

Health Navigation for People Experiencing Newly Acquired Long-term Physical Disability: A Realist-informed Integrative Review

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ABSTRACT

Navigating healthcare complexities can be challenging for disabled people, leading to challenges accessing services when required, and contributing to inequitable outcomes for disabled people and their families. Physiotherapists may be key health providers for people with newly acquired physical disabilities and may experience these navigational complexities themselves. Health navigators have been postulated as one solution and are well established in services for other health conditions such as cancer and mental health. However, navigation services for disabled people are less well developed and implemented. This realist-informed integrative review aimed to articulate and clarify underlying causal processes of health navigation programmes for people with newly acquired long-term physical disability, particularly within the New Zealand context. A two-phase literature search was conducted using integrative review methods. Two primary foci emerged for navigation programmes – a *targeted health focus*, directed towards reducing secondary complications and better service use and flow, or *holistic health focus*, directed towards more aspirational outcomes. Nine mechanisms of effect were identified across the spectrum of navigational programmes, with empowerment and self-determination overarching. Our findings are important for synthesising knowledge about existing navigation programmes and clarifying the aims and outcomes of future programmes addressing the navigational needs of disabled people.

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INTRODUCTION

Health navigators have been described as “brokers” for health in response to system complexity and the range of barriers experienced by people with health needs (Peart et al., 2018). Disabled people¹ with predominantly physical impairments often experience barriers (i.e., system complexity, costs, transport issues, physical barriers, and negative attitudes), meaning they are less likely to receive appropriate healthcare assessment, treatment, and rehabilitation (Gibson & O’Connor, 2010). Studies evaluating the effects of navigational programmes conducted with disabled people have demonstrated improvements in community reintegration, quality of life, depressive symptoms, and adherence to self-care practices (Claiborne, 2006; Egan et al., 2010; Hudson et al., 2019; Newman et al., 2014). For instance, navigation programmes for people after stroke, provided by healthcare professionals,

have shown more appropriate use of health services with resulting cost savings (Claiborne, 2006; Deen et al., 2018), medication compliance (Deen et al., 2018), and community integration (Egan et al., 2010). Likewise, an individualised programme delivered by social workers to people with severe brain injury (ranging from 30 to 300 interactions per participant) improved community integration, independence level, and functional abilities (Rosario et al., 2017). However, the diverse nature of these programmes and varied levels of reporting on the execution and outcomes of programmes makes drawing conclusions and replicating programmes for disabled people in a range of different contexts challenging. A deeper understanding of what specifically works well for people with newly acquired physically disabling health conditions could improve access, experiences, and outcomes for people navigating health and wellbeing services, while also promoting more appropriate use of services.

¹ The use of the term “disabled people/person” aligns with New Zealand Health and Disability Strategy documents (Ministry of Social Development, 2016), reflecting that people are disabled by attitudinal and physical barriers in the world.

Physiotherapists, like other allied health professionals, may be the sole or primary health provider supporting a newly disabled person. Improved knowledge and access to navigational support have the potential to improve appropriate access to physiotherapy input, which benefits both the disabled person and the service (Cook et al., 2023). While it is reasonable to expect all health providers to play a part in signposting and empowering disabled people to find their way through health services, optimal navigational support may reduce the need for physiotherapists, or other health professionals, to fill a navigation “void” and detract from the primary purpose of their role (Kokorelias et al., 2021).

In the New Zealand Disability Strategy improved health access for disabled people is prioritised (Ministry of Social Development, 2016) and in Australia, “disability health navigators” are specifically recommended (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2023). In New Zealand, some navigation-aligned services have been implemented to improve access to health care for people with chronic health conditions (Carrier et al., 2014). For example, Whānau Ora (translated as “family health”) was implemented in 2010 to provide navigational support, particularly to Māori (the Indigenous people of New Zealand). This approach aimed to support whānau (families and/or family groups) to optimise their health and wellbeing through empowering them collectively, rather than providing support to them separately as individuals (Savage et al., 2017). Within the Whānau Ora approach, navigators work with families, including people with a range of health needs, using strength-based, aspirational approaches. Enabling Good Lives (EGL), rolled out nationally in 2022, is another approach that uses a navigation model to support disabled people in New Zealand. The principles of EGL aim to provide disabled people with more choice, control, and support in order to live their vision of a good life (Anderson et al., 2014; Anderson et al., 2017; Were, 2017). The EGL principles are based around self-determination, empowerment, starting early, being person-centred, and ease of use. However, none of these navigational approaches are specifically aimed at people with newly acquired health conditions contributing to an experience of disability.

When co-designing and/or developing new programmes, there is a need to understand *how* complex interventions work. This means not just knowing if a programme achieves its desired outcome but also understanding the core elements of a programme and the influence of different delivery contexts – while also identifying key uncertainties so that any developments in programmes can be tailored for the target population(s) (Skivington et al., 2021). Therefore, this integrative review aimed to develop and refine programme theory, including key contextual considerations of navigation interventions, so that existing knowledge guiding navigational interventions can inform the ongoing development, adaptation, and use of navigational programmes for people experiencing newly acquired long-term physical disability in New Zealand.

Aim and rationale

The primary aim of this review was to articulate and clarify underlying causal processes (i.e., mechanisms of effect) of

health navigation programmes for people with newly acquired long-term physical impairments, thereby gaining a deeper understanding of how navigation programmes work, for whom, and in which contexts (Wong et al., 2017). We particularly wanted to gain a deeper understanding of contexts and resources relevant to New Zealand and how these might impact mechanisms of effect. The specific question guiding our review was: What type of navigation programmes work for people with newly acquired long-term physical disabilities, and under what circumstances?

Note some studies included in this review present evidence of navigation programmes that served people with a wide range of needs including, but not exclusively, disabled people. However, for consistency, in this paper, all navigation programme users will be referred to as disabled people.

Materials and methods

We used integrative review methods (Whittemore & Knafl, 2005) within a realist research approach (Pawson et al., 2005). This approach was appropriate since we needed to synthesise diverse types of literature, including qualitative, quantitative, review, and grey literature, to provide a more comprehensive understanding of relationships between context, mechanisms, and outcomes within navigational programmes for newly disabled people (Pawson et al., 2005; Wong et al., 2017). Using the integrative review guidelines published by Whittemore and Knafl (2005), we completed the following stages: (1) problem identification, (2) literature search, (3) data evaluation, (4) data analysis, and (5) presentation. Table 1 overviews the steps taken at each stage of the integrative review process, including how realist analytic methods were incorporated.

Ethical approval was not required.

Problem identification

We (ET and DT) conducted an initial scoping search to identify existing explanations of how navigation services work and how they might benefit people with physical disability. This was supplemented by searching the grey literature, which identified reports and policy documents from local navigation initiatives such as EGL and Whānau Ora, which are established navigation programmes in New Zealand (Anderson et al., 2014; Anderson et al., 2017; Savage et al., 2017; Were, 2017). This search highlighted the diversity of terminology relating to navigators, including titles such as peer navigators, care coordinators, case managers, connectors, brokers, and networkers (Carter et al., 2018; Kelly et al., 2019; Lukersmith et al., 2016; Wallace et al., 2018), and the need for a common language. Likewise, diversity in intervention and outcome focus was apparent, with some programmes taking a much narrower view of health (such as reduction in pressure areas) and others taking a more expansive view of health and wellbeing.

