



No research about us, without us.

Our contribution to a Review of the *Statement on Consumer and Community Involvement in Health and Medical Research 2016* (Position Paper).

Deafness Forum Australia, May 2024.



Introduction

The *Statement on Consumer and Community Involvement in Health and Medical Research*, created by the National Health and Medical Research Council and the Consumers Health Forum of Australia in 2016, guides research institutions, researchers, members of the community and citizen representative organisations, on the active involvement of citizens in all areas of health and medical research. It outlines the importance of this involvement and its benefits to the research process, explores various levels and types of involvement, and addresses several implementation issues.

The *Statement* is currently being revised to ensure its continued relevance and timeliness. In this submission, Deafness Forum Australia provides feedback for consideration in the updated version.

In our submission, we use the term 'citizen' in place of consumer. Citizen is a more comprehensive term in research contexts, as it reflects the broader spectrum of individuals' roles and motivations beyond mere consumption.

Deafness Forum Australia is the peak body representing the views and interests of the more than 4 million Australians who live with hearing loss, people with hearing difficulties, have ear or balance disorders, people who communicate using Australian Sign Language, and their families and

supporters. We are the trusted, national, independent citizen voice for the whole hearing health and deafness sector – the impartial advocate representing all voices that need to be heard.

Our purpose is to support these Australians to live well in the community by making hearing health & wellbeing a national priority. Hearing health and community inclusion are absolutely crucial to general health and wellbeing.

Our responses to the Discussion Questions

What parts of the current Statement have or have not worked well?

Awareness: Among our stakeholders, there was no awareness of the existence of this Statement. The workshop summary document indicates that 28 of 121 participants (23%) were not familiar with it, and 31 of 121 participants (25%) were familiar but had never used it. This may not be a statistically representative sample, but it hints at insufficient effort in promoting awareness, engagement, and uptake of the Statement.

Accessibility: Noting that ‘understanding’ is a shared value, how accessible is this Statement? We are not referring to how accessible the research is as this would be captured in implementation issues outside the scope of a revised Statement, but how accessible is the Statement itself? It is not just being able to easily access it wherever it is published but also making sense of it. Part of the intent of the Statement is to articulate the role of the citizen in the research, but can they understand their role if the Statement isn’t accessible? Language should be accessible.

Culture is also a barrier to accessibility. Different values, beliefs, etc., will influence how a person interacts with and engages with research. Cultural competency is a very big issue in delivering health and medical care and probably an issue on the research side, too.

Implementation: The Statement does address implementation to a degree. Existing documents about implementation are available, so the intention to remove implementation from the Statement to streamline and make the document more high-level is understandable. However, it isn’t easy to see how there can be a statement about the active involvement of citizens in research without some comment on implementation, even if it is a brief statement recognising implementation is essential and referring the reader elsewhere for more information.

Why is consumer and community involvement in research valuable? Why does it matter to you?

Involvement in research by members of the community and citizen representative organisations is essential for ethical, impactful research. It ensures diverse perspectives, enriching data and insights for more representative outcomes. Such practices enhance usability, credibility, and reach, particularly for underserved groups. Community engagement adds credibility to research, ensuring that research is practical, fit for purpose, and responsive to real-life situations. This involvement builds trust, aligns research with community needs, and fosters effective translations and sustained improvements. It empowers participants, enhancing their skills and capacity to influence change through their lived experiences.

Why does it matter to us?

Ethical and impactful research cannot happen in a vacuum.

Deafness Forum Australia, as the trusted, national, independent citizen voice for 4 million Australians affected by hearing loss, ear or balance disorders, and those who use Australian Sign Language (Auslan), recognises the vital importance of citizen involvement in research.

When research relates to a particular community group, it is vital that the diverse experiences and needs of this group are accurately represented in that research through direct citizen engagement across the research process.

In advocating for our constituents, we ensure that the research is not only ethical and impactful, but also accurately tailored to improve the quality of life and accessibility of those we represent.

What issues should be considered once the revised Statement has been finalised and published?

Accessibility: ensuring that the Statement is understandable by the community and available publicly in various accessible formats.

Education: making sure community members and citizen representative organisations are aware of this resource and how it would apply practically across research opportunities and making sure researchers adhere to the principles.

