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Identifying priorities for Australian disability research using Q methodology

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ABSTRACT

Background: Globally, there are over an estimated one billion people with disability. Research priorities with a focus on diagnosis and treatment of conditions or policy and service initiatives, traditionally decided by researchers, may not align with priorities of those with lived experience of disability.

Objective: To explore and inform disability research for Australia, including perspectives of people with disability.

Methods: As part of a research program, we used Q methodology to explore "what should guide the Australian research agenda?" People with disability, their families, community organizations and researchers were purposively recruited and sorted 25 statements, developed iteratively using data collated from systematic research mapping and a prior consultation process. The sorting grid ranged from −4 to +4, according to "*Which topics should guide disability research the least to the most?*" Factor analysis revealed four distinct but interrelated participant viewpoints.

Results: 52 participants (65 % female, aged 18–65+ years, 37 % people living with disability), sorted the statements. Viewpoint 1 – design and delivery of services across the lifespan. Viewpoint 2 – understanding the diverse experience of those with disability. Viewpoint 3 – designing systems to address impacts of disability for the individual, their families and society. Viewpoint 4 – addressing mental health for those with disability no matter where they live.

Conclusion: These viewpoints focused on design and delivery of services to address the impacts of disabling environments and attitudes on individuals living with impairments, their families and society. The four viewpoints provide a framework for future disability research in consultation with those with lived experience.

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) describes disability as including "those persons who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".[1] Globally, it has been estimated that there are over one billion people with disability.[2] This equates to 15 % of the population but with higher instances of disability amongst the world's poorest people. Ratified by 185 nations, the CRPD provides standards by which to monitor the inclusion of people with disability across all areas of social participation and citizenship. Many nation-states also have their own disability specific discrimination legislation (e.g. Americans with Disabilities Act 1990[3]; Australian Disability Discrimination Act 1992[4]) and data collection requirements (many based on the World Health Organization's

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approaches) that define disability and levels of support needs. However, the social context of disability and the levels of support needs reported vary substantially across these nation-states.[5]

In Australia, approximately one in five people have a disability[6] with 1.5 million requiring assistance to complete self-care, mobility and communication activities essential to everyday living.[7] In recognition of this need, iterations of a National Disability Agreement[8] governed disability service provision until the Australian government established the National Disability Insurance Scheme (NDIS)[9] in 2013. The NDIS provides a nationally consistent approach to the access to, planning for and funding of, supports for people with disability.[9] The change to a national scheme occurred as an action within the National Disability Strategy 2010–2020, where for the first time all levels of government committed to a national approach to improve the lives of people with disability.[10]

Despite significant investment in disability supports in Australia, there has been a historical focus on diagnosis and treatment of specific medical conditions,[11,12] with a lack of disability research focusing on mental and social wellbeing,[13] citizenship and social inclusion.[14] Research priorities have traditionally been decided by researchers which may not align with the priorities of those living with disability and those providing them with support.[15] In 2011, Australian State and Territory governments endorsed a National Disability and Research and Development Agenda[11] to set out research and development principles and areas of inquiry to guide allocation of national funding for disability research; however, the research agenda was encompassed within the National Disability Strategy 2010–2020.[10] There have been no previous system wide attempts to set a disability research agenda which include the voices of people with disability. Understanding the needs and research priorities of people with a disability and including their voice in informing priorities in all stages of the research process, can increase the relevance of the research and subsequent policy agenda.[16,17]

In 2019, the National Disability Research Partnership (NDRP) was established by the Commonwealth Government for two years (the Establishment Phase). The Establishment Phase was overseen by a Working Party which included advocates, academics and independent advisors who were tasked with setting up the structure and processes for a longer-term disability research partnership in Australia. One deliverable of the Establishment Phase was to develop a research agenda to guide the NDRP's investment in disability research.[18] In 2020, the NDRP funded a consortium of representatives from a wide cross-section of the disability sector to conduct research to identify issues affecting the social, heath, wellbeing and quality of life of people with disability, to inform a 10-year National Disability Research Agenda (NDRA) aimed at improving outcomes for people with disability through policy and practice.[18]

The inclusion of people with disability at the center of research is a guiding principle of the NDRP[18,19] and of the consortium funded to undertake the research agenda setting process. The consortium included disabled persons organizations and people with disability as partners so that their knowledge of disability[11] was recognized and included in the research decision making processes, the implementation methods, and analysis and interpretation of findings. Consistent with best practice in research,[20] our team was inclusive of lived experience, with opportunity for individuals and organizations to determine their level of involvement throughout each phase of the research and to enhance reach and engagement across diverse communities. The research consortium took a values and principles-based approach[21] where partnership and shared decision making were established throughout, rather than a specific participatory approach to involvement such as Participatory Action Research.[22]

