Response to 'Mobility For Life' Research

Thank you for the opportunity to engage with the *Mobility for Life* research project. It is encouraging to see DSS partnering with Enable to take a broader view of the needs of disabled youth and adults in New Zealand, and to incorporate qualitative insights that demonstrate the impact of timely access to powered mobility.

We look forward to reviewing the materials being developed for participants, including clinicians, suppliers, and wheelchair users and their whānau.

Following the discussion on 12 June, we would like to highlight several potential issues to ensure there is a shared understanding. As raised by the assessor group, the research appears to be predicated on an assumed level of unmet need. From a provider and assessor perspective, barriers to timely access to assistive technology are complex, interdependent, and occur across multiple points within the system.

We appreciate the intent of the *Mobility for Life* research and the opportunity to engage. However, the purpose, scope, and underlying assumptions are not yet clear. In particular, it is difficult to understand how "early" or "timely" access is defined, how participants are identified within current pathways, and what core problem the research seeks to address. We have outlined key areas where further clarification would support a shared understanding of the research intent and design.

Assessor workforce capacity, capability, and access to assessment

- Clarification is sought regarding the workforce profile being utilised for the research. Specifically, are assessors required to hold provisional, Level 1, or Level 2 credentials, and what level of experience and competency is expected of those participating?
- The client group described (e.g., CP, MS, MD - first-time power wheelchair users) may align more closely with Level 1 clinical indicators for assessment, rather than representing a Level 2 complexity cohort.
- It is also important to note that not all individuals described would meet current funding eligibility criteria or be prioritised for assessment. Waitlist management is typically informed by essential disability-related need, funding eligibility and clinical risk.
- From a system perspective, the most significant barrier to timely access to assistive technology across many regions in New Zealand is assess to assessment via Health NZ and specialist assessment services. Wait times

frequently exceed 12 months. These delays are primarily driven by workforce capacity constraints, including FTE allocation, funding limitations, and variability in skill mix and experience within allied health teams.

- In several regions, there are very limited numbers - or in some cases no - credentialed therapists available to undertake wheelchair and seating assessments, further compounding access inequities.

Current EMS criteria and system pathways

- Many individuals identified as potentially benefiting from early powered mobility may also ambulate using a walking aid or utilise a manual wheelchair for part of their mobility. It is unclear how provision of powered mobility in these cases would interact with current eligibility settings—specifically, whether the power wheelchair would become the primary mobility device and impact access to other supports (e.g., manual wheelchair, walking aids).
- Under current EMS criteria, individuals with an essential need for powered mobility within the home are typically prioritised and receive relatively timely assessment. In these cases, the primary barriers to timely equipment provision sit within Enable processes, including:
    - EMS advice process: up to 4 weeks (currently ~2 weeks)
    - Access to Enable Outreach support: variable across NZ
    - Service Request processing: up to 12 weeks (currently ~7 weeks)
    - Enable stores check: up to 3 weeks
    - Supplier trial initiation: up to 4 weeks, influenced by availability of product specialists, particularly in more remote regions
    - Absence of a clearly defined or consistently applied *urgent pathway* for individuals with rapidly deteriorating conditions (e.g., MND), pressure injuries, or high falls risk
- For individuals whose needs are not considered “essential” under current EMS criteria, they are often not visible within assessment services. This is either due to lack of referral or because they do not meet service entry thresholds for wheelchair and seating assessment.
- In some cases, these individuals may be intermittently known to services through other pathways (e.g., personal care, housing modifications, or rehabilitation services), but this does not necessarily translate to access to timely mobility assessment or equipment provision.

Barriers to the adoption of powered mobility

- Consideration must be given to the individual goals, preferences, and context of the disabled person and their whānau. Powered mobility is rarely the sole solution to functional mobility challenges; it is one of a range of options that may support participation and independence.
- For individuals such as those with GMFCS II–IV cerebral palsy, muscular dystrophy (MD), or early-stage multiple sclerosis (MS), mobility goals can often be achieved through a combination of interventions. It is important that research of this nature does not unintentionally position powered wheelchairs as *the* solution, but rather *a* potential option within a broader clinical framework.
- There are a number of intrinsic and environmental factors that influence the uptake of powered mobility, which require careful navigation by skilled assessors in partnership with the disabled person and their whānau. These include:
    - Concerns around physical deconditioning ("use it or lose it") and maintaining strength and fitness
    - Social perceptions and stigma (e.g., the belief that powered wheelchairs are only for those who are "severely" disabled)
    - The emotional impact and sense of loss associated with transitioning away from walking
    - Transport limitations, where lack of accessible transport can reduce access to community participation
    - Variability in home environments (e.g., accessibility differing between family homes)
    - Environmental constraints that may not be adequately addressed by standard (list/Band 2) power wheelchairs, requiring more specialised configurations (e.g., improved traction, torque, or battery capacity)
- In many cases, these barriers can be mitigated through alternative or complementary solutions, such as power-assist devices, which may better align with the individual's functional goals, environments, and stage of condition progression.