Value statement

The values that underpin the 2016 Statement are 'shared understanding, respect and commitment' (2016 NHMRC-CHF Consumer Statement). How might this be strengthened and improved in the revised Statement?

Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the Statement? What others would you like to see, and why?

Values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness should be included in the Statement. It would be beneficial to define these values to prevent misunderstandings. We define them as follows:

Accountability: Responsibility for actions and decisions and transparently addressing issues or concerns.

Transparency: Maintaining openness, ensuring participants and stakeholders understand the methods, goals, and outcomes.

Collaboration: Multiple parties working together bring unique skills, knowledge, networks and resources to the project. It is characterised by shared decision-making and mutual benefits. Each party contributes to the project's success while maintaining their agency.

Partnership: A more formal and often longer-term relationship with a higher level of mutual dependency than collaboration can be more suitable for complex or long-running projects requiring ongoing support from another player.

Equity: Moving beyond diverse representation to actively consider who is missing, why they are missing, and how to involve them to ensure equitable outcomes in research.

Diversity: Valuing and incorporating a variety of backgrounds, perspectives, and experiences to enrich the research and its outcomes.

Inclusiveness: Creating an environment where all voices are heard and valued, ensuring a broad range of perspectives and experiences are included.

Additional values to be included in the Statement

In this section we recommend additional values to be included in the Statement.

Accessibility: Ensuring that all individuals, including those who are deaf or have hearing loss, can fully participate by adapting communication methods and research styles to their needs.

Codesign: Emphasising the importance of more than just collaboration or partnership, but a deep, shared creation process with stakeholders.

Equality: Ensuring fair treatment and opportunities for all participants, regardless of their background or circumstances.

Integrity: Upholding ethical standards and honesty in all research activities, ensuring that actions align with stated values and principles.

Respect: Recognising each participant's dignity, autonomy, knowledge, and rights and understanding these as foundational to ethical research.

Safety: Prioritising the security and protection of participants in all aspects — physical, emotional, psychological, and data integrity — to encourage participation and potential for minimise harm and risk.

Asking individuals to participate in research and dependent on context research (recognising some research can be more confronting than others) means requiring people to have some element of vulnerability - certain groups are inherently more vulnerable than others.

Safety needs to be a priority to encourage community participation in research. People need to feel secure and protected throughout the process. This encompasses different elements of safety: physical, emotional and psychological. 'Respect' may encompass 'safety' based on how respect is defined in the 'Australian Code for Responsible Research'. Yet, 'respect' and 'safety' are different concepts. Respect matters as it is about recognising a participant's dignity, the unique knowledge and skills they bring to a project, their autonomy and their rights. Safety is about creating and maintaining an environment that minimises harm and risk.

Trust: Creating and maintaining trust with all participants, especially marginalised groups, ensures engagement and meaningful participation in research.

Trust is a significant inhibitor to participation in research – this is just a fundamental principle in anything when working with members of the community, be it research or a corporation marketing a product. If trust is not present, there will be no engagement. Research is an investment of time, and without trust, members of the community will not invest.

The values of 'respect' and 'commitment' are not possible without trust, and trust is a non-negotiable concept.

It is worth noting that the concepts of safety and trust, which are crucial for encouraging community participation in research, are currently absent from the Code for Responsible Research. Their inclusion would significantly enhance the ethical framework of the code.

What overarching values are essential to include in the value statement of the revised Statement?

All the values we have listed are central to the program's ethos. However, it might be beneficial to highlight a few as primary guiding principles.

Accountability: Responsibility for actions and decisions, maintaining integrity, openness, and transparently addressing issues or concerns.

Collaboration: Bringing together multiple parties with unique skills, knowledge, networks, and resources. This value emphasises shared decision-making and mutual benefits, with each party contributing to the project's success while maintaining their agency.

Equity: Moving beyond diverse representation and inclusiveness to actively consider and address gaps in involvement. This involves identifying who is missing, why they are missing, how to involve them and how to support them to ensure all voices are heard and valued.

Trust: Recognising each participant's dignity, autonomy, and rights to create trust – and for a participant, a belief in the reliability, truth, and ability of the researcher and the institution they represent.

Better Practice Principles for Consumer and Community Involvement in Research

What are the most important principles that should be included in the revised Statement?