Literature search

Informed by our scoping search and initial programme theory, we designed, piloted, and conducted a primary literature search in September 2021 by a librarian (DT) with experience in conducting searches for literature reviews. Inclusion criteria included the following: all study designs, English language, adults with acquired physical disability, and navigation focus of

Table 1*Integrative Review Steps and Realist-informed Actions Taken Iteratively in This Study*

Interpretative review steps	Actions aligning with realist approach
Problem identification	Clarification of scope: Identified the review question including defining the nature, content, and contexts of the intervention. Development of initial search term options using the PICO framework (ET, RM).
Literature search	Search evidence: ET conducted exploratory “background search”. Search terms further defined with RM and DT. Not enough known to start with an initial programme theory due to heterogeneity in studies. Search conducted in two phases: Initial literature search and then an iterative search, progressively focusing to identify key programme theories and refining inclusion criteria in the light of emerging data.
Data evaluation	Appraise articles and extract data: ET and RM developed critical appraisal checklist and bespoke data extraction process in terms of contexts, mechanisms, and outcomes.
Data analysis	Synthesise evidence: Conducted by ET using thematic analysis with a realist lens alongside ongoing discussion with RM to conceptualise plausible explanations of what works for whom, how, and under what circumstances. Review of “contradictory” evidence to generate insights about the influence of context particularly regarding the New Zealand context.
Presentation	Drafted and tested synthesised model with research team. Findings used to inform ET further research into stroke navigational supports locally.

Note. ET = Emily Timothy; DT = Donna Tietjens; RM = Rachelle Martin (authors).

intervention. The criteria were kept intentionally broad because the search results were already few. Purposeful sampling was utilised to test emerging theories that included capturing the Australasian navigation context, as narrowing to just New Zealand studies appeared limiting, and parallels exist between Indigenous and colonial communities in these countries (Zambas & Wright, 2016). This iterative search was broadened beyond people with physical disabilities to capture a broader understanding of Australasian navigation services for people with a range of health and social needs. This iterative search was intended to deepen theoretical concepts rather than be exhaustive. See Figure 1 for a summary of these searches and Table 2 for the key characteristics of the articles included.

Data evaluation

We read and appraised relevant articles using the Template for Intervention Description and Replication (TIDieR) checklist (Hoffmann et al., 2014) and a bespoke data extraction form. Given the low number of search articles, emphasis was placed on the relevance of the article to the research question and theory under exploration. Eligible articles were initially read by the first author (ET) to gain familiarity with the data. Then, coding commenced inductively using a combination of NVivo software (12th edition) and highlighting and annotation in electronic documents. The first rounds of coding focused on the conceptual level, which were then considered in analytical categories.

Data analysis and presentation

Selected articles ($n = 21$) were read and initially coded. Coding then became progressively focused on identifying contexts, mechanisms, and outcomes (CMOs). These were initially identified within NVivo (12th edition). However, the researchers

then moved to manual note-taking and coding to better understand relationships and possible causal mechanisms. These codes were consolidated, and CMO names were developed during the process, using “if-then” statements to test and refine ideas. Iterative analysis between inductive and deductive coding of articles then supported, refined, or refuted emerging programme theories. Mechanisms were initially considered in terms of both resources/activities and reasoning, as described by Dalkin et al. (2015). The developed CMOs were then considered in terms of an overall programme theory, and modelling/drawing was used to conceptualise how these statements related. Any contradictory evidence was also considered to generate further insights into the influence of context.

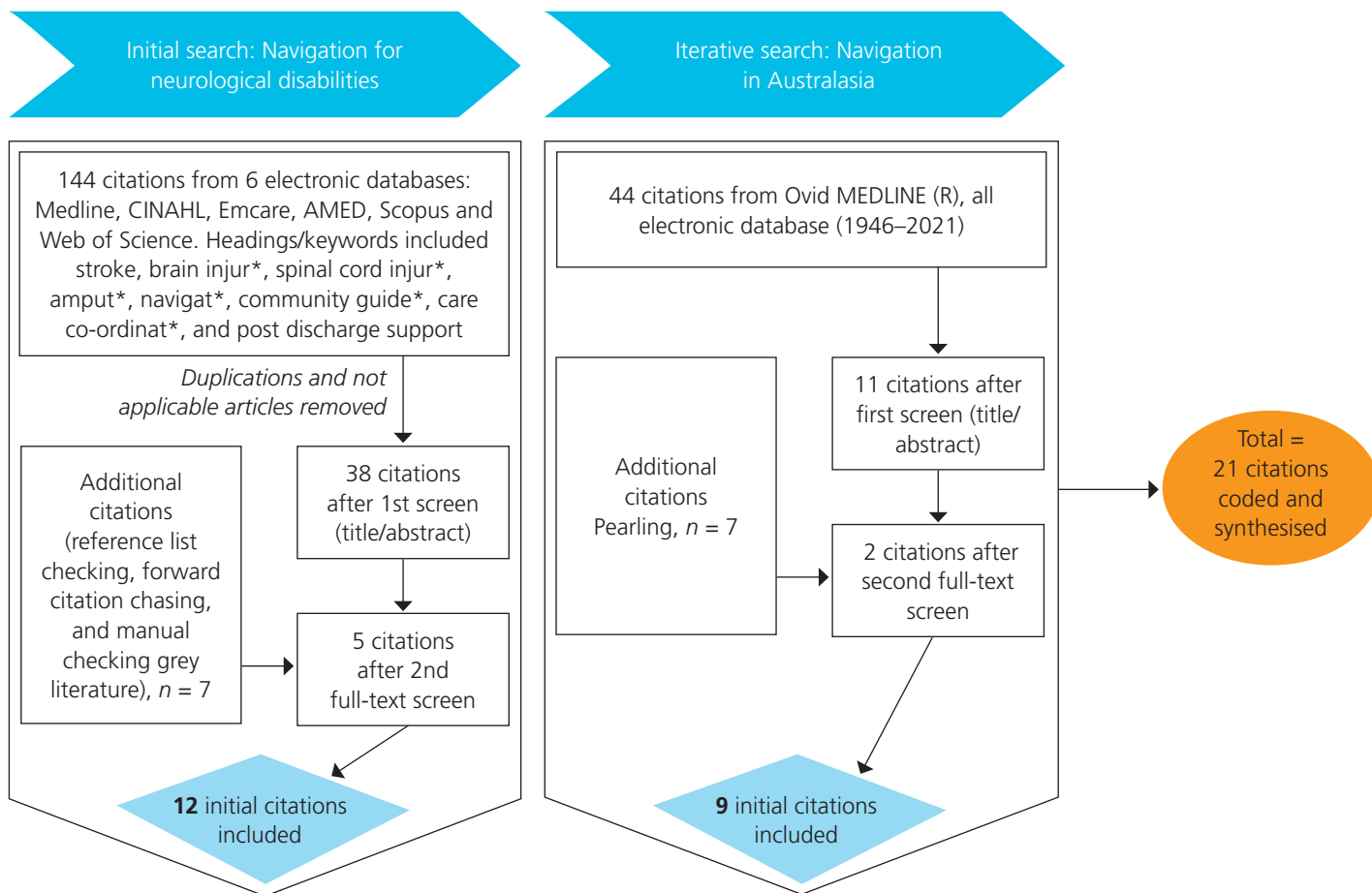
FINDINGS

Overall, navigational programmes benefitted disabled people, although the outcomes were diverse. There was evident contextual variation between navigation programmes orientated to need according to different domains of the World Health Organization’s International Classification of Functioning, Disability and Health (World Health Organization, 2002). At one end of the contextual spectrum were programmes addressing the impairments of body structure and function or activity limitations a disabled person was experiencing. On the other end of the contextual spectrum were programmes addressing the participation barriers a disabled person may have experienced, related to interactions between the disabled person and their environment (World Health Organization, 2002). This is illustrated in Figure 2.