A three-phased, multiple methods approach of mapping, consultation and prioritization was undertaken to develop priorities that could be used to guide investment in disability research in Australia. Findings from each phase were used to inform the subsequent phases. The first phase mapped existing Australian Disability research.[12] The second phase involved an online survey and face-to-face consultations with approximately 2000 people. The survey was responded to by 973 people, including 438 with disability, 251 unpaid carers and family members, and the remainder comprising other stakeholders within the disability sector. Consultations were conducted by 21 disability organizations inclusive of 974 individuals, of whom 149 had a disability, 498 were family members and 349 were in paid positions. The aim of the consultation phase was to develop a comprehensive understanding of how stakeholders use, and what they believe should be done, in disability research.[23,24] The third phase explored explicitly the research priorities of people living with disability, those providing them support and those involved in the disability sector.[18]

The purpose of this study – the third phase – was to explore and inform priorities for disability research in Australia. We used Q methodology which sought to answer the question: *What should guide the Australian disability research* agenda*?*

Materials and methods

Ethical approval

This study was approved by the University of Sydney Human Reserach Ethics Committee (reference 2021/858). Consent for participation in the study was implied once participants submitted their responses.

Design

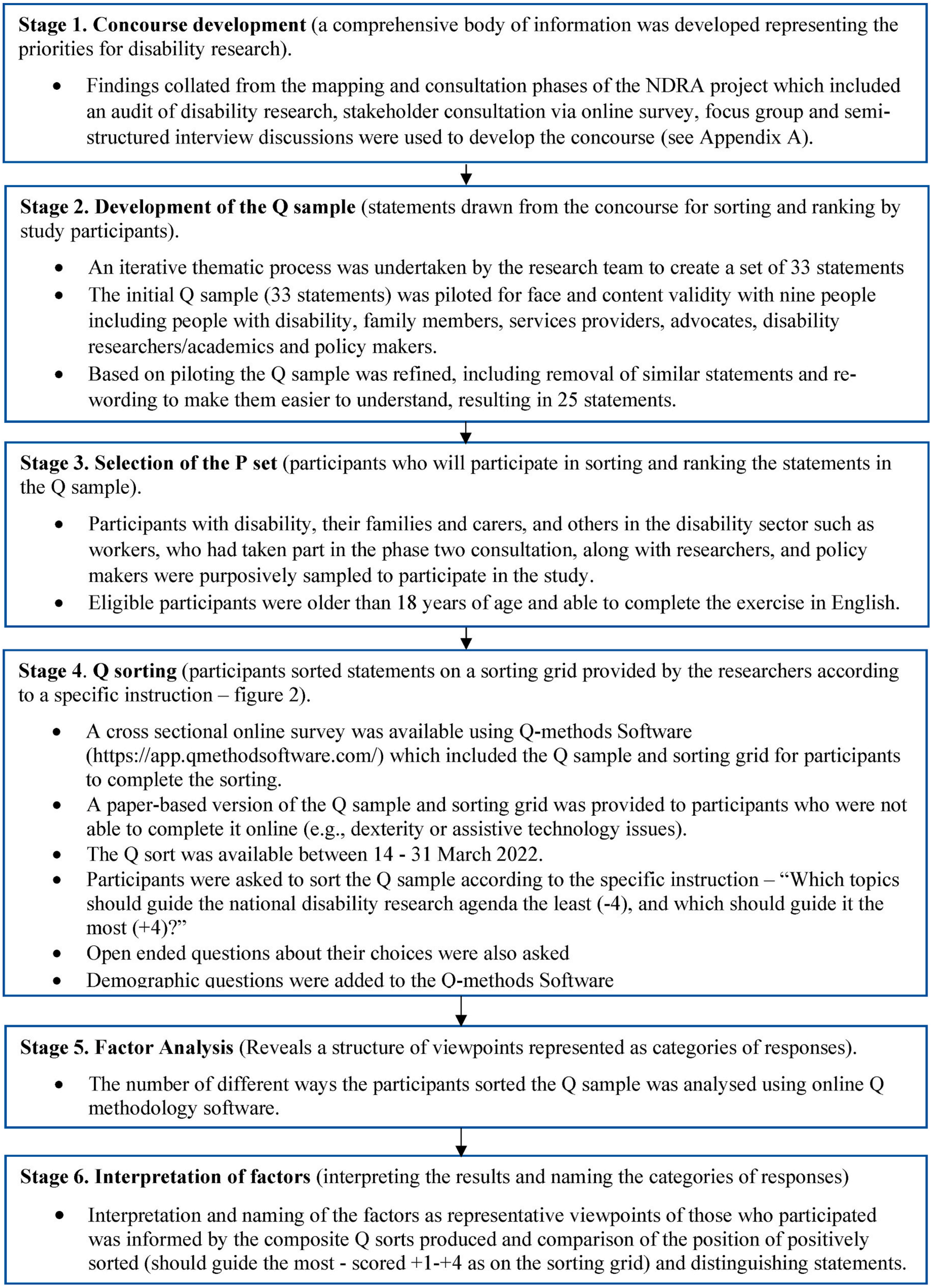
Q methodology was used to elicit participants' viewpoints. Q methodology is an approach that explores differing perspectives on complex issues and has been advanced as an approach for studying priorities in health care,[25] sociology,[26] natural resource management,[27] education,[28] ethics,[29] and economics.[30] The main focus of Q methodology is to maximize qualitative and subjective knowledge and experience to represent feelings and/or values related to a specific topic.[31,32] Q methodology integrates qualitative and quantitative approaches to reveal different views as categories of responses revealed through a factor structure.[25,33–35] A protocol paper for the whole research program was published.[36] At that time the methods for synthesis and prioritization were intended to follow the James Lind Alliance methods.[37] Subsequent progress through the research program resulted in a change to the protocol at the prioritization phase to the Q methodology approach described in this paper.