Given that the Statement's purpose is to guide health and medical research, it would be helpful to expand and clarify 'equity' principles in 'consumer and members should be involved with broad diversity and equity'. Diversity in citizen representation is not the same as 'equity' as a driving principle in research. Citizens are interested in who is at the table and having a voice and what is in it should they participate. Will their voice lead towards an equitable outcome? What will be done with this research if an investment of time is made to participate? Etc.

Meaningful Involvement: members of the community and citizen representative organisations should be active partners throughout the research process, from setting priorities to disseminating findings. Their input should be genuinely considered and incorporated.

Ensuring Comprehensive Representation: The members of the community and citizen representative organisations involved should not only represent the diversity of the target population but also include those from marginalised or underrepresented groups. Identifying and addressing barriers to participation is essential for a comprehensive and inclusive research process.

Transparency and Accountability: The research process should be transparent, with clear communication about expectations, roles, and decision-making. Researchers should be accountable to the members of the community and citizen representative organisations involved.

Capacity Building: Researchers, members of the community and citizen representative organisations should receive appropriate training and support to enable meaningful and effective participation. This includes building the skills and confidence of all stakeholders.

Respect and Reciprocity: All participants should treat each other courteously and respectfully, valuing diverse perspectives. Where possible, there should be a reciprocal exchange of knowledge and benefits. Respect for the expertise of citizen engagement also means ensuring that they are appropriately remunerated for their time as a valued source of first-hand knowledge.

Appropriate Resourcing: Sufficient time and funding should be allocated to enable genuine involvement of the members of the community and citizen representative organisations throughout the research lifecycle.

Evaluation and Continuous Improvement: The effectiveness of the involvement of involvement should be regularly evaluated, and the lessons learned should be used to improve future engagement efforts.

Roles, expectations and responsibilities of consumers and community members

What roles and responsibilities for citizens and communities should be included in the revised Consumer Statement?

Active Participation: Community members and citizen representative organisations are crucial in the research process. Their active engagement, from design and planning to implementation, analysis, and dissemination of results, is vital. Their input, which should be informed and constructive, helps shape relevant and impactful research.

Sharing Expertise and Experience: Community members and citizen representative organisations should share their unique insights, experiences, and knowledge to enhance the research's quality and relevance. This includes providing perspectives that researchers might otherwise overlook.

Collaborative Decision-Making: Participate in shared decision-making processes, ensuring that their voices are heard and integral in guiding the research direction and methodologies.

Feedback and Evaluation: Provide regular and honest feedback on the research process and outcomes. This helps refine research practices and ensure that the research remains aligned with community needs and expectations.

Advocacy and Representation: Act as advocates and representatives for their communities, ensuring that the research reflects the broader community's interests and concerns, especially those of underrepresented or marginalised groups.

Capacity Building: Engage in opportunities to enhance their understanding of research processes, methods, and ethics. This empowers them to participate more effectively and ensures their contributions are informed and meaningful.

Transparency and Accountability: Work with researchers to maintain transparency in the research process and hold all parties accountable for upholding the agreed-upon values and ethical standards.

Ethical Participation: Adhere to ethical guidelines in their involvement, respecting confidentiality, informed consent, and the rights of all research participants.

Communication and Dissemination: Help communicate research findings to the broader community in accessible and understandable ways.

Long-Term Engagement: Where possible, maintain a long-term commitment to the research process to ensure continuity, depth of insight, and sustained impact on the community.

Roles and responsibilities of researchers

What roles and responsibilities for researchers should be included in the revised Consumer Statement?

Engagement and Collaboration: Researchers should actively engage with members of the community and citizen representative organisations, seeking their input and feedback throughout the research process. This includes involving them in the research findings' design, implementation, analysis, and dissemination. Researchers should consider how they affect citizens and community members in developing, conducting, and communicating their research.

Transparency: Provide open communication about the research process, objectives, and outcomes. Researchers should provide clear, accessible information and updates to citizens and community members.

Respect and Sensitivity: Uphold a respectful approach that acknowledges citizens' and community members' experiences, knowledge, and contributions. This involves being sensitive to cultural, linguistic, and individual differences.

Capacity Building: Support the development of skills and knowledge among citizens and community members to enable meaningful involvement. This may include providing training or resources related to research methods and ethics. Researchers should provide meaningful opportunities for citizens and community members to engage in research.