A total of nine mechanisms of effect were identified for the navigation programmes, which resulted in health-focused outcomes or more holistic, aspirational outcomes. If-then

Figure 1

The Process of Literature Searching and Article Selection



statements are shown in Table 3. Two mechanisms (educating and guiding) applied to navigation programmes with a predominantly “targeted health focus”. Four mechanisms (motivating, timely, coordinating, and tailored) applied to navigation programmes with both a “targeted health focus” and “holistic health focus”. A further three mechanisms (relational, advocating, and dependable) applied to programmes with a more “holistic health focus”. These foci on different aspects of health can be seen as a spectrum. Data extracts for the developed CMOs are available on request.

Mechanisms directed to targeted health outcomes: Educating and managing

Education specific to a disabled person’s health condition was a key mechanism of navigation programmes orientated to a particular aspect of a person’s health condition. For instance, programmes educated individuals on stroke risk factors after stroke (Deen et al., 2018; Dewan et al., 2014; Egan et al., 2010) or preventing pressure areas after spinal cord injury (Ljungberg et al., 2010; Newman et al., 2014). Education also included upskilling disabled people and their families on how/when to access services, what personal information to share with health professionals, and other self-management strategies (Claiborne, 2006; Egan et al., 2010; Newman et al., 2014; Roy

& McKechnie, 2018; Wilkinson et al., 2022). Several studies suggested that healthcare professionals like nurses and allied health professionals were well suited to be navigators as they had experience in health and knowledge of the system, which better placed them to provide education (Deen et al., 2018; Dewan et al., 2014; Egan et al., 2010; Hudson et al., 2019; Rodgers et al., 2019). However, it was also argued that with training, a person without a health background who offered other strengths such as the lived experience of disability or community connections (Anderson et al., 2017; Doolan-Noble et al., 2013; Magasi et al., 2019; Wilkinson et al., 2022), could also provide education.

Several navigation programmes utilised a “managing” approach, often with a pre-defined intervention such as medication adherence or blood pressure review (Deen et al., 2018; Dewan et al., 2014). Typically, this was undertaken by a healthcare professional, and the programme was structured in terms of timing of contact and length of involvement. A more paternalistic approach was often taken with “managing” activities, and these programmes were often located or linked with a medical institution (Deen et al., 2018; Dewan et al., 2014; Rodgers et al., 2019).

Table 2
Overview of Key Characteristics of Included Articles

Author(s) Year Country	Population	Research design	Programme design	Primary outcomes measured
Anderson et al. (2014) New Zealand	Disabled persons and whānau (focus on school leavers) (n = unclear)	Mixed methods (semi structured interviews, descriptive data, and document review)	Navigators worked with people on an aspiration-based personal plan with individualised and portable funding. Principles served as a framework: (a) Self-determination; (b) beginning early; (c) person-centred; (d) achieving ordinary outcomes; (e) mainstream is default; (f) empowerment; (g) easy to use; (h) relationship building. Degree of involvement is negotiated between the parties and included their wider context (family, friends, and community). Resources were provided to assist understanding, educate, and promote increased knowledge of options and how to maximise choice and control. Supported people with outcomes such as education and training, employment, being with friends, having relationships, and taking part in community and cultural activities.	Evaluation of pilot; 2/3 of participants chose to purchase different supports from those traditionally available. Participants and their families also reported horizons had widened with some people attending courses, undertaking work experiences, and/or planning to live away from home.
Anderson et al. (2017) New Zealand	School leavers with high and very high disability needs (n = unclear)	Mixed method approach (case studies, survey, interviews, document analysis)	As per Anderson et al. (2014).	Case studies, quality of life survey, and interviews. Highlights who Enabling Good Lives works best for (families with high agency and hopes for their disabled person but who struggled to see what a good life would look like for them).
Carter et al. (2017) Canada	A range of health conditions but including people with disabilities (n = 145)	Descriptive study	Summarises a range of programmes through use of a questionnaire. Majority of programmes delivered by social workers / social services or nurses.	Identified barriers for clients (low income, lack of social supports, housing, mental health issues, transport, low education, and unemployment). Also identified barriers navigators experienced in providing to clients (time available, difficulty partnering with bureaucratic structures, differing philosophies, and lack of central information repository in the community).
Claiborne (2006) USA	People with stroke (n = 28)	Pre-post experimental design	Care coordination model in the community by a social worker (1–2 weeks post-discharge from hospital) including regular contact to assess and ameliorate unmet mental health, psychosocial, and environmental needs. Educational and support services also extended to caregivers. Depending on needs either continued home visits or follow up via phone call (mostly phone calls though 20 min–1 hr) for 3 months.	Hospitalisation, emergency room, and physician utilisation measures.

Author(s) Year Country	Population	Research design	Programme design	Primary outcomes measured
Deen et al. (2018) USA	People with stroke (n = 100)	Longitudinal study	"Stroke nurse navigation programme" with phone calls after initial in-person meeting as inpatient. Delivered by nurse with prescriptive intervention focused on patient education, targeted questions around medical adherence, and physician follow-up. Referrals for health psychology made as appropriate.	Medication compliance, physician follow-up, smoking cessation, emergency department visits, quality of life.
Dewan et al. (2014) UK	People with stroke (n = 55)	Service evaluation	"Camden Stroke Navigation Service" – a one-off joint doctor and allied health professional home visit review at 6 weeks post-discharge. Focused on medical, health, social, and secondary prevention. Education and advice on risk factor management, lifestyle modification, stroke rehab, and stroke prevention. Information on role and suitability of NHS community and third sector services. Carer featured strongly.	Readmission rates, attendance rate, GP feedback.
Doolan-Noble et al. (2013) New Zealand	People living with social complexity and other long-term conditions (n = 296)	Case study of service	Lay-led health navigator model using a tailored approach. Intervention included liaising and referring to health services, connecting with law system/social services/community providers, self-management skills, time management.	Retrospective data review including surveys and interviews. Served those most vulnerable in the community. Survey respondents were highly satisfied.
Egan et al. (2010) Canada	People with stroke (n = 35 and 26 carers)	Pre-test, post-test evaluation	"Community Stroke Navigation" programme with initial home visit and then mostly phone calls for up to 4 months. Delivered by OT with experience in stroke. Role included coaching, case coordination, service liaison, advocacy, and problem-solving.	Community reintegration physical and emotional health.
Funk & Hounslow (2019) Canada	Older adults (n = 22)	Interpretive inquiry	Summarises a variety of programmes including "patient navigators" and people outside the health system, which were run across one city. Roles described as educating, advocating, directing, clarification, pushing services to be more flexible, teaching how to interact with providers.	Interpretive inquiry; identified the navigation role as (a) "need" as being a lack of accurate knowledge, skills, and personal dispositions; (b) guidance or coaching towards particular options; (c) advocacy and direct support; (d) structural barriers (e.g., culture/language. although participants tended to view these more as individual problems than systemic). Navigation seen as individual empowerment.

