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Guidelines for Planning Appropriate Wheelchair and Seating Provision in Progressive Neurological Disorders.

Background

This study will focus on wheelchair and seating provision for people with Progressive Neurological Disorders (PNDs). It forms part of a larger collection of research being carried out on wheelchair provision across the lifespan. People with PNDs may have complex wheelchair and seating needs. The provision of an appropriate wheelchair has a huge impact on a person's ability to function and participate in society and guidelines to help the provision process are crucial in ensuring positive outcomes for this population.

Method

A scoping method was used to study the existence of guidelines to assist occupational therapists in wheelchair and seating provision with PNDs. Thematic analysis of the literature was used to extract the issues impacting upon the wheelchair provision process with this population.

Findings

There is limited evidence of standards and guidelines that inform therapists in wheelchair provision for PNDs. Numerous studies outline the wheelchair needs of people with PNDs and some guidelines exist on general wheelchair provision, yet limited guidelines exist to guide prescribing therapists specifically working with PNDs. From an Irish perspective, there is complete absence of any guidelines or standards; general or specific to any condition.

Conclusion

The importance of regular and planned review of the wheelchair and seating needs in PNDs is paramount. Barriers to appropriate wheelchair provision exist in the form of funding and ineffective resource management. Inadequate training of prescribing therapists raises questions about satisfactory outcomes for wheelchair users. There is an urgent requirement for development of national guidelines, drawing from existing national standards in other countries if necessary. Further research is recommended on therapists' own confidence in, and experience of wheelchair provision with PNDs.

Introduction:

People with Progressive Neurological Disorders (PNDs) may have enduring, complex and changing wheelchair and seating needs which can impact on their ability to function in everyday life (Devitt et al 2004, p.64). The appropriate provision of a wheelchair is primary to meeting basic needs and enabling active participation as a basic human right (Brownlee et al. 2011). Mobility impairment is a major consequence of PNDs (Finlayson and Denand 2003) and declines in functional mobility are linked to decreased performance in self-care, productivity and leisure, reduced participation and a loss of social connections (Atchison and Durette 2007, Einarsson et al 2006, Aronson 1997).

The irregular and complex nature of PNDs requires consideration when planning appropriate and timely wheelchair and seating provision. Appropriate wheelchair provision at the right time can allow maintenance of mobility, maximise independence and delay the onset of postural deformities in people with PNDs (Rolfe 2012, p.218). When the wheeled mobility needs of people are not met, they are unable to participate in the meaningful activities things they need or want to and are prevented from accessing the same resources in their communities as others. Wilcock (1998) calls these disturbances in engagement and barriers to participation 'occupational disruption' and 'occupational deprivation' respectively. Effective planning in wheelchair provision is essential in ensuring justice in engagement and participation for people with PNDs (Otter et al 2011, p.1).

The WHO (2008) highlight that central to planning appropriate wheelchair provision is the development of guidelines and standards to improve service delivery and outcomes for users. Occupational therapists are required to work from an evidence base to ensure the efficacy of any wheelchair or seating intervention. Gowran et al (2011, p.2) argue that an appropriate wheelchair is a primary piece of assistive technology and provision should be prioritised at a policy level. The objective of this study is to identify the wheelchair and seating needs of people with PNDs and establish what policies, guidelines or standards exists that help inform wheelchair provision. Appropriate wheelchair provision is crucial in ensuring occupational justice for a person with a PND.

The aims of the study are:

1. To scope academic literature on wheelchair provision in PNDs and grey literature for national and international guidelines, standards or policies for wheelchair provision for PNDs.
2. Identify the existing issues which impact upon appropriate wheelchair provision.
3. Discuss the development of guidelines for wheelchair provision in this population based on the findings.

Literature Review:

Progressive Neurological Disorders (PNDs) is a general term for degenerative conditions that affect the nervous system (Clark et al 2004). Some of the more prevalent PNDs are Multiple Sclerosis (MS), Motor Neuron Disease (MND), Muscular Dystrophy (MD) and Parkinson's disease (PD) (Umphred et al 2013, MacDonald et al 2000). In PNDs, signals between the brain and the body are interrupted, resulting in symptoms such as walking impairment, balance and coordination difficulties, pain and sensory disruption, uncontrolled movement, seizures and partial paralysis and even problems with breathing and talking (Clark et al 2004, p.367).

Table 1: Prevalence of PNDs in Ireland

Disorder	Estimated cases in Ireland at any time
Alzheimer's	40,000
Multiple Sclerosis	8,000
Parkinson's	8,000
Muscular Dystrophy	650
Huntingdon's	300
Motor Neuron Disease	200

Wheelchairs will become the primary means of mobility for most people with PNDs (Brown and Sliwa 2005, p.115). Many studies have shown the wide number of deficits associated with PND's with ambulatory impairment being the most common form of disability.