Q methodology was chosen for this study to systematically identify potential areas for future disability research based on the viewpoints of a range of stakeholders including people with disability, their families and carers, and others in the disability sector such as workers, advocates, researchers, and policy makers. Q methodology involves six stages. How these stages were followed in this study are outlined in Fig. 1.

Data collated from a systematic mapping of current research[12] and the prior consultation process[23,24] (see Appendix A) provided the crucial body of knowledge known as the concourse (see Fig. 1). An iterative qualitative data synthesizing process was used to develop statements (called the Q sample) from the concourse for sorting (called Q sorting). The final step of the analysis (step 6, Fig. 1: interpretation and naming of factors) involved the research team working together to understand and interpret the quantitative and qualitative data to craft the summary statements for each viewpoint.

Participant set (P-set)

People were eligible to participate if they were aged 18 years or older, lived in Australia, and were individuals or representatives of organizations with knowledge of and an interest in the development of an Australian disability research agenda. Participant characteristics are presented in Table 1. Given we sought participants from diverse



Stage 1. Concourse development (a comprehensive body of information was developed representing the priorities for disability research).

- Findings collated from the mapping and consultation phases of the NDRA project which included an audit of disability research, stakeholder consultation via online survey, focus group and semi-structured interview discussions were used to develop the concourse (see Appendix A).

Stage 2. Development of the Q sample (statements drawn from the concourse for sorting and ranking by study participants).

- An iterative thematic process was undertaken by the research team to create a set of 33 statements
- The initial Q sample (33 statements) was piloted for face and content validity with nine people including people with disability, family members, services providers, advocates, disability researchers/academics and policy makers.
- Based on piloting the Q sample was refined, including removal of similar statements and re-wording to make them easier to understand, resulting in 25 statements.

Stage 3. Selection of the P set (participants who will participate in sorting and ranking the statements in the Q sample).

- Participants with disability, their families and carers, and others in the disability sector such as workers, who had taken part in the phase two consultation, along with researchers, and policy makers were purposively sampled to participate in the study.
- Eligible participants were older than 18 years of age and able to complete the exercise in English.

Stage 4. **Q sorting** (participants sorted statements on a sorting grid provided by the researchers according to a specific instruction – figure 2).

- A cross sectional online survey was available using Q-methods Software (https://app.qmethodsoftware.com/) which included the Q sample and sorting grid for participants to complete the sorting.
- A paper-based version of the Q sample and sorting grid was provided to participants who were not able to complete it online (e.g., dexterity or assistive technology issues).
- The Q sort was available between 14 - 31 March 2022.
- Participants were asked to sort the Q sample according to the specific instruction – "Which topics should guide the national disability research agenda the least (-4), and which should guide it the most (+4)?"
- Open ended questions about their choices were also asked
- Demographic questions were added to the Q-methods Software

Stage 5. Factor Analysis (Reveals a structure of viewpoints represented as categories of responses).