Author(s) Year Country	Population	Research design	Programme design	Primary outcomes measured
Gray et al. (2017) New Zealand	Pacific community – patients and carers (n = 13)	Mixed method review (literature review and interviews). Thematic analysis	Nurses, social workers, and lay community support workers provided tailored support, overcoming language barriers, educator, advocator, mediator, liaison, and gatekeeping.	Individual and group interviews with managers and staff. Identified barriers – structural (complexity, inflexibility, and insensitivity of system, poor admin systems, physical location of clinics); staff (attitudes, communication); population (health literacy, language barriers, cultural barriers, previous negative experience, work constraints).
Henderson & Kendall (2014) Australia	People with culturally and linguistically diverse background (n = 9)	Reflective case study	Navigators were community leaders who could work up to 11 hours a week in the role to support people in attempts to access health and social service, build relationships with health services, and support health and wellbeing promotion in the community.	Reflective approach to the navigator model especially exploring critical decisions and tensions. Navigators were trusted and more effective at assisting community members to gain access to health care especially mental health. Tensions identified; (a) using a navigator-centric versus a community-centred approach; (b) training of navigators versus the construction of a broader learning culture; (c) supporting grassroots approaches versus managing risk within a bureaucratic system; (d) maintaining the integrity of the model versus attracting funds.
Hudson et al. (2019) Australia	A range of health conditions but including people with stroke (n = 25)	Semi-structured interviews with thematic analysis	Nurse navigator programme at outpatient setting, in home or phone including emotional support, practical and specific advice, check ins, funding assistance, access, understanding options.	Thematic analysis: Four key themes identified; being there for us, being our compass, bringing it together, and knowing is power. Spoke of control, reduced stress, and empowerment as outcomes.
Ljungberg et al. (2010) USA	People with spinal cord injury (n = 30)	Randomised controlled trial	In person or via phone to provide pressure ulcer education. Not much detail on the programme.	Pressure ulcer knowledge.

Author(s) Year Country	Population	Research design	Programme design	Primary outcomes measured
Magasi et al. (2019) USA	People with physical disabilities (n = N/A)	Community-based participatory research	"Our Peers – Empowerment and Navigational Support" programme delivered by people with physical disabilities. Combination of in-person (at university setting) or phone meetings focused on goal setting, barrier identification, asset mapping, action planning, and supporting development of long-term skills navigating health system. Navigators had 40 hr of training and support from clinical coordinator.	Patient activation and social support, improved health care access, quality, increased global health status, community participation, decreased secondary conditions, and cost utilisation.
Newman et al. (2014) USA	People with spinal cord injury (n = N/A)	Community-based participatory research	SCI Peer Navigator programme of 4 weekly in-person sessions at the person's home. Sessions focused on health education, goal setting, and barrier identification. Pilot study with focus on describing framework to inform intervention research.	Preliminary findings focus on improvements in pressure ulcers and participation in productive and preferred community activities.
Rodgers et al. (2019) UK	People with stroke (n = 573)	Randomised controlled trial	"EXTRAS" was in the form of phone calls delivered until 18 months after the usual Early Supported Discharge Service. They discussed range of possible issues including mobility, personal cares, mealtimes, domestic activities, work and volunteering, hobbies and interests, driving and transport, communication, memory and concentration, mood, anxiety, medical issues, and pain. Agreed goals were set and action plan.	Extended activities of daily living, quality of life, and cost effectiveness.
Rosario et al. (2017) USA	People with traumatic brain injury (n = 18)	Prospective programme evaluation	In-person meeting and phone/text/e-mail (both scheduled and as required) for 1 year (ranged from 30 to 300 interactions) by social worker. Role included coordinating care among providers, providing psychosocial support to patients and families, incorporating patient and family education, linking patient and/or families with community resources, and assisting with insurance and other financial issues.	Readmission rate, falls, independence, activities of daily living, mobility, caregiver burden.
Roy & McKechnie (2018) New Zealand	People with stroke and their families (n = 31)	Mixed method intervention study	Two navigators (one Māori) employed by District Health Board who worked with people with stroke and their families for 6 months. Contact made as soon as possible after stroke with primary focus on whānau during inpatient stay.	Qualitative findings were Easing the journey, Advocating, Supporting "self" management. Navigators were valued by whānau and eased health professionals' workloads.
Savage et al. (2017) New Zealand	Broad variety of wellbeing needs but including health and disability issues (n = 27 plus 7 chief executives/managers and 2 whānau)	Semi-structured interviews with kaupapa Māori research principles	Navigators work within the Whānau Ora system and work to support people in core sectors such as housing, education, primary health, employment, and link/coordinate with specialist services. Role is to support whānau to achieve their aspirations. Approach is founded in relationships. Pathway planning tool utilised to identify long-term goals and short-term actions. No restrictions on how often/how long/where sessions are. Usually people are not "discharged" from the service.	Qualitative approach using kaupapa Māori principles (emphasises Māori culture and values) to review the approach and understand the impact of the service. Navigator role was described as "walking alongside whānau" with freedom to work in naturalistic ways. Relationships through shared experiences was seen as the foundation of the approach.

Author(s) Year Country	Population	Research design	Programme design	Primary outcomes measured
Were (2019) New Zealand	Disabled people and family/whānau (n = unclear)	Developmental evaluation and mixed method design	As per Anderson et al. (2014). Refers to navigators as "connectors".	Qualitative interviews with service users and their providers. Participants reported the programme was person-centred, provides skilled connectors to work with disabled people/family taking a whole life approach to investing in people's personal budgets to create options. Felt to empower and take a collaborative approach.
Wilkinson et al. (2020) New Zealand	People with long-term conditions (n = 9)	Semi-structured interviews with thematic analysis	Partnership Community Worker Service with navigators being embedded in the community. Action planning and supporting people to reduce barriers a person and/or their whānau may experience accessing a service. Interventions individualised and ultimately manage their own health and social care needs.	Qualitative interviews with clients to describe perspectives of engaging with the navigation service. Main theme was "restoration of my essence or being and sense of belonging". Feeling of being renewed and validated as human beings. Participants had a renewed confidence and self-determination to be able to plan and action for life.

