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A good life for people living with disability: the story from Far North Queensland

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ABSTRACT

Purpose: People with disability in regional, rural and remote Australia have poorer service access compared to people from metropolitan areas. There is urgent need for reform. This study's aim was to explore the needs and aspirations of people with lived experience of disability in Far North Queensland (FNQ) to inform a new service framework.

Materials and methods: Twenty-five individuals with diverse experience of disability were engaged in semi-structured interviews. Participants were recruited from four sites that differed geographically, culturally, and socioeconomically. Using an inductive then deductive thematic approach to data analysis, statements of needs and aspirations were compiled and aligned with three pre-determined vision statements.

Results: Needs and aspirations aligned well with the vision statements which were to: feel "included, connected, safe and supported"; have "opportunities to choose one's own life and follow one's hopes and dreams"; and have "access to culturally safe services close to home." To realise this vision in FNQ, support to navigate and coordinate services across sectors is essential.

Conclusion: People of FNQ of all abilities, need and aspire to experience "a good life" like their fellow Australians. Any new service model must focus on providing service navigation and co-ordination amid the complexities of service delivery in FNQ.

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Needs and Aspirations



> IMPLICATIONS FOR REHABILITATION

- The perspective of people with lived experience of disability needs to be heard and respected when designing services to support them.
- Service navigation and co-ordination are required to manage the complexity of service delivery for people living in regional, rural and remote Australia.
- Engaging with the whole the community is prudent when designing community disability, rehabilitation, and lifestyle services in regional, rural, and remote Australia.

Introduction

People of all abilities want to, and deserve to, live a good life. For many with a disability, this is not easy [1]. People living in Far North Queensland (FNQ), compared to their fellow Australians, face a higher burden of disease and injury [2], yet have fewer services and supports to address the disabling consequences [3]. Moreover, the services and supports that are currently offered are fragmented, making them difficult to access and navigate. As a result, most FNQ people living with disability do not enjoy the supports they need to lead a full life and participate in activities with family, community, and the wider society. Similar to people living with disability in all of rural and remote Australia, their ability to access services and supports diminishes in proportion to their distance from the major regional centre of Cairns [3].

FNQ providers face unique challenges when delivering services and support for people with disability. Remoteness poses critical challenges, along with cultural and socio-economic diversity, a geographically dispersed population, and a high-staff turnover [4–7]. Amid vast distances, expensive transport options, and often unruly weather, providers offer an assortment of siloed, single-sector, community-based, and/or fly-in fly-out services [8]. With many essential health and disability services only available in Cairns, people living in remote communities must often leave home and travel long distances to gain the services they need [9]. The resultant separation from the support of family, culture, community, and country is often distressing, particularly for First Nations people [7,10]. It is no surprise that essential services often fail to meet the needs of FNQ people. Clearly, cross-sector system reform in FNQ is required.

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Strategies to ensure that all people are able to access good quality services when and where they need them are proposed by the World Health Organisations (WHO) Framework on Integrated People-Centred Health Services (IPCHS) [11,12]. Rather than a typical disease-based model, the WHO advocates for a shift to people-centred care that involves co-design and co-production of innovative services created around, and with individuals, carers, and communities [11,12]. Similarly, when considering the specific needs of people with disability in Australia, the National Disability Insurance Scheme (NDIS), Australia's national scheme for people with disability, provides funds to individuals to meet their life goals and aspirations [13]. The NDIS sets out to provide them with greater choice and control over the support they receive [14]. To accomplish the ideals of the WHO and NDIS, the only course is to learn from those people with lived experiences of disability. Previous studies show that people with disabilities wish to enjoy a good life with the same opportunities and experiences as the rest of the population. They aspire to achieve social connectedness [15], finding meaning and enjoyment from employment and leisure, and "strong supportive relationships with their family friends, and the broader community" [16,p.113]. They want to be able to choose their own life [17] and achieve their career aspirations [18]. Aboriginal people in Central Australia feel that "participating in cultural, family and community activities" is a "good life" [10,19,p.9]. Hence, the critical groundwork for FNQ system reform is to listen to the perspectives of people in the region with lived experience of disability. The process requires active listening to their needs and aspirations and what a good life means to them [11,20–22]. Only then can services and modes of delivery be re-shaped.