Other considerations

- The impact of assistive technology on quality of life is influenced by multiple factors beyond initial provision. These include the suitability of the device, user training, aftercare and support, access to timely repairs and servicing, and

ongoing review as needs change. Without clearly defined minimum expectations across these domains, it will be challenging to draw meaningful conclusions from a broad cohort of assessors and wheelchair users.

- There are several validated outcome measures that could strengthen the research design and provide more consistent data capture across participants. These tools can be implemented with minimal training, including:
    - *Wheelchair Use Confidence Scale (WheelCon-P)* – a self-report measure assessing confidence in using a powered wheelchair (available in short and full versions) WheelCon-P
    - *Wheelchair Outcome Measure (WhOM)* – a client-centred, goal-based tool assessing participation in meaningful activities, satisfaction with wheelchair use, and relevant body function factors (e.g., comfort, positioning, skin integrity) WhOM
    - Established skills-based frameworks such as the Wheelchair Skills Program - Dalhousie University
- As noted previously, some participants may continue to ambulate with a walking aid or use a manual wheelchair indoors. Clarification is required on whether provision of powered mobility within the study would be considered their primary means of mobility, and whether this has implications for ongoing eligibility for other mobility supports.
- Functional outcomes are significantly influenced by the configuration of the prescribed power wheelchair. It would be important to clarify whether equipment provision is limited to tilt-in-space only, or whether other seat functions (e.g., recline, seat elevation, elevating leg supports) may be included where clinically indicated.
- Similarly, outdoor performance and indoor manoeuvrability will impact user outcomes. These factors are closely linked to the accessibility of the individual's environments (home, school, work, community) and their access to suitable transport.
- Clear definition is required for what constitutes "early," "timely," or "on-time" provision within the context of this research, given the variability in current system pathways and regional access
- We would also like to provide feedback on the visual materials. The current imagery feels stylised and does not reflect the realities of clinical practice or authentic interactions with wheelchair users and their whānau. Some portrayals risk appearing patronising, unintentionally reinforcing power imbalances rather than partnership. We encourage the use of imagery that better reflects

respectful, natural, and collaborative practice, and that is informed by the perspectives of disabled people themselves. Power wheelchair users living a good life – performing ordinary activities etc may better visually reflect the intent.

- We also emphasise the importance of co-design in research of this nature. Understanding the impact of powered mobility requires meaningful involvement of disabled people and their whānau in shaping the design, priorities, and interpretation of findings, as lived experience is critical to defining what "timely" and "meaningful" access looks like in practice. At this stage, it is not clear how co-design has informed this proposal, and we would welcome further detail on how disabled voices have been incorporated.

Assumptions (based on information shared 12 June)

- It is understood that the initial cohort will comprise the first 100 eligible participants (on a first-come, first-served basis), aged 14 years and over, with cerebral palsy (CP), muscular dystrophy (MD), or multiple sclerosis (MS). These individuals will be identified by participating assessors as likely to benefit from powered mobility and will be allocated a Band 2 list power wheelchair.
- Depending on the number of assessors recruited, it is likely the 100-person cohort will be reached within a relatively short timeframe.
- Participants are expected to be first-time power wheelchair users.
- EMS criteria, particularly the requirement for essential indoor mobility, is not a determining factor for inclusion. Instead, the focus is on broader functional benefit across life domains. As a result, some participants may use powered mobility intermittently, or primarily for community access and participation rather than as a primary mobility solution. The cohort is expected to be a very diverse group. The lived experience, goals, and functional needs of 100 individuals aged 14 to 80+ years, across a range of neurological conditions and stages of progression, will vary significantly.
- There will likely be variability in assessor capability and experience, as well as in the quality and consistency of associated interventions (e.g., assessment processes, equipment prescription, training, and follow-up support).
- It is understood that the Ministry of Social Development has an interest in return on investment. The research design appears to include baseline measures of functional impact and self-reported quality of life prior to powered mobility provision, with follow-up data collected after a period of device use (potentially at multiple time points).