Feedback and Accountability: Offer regular opportunities for feedback and incorporate citizen perspectives into decision-making processes. Researchers should be accountable for responding to citizen input and demonstrating how it has influenced the research.

Researchers should undertake to keep citizens and community members informed about the research they have participated in, including advising them of any final reports/outputs, etc.

Equity and Inclusivity: Ensure that the involvement of citizens and community members is equitable and inclusive, representing diverse experiences and backgrounds, especially those most affected by the research topic. Researchers should facilitate accessible means for members of the community with disability to participate in research (for those who are Deaf or experience hearing loss, this might include things like Auslan interpreters). Researchers should ensure that members of the community and citizen representative organisations can participate in research opportunities equitably and informally.

Ethics and Safety: Maintain high ethical standards in all interactions with citizens and research. This includes ensuring the safety and well-being of all participants. Researchers should safeguard citizens and community members' data and other personal information.

Reporting and Dissemination: Include members of the community and citizen representative organisations in the dissemination of research results, ensuring that findings are communicated in ways that are meaningful and accessible to the broader community.

Advocacy: Researchers should advocate for the involvement of citizens and community members in research as a critical component of any standard research process. They should also advocate for members of the community and citizen representative organisations to be reimbursed for their time and expertise in grant applications and other relevant contexts.

How should researchers involve citizens and community representatives in their research?

Early Involvement: Involve members of the community and citizen representative organisations from the outset of the research process, including the initial planning and design stages. Their perspectives help shape the research questions, methodologies, and objectives.

Ongoing Engagement: Maintain consistent and meaningful engagement throughout the research lifecycle, with regular updates, discussions, and opportunities for feedback at various stages, such as data collection, analysis, and interpretation of results.

Accessible Communication: Use clear, accessible language and multiple communication methods to ensure that all participants can understand and contribute to the research. For individuals who are Deaf or experience hearing loss, this includes providing Auslan interpreters or other appropriate communication aids.

Capacity Building: Empower citizens and community representatives by providing the necessary training and resources to understand and participate effectively in the research process. This includes education on research methods, ethics, and data interpretation.

Equitable Participation: Ensure equitable and inclusive participation by actively seeking out and involving diverse groups, especially those who are typically underrepresented in research. Address barriers to participation, such as physical accessibility, language, and cultural considerations.

Decision-Making Roles: Give members of the community and citizen representative organisations decision-making roles, ranging from advisory roles to more formal positions within the research team or steering committees.

Feedback and Iteration: Use the feedback from citizens and community representatives to refine and improve the research, ensuring that it remains aligned with the community's needs and priorities.

Ethical Considerations: Follow all ethical guidelines, including informed consent, confidentiality, and the right to withdraw. Safeguard personal data and respect the privacy of all participants.

Compensation and Recognition: Recognise the value of the time and expertise members of the community and citizen representative organisations contributed by offering appropriate compensation, such as financial remuneration and/or acknowledgments in publications.

Dissemination of Results: Include members of the community and citizen representative organisations in disseminating research findings, ensuring they have access to the results and assisting in communicating these findings to the broader community.

Meaningful Participation: Ensure members of the community and citizen representative organisations can participate meaningfully in the research process, knowing their expertise is respected, valued, and acknowledged.

Collaborative Journey: Treat the research process as a collaborative journey, where members of the community and citizen representative organisations, and researchers work together as partners in codesign across all stages, including design conception, planning, implementation, and review.

Equal Peers: In the research process, consider members of the community and citizen representative organisations participants as equal peers. Researchers should be responsive and adaptive to the specific needs of particular consumer cohorts, such as using Auslan Interpreters to communicate with consumers who are deaf or hard of hearing.

Should involvement be an expectation of research and is there an ethical imperative to do so?

Involvement of members of the community and citizen representative organisations should be an expectation of research and there is an ethical imperative to do so.

In the citizen advocacy space, we often use the phrase 'no research about us, without us.' This underscores the principle that people with health conditions or disability, including those with deafness and hearing loss, should be at the forefront of any research that concerns them. Ideally, those who possess relevant expertise should lead the research related to their experiences and needs.