The aim of this study was to explore the needs and aspirations of FNQ people with lived experience of disability. The primary objective was to understand what participants feel is a good life, what they need, and what they aspire to, to have a good life. The secondary objective was to identify drivers and challenges to living a good life. The study was part of a larger collective impact study [23] to reform services in FNQ. The information gained from this study will be used to inform a new community-informed aspirational model of service delivery [24].

Method

Design

A qualitative descriptive-interpretive methodology [25] was employed. Data were collected through semi-structured interviews, in-person or via ZOOM®, and analysed using an inductive then deductive thematic approach. The study occurred during implementation of the first Queensland COVID-19 restrictions, when most of FNQ was declared a bio-security zone [26].

Disability was defined in the study protocol according to the World Health Organisation as "an umbrella term, covering impairments, activity limitations, and participation restrictions" [27]. "People with lived experience" was defined as individuals with a disability or a person directly caring for a person with a disability.

The project was conducted by researchers who formed part of a Backbone Team. They took guidance from three reference groups that provided advice and a sounding board for ideas: a Consumer Group ($n=10$), an Aboriginal and/or Torres Strait Islander Group ($n=14$) and a Service Provider Group ($n=25$) (Table 2). The researchers were also accountable to the FNQ Collective which was made up of the Backbone Team, the reference groups, together with individuals and organisations interested in contributing to design of the service reforms.

Ethical approval

The Far North Queensland Human Research Ethics Committee (HREC Reference Number HREC/2019/QCH/54978–1371) approved the study in 2019.

Setting

FNQ is the northern-most part of the State of Queensland and covers a geographic area of 380,000km²; this is greater than the land area of the British Isles (Figure 1). It has a population of just over 280,000 [28]. Cairns is the major city in the region, located almost 1700km from the state capital, Brisbane. Residents of FNQ live in outer regional (88.6%), remote (3.3%), and very remote (8.1%) areas [4]. Aboriginal and/or Torres Strait Islanders (hereafter respectively referred to as First Nations Peoples) make up 15% of the population [29], but the proportion is much higher in remote FNQ communities. The population is widely dispersed and distances to services can be vast, particularly in more remote parts of the region (>900km) [8]. Service access difficulties are a major contributor to the inequality of opportunity when compared to metropolitan-based populations [30]. The people of FNQ experience substantial socio-economic disadvantage with approximately a third (35%) in the most disadvantaged quintile [29]. This compounds the impact of disability on the lives of many FNQ people [5,6].

Research Team

The four-person research team (Authors A1, A2, A5, A12) responsible for data collection and analysis was part of the Backbone Team. The research team included a First Nations Research Assistant and non-Indigenous researchers with local connections to FNQ communities. All researchers were women with experience working in regional, rural, remote, and very remote regions of

Table 2. Reference group members.

Reference Group	Number of members	Sectors	Experience, expertise or influence
Consumer	10	Representative of different life-stages and impairments	Lived experience of disability – individual or family member.
Aboriginal and/or Torres Strait Islander	14	Aboriginal community-controlled sector; Federal, State and Local Government; Other	Expertise and/or influence in health and disability services for Aboriginal and/or Torres Strait Islander people in FNQ.
Service Provider	25	Executive or clinicians; government and non-government; local, state, federal; health, education or disability sector; private allied health	Expertise and /or influence in health and disability, rehabilitation and lifestyle services in FNQ.