Mobility for Life Evaluation

Response to assessor and clinical staff feedback

Firstly, we would like to thank the assessor and technical staff for taking the time to provide detailed feedback on the proposed Mobility for Life evaluation. The issues raised reflect the complexity of wheelchair and seating services across New Zealand and highlight many of the contextual factors that influence access, outcomes, and experiences of powered mobility.

The purpose of the Mobility for Life evaluation is not to test a predetermined assumption that powered wheelchairs are universally beneficial, nor to advocate for powered mobility as the preferred intervention for all individuals. Rather, the evaluation seeks to understand the circumstances under which early access to powered mobility contributes to participation, independence, wellbeing, and quality of life, and the circumstances under which anticipated benefits are constrained by personal, environmental, organisational, or system factors.

Your feedback received will strengthen the evaluation design and provides important areas for exploration within both the realist evaluation and Social Return on Investment (SROI) components.

Assessor workforce capacity and capability

We agree that workforce capacity is a significant determinant of access to wheelchair and seating services throughout New Zealand. One of the strengths of the evaluation is that it will allow examination of how workforce factors influence access, timeliness, implementation, and outcomes.

The evaluation is not designed to compare assessor competence or credentialling levels. Rather, assessor capability, experience, credentialling, and service context will be documented as contextual factors within the realist evaluation framework. This will allow exploration of whether and how these factors influence referral decisions, implementation processes, and participant outcomes.

We also acknowledge that some of the proposed participants may align with current Level 1 assessment complexity indicators. This is intentional. The project seeks to understand whether access to powered mobility earlier in the progression of disability may influence participation, independence, and quality of life before individuals reach levels of need that typically trigger prioritisation within current systems.

The evaluation does not seek to replace existing prioritisation frameworks or challenge assessor clinical judgement. Rather, it seeks to generate evidence regarding outcomes associated with earlier intervention approaches. The Mobility for Life Evaluation welcomes all accredited assessors.

Workforce capacity as a system barrier

We acknowledge the feedback that access to assessment represents one of the most significant barriers within the current system.

Indeed, the evaluation team agrees that workforce shortages, regional variability in assessment services, and credentialling constraints contribute substantially to delays in access. These factors will be explicitly examined as contextual influences within the evaluation.

Rather than assuming that equipment availability is the primary barrier, the evaluation seeks to map the full pathway from identification of need through assessment, funding, fitting, training, and sustained use. This systems perspective is intended to identify where delays occur and how these delays influence outcomes.

Clarification of "early" and "timely" access

Several respondents requested clarification regarding the concepts of "early" and "timely" access.

The evaluation does not assume a single universal definition of timeliness. One objective of the study is to understand how disabled people, families, clinicians, and service providers define timely access and whether these definitions differ.

For the purposes of the evaluation, "early" access refers broadly to provision occurring before significant loss of participation, independence, or quality of life has occurred. "Timely" access refers to provision occurring at a point where the equipment is able to meaningfully support desired outcomes.

The evaluation will specifically explore participant, whānau, clinician, and service perspectives regarding what constitutes timely provision.

Current EMS criteria and eligibility

We acknowledge concerns regarding the relationship between the proposed cohort and current EMS eligibility criteria.

The purpose of the evaluation is not to assess compliance with existing EMS criteria. Rather, the project seeks to explore outcomes among individuals who have been clinically identified as potentially benefiting from powered mobility.

Importantly, the study recognises that many participants may continue to walk, use manual wheelchairs, or utilise multiple mobility options depending on circumstance and environment.

The evaluation therefore does not conceptualise powered mobility as replacing other mobility strategies. Instead, it seeks to understand how powered mobility contributes to an individual's overall mobility repertoire and participation opportunities.

Questions regarding impacts on eligibility for other supports will be documented and explored as part of the broader system analysis. Many of these barriers have been removed as part of the research pathway

Powered mobility as one option among many

We strongly agree that powered mobility should not be positioned as the sole solution to mobility challenges.

The evaluation explicitly recognises that powered wheelchairs represent one component within a broader rehabilitation, participation, and support framework.

Participants, clinicians, and family members will be asked about alternative mobility strategies, including walking aids, manual wheelchairs, power-assist devices, environmental modifications, transport supports, and other interventions.

The evaluation seeks to understand how powered mobility interacts with these other supports rather than evaluating it in isolation.

Concerns regarding deconditioning

The concern regarding physical deconditioning is acknowledged and considered important.