Conducting research without the involvement of members of the community and citizen representative organisations, especially in the context of health and disability, would likely be met with scepticism by the community. This reflects the growing awareness and assertion of disability rights in Australia. This approach not only aligns with ethical imperatives but also strengthens the research's credibility, relevance, and acceptance within the communities it aims to serve.

Such involvement is crucial for democratising the research process, enhancing its impact and relevance, and building the necessary trust between researchers and the community. It is a fundamental ethical responsibility to involve those most affected by the research in a

meaningful way, ensuring that their voices guide and shape the research from inception to dissemination.

Roles and responsibilities of research institutions

What roles and responsibilities for research institutions should be included in the revised Statement?

Research institutions should commit to the involvement of members of the community and citizen representative organisations in various levels of research activity through:

Institutional Commitment: Demonstrate a clear public commitment to citizen and community involvement. This could include policy statements, strategic plans, or dedicated resources that emphasise the importance of this involvement in all research activities.

Governance Structures: Implement governance structures, including boards and committees, policies, and procedures, which incorporate the principles, values, and elements for effective citizen participation. These should be established in consultation with various citizen cohorts to ensure they truly reflect the needs and preferences of the communities involved.

Infrastructure and Support: Provide the necessary infrastructure and support for effective involvement. This might involve dedicated staff roles (such as consumer liaison officers), training programs for researchers and citizens, and resources like accessible communication tools.

Capacity Building: Invest in capacity-building initiatives for both researchers and citizens. For researchers, this can include training on effectively involving citizens in research. For members of the community, it can involve training on research methodologies, ethics, and advocacy skills. Additionally, it provides upskilling opportunities for researchers to learn how to engage with specific cohorts of members of the community and citizen representative organisations inclusively.

Funding and Resources: Ensure adequate funding and resources to support members of the community and citizen representative organisations involvement. This includes funding for compensating members of the community and citizen representative organisations for their time and expertise and for necessary accommodations like Auslan interpreters, hearing augmentation and other accessibility aids. Advocate for the fair provision of costs associated with engagement, including costs associated with meeting accessibility requirements.

Equitable Involvement: Promote and ensure equitable involvement of a diverse range of members of the community and citizen representative organisations, particularly those from underrepresented or marginalised groups. Institutions should actively work to remove barriers to participation and ensure that all voices are heard. Employ staff who are skilled in community engagement, or themselves represent culturally or linguistically diverse groups in society, including people with disability, those from CALD backgrounds, and people of Aboriginal and Torres Strait Islander descent.

Ethical Standards: Uphold high ethical standards in citizen and community involvement, ensuring all activities are conducted with respect, dignity, and fairness. This includes following ethical guidelines for informed consent, confidentiality, and the right to withdraw.

Accountability and Transparency: Maintain transparency and accountability in citizen and community involvement practices. This includes regular reporting on how citizen input has influenced research processes and outcomes and open communication about the impact of citizen involvement.

Partnerships and Collaboration: Collaborate with citizen representative organisations and advocacy groups. These partnerships should be based on mutual respect and a shared commitment to meaningful involvement.

Research Dissemination: Include members of the community and citizen representative organisations in disseminating research findings. Ensure that results are shared in formats that are accessible and understandable to the broader community and involve citizens in public outreach and education efforts.

Continuous Improvement: Commit to ongoing evaluation and improvement of involvement practices. This involves seeking regular feedback from members of the community and citizen representative organisations and using this feedback to refine and enhance involvement strategies.

Roles and responsibilities of funders

What roles and responsibilities for funders should be included in the revised Statement?

Financial Support for Optimal Citizen Participation: Ensure adequate financial resources are allocated in approved budgets to support meaningful members of the community and citizen representative organisations involvement in all stages of the research process. This includes funding to compensate members of the community and citizen representative organisations for their time and expertise and cover out of pocket costs. Funders should ensure adequate resourcing is available to cover the costs of having members of the community and citizen representative organisations engaged in a research project.

Mandate Involvement: Funders should mandate the involvement of members of the community and citizen representative organisations in research – and a financial remuneration in exchange for both their time and intellectual property contributed to the project - ensuring that their perspectives are integral to the research process from inception to dissemination.