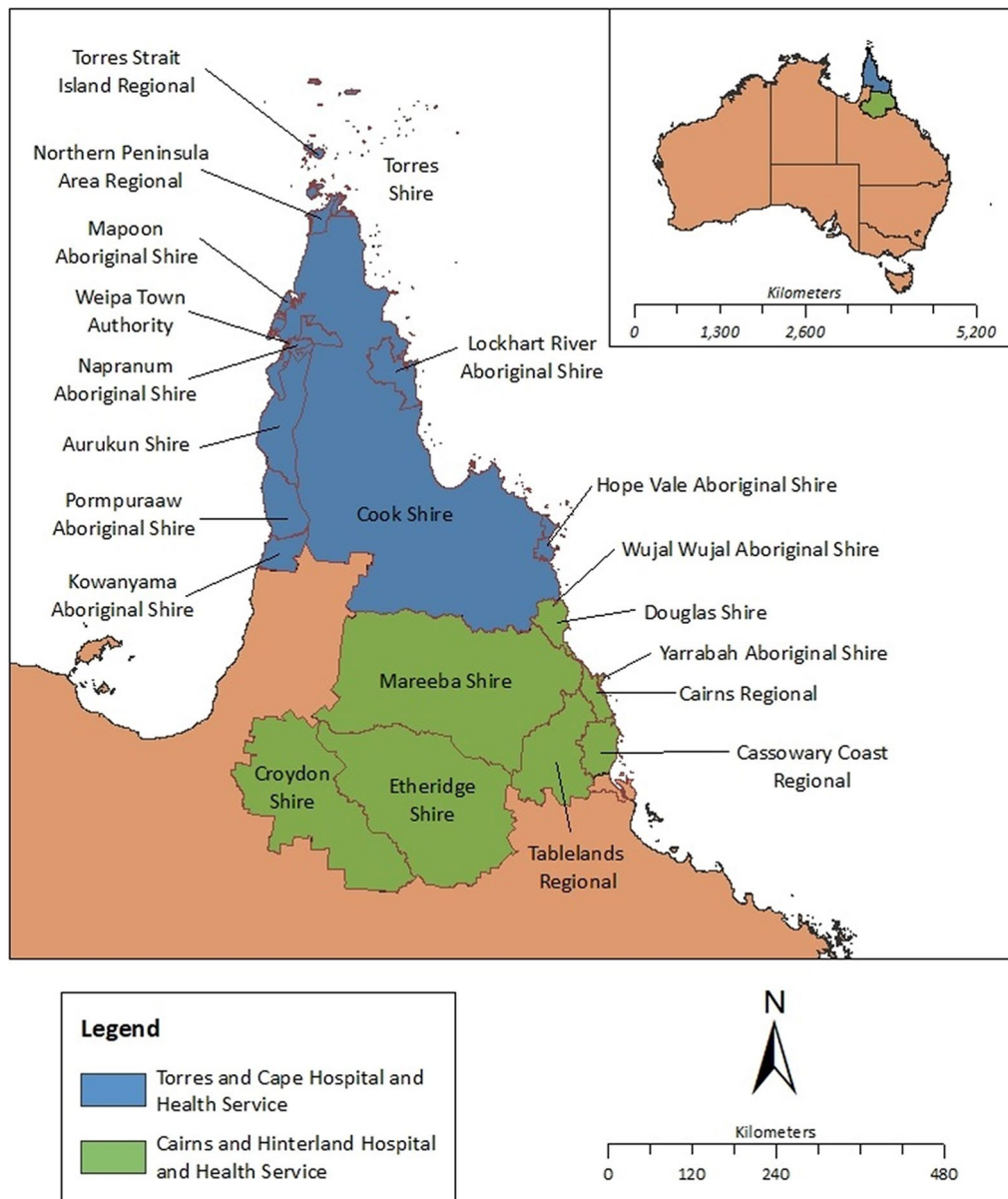


Figure 1. Far North Queensland Local Government Areas.