- The number of different ways the participants sorted the Q sample was analysed using online Q methodology software.

Stage 6. Interpretation of factors (interpreting the results and naming the categories of responses)

- Interpretation and naming of the factors as representative viewpoints of those who participated was informed by the composite Q sorts produced and comparison of the position of positively sorted (should guide the most - scored +1-+4 as on the sorting grid) and distinguishing statements.

Fig. 1. Stages of Q methodology used in this study.

stakeholder groups, demographic data items were kept to a minimum and were related to age, gender, state or territory of residence and Indigenous or other cultural identity. In total, 52 participants sorted the final Q sample on the sorting grid according to the researcher's instructions (see Fig. 2). A further 18 started the sort but did not complete it. Of the 52, one participant completed the Q sorting, which was included in the analysis, but did not provide any demographic information. Of the 51 participants who completed the demographic

Table 1
Demographic data of P set (n = 51).

Characteristic (N = 51)	N	%
In which state/territory do you live? (n = 49)		
Victoria	20	40.8
New South Wales	18	36.7
Australian Capital Territory	3	6.1
Queensland	3	6.1
South Australia	3	6.1
Western Australia	2	4.1
Which of the following describes you? (n = 51)[a]		
I am a person with disability	19	36.5
I am an unpaid carer, family member or supporter of someone with disability	12	23.5
I am an academic with an interest in disability research	10	19.6
I work in disability services which provide direct care or support for people with disability	6	11.8
I work in an advocacy service or peak body that has an interest in disability	5	9.6
I am a policy maker/civil servant/government employee with interest in disability research	1	2.0
Gender (n = 51)		
Female	33	64.7
Male	18	35.3
Do you identify as Aboriginal or Torres Strait Islander? (n = 51)		
No	47	92.2
Yes Aboriginal	3	5.9
Prefer not to say	1	2.0
Do you identify as LGBTIQA + ? (n = 51)		
No	44	86.3
Yes	6	11.8
Prefer not to say	1	2.0
Do you identify as being part of a culturally and linguistically diverse community? (n = 51)		
No	44	86.3
Yes	7	13.7
Age (n = 50)		
18–24 years	3	6.0
25–34 years	3	6.0
35–44 years	9	18.0
45–54 years	14	28.0
55–64 years	17	34.0
65+ years	4	8.0
What type of area do you live in? (n = 49)		
Urban (city)	31	63.3
Regional	14	28.6
Rural	4	8.2

[a] Total sums to 53 as two participants identified as a person with disability and one other category.

questions, the majority were female (65 %), and one third (34 %) were aged 55–64 years. Most lived in Victoria (41 %) or New South Wales (37 %), Australia's two most populous states. The largest single group of participants were people with disability followed by unpaid carers/ family members. Two participants reported that they identified with more than one category (e.g., as a person with disability and an academic).

Results

The number of different ways the participants sorted the Q sample was analyzed using online Q methodology software.[38] Each Q sort represented one participant's viewpoint which in turn contributed to the factors.[39] Analysis of the Q sorts was conducted following the Q method factor analysis steps as outlined by Garbellini, Randall, Steele, Elliott, Imms[40] and included.

1. A correlation matrix to show association between two sets of Q sorts
2. A Principal Component Analysis (PCA) to condense the correlation matrix into factors
3. Rotation of factors (from the PCA) to structure how the Q sorts loaded onto each factor

Table 2
Factor arrays – average scores against each statement loading on named viewpoint.

