages

- Involve people with a learning disability and supporting organisations in the policymaking process from the outset and throughout the policy making process.
- Keep people updated on progress. People with a learning disability often felt that they were asked for their input but not kept informed of the outcomes.
- Avoid repetition of consultations on the same topics and asking the same questions in a short space of time.
- Consider if you have identified and responded reasonably to the views of people with a learning disability.

Ensure communication is meaningful

- Improve the quality of Easy Read documents. Easy Read versions

should cover all important information and clearly explain key points.
- Work with experienced supporting organisations and draw on their expertise in how to engage people with a severe learning disability. For example, Mencap 'Involve Me' project which provides a practical guide on how to involve people with Profound and Multiple Learning Disabilities (PMLD) in decision-making and consultation.
- Have realistic timeframes in which co-produced policies can be developed. Send materials at least two weeks in advance to allow time for preparation.
- Face-to-face conversations and discussions are more useful than written consultations.

Utilise different sources of evidence

- Ensure the policy process has been informed by evidence that is high quality and up to date.
- Evidence should include evaluations of previous policies and the experiences of 'frontline' practitioners and people with a learning disability.
- Consider proactive policymaking which makes necessary changes before people come to harm.

Supporting Organisations and People with a learning disability

Build relationships and networks

- Recognise that having an influence takes time as policy and law-making are complex procedures that require the input of a number of people and organisations. You can't change policy by yourself. Work together to build trusting relationships and alliances and have a collective voice on issues of importance.
- Create coalitions with other organisations around a common theme and where possible agree on shared standpoints on these.
- Smaller groups/organisations may find it useful to have an affiliation with a larger organisation, which may have more contacts and resources to help with gaining influence.
- People with a learning disability living in rural areas had fewer opportunities to be involved with supporting organisations than people living in urban areas. Consider rural outreach programmes or the facilitation of smaller groups by large supporting organisations.

Have a clear message utilising different sources of knowledge

- Empower people with a learning disability to share their personal stories and lived experience.
- Use examples of how projects have had a positive impact on people's lives and how this learning could be adopted in a policy environment.
- Explain how policies and legislation affect the lives of people with a learning disability. In particular, highlight paternalistic or protectionist practice in relation to safeguarding.
- Referencing official statistics or research can lend weight to your argument.

Design messages to maximise influence, framed for different audiences

- Present respectful and strong, well thought-out arguments that are solution-focused.
- Know your audience and their job role. Tailor information outputs to different audiences, for example, consider using professional, formal language in information given to policymakers.

Engage in policy making processes

- Involvement in campaigns can increase the levels of attention given to policy issues and is a useful way to raise awareness.

- Try to gain membership of policy technical or advisory groups as these are often consulted on policy from the outset and throughout the policymaking process.
- Use windows of opportunity such as the exposure of safeguarding scandals in the media to have your influence. In instances like this, public and political attention is more likely to be focused on the topic, so your input is more likely to be picked up on.
- Appreciate that policy-making is not a linear process but is often complex and dynamic. It may involve trying to influence a lot of different people and overcoming a range of challenges.

Support individuals with a learning disability to contribute

- Provide opportunities for people with a learning disability to experience participation and advocacy in their own lives so they can develop skills which may enable them to engage in influencing policy.

7. Conclusion and Action Plan

7. Conclusion and Action Plan

This report presents comprehensive information about the current state of engagement in policy development from the perspectives of learning disabled individuals, carers, supporting organisations and those involved in policy development. Based on the findings and recommendations presented in this report, an Action Plan will be developed. The Action Plan will focus on ways in which individuals with a learning disability and their supporting organisations can influence adult safeguarding and associated policy and its implementation. This action plan will be made available on the DRILL website.

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Appendix A: Interview Schedules

Interview Questions: Policy maker

1. Tell me about your role in making the safeguarding law in _____.

    a) Tell me about the processes involved in making this law.

    b) Why did you decide to consult the public at the stage you did?

2. Tell me about the things that influenced the development of the law.

    a) How do you use evidence from research to affect the law?

