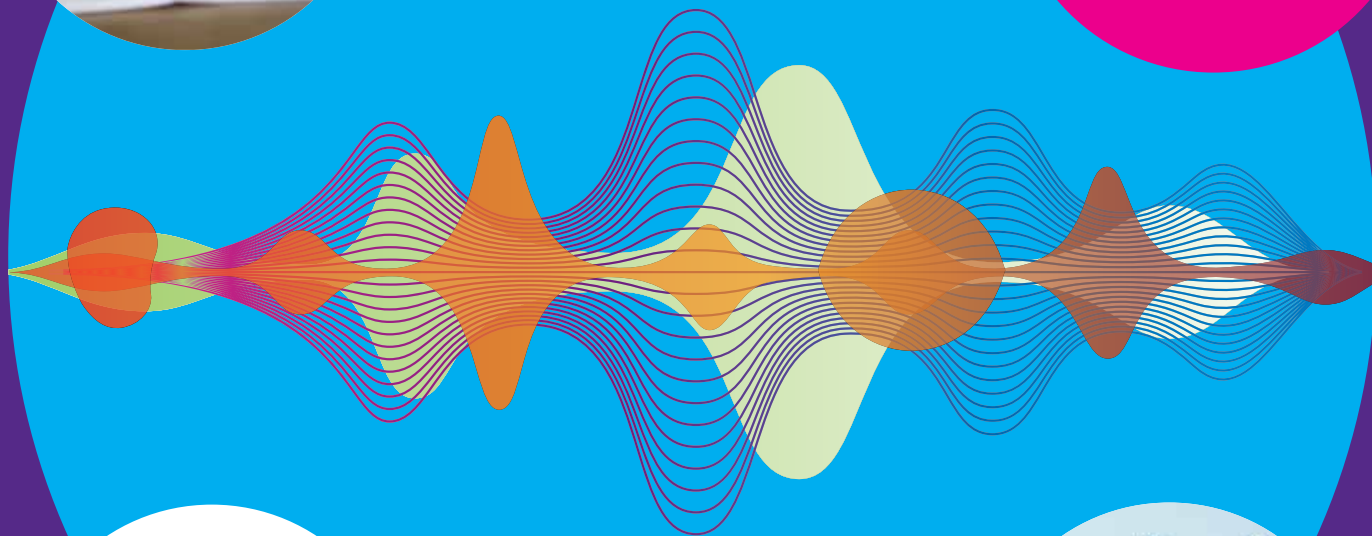




# GETTING OUR VOICES HEARD

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



## SAFEGUARDING YOU, SAFEGUARDING ME




### EXECUTIVE SUMMARY

## Introduction

**In order to exercise equal citizenship, 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 equal citizenship is the risk of harm or abuse and the potential for over-protective responses, or responses which do not fully consider the relevant risks. Within the past ten to fifteen years 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 policy which have been taken by people with a learning disability and relevant support organisations.



To **explore what works in different contexts** by looking closely at successful examples where people with a learning disability and relevant support organisations have influenced adult safeguarding policy or practice.



To **make recommendations on approaches** to take, identifying barriers and enablers to exerting influence on adult safeguarding and associated policy.

## 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 an identified policy maker/policy advocate/politician in each nation.

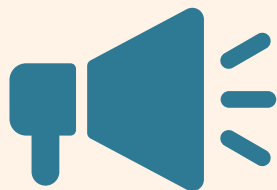


**Phase 4:** four in-depth case studies; one 'best-practice' case study example of support organisations influencing policy in each of the four nations. These were based on focus groups and semi-structured interviews with key stakeholders.



**Phase 5:** an online survey completed with support organisations and individuals who have contributed to relevant policy consultations focused on their views and experiences.

## Findings and Conclusions



In the first stage of this project we examined the consultation processes in each jurisdiction, 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.



The written responses to consultation 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 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. 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 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. A high value was placed on personal stories and experiences.





A case study of support 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. Respondents 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.



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 interviewees 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 in 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 and legislation that have a direct impact on their lives.



*UK Wide Consultation*



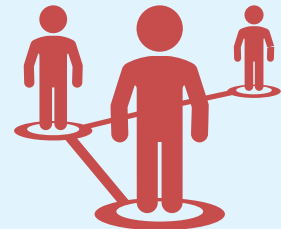
## Help people with a learning disability understand the political process

- 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 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.



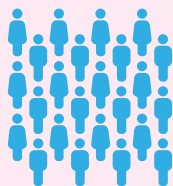
## Build relationships and networks

- 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 than people living in urban areas. Consider rural outreach programmes or the facilitation of smaller groups by large support organisations.



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

- Involve people with a learning disability and support organisations in the policymaking process from the outset and throughout the policy making process.
- Keep people updated on progress. People with 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 support organisations and draw on their expertise in how to engage people with severe learning disabilities. 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.