Table 3
If-then Statements Relating to How Navigation Programmes Work for Disabled People, Under What Circumstances

If (context)	Then (outcome)	Because (mechanism)	Example of paper(s) featuring this CMO
<i>Targeted health focus</i> If a disabled person understands why, how, and when to access health services ... (impairment/activity limitation need)	... Then they are more likely to utilise health services appropriately and in a timely way (including reduced hospital admissions) AND may have a better health outcome, including reducing secondary complications (e.g., falls) AND/OR cost-saving (more likely to be seen in social than health services) Because navigation services can provide education on a specific health need that is common to all disabled people with this long-term condition. Education may include the role of services, how best to communicate with services and prevention strategies.	Deen et al. (2018)

If (context)	Then (outcome)	Because (mechanism)	Example of paper(s) featuring this CMO
<p>If a disabled person is supported to self-manage their health condition ... (<i>impairment/activity limitation need</i>)</p> <p>If a disabled person has their complex health needs addressed collectively instead of "standard" silos of health services ... (<i>impairment/activity limitation need</i>)</p>	<p>... Then they are more likely to utilise health services appropriately AND are empowered to take control of their health with potential for improved mental health such as reduction in anxiety and depression ...</p> <p>... Then they may have reduced secondary complications, re-hospitalisations, and "did not attend" rates but also increased medication compliance and GP visit adherence ...</p>	<p>... Because when people are given the tools to understand and manage their health condition they can regain control over their life and are more likely to access services appropriately. Education may be standardised based on what people with their health condition commonly need/want to know.</p> <p>... Because when disabled people are understood as whole people, they are more likely to be able to access available health services optimally. This may include holistic conversations, coaching, and "just in time" education.</p>	<p>Claiborne (2006); Ljungberg et al. (2010); Newman et al. (2014); Rodgers et al. (2019); Roy & McKecknie (2018)</p> <p>Carter et al. (2017); Claiborne (2006); Deen et al. (2018); Dewan et al. (2014); Egan et al. (2010); Hudson et al. (2019); Rodgers et al. (2019); Rosario et al. (2017); Roy & McKecknie (2018)</p>
<i>Targeted and holistic health focus</i>			
<p>If a person has a newly acquired physical disability AND/OR is at a transition point in their life (e.g., leaving hospital or moving between services) ... (<i>impairment/activity limitation need</i>)</p>	<p>... Then people can achieve better health outcomes in the short and longer term ...</p> <p>... Then identified barriers and obstacles to accessing health and social services can be reduced ...</p>	<p>... Because when people are given timely support at moments when they are more likely to be vulnerable/ have health needs, issues can be anticipated and avoided.</p> <p>... Because inequities significantly influence how likely and able a person is to access available services (e.g., transport, costs for treatment, and cultural minorities).</p>	<p>Egan et al. (2010); Newman et al. (2014); Rodgers et al. (2019); Roy & McKecknie (2018)</p> <p>Funk & Hounslow (2019); Henderson & Kendall (2011)</p>
<p>If a disabled person experiences significant social and economic deprivation AND they have complex health needs ... (<i>impairment/activity limitation need AND barrier to participation</i>)</p>	<p>... Then services can be tailored to the person and the specific barrier of access removed ...</p>	<p>... Because when there is flexibility in navigational services an individual person's needs can be accommodated. This might be through longer or a flexible period of intervention, in a place that suits the individual.</p>	<p>Funk & Hounslow (2019); Hudson et al. (2019)</p>
<p>If a disabled person's wellbeing is considered holistically encompassing social determinants of health like housing, healthy eating, food security, and transportation ... (<i>barrier to participation</i>)</p>	<p>... Then they are more likely to be inspired to engage in activities that enhance their wellbeing AND be activated with improved community participation, global health status to ultimately have productive and fulfilling lives ...</p>	<p>... Because navigation services can be motivating and support people practically to live their best life possible. This might be through motivational interactions, goal setting, action planning, problem-solving, and boundary spanning across community services.</p>	<p>Hudson et al. (2019); Magasi et al. (2019); Rosario et al. (2017); Wilkinson et al. (2022)</p>

If (context)	Then (outcome)	Because (mechanism)	Example of paper(s) featuring this CMO
<i>Holistic health focus</i>			
If a disabled person has complex social needs that are not being met by "standard" silos of health services ... (<i>barrier to participation</i>)	... Then navigational services can support people and their family/networks through understanding, validation and taking an inspirational approach Because navigation services can be relationship focused and be delivered by people with lived experiences of the health condition and/or the community/services they are serving. This is through rapport building, facilitation of relationships within families and the community, and mitigation of barriers.	Anderson et al. (2014); Anderson et al. (2017); Doolan-Noble et al. (2013); Magasi et al. (2019); Were (2017)
If a disabled person is facing system and societal barriers ... (<i>barrier to participation</i>)	... Then they can be empowered to flourish and feel validated AND service providers are shaped to better serve <i>all</i> individuals, recognising the environment as either enabling or disabling Because navigation services can advocate for disabled people and be autonomous of traditional health systems. This may include having independent funding and processes, impartial advice, being embedded/visible in the community, and helping to shape/push services to be more flexible.	Anderson et al. (2014); Anderson et al. (2017); Funk & Hounslow (2019); Were (2017)

Note: CMO = contexts, mechanisms, and outcomes.

Mechanisms directed to both targeted and holistic health outcomes: Motivating, timely, co-ordinating, and tailored

These mechanisms applied to navigation programmes when there was a specific health need and when a more holistically focused approach to health was required. For example, navigators frequently supported disabled people and/or their families to work towards activities that had often been identified or agreed upon at an initial assessment or goal-setting conversation (Claiborne, 2006; Deen et al., 2018; Dewan et al., 2014; Magasi et al., 2019; Newman et al., 2014; Roy & McKechnie, 2018). These activities were diverse and included health-promoting activities like smoking cessation and increasing physical activity or broader wellbeing activities like creating a more optimal home environment for a disabled person's family or increasing social opportunities (Egan et al., 2010; Magasi et al., 2019; Savage et al., 2017; Wilkinson et al., 2022). The ways that navigators supported disabled persons' motivation also varied, with some services checking in via phone, text, or e-mail (Deen et al., 2018; Rodgers et al., 2019; Rosario et al., 2017) and others "walking alongside" a disabled person with face-to-face sessions in a variety of settings that suited the disabled person (Anderson et al., 2014; Savage et al., 2017; Wilkinson et al., 2022).

Navigation programmes were set up to be timely for a disabled person, such as in response to a new event/concern like a hospital admission when the programme was often for a pre-defined length of time as either a one-off or clearly defined "block" of intervention (Claiborne, 2006; Deen et al., 2018; Dewan et al., 2014; Egan et al., 2010; Newman et al., 2014; Roy & McKechnie, 2018). Timeliness also referred to some programmes that worked in response to a person's ebbs and flows of life, such as the loss of a loved one or a growing need to move home (Hudson et al., 2019; Magasi et al., 2019; Savage et al., 2017; Wilkinson et al., 2022). The programmes with the latter focus were frequently set up so that the disabled person could re-access them when they chose, and the navigator could be responsive to their needs in a timely way.