3. Please describe the ways in which the broader context has been influential.

    a) In what ways has the political climate had an influence?

    b) In what ways has the socioeconomic context had an influence?

4. Please describe the role personal or family experiences have played.

5. What is the value of feedback from consultations?

    a) What would you say is most useful about this feedback?

    b) What is least useful about this feedback?

    c) Can you give an example of feedback that was most valuable?

6. When making the law, were people with a learning disability asked what they thought the law should look like?

7. What do you feel are the best strategies to use to influence law?

Organisational Case Study Interview Questions

1. **Organisational ethos: We're going to begin the interview by finding out a bit more about you and the organisation.**

a) Could you tell me a bit about your organisation and what your role entails?
b) Could you tell me a bit about how your organisation develops political strategies?
c) Could you tell me about how your organisation tries to influence policy development?

2. **Moving on, we would interested to hear about any projects you have been involved in that have helped to get the voice of people with a learning disability heard.**

a) Could you tell me about the Transforming Care De-institutionalisation programme and how your organisation is involved in this?
b) (Prompt) Could you tell me how you work together with family members/carers within the Transforming Care programme?
c) Could you tell me more generally how your organisation works with family carers and helps to get their voices and the voices of people with a learning disability heard?

3. **Now we would like to find out how you interact with politics and with other organisations when trying to influence policy. We would also like to look a bit more closely at the processes that surround your approach to influencing policy and what you think are the best ways to have an influence.**

a) How does your organisation try to engage with policymakers and politicians?
b) Are policymakers and politicians open to engagement with your organisation?
c) In what ways do you work with other organisations when trying to influence policy or law?
d) In your experience, what are the best ways to influence policy development?
e) What do you think are the barriers to influencing policy?
f) Could you identify any particular recommendations that you have given regarding safeguarding, that have been integrated into policy or practice?
g) How do you think policymakers and politicians could make it easier for people with a learning disability and their organisations to have their say on policy/law that will affect them?

Appendix B: Policy making in context

Introduction

The purpose of this appendix is to provide a brief overview of the policy making processes in the UK. The first section is a description of the main political institutions in the UK. The general policy making process is then summarised, followed by how this process may be informed and influenced by disabled people including possible supports, barriers and some examples. It is acknowledged that these main political institutions are not the only potential focus of campaigning on disability issues. There are also relevant opportunities to inform and influence policy through working with other organisations such as: a wide range of other government related bodies, for example equality and human rights Commissions; the policy and campaigning aspects of voluntary and community sector organisations; professional bodies; the institutions of the European Union; and the United Nations. The focus in this appendix, however, is relatively narrowly on the government policy making processes in the UK and 'policy' is used to refer to the formal aims, plans and rules set out by those working in government.

The political institutions in the UK

The UK's Central Government, based in London, makes laws and policies for the whole of the UK and also specific laws and policies for England. Some responsibilities, including for Health, Social Care and Justice are devolved to each of the other three nations that make up the UK – Scotland, Wales and Northern Ireland. The UK government website (www.gov.uk/government/how-government-works) provides an outline of the main components of government in the UK and each of the devolved administrations provide a similar summary on their websites for Scotland (www.gov.scot/about), Wales (www.gov.wales/about-us) and Northern Ireland (www.niassembly.gov.uk/about-the-assembly/general-information/history-of-the-assembly/). In each jurisdiction there are also local government institutions which provide further opportunities to inform and influence policy at that level (www.gov.uk/understand-how-your-council-works). This section provides some of the key information from these resources.

UK government

The 'Government' with a capital G, usually refers to the people who have responsibility for running the UK; and government, with a lower case g, refers to all the wider structures, bodies and processes involved. The political party that

wins the most seats at a General Election takes responsibility for forming the Government for up to five years. The leader of that political party is appointed Prime Minister. In the UK the Government, also referred to as Her Majesty's Government, is led by the Prime Minister who: has overall responsibility for policies; oversees the Civil Service and the other government agencies; and appoints other members of the Government.