## 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.



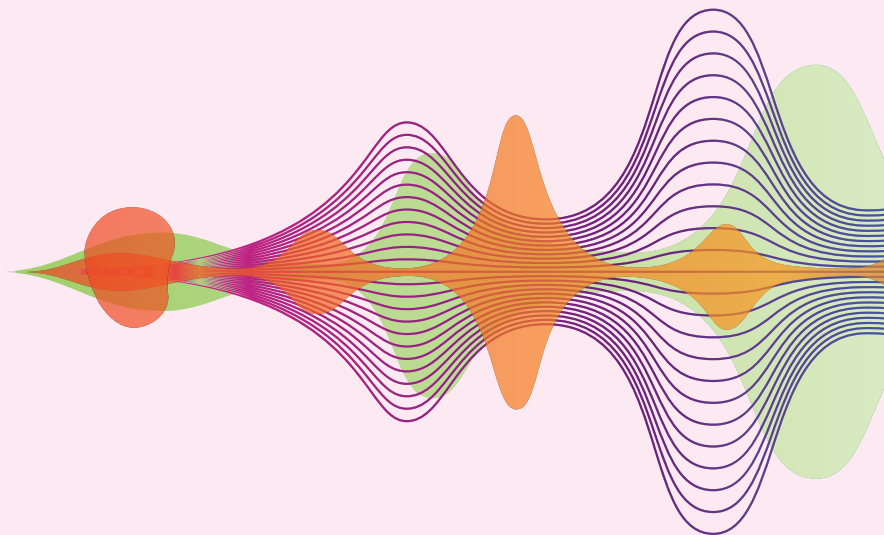
## Design messages to maximise influence, framed for different audiences

- 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.



## 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.



## Engage in the 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 where public and political attention is more likely to be focused.
- Utilise social media to share petitions, to engage influential figures in policy discussions and to disseminate information to a broad audience at limited financial cost.
- 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.



## 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.

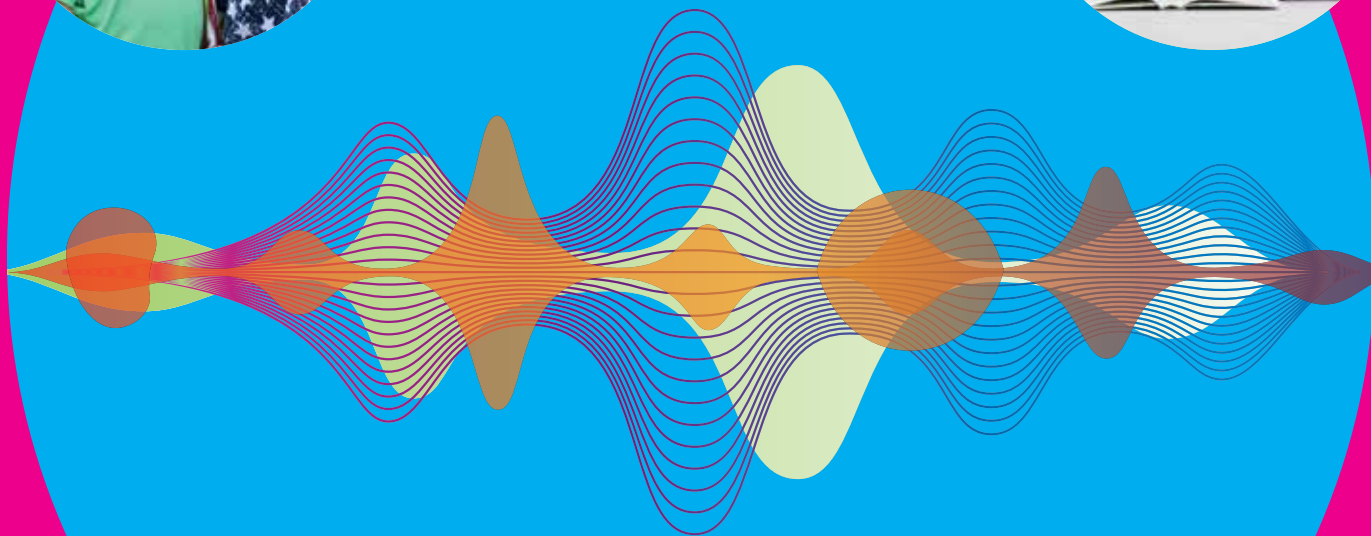
This project was based on a participatory disability research design, in that it was co-led by people with lived experience of learning disability and coproduced in partnership with them. In this process Queen's University partnered with Leslie-Anne Newton from Association for Real Change (ARC), and 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).





## CONTACT US



Dr Lorna Montgomery  
School of Social Sciences, Education and Social Work  
Queen's University Belfast  
6 College Park  
Belfast  
BT7 1LP  
T: +44 (0) 28 9097 1480  
[www.qub.ac.uk/ssesw](http://www.qub.ac.uk/ssesw)