Co-ordination was a prominent theme, and often a "case co-ordinator" and "case manager" overlapped with navigators (Kelly et al., 2019). Coordination tasks included communication between service providers and the disabled person, facilitating transitions between services, linking resources, assessing needs, coordinating follow-up, and addressing barriers such as transport or low income (Braaf et al., 2019; Kelly et al., 2020; Wilkinson et al., 2022). Again, this mechanism could be activated for a targeted health outcome or towards a more aspirational outcome. For navigators working more holistically, they often could be considered "community connectors" or "boundary spanners" as they were usually people who were already well embedded and connected with their community and, therefore, would draw on their previously established networks to aid coordination (Henderson & Kendall, 2014; Wallace et al., 2019).

Tailoring could also be seen on a spectrum, with health-focused navigation programmes tending to take a goal-focused approach to interventions but with a structured delivery, which would partially dictate the degree to which interventions could be individualised. On the other end of the spectrum, one programme used a tool for families to "identify their aspirations, dreams and goals" and was set up to allow navigators to support people with these longer-term goals (Savage et al., 2017). Tailoring required a degree of "getting to know" a disabled person and/or their family to meet their unique needs. However, how this was approached and prioritised differed significantly between navigation programmes.

Figure 2

Contextual Spectrum of Perceived Need for a Navigation Programme for a Disabled Person



Note. This terminology relates to the WHO International Classification of Functioning, Disability and Health (2002).

Mechanisms directed to holistic health outcomes: Relational, advocating, and dependable

Navigation programmes that worked towards more holistic, aspirational goals were founded on strong relationships between navigators, disabled people, and their families (Savage et al., 2017; Were, 2017; Wilkinson et al., 2022). These programmes described the value of making connections and “feeling comfortable” with navigators, especially in Australasian-specific programmes (Henderson & Kendall, 2014; Hilder et al., 2016; Savage et al., 2017). Relationships would provide a platform of mutual respect and trust, a natural “conversation” enabling outcomes that “conventional” health services could not achieve (Henderson & Kendall, 2014). A direct understanding of the culture and background of the disabled person was crucial in developing relationships for some services and a deliberate choice of navigators with the same cultural background (Henderson & Kendall, 2014; Hilder et al., 2016; Savage et al., 2017) or with the same health condition (Magasi et al., 2019; Newman et al., 2014) were selected. Nonetheless, these relationships were sometimes identified as conflicting with a Western model of support where this level of connection is viewed as “inappropriate” (Savage et al., 2017), with some tensions arising when trying to support grassroots approaches within a bureaucratic system (Henderson & Kendall, 2014).

Building relationships is also related to the emphasis that some navigation programmes placed on promoting connections for disabled people, such as developing new friendships (Anderson et al., 2014; Anderson et al., 2017; Were, 2017) or interests with others (Egan et al., 2010). At times, this was through directly linking a disabled person within their community. However, it could also be indirect by ensuring that allocated funding allowed for an age-matched peer to take a disabled person partying instead of relying on their family, who may not wish to do this, thereby promoting a disabled person’s ability to develop new relationships with like-minded people (Anderson et al., 2014). In addition, more holistic navigation programmes often took a strengths approach, recognising that a disabled person has existing relationships and networks that could be utilised or built upon (Anderson et al., 2014; Anderson et al., 2017).

Advocacy was an approach to address barriers to accessing services, especially where there were individual or societal barriers for disabled people. For instance, navigators were described as helping a disabled person who could not always “ask the right questions” (Egan et al., 2010; Wilkinson et al.,

2022). Advocacy was less often described in terms of trying to shape services to be more flexible and raising awareness of the needs of the disabled community within society (Funk & Hounslow, 2019).

A final mechanism that enabled more aspirational outcomes for disabled people was navigators being dependable, which meant being available in times of need (Savage et al., 2017; Wilkinson et al., 2022) and often going “over and above” what might be expected as a minimum service requirement. This was more apparent in programmes that were separate from health institutions, such as not-for-profit organisations that usually had far fewer organisational requirements and could adapt to the specific needs of the disabled person. This included taking a “naturalistic approach” that did not require navigators to “put them in a box and tick the box” (Savage et al., p. 11) and included flexibility in funding systems (Anderson et al., 2014; Anderson et al., 2017) that allowed disabled people to make choices and have more control. Strong relationships and trust were at the foundation of dependability, but also assumed that navigators could and would prioritise being available for disabled people and their families in times of need, ensuring continuity (Henderson & Kendall, 2014; Hilder et al., 2016; Savage et al., 2017; Wilkinson et al., 2022).

Proximal outcomes

Overall, navigation programmes were beneficial for disabled people, but as anticipated, the outcomes were diverse and sometimes challenging to measure, depending on the contexts and resulting activated mechanisms.

Reduced secondary complications

Navigation programmes targeting specific health issues showed reductions in secondary complications, such as pressure areas after spinal cord injury (Newman et al., 2014) and falls after traumatic brain injury (Rosario et al., 2017). Navigation has also been shown to promote health-protective behaviours such as smoking cessation (Deen et al., 2018), health literacy (Wilkinson et al., 2022), medication adherence (Deen et al., 2018), and increased physical activity (Wilkinson et al., 2022).

Better service use and flow

Several navigation programmes showed more appropriate use of health services with reduced emergency department visits (Claiborne, 2006; Hilder et al., 2016), reduced re-admissions (Deen et al., 2018; Dewan et al., 2014; Rosario et al., 2017), improved healthcare access (Magasi et al., 2019), better use of primary care services (Deen et al., 2018; Henderson & Kendall,

2014), reduced did not attend rates (Hilder et al., 2016), and reduced length of hospital stay (Hilder et al., 2016). To varying degrees, this was shown to result in cost savings in both health (Magasi et al., 2019) and social care (Rodgers et al., 2019).

Aspirational

Navigation programmes have been shown to improve the wellbeing of disabled people and their families in terms of reduced long-term anxiety and depression (Rodgers et al., 2019) and managing caregiver burden (Rosario et al., 2017). Many navigation programmes aimed to increase community participation and connectedness (Claiborne, 2006; Magasi et al., 2019; Wilkinson et al., 2022). However, some programmes had much broader outcomes reflecting more wide-ranging interventions such as addressing housing, supporting victims of domestic violence, drug and alcohol support, and family dynamics (Doolan-Noble et al., 2013; Savage et al., 2017). These programmes were challenged in specifying clearly defined and reported outcomes. However, some programme participants described outcomes of “restoration of my essence and sense of belonging” (Wilkinson et al., 2022, p. 4), which ultimately enhanced confidence and self-determination. When navigation programmes were more holistic with resulting aspirational outcomes, it was less likely that navigators would be focused on cost savings or efficiencies for the health system. Instead, they strived for the best outcome for the disabled person (Hilder et al., 2016).

Distal outcomes: Empowerment and self-determination

Navigation was frequently cited as empowering for disabled people and their families (Carter et al., 2017; Funk & Hounslow, 2019; Hudson et al., 2019; Ljungberg et al., 2010; Magasi et al., 2019). For instance, education was thought to empower disabled people and their families to manage their health, including knowing where to go to get the needed information (Funk & Hounslow, 2019; Ljungberg et al., 2010; Magasi et al., 2019). However, empowerment was less often described in relation to navigation programmes “pushing” systems to become more flexible and respectful for disabled people, and barriers to accessing health and wellbeing services were mostly addressed at an individual level (Funk & Hounslow, 2019). Some of the more holistically focused navigation programmes specifically identified being underpinned by self-determination theory (Anderson et al., 2014; Anderson et al., 2017; Wilkinson et al., 2022) with an assumption that “disabled people are in control of their lives” as a starting philosophy (Anderson et al., 2014, p. 2; Anderson et al., 2017, p. 15). In these programmes there appeared to be a cyclical reinforcement of self-determination where disabled people were assumed as *having* control, but the navigation programme could also enable disabled people to have *more* control of their lives (Enabling Good Lives, 2024).