FNQ and with First Nations and non-Indigenous people. All had limited personal experience of living with a disability. The three non-Indigenous researchers had experience in conducting qualitative research on people with disabilities. One researcher was also an experienced rehabilitation clinician who had been involved in development of innovative models of service delivery for rural, remote First Nations communities across northern Australia. The First Nations Research Assistant was new to her role but had strong family connections within the region and previous experience in community engagement and administration within the First Nations community-controlled sector.

Study sites

Interviews were conducted at sites in Cairns, the Atherton Tablelands, on Waiben (Thursday Island) in the Torres Strait, and the Cape York community of Kowanyama. These four sites were selected to reflect diversity within FNQ, geographically, culturally, and socioeconomically.

Recruitment

People with lived experience of disability were recruited to the study using a combination of purposive, snowball, and opportunistic sampling approaches to achieve maximum variation in age, gender, indigeneity, life stage, disability, and remoteness. Researchers approached previously-identified local contacts at each study site and asked if they could nominate potential participants who were >18 years of age and self-identified as having lived experience of disability or a person directly caring for a person with a disability. Older people living with disability associated with ageing were included. The local contact person then approached the potential participants and informed them about the study. If the potential participants expressed interest and gave their permission, their contact details were passed on to the research team. A researcher then contacted each potential participant by telephone to arrange an interview. All participants were provided with an easy-to-read information sheet and informed consent form prior to the interview.

Table 1. Characteristics of FNQ people with lived experience of disability.

Sample characteristics		Samples	Percentage
		N=25	100.0%
Indigenous Status	Indigenous	9	36.0%
	Non-indigenous	16	64.0%
Gender	Male	9	36.0%
	Female	16	64.0%
Lived experience	Person with a disability	18	72%
	Carer of a person with a disability	6	24%
	Carer and person with a disability	1	4%
Age	25–34	2	8.0%
	35–44	6	24.0%
	45–54	7	28.0%
	55–64	4	16.0%
	65–74	2	8.0%
Life Stage	75 years or older	4	16.0%
	Children	6	24.0%
	Young people	3	12.0%
Primary Underlying Impairment	Adults	10	40.0%
	Older people	6	24.0%
	Physical	12	48.0%
	Neurological	6	24.0%
Remoteness	Sensory	3	12.0%
	Intellectual	4	16.0%
	Regional	5	20.0%
	Outer Regional	12	48.0%
	Remote	0	0.0%
	Very remote	8	32.0%

Interview participants

Twenty-five participants were recruited from across the four study sites: five from Cairns (regional area); 12 from outer regional (Atherton Tablelands); and eight from a very remote area (Kowanyama and Waiben) (see Table 1 for Participant Characteristics). Eighteen participants had a disability and seven were caring for an individual with a disability. All people caring for an individual were caring for a child or young person, one of which was both a carer and a person living with a disability.

Data collection

The Research Team conducted semi-structured interviews at times and locations nominated by each participant and according to requirements of the local COVID restrictions. Locations of in-person interviews included participants' homes (7), workplace (2), aged care facility (5), community facility (6), a local park (1) and a local café (1). Two participants were interviewed via Zoom®. Six participants were accompanied by a nominated support person. Communication supports, used by five participants, included a support person (3) or a communication device (2). Two researchers conducted the interviews (AI and/or author A2) plus A5. The First Nations Research Assistant was a co-interviewer in 18 of 25 interviews. One interview was conducted by just a single researcher. Interviews averaged 42min in duration (range 17 to 66 min).

Interview questions were strength-based and aimed to stimulate discussion around participants' needs and aspirations. A strengths-based approach focuses on an individual's strengths including their personal strengths and social and community networks rather than on their deficits. In essence, we focused on what the individual was able to do, and not on what they were unable to do. Initial questions focused on what is "a good life", "what matters" and "what helps you to live a strong, safe and healthy

life". Subsequent questions focused on drivers and challenges faced in meeting their needs and achieving their aspirations. Immediately after each interview, researchers recorded their reflections, together with notes on key information reported by participants.