Statement Number	Statement	Factor array			
		V1	V2	V3	V4
1	How to design buildings and spaces that work for people with disability	−4	−4	0	−4
2	How to design assistive technologies (physical support that helps someone do something more easily or safely) that work for people with disability	0	−3	−1	−3
3	Ways to make information more accessible for people with disability	−1	−3	1	0
4	Experiences of discrimination and stigma for people with disability and their family members	−1	−2	−2	0
5	Ways to reduce discrimination and stigma experienced by people with disability and their family members	1	−2	−1	0
6	Experiences of abuse, violence, neglect, exploitation and coercion on people with disability	−2	−2	2	1
7	Ways to address abuse, violence, neglect, exploitation and coercion	3	−1	2	2
8	Ways to increase equal educational opportunities across the life course (e.g., pre-school, school, TAFE, university)	2	−1	0	1
9	Impacts of educational opportunities across the life course	−1	0	−2	−1
10	How to improve access to work opportunities	1	−1	−3	−1
11	Links between work opportunities and outcomes for people with disability	0	0	−1	−1
12	How to design and deliver health services that work for people with disability across the life course	2	0	0	1
13	How to design and deliver mental health services and supports that work for people with disability across the life course (e.g., preventative, crisis and ongoing treatment, recovery)	0	0	0	4
14	Impacts of lack of access to appropriate mental health services and supports	−3	−1	1	3
15	Understanding the experiences of family (parents, siblings, partners, children, others)	2	0	−4	−2
16	Experiences of changing needs and supports for ageing people with disability and their family members	0	2	−3	1
17	Influences on community attitudes towards disability	1	1	−2	−2
18	Enablers and benefits of inclusion and participation in social and community life	1	1	−1	0
19	Ways to continuously improve the design and delivery of the National Disability Insurance Scheme	3	2	2	−2
20	Impacts of the National Disability Insurance Scheme on people with disability, the economy and broader society	−2	1	3	−3
21	How to design systems and services that work together to support a person's whole-of-life needs (e.g., disability services, health, education, employment, housing, transport etc.)	4	3	4	2
22	Experiences of people with disability and families from Aboriginal and Torres Strait Islander backgrounds	−2	3	3	−1
23	Experiences of people with disability and families from Culturally and Linguistically Diverse backgrounds	−3	4	1	0
24	Experiences of people with disability experiencing marginalization (e.g., those in criminal justice system, homeless or in unstable housing, substance use)	0	2	1	3

(*continued on next page*)

Table 2 (*continued*)

Statement Number	Statement	Factor array			
		V1	V2	V3	V4
25	Access to supports and services for people with disability and families living in regional, rural and remote areas of Australia	−1	1	0	2

Note: V1 – Viewpoint 1; V2 – Viewpoint 2; V3 – Viewpoint 3; V4 – Viewpoint 4.

4. Factor scores calculated from factor loadings then standardized to represent z-scores
5. Composite Q sorts were created by ranking the z-score for each factor

Further detail of the factor analysis stage for this project can be found in the report "Setting an agenda for Disability Research".[41]

In this study, interpretation of the emergent factors and naming them as viewpoints was aided by using composite Q sorts, positively ranked distinguishing statements and participant comments on the sorting process. Composite Q sorts were constructed using factor arrays which showed the weighted average of the participants' Q sorts that loaded on each factor.[25,42] Factor arrays for each named viewpoint are shown in Table 2. Distinguishing statements are statements placed in statistically significant locations between any pair of factors.[42] Positively ranked distinguishing statements are presented with each viewpoint.

The factor analysis and qualitative interpretation, as outlined in stages 5 and 6 in Fig. 1, resulted in four viewpoints that express common perspectives about what should guide the focus of the NDRA. The order of presentation of these viewpoints, and their positively sorted distinguishing statements is not hierarchical.

Viewpoint 1 - The design and delivery of integrated, safe, and equitable services that contribute to inclusive communities to benefit people with disability and family members across the life course. Viewpoint 1 is characterized by its emphasis on research into services, including health services, that provide targeted opportunities to improve individual and family wellbeing and quality of life, across sectors including, for example, health, education, employment, housing, transport and disability services.

Viewpoint 1 – Positively sorted distinguishing statements.

1. How to design and deliver health services that work for people with disability across the life course
2. Ways to increase equal educational opportunities across the life course (e.g., pre-school, school, TAFE, university)
3. Understanding the experiences of family (parents, siblings, partners, children, others)
4. Ways to reduce discrimination and stigma experienced by people with disability and their family members
5. How to improve access to work opportunities

Viewpoint 2 - Understanding and responding to the intersecting and diverse experiences of individuals with disability and families. Viewpoint 2 is characterized by highlighting the need for research into the complex and intersecting needs of those experiencing multiple disadvantages that compound the experience of disability. Research into the experiences of people from culturally and linguistically diverse communities, those from marginalized communities (for example in the justice system, or unstable housing) and those living in regional and remote communities were in focus in this viewpoint.

Viewpoint 2 – Positively sorted distinguishing statements.

1. Experiences of people with disability and families from Culturally and Linguistically Diverse backgrounds
2. Experiences of people with disability experiencing marginalization (e.g., those in criminal justice system, homeless or in unstable housing, substance use)
3. Impacts of the National Disability Insurance Scheme (NDIS) on people with disability, the economy and broader society

Viewpoint 3 - Understanding and designing systems to address the social, emotional, and economic impacts of disability for individuals, families, communities and society. Viewpoint 3 brings varied perspectives to the fore, placing an emphasis on the need for research into whole of society/community outcomes in a way that distinguishes it from other viewpoints. This included issues related to the impact of the NDIS on people with disability, the economy and broader society.