Programme theory

The visual representation of our revised programme theory (Figure 3) was developed after refinement of the interplay between identified CMOs identified in the analysis. The contexts of the perceived need of the disabled person being an “impairment/activity limitation” versus “barrier to participation” (World Health Organization, 2002) is the

foundation that influenced how navigation programmes could support people and what outcomes were likely to result for disabled people and their family. If the primary context for a disabled person requiring a navigation service was because of a specific impairment of body function or activity limitation, a more targeted health intervention could be utilised, activating mechanisms “educating and managing” and possibly “motivating, timely, coordinating, and tailored” to help reduce secondary complications and promote better use of services and flow. If, however, the primary context for a disabled person requiring a navigation service was because of barriers to participation they were facing either as a result of their disability or as well as their disability (such as low income, abusive relationships, English as a second language, or drug dependence), a more holistic health focus of navigation was beneficial. This more “relational, advocating, and dependable” approach, but still with “motivating, timely, coordinating, and tailored” approaches, helped promote aspirational outcomes for disabled people. “Impairment/activity limitation” and “barrier to participation” as contexts were not mutually exclusive and could both be present concurrently. Thus, someone with impairment/activity limitations and experiencing barriers to participation could benefit from *all* the mechanisms of effect with *all* possible outcomes being achieved. Like the contexts, outcomes could be considered on a spectrum of empowerment and self-determination.

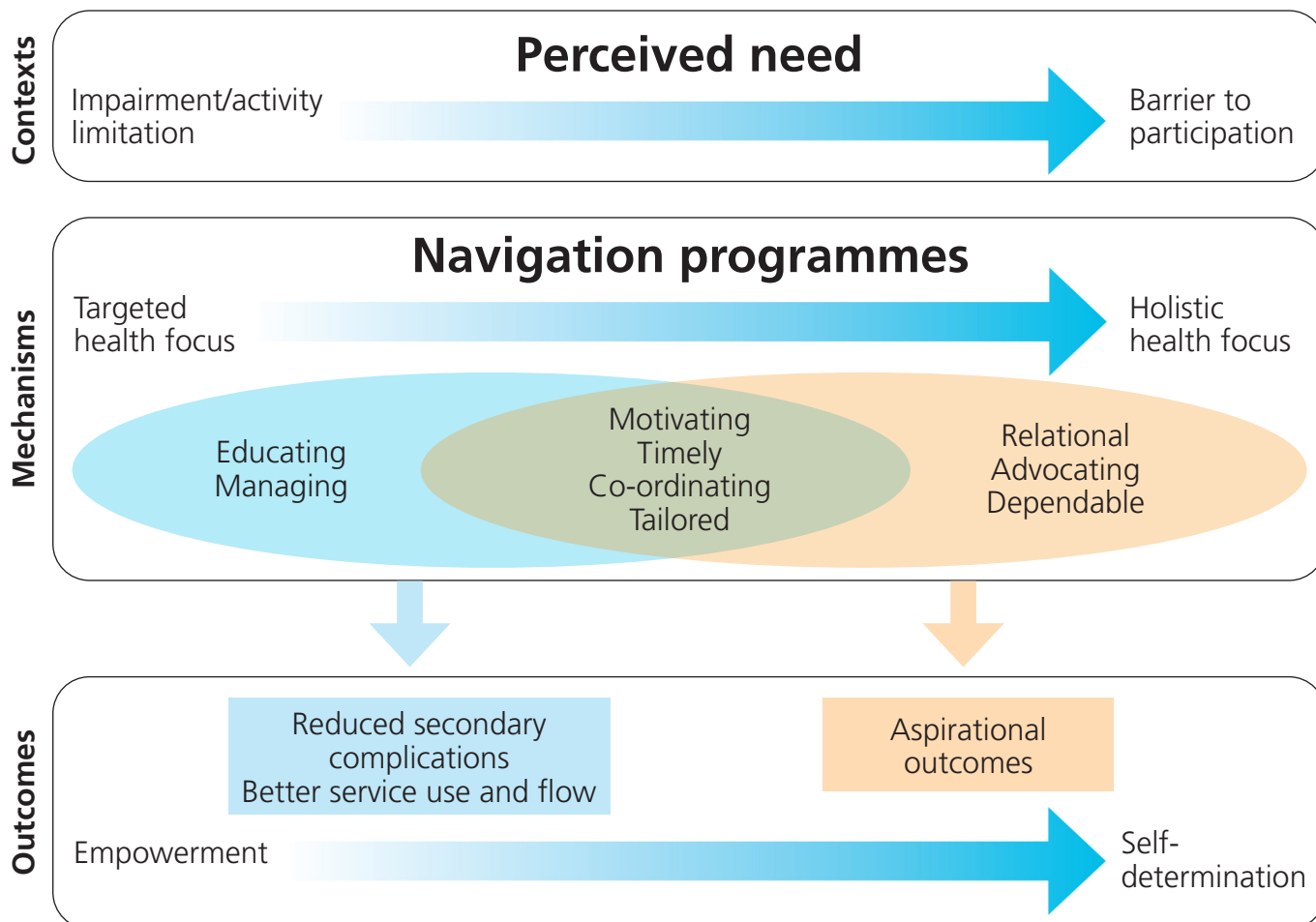
DISCUSSION

This review has articulated and clarified the underlying causal processes of health navigation programmes for disabled people, particularly considering the New Zealand context. Our review adds to the existing literature by specifically exploring navigation programmes for disabled people and providing a theoretical model of what works for whom and in what situations. Our realist-informed integrative review indicates that disabled people’s need for navigational support should be well understood in terms of the International Classification of Functioning domains (World Health Organization, 2002) so programmes can be tailored either to address specific health-related issues or to address more holistic health needs. There was a need and value in both approaches. However, clarity is required when navigation programmes for disabled people are developed and delivered so that intended outcomes are actively being worked towards. If not, there can be a conflict in approach and how to measure success (Donovan et al., 2018).

Our findings echo previous research that considers navigation’s duality but categorises it in different yet related ways – such as individual versus systemic interpretation (Funk & Hounslow, 2019) or complex health needs versus social needs (Carter et al., 2018). This spectrum is perhaps expected given the historical guiding principles for patient navigation, including that it is “patient-centred” with a core function of “elimination of barriers” (Freeman & Rodriguez, 2011). However, it appears there remains a lack of clarity around how this translates to the more holistically focused navigation services, which do not align with this more traditional medical model of health. This is especially poignant for the disabled community, striving for equal rights to flourish and not simply survive (Berghs et al., 2019).