The Prime Minister appoints the Cabinet which is made up of the other senior members of the Government (Secretaries of State from all Departments and some other ministers) and usually meets every week in Downing Street, London. There are currently twenty-one Cabinet Ministers (including the Prime Minister) and 94 other Ministers. The role of Ministers is to take responsibility for their Departments. There are twenty-five Ministerial Departments and some, such as the Ministry of Defence, cover the whole of the UK but others, such as the Department of Health, just cover England, as responsibility for some aspects of government is devolved to Scotland, Wales and Northern Ireland. There are also twenty non-ministerial Departments, such as the Crown Prosecution Service and the UK Statistics Authority; and four hundred and seven agencies and other non-departmental public bodies such as Advisory Committees, Arts Councils and Research Councils. The role of the Civil Service is to do the practical and administrative work of government.

Parliament (pictured above) is different from the Government but the Government needs Parliament's agreement to pass new laws. Parliament is made up of the House of Commons and the House of Lords. In general it is Parliament's role to monitor, question and, at times, challenge the Government. The House of Commons consists of everyone who has been elected in a general election (Members of Parliament, MPs) from across all political parties. After a general election the largest non-Government party forms the Opposition. The Leader of the Opposition takes the lead in questioning the Prime Minister and also appoints a Shadow Cabinet that takes the lead in questioning the relevant

Government Ministers. Currently there are six hundred and fifty MPs representing each constituency in the UK. In the House of Lords there are about 800 members, most (about seven hundred) are appointed for life and the rest are Church of England bishops or hereditary peers. In order for Parliament to consider making a new law, or Act, there are usually a number of stages: a Green paper which sets out the proposals for the new law for consultation; a White paper which proposes the new law; a Bill or draft law; and then, to become law, or an Act, the Bill must be approved by the House of Commons, the House of Lords and the Queen. Westminster is the part of London where many of the key institutions of the UK government are based (including Downing Street and the Houses of Parliament) and sometimes the UK government is referred to as Westminster.

Devolved government

Responsibility for some aspects of government is devolved to Scotland, Wales and Northern Ireland. The Scottish Government, the Welsh Government and the Northern Ireland Executive are responsible for a range of areas including: health and social care, education, culture, the environment and transport. They appoint Ministers to take responsibility for each of these areas and civil servants to enable the relevant Government's policy to be implemented. Each country also has a legislature, or law-making body, which is able to make laws for these areas. The legislatures are the Scottish Parliament, the National Assembly for Wales and the Northern Ireland Assembly.

In Scotland, the First Minister has responsibility for the development and implementation of the Scottish Government's policies. The Scottish Cabinet is made up of the First Minister, all Cabinet Secretaries (who each have responsibility for a specific area, the Minister for Parliamentary Business and the Permanent Secretary (who is the most senior civil servant in Scotland). It usually meets weekly in Bute House in Edinburgh. Each Cabinet Secretary is supported by one or more Ministers. In Scotland, government is organised into more than thirty directorates and agencies which are responsible for proposing legislation and putting Scottish Government policy into practice.

The Scottish Parliament (pictured above) is separate from the Scottish Government and is made up of all the one hundred and twenty-nine elected members of the Scottish Parliament (MSPs). There have been Scottish Parliaments from at least the 1200s but the current Parliament was established in May 1999 and the new Scottish Parliament building was opened in 2004. The Scottish Parliament can make laws for all the areas of government that are devolved. It works in a similar way to the Houses of Parliament and its role is also to consider any proposed legislation and scrutinises the policies of the Scottish Government through questions, debates and committees.

In Wales, there is also a First Minister who has the overall responsibility for the Welsh Government and the development of policies. The Welsh Cabinet is made up of the Ministers and deputy Ministers with responsibility for each of the devolved areas, including health and social care, education and the environment. The Welsh Government is also supported by the civil service who administer the policies that have been developed by the Government.