Viewpoint 3 – Positive distinguishing statements.

1. Impacts of the NDIS on people with disability, the economy and broader society
2. Experiences of abuse, violence, neglect, exploitation and coercion on people with disability
3. Ways to make information, including health information, more accessible for people with disability

Viewpoint 4 - Design, delivery and impacts of services and supports addressing mental health and wellbeing across the life course of all Australians with disability no matter where they live. Viewpoint 4 is characterized by its emphasis on research investigating the needs of those experiencing mental ill-health, marginalization, abuse or neglect and the need for research to focus on designing and delivering effective, equitable and safe services and systems across the life course. The viewpoint applies to both those with mental ill-health as a single disability cohort and those with mental ill-health as a secondary disability for other disability cohorts.

Viewpoint 4 – Positive distinguishing statements.

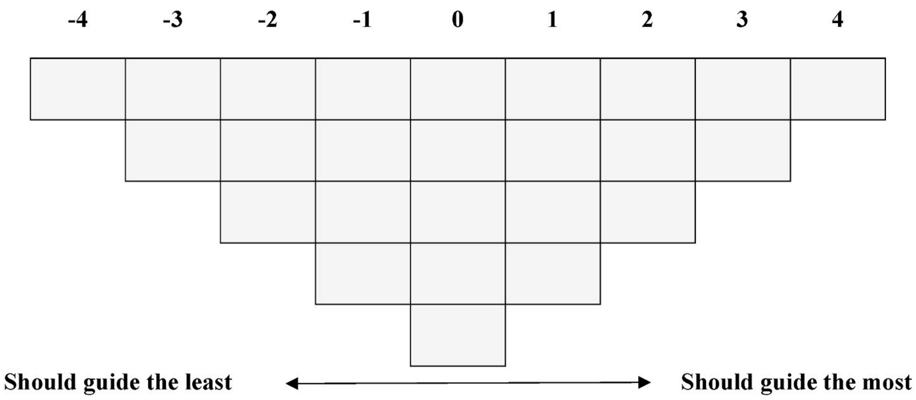


Fig. 2. The Q sorting grid.

1. How to design and deliver mental health services and supports that work for people with disability across the life course (e.g., preventative, crisis and ongoing treatment, recovery)
2. Experiences of people with disability experiencing marginalization (e.g., those in criminal justice system, homeless or in unstable housing, substance use)
3. Experiences of abuse, violence, neglect, exploitation and coercion on people with disability

Of note, distinguishing statements positively sorted (i.e., should guide the most) for some factors were negatively sorted (i.e., should guide the least) for others, highlighting the difference between the viewpoints. Participants with the same demographic background (refer to Table 1) had differing views on the topics as evidenced by the difference of viewpoint on which their Q sort loaded. Analyses of Q sorts of participants with similar backgrounds was not conducted. On visual inspection of the composite Q sorts for each viewpoint, the statement "How to design buildings and spaces that work for people with disability" was the one statement that was sorted the lowest (i.e., should guide the least) on viewpoints 1, 2 and 3, although this was not identified as a distinguishing statement.

Thirty-two participants (63 %) provided comments on topics they thought were missing from the Q sample and additional thoughts on their Q sort. Several comments – including topics on specific disabilities, whole-of-life needs, not only disability-related needs, access to safe and equitable services and transition to adult services – were viewed as encapsulated in the four viewpoints and understood to be a way of emphasizing the participant's perspective. Additional comments, reported as not addressed in the statements, included a need to prioritize research that focused on.

- climate change, emergency planning and preparedness, and disaster preparedness and management (including the impacts of COVID-19);
- aspects of human rights such as advocacy and political campaigns; self-advocacy, supported decision-making and legacies of segregation and institutionalization.

Discussion

This study used Q methodology to address the question "what should guide the Australian disability research agenda?" It built upon previous work that mapped the existing disability research landscape (phase 1) and a national consultation involving people with disability, family members, service providers and researchers (phase 2). The recommendations for setting research priorities based on the four viewpoints elicited from the Q methodology are discussed using an ecological model. The ecological model was developed 40 years ago by Uri Bronfenbrenner to account for influences on children's development,[43,44] but it has subsequently been applied across a wide range of other settings including health,[45] disability and public policy research.[46,47]

The ecological model was seen as appropriate for framing the four viewpoints as the findings of this study revealed research is required at individual, service and system levels. The ecological model describes the individual/micro-system, the meso-system which connects the individual to the service and system structures with which they have direct contact, the exo-system which is the broader social system which influences the individual but may not be directly engaged in by the individual, and the macro-system which comprises the outermost level of influence and includes cultural values, customs, laws and regulations. Fig. 3 provides a diagrammatic representation of this model showing the relationship to the viewpoints.