The evaluation does not assume that increased powered mobility use automatically results in positive outcomes. For some individuals, concerns about maintaining physical activity and functional capacity may influence uptake and use.

Interview schedules have been designed to explore these issues directly. Participants and clinicians will be asked about perceived benefits, unintended consequences, concerns regarding physical activity, and strategies used to maintain strength, fitness, and participation.

The evaluation therefore provides an opportunity to better understand whether concerns regarding deconditioning influence decision-making, uptake, and outcomes.

Social stigma and identity

The feedback regarding social perceptions and stigma is particularly valuable.

The emotional transition associated with adopting powered mobility is increasingly recognised as a significant determinant of successful uptake and sustained use.

The evaluation will explore experiences of identity, stigma, confidence, social acceptance, and emotional adjustment. These factors align closely with the realist evaluation focus on mechanisms of change and may help explain variations in outcomes across participants.

Environmental and transport barriers

We agree that environmental accessibility, housing, and transport are critical determinants of outcomes.

The evaluation does not assume that provision of a wheelchair automatically results in participation gains.

Indeed, one of the central hypotheses of the realist evaluation is that outcomes are dependent on contextual factors such as housing accessibility, transport availability, family support, community accessibility, and local service infrastructure.

These factors will be systematically explored through participant, whānau, and clinician interviews.

Equipment configuration and clinical variability

The importance of wheelchair configuration is acknowledged.

The evaluation will document key equipment characteristics, including seating functions, power functions, and environmental requirements where feasible.

The objective is not to compare specific wheelchair models but to understand how equipment suitability influences outcomes and user experiences.

Variation in prescription practices, assessor expertise, and training approaches will also be considered within the realist evaluation framework.

We considered the suggestion of including a power-add-on as part of this project but concluded that it falls outside of the intended scope of this project.

Repairs, maintenance, training, and ongoing support

We strongly agree that outcomes are influenced by much more than initial equipment provision.

The evaluation has therefore been designed to examine the full pathway of care, including assessment, fitting, training, implementation, follow-up, repairs, maintenance, and ongoing support.

These factors will form part of the Total Cost of Ownership (TCO) analysis and will also be examined as contextual factors influencing outcomes.

Outcome measures

We appreciate the suggestions regarding WheelCon-P, WhOM, and the Wheelchair Skills Program.

The evaluation currently includes WATCh-Ad, WATCh, the Living in the Community Questionnaire, WHO-5, administrative data, and qualitative interviews. The proposed measures will be reviewed during finalisation of the data collection framework and may provide useful supplementary information regarding confidence, participation, and wheelchair skills.

Co-operative-design and lived experience involvement

We fully support the importance of co-design and lived experience leadership.

The evaluation has incorporated consultation with disabled people, family representatives, and stakeholder groups during development. However, the feedback highlights the need to make these processes more visible and explicit within study documentation.

The study is grounded in the principle that disabled people are experts in their own lives and that meaningful evaluation requires understanding outcomes that matter to wheelchair users and whānau themselves.

Interview schedules have therefore been designed to privilege lived experience perspectives regarding participation, wellbeing, independence, and quality of life.

Visual materials

We appreciate the feedback regarding imagery and presentation materials.

The intention is to portray disabled people as active participants in their communities rather than passive recipients of services. Future visual materials will seek to better reflect authentic experiences, partnership, participation, and everyday life outcomes identified as important by wheelchair users themselves. The materials advertising the evaluation have been approved by the National Health and Disability Ethics Committee, in consultation with power chair users.

Diversity of the cohort

We agree that the proposed cohort will be highly heterogeneous.

This diversity is not viewed as a limitation but rather as an important feature of the evaluation. The realist methodology is specifically designed to understand why outcomes differ across people, settings, and circumstances.

The central evaluation question is not whether powered mobility works universally, but rather:

"What works, for whom, under what circumstances, and why?"

Understanding variation is therefore a core objective rather than a source of methodological weakness.

Return on investment

Finally, we acknowledge the observation that MSD has a strong interest in return on investment.

The evaluation adopts a broader perspective than financial return alone. Through integration of Realist Evaluation, Total Cost of Ownership (TCO), and Social Return on Investment (SROI), the study seeks to understand not only the costs associated with powered mobility but also the social value generated through increased participation, independence, wellbeing, family outcomes, educational engagement, employment opportunities, and community inclusion.

The intent is to provide decision-makers with a more comprehensive understanding of value than can be achieved through cost analysis alone.

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