Interviews were transcribed verbatim before they were checked for accuracy by the interviewer. Interview transcripts, notes and reflections were all included as data which was managed, and stored securely using *Nvivo 12*.

Data analysis

The research team (A1, A2, A5, A12) initially analysed the data using an inductive approach to form statements reflecting the needs and aspirations expressed. They then employed a deductive approach to group these statements within three overarching vision statements for FNQ that had been previously determined by the three project reference groups, to feel "included, connected, safe and supported"; to have "opportunities to choose one's own life and follow one's hopes and dreams"; and to have "access to culturally safe services close to home" (see Table 3).

In the first inductive phase of analysis, A1 read and re-read the interview transcripts, notes, and reflections, making notes on sentiments that were commonly expressed. Next, A1 discussed these sentiments with A2. A1, A2, and A12, then drew the sentiments together into structured statements of the needs and aspirations, together with key drivers and challenges to achieving them. Author A5, later reviewed, refined and confirmed that the statements "rang true" with the sentiments expressed.

The second deductive phase of analysis involved grouping the Needs and Aspirations Statements within the three Vision Statements. The purpose of this phase was to confirm consistency or identify discordance between the Vision Statements and the Needs and Aspirations Statements and then modify either or both to achieve consistency. To ensure data analysis reflected the broader lens of the people of FNQ, and not just of the Research Team and Backbone Team, the Vision Statements and corresponding Needs and Aspirations Statements, along with key drivers and challenges, were then presented, refined, and endorsed by the Consumer Reference Groups in-person and then again with the FNQ Collective through four Zoom® workshops. Lastly, the findings were expressed in a narrative form to reflect everyday life across the lifespan.

Results

Needs and Aspiration Statements all aligned well with one or more of the Vision Statements. Hence, the Needs and Aspirations Statements (Table 3) and the Drivers and Challengers (Table 4) are presented under the Vision Statements to which they were most strongly aligned. Although each participant expressed their own set of unique needs and aspirations, these statements reflect the consistency that was found across the different ages, gender, indigeneity, life stages, disability and remoteness.

To feel included and connected, safe and supported

Feeling included and connected, safe and supported were priorities universally expressed by participants. Feeling included and connected could mean various forms of social interaction, and engaging in group and community activities. Parents wanted their child with a disability to be able to make friends of a similar age. Adults with a disability wanted the option to join a group of peers with similar interests. Older people wanted to maintain a

Table 3. Needs and Aspirations of FNQ people with lived experience of disability.

Major themes	Needs and aspirations statements
<i>To feel included and connected, safe and supported</i>	To have my own friends and social life of my own age or interests.
	To do things for myself, with support from others.
	To love and be loved.
	To have a valued role within my family and community.
	To enjoy experiences in the community together with my family or as a group of friends.
	To be included in everyday community life and to live as good a life as possible.
	To have support to plan and take the next step in life, to have certainty around my future.
	After injury or illness, have support for me and my family to return home and get on with life.
	To have support to be mentally healthy to be my best self.
	To be respected for my rights - my privacy and to choose what I want and where I want to live.
<i>To have opportunities to choose our own life and be the best that we can be</i>	To fully understand my rights, options and supports available to me.
	To have my hopes, dreams and passions taken seriously and to excel at what matters to me.
	To live how I want to live – with family with me, or independently with supports if needed.
	To join interest groups including outdoor interests and recreational activities.
	To learn, undertake study, education and training of my choosing.
	To be able to work, whether volunteer or paid work, to pursue a worthwhile career.
	To be connected to my spiritual or cultural life and take my place within it.
	To have access to stable/sustainable independent living options within my own community.
	To have access to quality rehabilitation services across the lifespan that are close to home.
	To have access to specialist services with support and minimum time away from home, family.
<i>To have access to culturally safe services close to home, to be well and stay well</i>	To have access to transport options that are reliable, supported and affordable.
	To have appointments coordinated to reduce the burden on me and my family.
	To understand services available to me and to access them with minimal red tape.
	To have support to transition between services across life-stages
	To have support to transition and navigate between services in the city and home

meaningful role in the family and the wider community, particularly by sharing experiences and life skills and mentoring young people. Being included and connected gave participants a sense of belonging.