The National Assembly for Wales is the law making body which was created in 1999 and, since 2006 the Assembly's Siambr (debating chamber) and Committee Rooms have been accommodated in the Senedd, the main Assembly building in Cardiff (pictured above). The Assembly has sixty Members (AMs) who represent all the constituencies and regions of Wales. The role of the Assembly is to hold the Welsh Government to account and to make laws on the areas the Welsh Government has responsibility for.

In Northern Ireland, the devolved administration is led by a First Minister and Deputy First Minister who, along with two Junior Ministers and eight Departmental Ministers, make up the Northern Ireland Executive. The Ministers of the Executive are nominated by the political parties represented in the Northern Ireland Assembly depending on

their number of seats. The party with the highest number of seats can nominate the First Minister and so on. The First Minister and Deputy First Minister are the chairpersons of the Executive. The Executive has responsibility for leading policy and proposing legislation and is supported by the Northern Ireland Civil Service.

The Northern Ireland Assembly was established in 1998 following the Good Friday Agreement and Northern Ireland Act 1998 and has one hundred and eight elected members (Members of the Legislative Assembly MLAs). As with the other legislatures in the UK, its main role is to scrutinise and make decisions on the areas for which the Executive has responsibility including new laws. The Northern Ireland Executive is based in Stormont Castle and the Assembly in Parliament Buildings (pictured above) both on the Stormont Estate in Belfast.

Local government

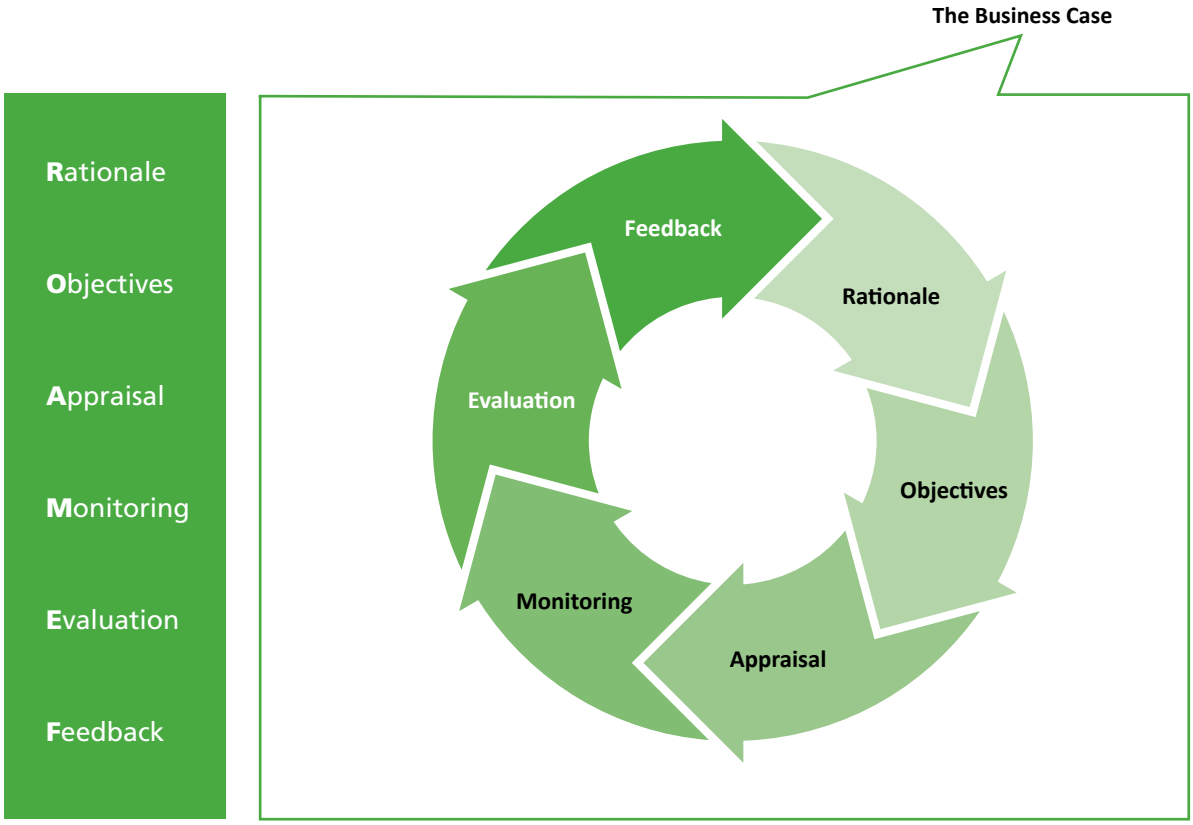
In England, Scotland, Wales and Northern Ireland there are also local government structures; councils, that make decisions about local services. Each Council is made up elected councillors and chaired by a mayor. The functions of the Council are usually organised into committees and supported by Council Officers. Councils tend to be responsible for local issues such as education, transport, planning, fire and public safety, social care, libraries, waste management and trading standards. In England there are three hundred and forty-three councils; in Scotland there are thirty-two local authorities (or councils); in Wales there are twenty-two unitary authorities with elected councils; and in Northern Ireland there are eleven local councils. In Northern Ireland the local councils do not have responsibility for housing, education and social care.