Mandate Public Access to Research: All publicly funded research should be made available. This transparency is essential because it ensures that taxpayers and the broader community can see and benefit from the outcomes of research they have funded. Making research findings public supports informed decision-making, stimulates further scientific and policy discourse, and fosters an environment of accountability and openness. Additionally, public access to research promotes the dissemination of knowledge, encouraging further innovation and collaboration across various sectors and communities. This approach aligns with principles of transparency and accountability, reinforcing that publicly funded research should serve the public good.

Promote Equitable Involvement: Encourage and require that funded research projects demonstrate equitable involvement of diverse community groups, particularly those from underrepresented or marginalised communities such as people with disability, those from CALD backgrounds, and Aboriginal and Torres Strait Islander peoples.

Capacity Building: Provide funding for capacity-building initiatives that enhance the ability of citizens and researchers to engage effectively. This can include training programmes, workshops, and resources that build skills in citizen engagement and participatory research methods.

Transparency and Accountability: Require transparency in how citizen involvement is planned, implemented, and evaluated in funded research. Funders should expect regular reporting on citizen and community engagement activities and their impact on the research

outcomes. Additionally, ensure that researchers and academics are accountable for spending these funds appropriately.

Policy and Guidelines: Develop and enforce policies and guidelines that mandate citizen and community involvement in research. These policies should outline clear expectations for how researchers engage with members of the community and citizen representative organisations and the standards they must meet.

Incentivise Best Practices: Reward and recognise research projects that exemplify outstanding community involvement. This could be through awards, additional funding, or public recognition highlighting the value of meaningful engagement.

Research Prioritisation: Involve members of the community and citizen representative organisations in setting research priorities and deciding on funding allocations. This ensures that the funded research is aligned with the actual needs and interests of the community.

Support Innovative Approaches: Encourage and fund innovative approaches. These include novel methods of engagement, the use of technology to facilitate broader participation, and research projects led by or co-designed with members of the community and citizen representative organisations.

Partnerships and Collaboration: Foster partnerships between researchers and members of the community and citizen representative organisations to strengthen the ecosystem of participatory research. Encourage collaborative grant applications and projects that demonstrate strong community leadership.

Long-Term Commitment: Demonstrate a long-term commitment to enhancing community involvement in research. This involves not just one-time funding but sustained support and investment in building a culture of participatory *research*.

Should funders of research mandate the involvement of citizen and community representatives in the research they fund?

Funders of research should mandate the involvement of citizen and community representatives in the research they fund.

Funders should not only mandate this involvement but also ensure adequate financial remuneration for the time and intellectual property citizens and their representative organisations contribute. This acknowledges the value of their contributions and supports sustainable and equitable engagement.

This approach has several significant benefits:

Enhanced Relevance and Impact: By mandating community involvement, funders ensure that research is more closely aligned with the needs, priorities, and lived experiences of those it aims to serve. This increases the likelihood that research outcomes will be relevant, applicable, and impactful.

Improved Quality and Rigour: Members of the community and citizen representative organisations provide unique insights and perspectives that can enhance the quality and rigour of the research. Their involvement can help identify potential issues, improve study design, and contribute to more robust and comprehensive analyses.

Promotion of Equity and Inclusivity: Mandating involvement ensures that diverse voices, especially those from underrepresented or marginalised groups, are heard and considered in the research process. This promotes equity and inclusivity, making research more representative of the broader population.

Accountability and Transparency: When funders mandate members of the community and citizen representative organisations involvement, they promote accountability and

transparency in research. Researchers must demonstrate how they have meaningfully involved these groups and how this involvement has influenced the research outcomes.

Building Trust and Collaboration: Mandating involvement fosters trust between researchers, members of the community and citizen representative organisations and funders. It shows a commitment to collaboration and partnership, which can enhance the credibility and acceptance of the research within the community.

Ethical Considerations: From a moral standpoint, involving members of the community and citizen representative organisations is crucial for respecting the rights and dignity of those affected by the research. It aligns with the principle of "nothing about us, without us", ensuring that research is conducted with, rather than on, the community.

Contact Us

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Deafness Forum Australia is Australia's Hearing Health peak body for Citizens and a National Disability Advocacy peak organisation | Foundation Member of the WHO World Hearing Forum | Member of the International Federation of Hard of Hearing People | Associate Member of World Federation of the Deaf | Foundation Member of Australian Federation of Disability Organisations.