“We wanted him to be able to get out in the community and be a part of things again. Do stuff with other people. Rather than being stuck at home.”

(Mother of an adolescent son with disability).

Table 4. The key drivers and challenges experienced by FNQ people with lived experience of disability.

Key drivers	Key challenges to a good life
Infrastructure	Infrastructure to participate and be included
Support	Transport options
Navigation”	Complexities of service delivery:
Integration	Distance from services
	Red tape to access services
	Time away from home
	Navigating multiple services

Support from family or friends was a pivotal aspect in participating in social activities. For many, fishing, going to the beach or to a local swimming hole depended on support from family and social networks. Appropriate community infrastructure was an essential element, so people could access recreational areas. Such infrastructure could include ramps or tactile paving or playgrounds with wheelchair swings or adult change facilities. Recreational activities provided participants with opportunities to spend quality time with their whole family and/or peers. Some First Nations participants, expressed how being “on country” provided a sense of comfort and connection and allowed participation in cultural activities:

Because we are a real family who do a lot of that stuff. And whoever thought that Babinda Boulders would be accessible for wheelchair users? And now it is. It’s just a way of life in Cairns you know. So, I think that should be everywhere.”

(Mother of an adolescent daughter with disability).

Participants spoke of the detailed planning required to attend community events or visit local community areas. The challenge was not only having the community infrastructure and supports but also finding out whether they were available in the place they wanted to visit. Transport was almost always a limiting issue; whether it be transport of any sort, or transport that could accommodate peoples’ physical needs. While wheelchair accessibility mattered, so too did the presence of personal support that would allow a person with a disability to travel independently of a family member.

“One of the big ones we’ve actually found, and obviously, equity of access to education and information, so inclusive communication strategies and platforms need to be utilized by local councils and community groups”

(Mother of an adolescent son with disability).

To have opportunities to choose our own life and to follow our hopes and dreams

Personal choice was paramount. As far as possible, participants wanted to choose their own life path. They felt that their decisions mattered; they wanted those decisions to be respected and supported by others. Such decisions included making their own choices about friends and about key milestones throughout their life, particularly around health care, finances, and living arrangements:

“It wasn’t until actually NDIS came about and there was more funding around, that we could make choices. And [son] could be involved in those choices about getting help with his speech, with his movement and all that type of stuff. NDIS made a big difference with what’s available in the community now. We’ve got [son] into so many therapies

now since; he's actually going to go in the pool in a couple of weeks so were so excited." (Mother of an adolescent son with disability).

Many adult participants with a disability were still living in the family home yet aspired to live independently. Finding appropriate independent living options with access to local supports was often the challenge. Once living independently however, family members could pursue and invest time into other aspects of their lives, including return to work and relationships with partners or other family members.

"I think, where NDIS has helped to get as well, 'coz we've got the funding now that we can have support workers coming in and take him out and about so that we can still have – like [husband] and I are now getting to spend time together and our daughter can come home and feel like it's more of a family and not, oh,[son]'s got to have this, [son] got to do that." (Mother of an adolescent son with disability).

Living a good life for participants meant being able to follow their hopes and dreams which included having intimate relationships, a career path, and the freedom to do the things that mattered to them. They wanted to have opportunities now and as life progressed. They wanted opportunities to gain an education, develop new skills and achieve financial security. For some, this meant having support in the workplace so that they could return to work after illness or injury. For others, it meant learning new skills through retraining programs or finding a new career path. Having a NDIS package had made it possible for some to achieve their dream of employment. For others, it could be liberating for their parents to return to employment, or to have broader opportunities for a richer family life.