The policy making process

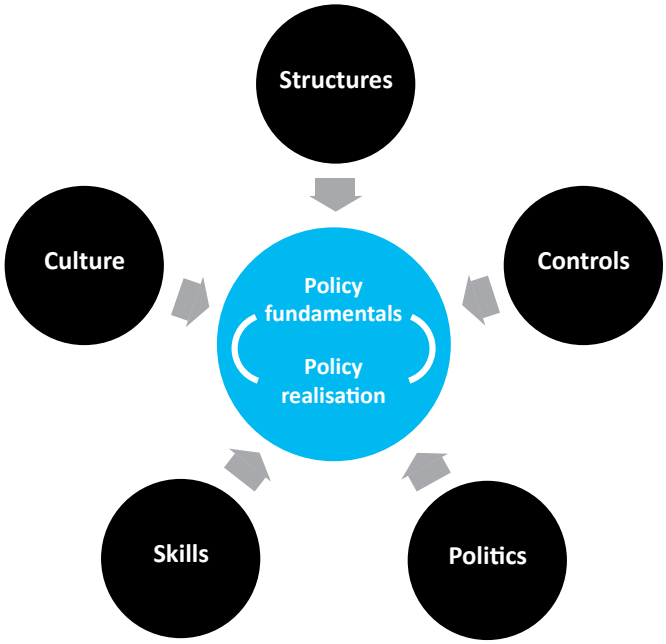
In general the policy making process is based on the election of representatives to central, devolved and local government. The party with the most

elected representatives usually then takes the lead in deciding which laws and policies should be made. The Parliaments, Assemblies and Councils debate, challenge and inform the law and policy making process. The Civil Service and Council Officers further develop the policies and work out how they can be implemented. The Northern Ireland Executive have defined the policy making process as "the process by which governments translate their political vision into programmes and actions to deliver 'outcomes' – desired change in the real world." (The Northern Ireland Executive, 2016:6).

The process of making a policy may vary and can be presented in a variety of ways. Involve (2018) have identified the main stages in the policy making cycle as: political vision; policy formation; policy proposals; decision making; and implementation. Another example, from HM Treasury (2018), suggests that the main components of the policy cycle can be described as Rationale, Objectives, Appraisal, Monitoring, Evaluation and Feedback (ROAMEF):



The Institute for Government (Hallworth & Rutter, 2011:13) highlights that the policy process, in reality, often doesn't follow these clearly defined stages and many factors can affect the process. Some of these factors are presented below and include budget restrictions, public opinion, political parties, values and ideology, mass media, interest groups, events, social and economic conditions, and research:



The Institute of Government (The Institute of Government, 2011:14) has also identified seven elements that are important to the policy development process:

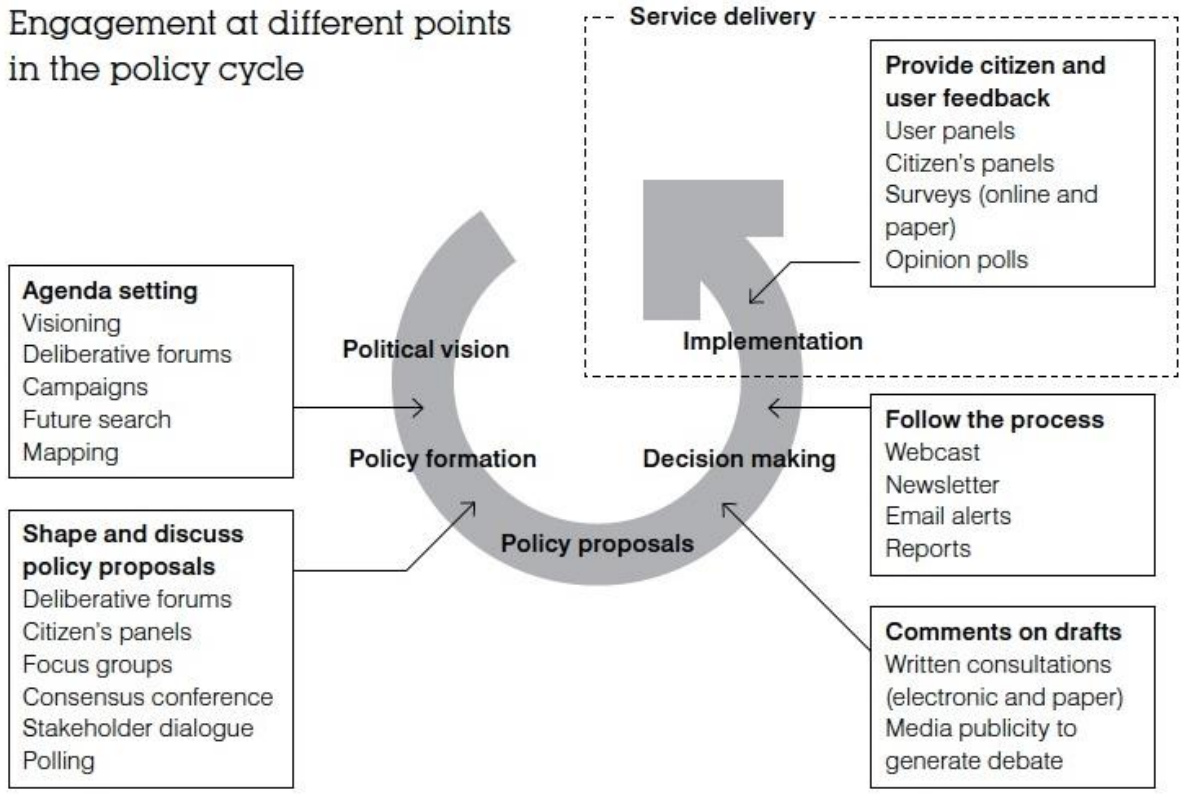
- ”Goals. Has the issue been adequately defined and properly framed? How will the policy achieve the high-level policy goals of the department – and the government as a whole…?
- Ideas. Has the policy process been informed by evidence that is high quality and up to date?
  Has account been taken of evaluations of previous policies?
  Has there been an opportunity or licence for innovative thinking?
  Have policy makers sought out and analysed ideas and experience from the ‘front line’, overseas and the devolved administrations?
- Design. Have policy makers rigorously tested or assessed whether the policy design is realistic, involving implementers and/or end users? Have the policy makers addressed common implementation problems? Is the design resilient to adaptation by implementers?
- External engagement. Have those affected by the policy been engaged in the process?
  Have policy makers identified and responded reasonably to their views?
- Appraisal. Have the options been robustly assessed? Are they cost-effective over the appropriate time horizon? Are they resilient to changes in the external environment?
  Have the risks been identified and weighed fairly against potential benefits?

- Roles and accountabilities. Have policy makers judged the appropriate level of central government involvement? Is it clear who is responsible for what, who will hold them to account, and how?
- Feedback and evaluation. Is there a realistic plan for obtaining timely feedback on how the policy is being realised in practice? Does the policy allow for effective evaluation, even if central government is not doing it?"