Starting at the individual/micro level, research is required to address issues of concern for individuals with disability and their closest supports. Research is required that contributes to our understanding of, and develops responses to, the experiences of individuals with disability and families with complex and intersecting needs resulting in multiple disadvantages that compound the experience of disability. Linking the micro, meso and exo-systems is the need for research that explores the design, delivery and impacts of supports to address the mental and physical health needs of people with disability and their family members. Research is also needed on the impact of these meso and exo-systems on individuals' wellbeing across the life course and across geographic location. Research on these issues is particularly important for considering people with mental health issues as a single disability cohort as well as for further exploration of the emerging research that indicates much higher rates of mental health issues as a secondary disability for all other primary disability cohorts.[48]

Moving outwards through the ecological model to the meso-, exo-, and macro-systems, is the need for research that investigates and informs the design and delivery of services and systems that are integrated, safe, and equitable.[49] A range of services and systems were identified by stakeholders responding to all phases of this NDRP research project, including health, education, employment, justice and NDIS. There is an identified need for research about these areas across the life course which is inclusive of the viewpoints of multiple stakeholders including the wide family circles of people with disability.

Related to the exo-, and macro-system levels is the need for research that focuses on the outcomes and impacts of broader whole-of-society systems which underpin service delivery. Disability research which interrogates and informs public policy and addresses cost/benefit is vital

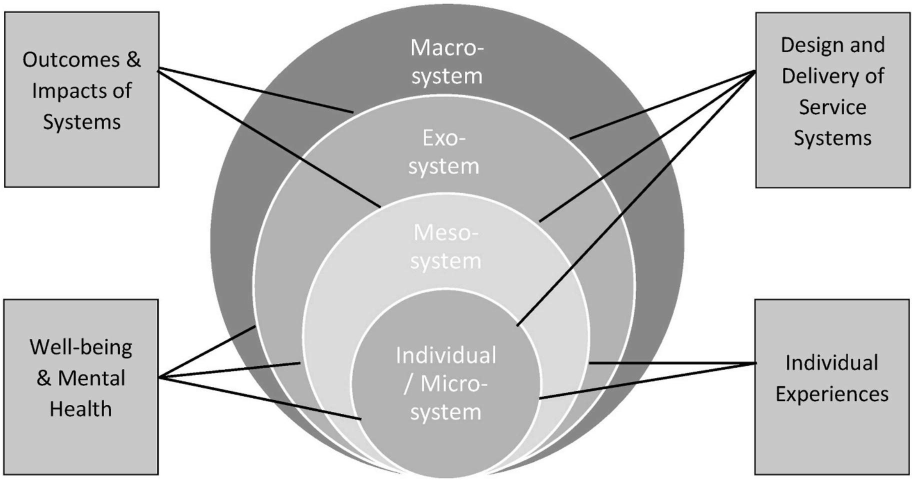


Fig. 3. Disability research viewpoints aligned to an ecological model.

to inform future policy and public funding. Another priority area at this level is research that focuses on community and social attitudes towards understanding, at a broad societal level, the imperative of inclusion and participation of all people with disability in social and community life.[50]

The four viewpoints reinforce and make explicit the findings across all phases of the larger NDRP research project. People with disability and those providing them support, identified the need for research which attends to, and provides knowledge about, how people are supported at individual, service delivery and systems levels. Viewpoints 1 and 3 emphasize the need for research about services and systems. Viewpoint 1 focuses on research to improve individual and family health, well-being and quality of life, with Viewpoint 3 more focused on research that documents and can lead to changes across whole of society and community systems. Viewpoints 2 and 4 highlight the need for research focused on the complex and intersecting needs of people from diverse backgrounds and with diverse experiences and the need for research that informs effective, equitable and safe services and systems across the life course. These two viewpoints are distinguished by a focus on issues of marginalization, discrimination and abuse in Viewpoint 2, and on issues related to mental health specifically in Viewpoint 4.