Challenges during life transitions were common yet varied: children moving from childcare into school, from school to work or further education and then to living independently. Many participants spoke of needing help to plan and take the next step, regardless of stage. Parents spoke about needing support to navigate their child's transition into adult life, particularly around living options:

"In terms of future all I can see is that she will be with us. And as long as it's [NDIS] around we'll have in home support and that's been amazing. I do want more for her but I don't know what more for her looks like – like a rich life you know." (Mother of a child with disability)

Many participants who had experienced a disabling injury or illness as an adult, found the challenges formidable, especially when navigating services needed for transition back home and/or to work. For older people, being able to stay in their homes around their family and friends meant they could avoid moving to an aged care facility. Moving into aged care was often a difficult time, with many older people describing how lonely they felt. For some, being included in activities and groups by staff and volunteers softened this transition. Others who had attended to succession planning, estate distribution and funeral planning, described a sense of closure and the ability to reach the end-of-life at peace. They felt things were how they wanted them to be and according to their choice. Others needed support to prepare for these events.

Participants felt life transitions needed to involve changes of one's choosing; such as entering the workforce. But change could sometimes be forced upon some participants; such as relationship breakdown or functional decline due to disease progression. For

others change could be anticipated; such as going on a holiday with family.

To have access to culturally safe services close to home

Regardless of where they lived, participants wanted to have quality services close to home. Rather than explicitly expressing the need for culturally safe services, participants wanted services and supports where they felt welcome, that worked for them in their way, in their community.

When participants felt there were good local services and supports, they were happy to remain in community surrounded by family and friends. When local services were lacking, participants found that having to travel long distances for appointments was particularly onerous. Some needed to remain away from home for weeks or months. Others had to stay away permanently. Others could leave hospital sooner when they could continue rehabilitation in their own community.

"I think personally, because of what I want to achieve, if I had a little bit more accessibility, I probably wouldn't have the arthritis or anything, because I probably would have got it fixed. I wouldn't have to wait so long to get into a physio." (Adults, female)

For many, travelling long distances to appointments was the only way they could access specialist care. Safety was a concern and most participants indicated that they needed a support person to travel with them. They spoke about the importance of having well-coordinated appointments, for themselves and for their family members or their support person. Some participants living in remote communities felt they were already benefiting from having Nurse Navigators helping them in this way. They were finding that coordination of transport, travel supports, accommodation, and appointments meant spending less time away from home.

Participants moving from one stage of life to another often needed to transition to new services. For many parents, helping their child move out of the school system and into independent "adulthood" was daunting, because they found there were so many service gaps that they could fall into. They spoke about the limited options and resulting uncertainty for their child's future.

Participants frequently spoke about needing more information about services plus more help with navigating them, particularly during periods of change. Participants regularly raised "red tape" as a formidable barrier to access services:

"Oh, the red tape in that." And that's how come with our people, they don't want to go and see a doctor or something. Or they don't want to go to that hospital in Cairns and that." (Older person, female)

Discussion

To the authors' knowledge, this is the first study to explore the lived experience of people with a range of abilities and across different life stages, living in regional, rural, remote and very remote Australia. The findings reveal what constitutes a meaningful life for a range of people with lived experience of disability. Similar to people with lived experience of disability across the nation and across the world [10,15–19], people in FNQ of all abilities at any age or life stage, aspire to be included and connected; to have choice and control over their life; and have access

to services close to home, regardless of where they live. What this study particularly highlights, is that each individual's life circumstances, cultural, economic, and geographical context, frame their needs and aspirations. The quest is to design services to match each individual's unique life circumstances so that people of all abilities can have a good life. The process must be in collaboration with the individual, their support network, and their community [11,12]. For a person with a disabling health condition living in FNQ, for instance, the large distances to services would mean that accessible transport and accommodation options could be a priority for access to health care, education, and sporting opportunities. For someone with a similar condition, in an urban setting, this would be unlikely to be the case.