The policy making process does therefore appear to be complex, involves a lot of different people and can include a range of challenges. This also means, however, that there are lots of opportunities to try to inform and influence which laws and policies are proposed; and then to try to inform and influence how they might be developed and implemented.

How policy may be informed and influenced

Involve (2018) has developed a useful diagram of the policy cycle and the different points and methods that may be relevant to inform and influence the process.



The Overseas Development Institute (Tilley et al., 2017) have highlighted 10 things to consider when trying to inform and influence policy with research but these key messages apply more generally:

1. "KNOW WHAT YOU WANT TO INFLUENCE. Being clear about the policy issue, theme or process you want to change is the first step to effective policy influencing. Are you looking to influence

legislation, or a change in government policy? You might want to encourage greater investment in a certain programme or approach, or a change in practice. You might want to influence perceptions or attitudes, or the language people use around an issue.

2. KNOW WHO YOU WANT TO INFLUENCE. Who has the power to enact a change in a policy process or change the debate on an issue? Is it a senior government official, a parliamentarian, a government minister or a head of state? You need to be clear about who you want to influence. It's also useful to identify who can indirectly influence your target audience – an adviser, a respected commentator, a media outlet, a well-known academic? Know the routes to the people and organisations you need to influence and build relationships with them. And remember that you might not always be the best messenger.
3. KNOW WHEN TO INFLUENCE. Your research needs to reach your target audience at a moment when they can take action. For example, this could be in the lead-up to an election, during a budget cycle, as part of a government consultation, ahead of an international decision-making summit, or at a key meeting. Unexpected opportunities will also emerge. So having the flexibility to react and adapt your plans as you go is important. If you can quickly spot policy opportunities as they arise, you may be able to have greater impact. Think 'strategic opportunism'.
4. BUILD RELATIONSHIPS AND NETWORKS. You can't change policy by yourself, no matter how ground-breaking your research is. You should find and work with other people and organisations who share your policy influencing objective – your allies and collaborators. Working together, building trust and developing a joint plan will increase your impact.
5. POLICY DEVELOPMENT IS NOT A LINEAR PROCESS. It is tempting to think that policy processes are linear: you identify a problem, gather evidence and implement a policy. But they aren't. Policy-making is complex, dynamic and involves a lot of different people and moving parts. Nonetheless, policy formulation does have its own formal and informal rhythms. If you understand these, you'll know where your evidence will be most useful and have greatest impact.
6. POLICY-MAKING IS INHERENTLY POLITICAL. Policy-making is often a very political process. Alongside research, policy-makers' own values, experience and expertise play an important role in influencing how they make decisions. For example, in the lead-

up to a general election it's not uncommon to see the same research being used by competing political parties to argue different points. You should factor this into your plans and develop a political strategy.

7. PLAN YOUR ENGAGEMENT. You need to think carefully about how to communicate your research. Policy-makers are busy so won't always have time to read a long report. A short, sharp executive summary or policy brief can be a powerful tool. Focus on clear messages and avoid overly technical language. Infographics can also help to make your data accessible. Consider other outreach activities too, such as press releases, public events, bilateral meetings, presentations or side events at summits and conferences.
8. FOCUS ON IDEAS AND BE PROPOSITIONAL. Policy-makers don't need to be told the problem; they need constructive ideas, so be propositional. Based on your research, tell them what should happen, who could take action, when and how. It's also important to frame your recommendations within the realms of what is possible, both technically and politically. Be ambitious, but realistic.
9. IT TAKES TIME, STICK AT IT. Influencing policy takes time and commitment. Make a plan, break it down, and be realistic about what you can do. Often it can be a slow process with no obvious impact in the short term. But stick with it, recognise that policy influencing is usually a marathon not a sprint, and be sure to set milestones and capture the small successes as you go. Continue to engage with your target audience and always keep up-to-date on the decision-making process.
10. MONITOR, LEARN AND ADJUST ALONG THE WAY. External factors will affect your plans along the way so it's important to remain flexible and adapt to new contexts and opportunities. You should also seek feedback from allies, partners, and even your target audience. Ask them what they need and when, as well as what format they prefer and adjust your plans accordingly. If you find an approach is not working, you should stop, assess and try something new. Continuously review, and capture your learning as you go so you can apply it to future influencing plans. And, be willing to share your learning with key partners."