Findings of this study, in addition to findings from the first two phases of this research agenda setting project, were used by the NDRP to formulate a preliminary research agenda.[19] The viewpoints identified in this study by people with disability and a variety of stakeholders, provided a foundation of areas where research is needed. The areas include research about: making services better (Viewpoint 1); different experiences of people with disability (Viewpoint 2); how systems can support people better (Viewpoint 3); and, improving mental health and well-being (Viewpoint 4).[19] The preliminary research agenda[19] uses content from this 3-phase approach to agenda setting to (i) set four guiding principles for all disability research (high quality collaborative research, people with disability at the center; value all forms of knowledge; build research capacity); (ii) identify the four key research areas based on the four viewpoints articulated in this study; and (iii) map specific research topics and questions identified through phases 1, 2 and 3 to those four areas within the eight outcome areas of Australia's Disability Strategy 2021–2031.[51]

Strengths and limitations

A major strength of this study was that it provided an opportunity for and a practical means by which a variety of stakeholders, including people with disability, could have their say in the final synthesis of the results from the larger program of research contributing to the formulation of a preliminary research agenda. A further strength was the engagement of stakeholders who had already provided input in the consultation phase and indicated an interest and commitment to participating in this third phase of the larger program of research. This resulted in participants who brought knowledge of the aims of the overall project.

Because this study sought the perspectives of a range of stakeholders, we sought only minimal demographic data using questions that were pertinent to all participants. Hence it is not possible to describe the disability or health-condition characteristics of those with disability, nor provide any greater detail about the professional experience of other stakeholders who took part. Here it should be noted that this phase of the study only included 51 participants, with relatively fewer younger and older participants, which may have influenced findings given life-course priorities may vary. However, the survey and consultation phases that informed the content of this study involved many more in these age groups. For example, of the 988 survey participants, 33 (3.3 %) were young adults, and 152 (15.2 %) were over 65 years. In this phase people were able to have their say on the relative importance of issues emerging from the larger program of research and express additional issues they believed had not been articulated in the earlier work, but which should be guiding the NDRA.

Other limitations included the impact of COVID-19 restrictions. The restrictions may have influenced recruitment, with traditional face to face methods not possible. The study recruited 36.5 % of people with disability which, while inclusive of those with disability, highlighted the need for strategies addressing how to best recruit people with disability in future research. The restrictions also required a change to online engagement as the main method of participation. Online methods do not suit all people with disability as not everyone has access to computers and the internet or support to use these technologies. We acknowledge that we did not conduct analyses by different groups and the groups were given equal weight in the analyses. Even though the perspective of people with disability were included in the factor analysis, their specific views may not be fully represented.

Accessibility was also constrained by the online version of the Q sort, as it was not compatible with screen-readers used by some people who are visually impaired to access written material. The complex nature of the sorting task and the Q sample complexity meant the task was difficult for some other people with disability, including those with cognitive impairments, to complete without external support. To address these limitations, support and alternate formats were made available to anyone who indicated they needed these to take part. Despite our recruitment targeting stakeholders across Australia, the majority of participants were from the most populous states of NSW and Victoria.

Conclusion

Including people with lived experience of disability in all stages of the research process is fundamental to driving effective change, as is significant investment in future disability research. This study explored the research priorities of people with disability and those involved in the disability sector, through Q methodology, and developed four viewpoints to guide disability research. These viewpoints extend beyond medically focused research and highlight the diversity of research required to address problems with the design and delivery of services; the disadvantages that compound the experience of disability; social, emotional and economic aspects of disability; and mental health and wellbeing. The findings of this study and those that provided foundational knowledge to it, have been incorporated into a national disability research agenda. Although this research is set in Australia, the viewpoints provide a framework for disability research in other settings, and generate discussion about future research with those with lived experience.

Data availability statement

The data that supports the findings for this project can be found in the report "Setting an agenda for Disability Research".[41]

Ethical approval

This study was approved by the University of Sydney Human Research Ethics Committee (reference 2021/858).

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CRediT authorship contribution statement

Simon Garbellini: Writing – review & editing, Writing – original draft, Methodology, Formal analysis. **Angela Dew:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Christine Imms:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Simon Darcy:** Writing – review & editing, Writing – original draft, Formal analysis, Data curation, Conceptualization. **Keith McVilly:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Conceptualization. **Gisselle Gallego:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

The authors have no competing interests to declare apart from a general interest in the findings given that the authors are all disability researchers with an interest in the field. Any potential conflicts of interest in the project will be mitigated by the public scrutiny of results and methods as they emerge, along with the collaborative nature of the large research consortium. The design, findings and interpretation of this study represent the Consortium's views and process, not those of the funder.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.dhjo.2024.101634.

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