Living with a disability in rural and remote settings brings with it many service complexities. With long distances and widely dispersed populations, the range of health and disability services is so often disjointed, siloed, and thinly spread. Further complications arise due to difficulties with recruitment and retention of the health and disability workforce [3,7,8,24,31,32]. Under these circumstances, it is a challenge to provide services, let alone choice and control over those services [33,34]. There are often long and extensive delays in accessing therapists and therapy supports [35] plus frequent changes in health and disability providers and schedules [36]. Regardless of location, participants reported difficulties navigating systems, particularly during life's transitions. People with disabilities faced with such challenges have been known to withdraw from health services altogether [37]. To address such complexities participants in this study agreed that engaging with a Nurse Navigator made access to services and travel less daunting. Nurse Navigators have been previously shown to play a "pivotal role in navigating the seemingly insurmountable obstacles of accessing advice, services, equipment, and appointments in a seamless way" [38]. Navigators or coordinators could be employed in FNQ to support people to find their way through complex systems to ensure some control over, and timely access to services of their choosing.

Difficulties accessing services mean that many people with disabilities have to entirely rely on family and friends [39–42], particularly in rural and remote locations [43]. In this current study, participants who had lived experience of supporting a person with a disability spoke of the importance of connection and the support needed to cope with stress, so that they could focus on other aspects of their life as well. This was particularly important for those supporting a family member (e.g., child or parent) who were balancing their family member's needs with that of other children and their partner. Similar to other studies [39,41], caring for a family member was usually not regarded as a burden even though it was hard to find time to focus on relationships with other family members and engage in workforce and social activities. Carers spoke of the potential benefits offered by the NDIS; with better focus on their entire families, social activities, health and wellbeing. Hence when designing services, carer support, inclusive of information and education, respite, and financial support [39–42], must be a priority.

Strengths and limitations

Travel restrictions mandated by the Queensland COVID-19 pandemic response substantially limited the study sample size and composition. Much of FNQ was declared a designated biosecurity zone [44]. Study participants were predominantly female and over 24 years of age. Hence the findings may not necessarily reflect the views of local men and people under 24 years. Online interviews were used where in-person interviews were not possible.

This may have compromised the level of rapport that could be established between participants and interviewers, possibly limiting the depth of information provided [45]. It is also likely that many participants were overwhelmed by the most recent COVID-19-imposed restrictions and community isolation. This may have coloured their responses.

A study strength was that it was conducted by experienced researchers, backed by and accountable to an entire FNQ collective with experience of life in FNQ. Study participants were from four sites representative of FNQ urban, rural, and remote communities. First Nations Peoples were appropriately and respectfully represented in the research team and among the participants. Cultural safety was paramount. Great care was taken to listen to, respect, and document the stories of people with disability and their families.

Future directions

The findings of this study have implications that go beyond the health and disability service sector. For example, any inclusive community needs to closely involve local councils, and community and cultural organisations. In keeping with the WHO Framework on IPCHS, this requires a shift to systems designed around people [11]. As a starting point, the IPCHS framework can be used to guide the transformation of services in line with the FNQ vision for a good life for people of all abilities. The five strategies within the framework offer practical approaches for transformation: engaging and empowering people and communities; strengthening governance and accountability; re-orienting the model of care; co-ordinating services within and across sectors and creating a supportive environment [11]. This can be achieved through a whole-of-community response, proper resourcing, and robust processes to evaluate the impact of change. Resourcing requires community pressure and political will.

Conclusion

People of all abilities in FNQ want to be included, connected, safe and supported regardless of age or stage in life. They want access to culturally-safe services close to home and tailored to their unique home circumstances. They want a choice. They want opportunities to follow their own path and live a rich life. To meet the needs and realise the aspirations of people of all ages and abilities, including people living with disability in FNQ, the focus of any new service model must be on providing support in service navigation and co-ordination to manage the complexity of service delivery. Ultimately, the challenge is to reduce the complexity of service delivery. To accomplish this, a whole-of-community response in FNQ is essential to ensure people with disability have equity of access and support, in line with their fellow Australians.

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