Cairney and Kwiatkowski (2017) have developed a three step strategy to communicating with policy makers: "1. Understand your audience. To help tailor your approach to the cognitive processes present in human beings, synthesise evidence concisely to minimise its cognitive burden, and 'frame' your

conclusions rather than expecting evidence to speak for itself.
2. Identify the right time to exploit 'windows of opportunity'. 'Timing' can refer to the right time to influence an individual, depending on their current way of thinking, or to act while the political conditions are just right.
3. Engage with real world policymaking rather than waiting for a 'rational' and orderly process to appear. To present evidence during mythical stages of a 'policy cycle' may be misguided, and to 'speak truth to power' without establishing trust in networks and an open culture in organisations may be counterproductive." (Cairney and Kwiatowski, 2017:2)

Mayne et al. (2018) have distilled their analysis of how to inform and influence policy into four key points: "(1) learn how policymaking works, (2) design evidence to maximise its influence on specific audiences, (3) design and use additional influencing strategies such as insider persuasion or outsider pressure, and adapt the presentation of evidence and influencing strategies to the changing context, and (4) embrace trial and error." (Mayne et al., 2018:1)

There may also be additional considerations when the focus is disability. Irvine (2017) has highlighted that people with intellectual disabilities are often under-represented in policy making processes in general and even when the focus is disability. Most people, with and without disabilities, need support to effectively participate in the policy process. This may include time, resources, training, information in accessible formats, the invitation to join advisory groups and opportunities to engage with policy makers. Pearson and Trevisan (2015) have outlined the history of disability activism in the UK since the 1960s and have also explored how new digital media may influence how strategies to inform and influence policy may develop. They identified that in the 1960s the focus was on the social and economic exclusion of disabled people and this developed through the 1970s to 1990s with an emphasis on civil rights, anti-discrimination legislation, power and direct payments for independent living. Since 2010, the public spending cuts involved in austerity have created additional barriers to social and economic inclusion. Pearson and Trevisan (2015) have identified that "Since the outset of the austerity programme, platforms such as blogs, Twitter and Facebook have proved important tools for disability activism in challenging government policy". This also enabled the effective use of personal stories to highlight the impact of policy decisions on the lives of disabled people. Pearson and Trevisan (2015) conclude that "whilst not negating the role of more traditional protest and the need for a plurality of tactics to be used in combination with one another, the role of digital activism is now embedded in disability protest culture and set to play a crucial role in future disability politics more generally." (Pearson and Trevisan, 2015:937).













Project Team

The project team was lead by Queen's University, Belfast in partnership with Association for Real Change, NI; Compass Advocacy Network, NI and Praxis Care, NI.

The Queen's University team included three academic staff; Dr Lorna Montgomery, Dr Berni Kelly and Prof Gavin Davidson, and Lisamarie Wood a researcher from Praxis Care.

This project was based on a participatory disability research design, in that it was co-led by people with lived experience of learning disability and coproduced in partnership with them. In this process Queen's University partnered with Leslie-Anne Newton from Association for Real Change (ARC), and Linda McKendry from Compass Advocacy Network (CAN), who were core members of the research team, and facilitated the co-production of the programme.

Additionally, three partner organisations from across the UK helped to contextualize the findings for each country, supporting the dissemination of findings: The Richmond Fellowship, Scotland, Mencap Cymru, Wales and Ann Craft Trust, England. The project was supported by an Advisory group and a Peer Reference group. The project was funded by Disability Research on Independent Living & Learning (DRILL).

“the more you care, ...the more you understand the need to do something to change it.”

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