Figure 3

Model of How Navigation Programmes Work for Disabled People in Particular Circumstances



Divisions have also been previously made around who is best placed for navigation roles. For example, a scoping review of primary care navigation suggested that programmes delivered by healthcare professionals were better suited to people with complex health and social needs, and those delivered by laypeople were tailored to more stable populations with a central focus on social determinants of health (Carter et al., 2018). Our study mirrored this division of programme context in terms of the International Classification of Functioning (World Health Organization, 2002) constructs. However, it did not make an explicit link regarding who was best suited to deliver these navigation programmes. Regardless, disabled people are likely to face health issues that are both specific in nature (such as managing spasticity or maintaining mobility) as well as broader issues like barriers to employment, parenting, or discrimination (Gibson & O'Connor, 2010). Therefore, navigation programmes aimed at both ends of the spectrum are important.

Similarly, the mechanisms this theoretical model identified resonated with previous research. However, our research furthers this by considering the points of difference in mechanisms according to the context of the navigation programme. For instance, Kelly et al. (2019) conducted

a systematic review and identified nine key functions of navigators, some of which echo or overlap with the mechanisms we identified, particularly advocacy, care coordination, and education. However, it was apparent in our realist review that these mechanisms were activated for particular people in particular contexts. For example, someone with a new disability needs a targeted health focus, which may include more of a guiding and education approach. Conversely, these approaches were not likely to be effective for disabled people requiring navigation programmes for a more holistic health need who responded to a more relational and dependable approach through "connective and supportive experience(s)" (Wilkinson et al., 2022, p. 173). Yet being dependable is not a requirement for someone needing specific health advice and would likely be a waste of time, energy, and resources. Therefore, appropriately focused navigation programmes are vital.

Several studies have raised the necessity, yet challenge, of measuring outcomes of navigation programmes (Anderson et al., 2014; Anderson et al., 2017; Kelly et al., 2020; Savage et al., 2017). Navigation programmes with a targeted health focus were easier to measure as they tend to result in more immediate and tangible benefits to both health services and disabled

people. However, more holistically focused health outcomes were likely to be longer-term and are usually less quantifiable but likely to be more profound (Henderson & Kendall, 2011; Hudson et al., 2019; Wilkinson et al., 2022). For instance, the New Zealand programme Enabling Good Lives specifically considers and explores what constitutes a “good life”, the programme’s ultimate goal (Anderson et al., 2014; Anderson et al., 2017; Were, 2017). Although it is acknowledged that living a “good life” will be viewed and therefore measured differently by everyone, there were commonalities among disabled people and their families, including opportunities for valued relationships, security for the future, choices, and opportunities to make a meaningful contribution and have challenges (Anderson et al., 2014; Anderson et al., 2017; Were, 2017). These more aspirational outcomes will likely require more longitudinal, qualitative, and holistic measures for success. Accordingly, attempts have been made to develop measures of success such as a ‘Patient Satisfaction with Interpersonal Relationship with Navigator’ measure (Jean-Pierre et al., 2012) or patient-reported outcomes related to initial needs assessment (Crane-Okada, 2013). However, most of this research on appropriate outcome measures sits within cancer care research and may not be directly translated for disabled people, representing an area for further research.

A further challenge raised in the reviewed articles that needs to be considered when developing navigation programmes for disabled people are the potential conflicts between navigator-centric versus community-centric models. For instance, Henderson and Kendall (2014) considered the challenge of supporting grassroots approaches while also managing risk in a bureaucratic system, giving the example of a navigator assisting a family with transport without the appropriate child car seat, posing a health and safety issue. Similarly, they discuss the challenge of maintaining the integrity of a holistically focused health model while attracting sufficient operational funds, which may inadvertently undermine the programme’s philosophy (Henderson & Kendall, 2014). Consequently, the guiding principles, including the day-to-day operations of navigation programmes for disabled people, should be carefully considered.

Throughout the data extraction phase, the link of navigation programme outcomes to empowerment (Carter et al., 2017; Funk & Hounslow, 2019; Hudson et al., 2019; Magasi et al., 2019) and self-determination (Anderson et al., 2014; Anderson et al., 2017; Were, 2017; Wilkinson et al., 2022) was evident. Empowerment can be considered as the process by which people, organisations, and communities gain mastery over their affairs (Rappaport, 1987). Although several definitions exist for empowerment, most acknowledge that it can occur at an individual, organisational, or community level, which echoes the contextual levels at which barriers may occur for a disabled person. Likewise, according to our conceptual model, this echoes the levels at which navigational programmes operate regarding their mechanisms of effect. Empowerment can be considered a prerequisite to self-determination whereby a person has freedom over their life, a much more aspirational focus, but also a fundamental human right. Satisfaction of three innate human needs is thought necessary for self-

determination to occur: autonomy (control over activity and behaviour), relatedness (sense of connection), and competence (ability to influence outcomes) (Hanlon et al., 2021). Therefore, those navigation programmes that believed in the value of, and invested in, autonomy, relatedness, and competence of a disabled person were best placed to achieve more autonomous forms of health and wellbeing behaviours and all the benefits that come with it (Ng et al., 2012).

This realist review was not intended to be exhaustive; however, it could have been limited by electing to stop literature searching at the stage we did, meaning that relatively few papers were evaluated. This is partly due to the relatively few published articles researching navigation programmes for disabled people. However, this is also a common deliberation in realist research, and limiting how much “territory” can be covered is an important theoretical consideration (Pawson et al., 2005). Nevertheless, we reached a point in our search that answered our initial question and when new insights were not being gained from searching. Therefore, although this realist review is relatively small, it provides important insights towards a better understanding of how navigation programmes work for disabled people and under what circumstances, with particular consideration of Australasian contexts.

Physiotherapists can utilise these insights to help guide service development aimed at enhancing navigational support. These findings may also enable physiotherapists to refer to available navigational programmes more appropriately by better considering a disabled person’s need and the desired outcome of navigational support.

CONCLUSION

In conclusion, our review adds to the existing literature by specifically exploring navigation programmes for disabled people and providing a theoretical model of what works for whom and in what situations. Key findings from our realist-informed integrative review are that disabled people’s need for navigational support should be well understood in terms of the International Classification of Functioning (World Health Organization, 2002) domains so that programmes can be tailored accordingly. Empowerment and self-determination are theoretical concepts that underpin navigation programme outcomes and should guide programmes supporting disabled people. Future research should explore the practicalities of setting up and delivering navigation programmes for disabled people in New Zealand, considering details like training, funding, and integration with existing services. However, we have provided one further piece in the puzzle to support disabled people to access the health services they need and live the life they aspire to.

KEY POINTS

1. Navigational support needs for disabled people should be well understood in terms of the International Classification of Functioning domains (World Health Organization, 2002) so that programmes can be tailored accordingly.
2. Empowerment and self-determination are theoretical concepts that underpin navigation programme outcomes and should guide programmes supporting disabled people.

- Navigational support can potentially reduce secondary complications for disabled people, improve service use and flow, and support aspirational outcomes.

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PERMISSIONS

None.

CONTRIBUTIONS OF AUTHORS

Conceptualisation and methodology, ET and RM; literature search, DT and ET; formal analysis, ET and RM; writing – original draft, review, and editing, ET, JD, and RM.

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