Noseworthy et al (2000) found that within 15 years of onset, 50% of all individuals with MS

will require assistance with walking, while Whetten-Goldstein et al (1998) found this figure to be even greater at 80%. Children with PND's may never be able to walk and will require a suitable wheelchair in order for them to maximise their developmental potential. Clark et al (2004) reports that children with Duchenne muscular dystrophy (DMD) will typically require their first manual wheelchair between the ages 6-12 years for self-propulsion over long distances. After some time as muscle weakness progresses, they will no longer be able to self-propel and a powered wheelchair will be necessary. Physical deformities such as scoliosis may develop and wheelchair features such as tilt-in-space will be required (Clark et al 2004, p.368).

There is a huge variation in the wheelchair and seating needs of specific PNDs. People with disorders such as the relapsing-remitting form of MS can mobilise independently for significant periods but may require a wheelchair during relapse (Savage 2005, Fay et al 2004), while a person with MND will experience a rapid deterioration in their mobility requiring swift, regular and planned intervention (Rolfe 2012). In contrast, a person with Parkinson's may very gradually lose their ability to ambulate independently and therefore, wheelchair and seating intervention can be planned over longer periods with more informed predictions made on mobility needs over time (Zampieri et al 2011, p.559).

To date many studies have focussed on user satisfaction and what constitutes an 'appropriate' chair from the user's perspective. Amyotrophic Lateral Sclerosis (ALS) is a PND whose symptoms include atrophy, spasticity, dysarthria, dysphagia (Ward et al 2010, p.269) and almost always leads to death from respiratory complications (Trail et al 2001, p.98). People with ALS rate comfort and support for their head, neck, trunk and extremities as their priority needs in a wheelchair (Trail et al 2001, p.100), while people with MS specify chair manoeuvrability (lightweight frame, smaller wheelbase) as key satisfaction indicators (Brown and Sliwa 2005). In each case, a disorder's complexity and individual perspectives of users require careful consideration. Guidelines to assist occupational therapists in this process may be required to increase the likelihood of a satisfactory outcome for the user.

The Convention on the Rights of Persons with Disabilities (2006) outlines the responsibility of states to provide appropriate wheelchairs and assistive devices to citizens of all ages and conditions. The WHO defines an appropriate wheelchair as one which "meets the user's

individual need, provide postural support...be affordable, maintainable and sustainable in the country of use" (WHO 2008, p.9). The benefits of appropriate seating and wheelchairs to people with PNDs include; independence of mobility, self-care, socialisation, increased physical function, postural support, trunk/head/limb control, improved comfort, respiration and digestion (Otter et al 2011, Richardson and Frank 2009, Clark et al 2004, Finlayson and Denand 2003, Janssens et al 2003).

The World Health Organisation (2008) defines wheelchair provision to be a broad process involving design, production, supply and service delivery. Within the service delivery aspect of provision, several factors exist which are crucial in determining whether or not a person will receive an appropriate wheelchair. The factors include referral, assessment, wheelchair selection, fitting, training, funding, review/follow-up, repair, maintenance and outcome measurement (WHO 2008, p.25). Gowran (2013) identifies waiting times, funding and wheelchair breakdown service as particular areas of concern in an Irish context. Gowran (2013) calls for sustainable solutions for wheelchair and seating provision to be developed in order to create a better flow to the already complex system of wheelchair provision.

Methods:

Specifically designed to identify gaps in the evidence base where little research has been conducted (Mays et al 2001, p.189); a scoping study method was chosen for this research. This method is recommended for reviewing complex processes (Lambert 2006) such as wheelchair provision and healthcare delivery (Davis et al 2009). Scoping reviews follow many of the same steps as systematic reviews but one key difference is that quality assessments are not typical for scoping reviews due to differing conceptions of what quality means (Arksey and O'Malley 2005). As this study attempts to discover the existence of guidelines, standards and policy in the area of wheelchair provision, a scoping review is more appropriate than a systematic review for example, which is more concerned with exhaustive searches and rigour of primary research. Scientific evidence on the effects of appropriate wheelchair provision on health and function of people with PND is limited. However there is extensive phenomenological research around the effects of loss of function and occupation from the perspective of people with PNDs. Considering the design

of studies on this topic and with existing guidelines on wheelchair policy largely limited to grey literature, a scoping review was deemed most appropriate for this study.

Inclusion criteria

Due to the complex nature of the study's topic, much of the literature is heavily compiled of non-experimental designs, grey literature and position papers. Articles that focussed on general non-disorder-specific wheelchair assessment or solely on one stage of wheelchair provision were not included as the author sought to focus on PND specific articles. Articles on the overall wheelchair service delivery process were included as they provided direction required to further hand searches for wheelchair provision guidelines and policy from both academic and grey sources. The process of selecting literature involved screening titles firstly before then reading the abstract of articles deemed of possible relevance. Quite a lot of 'post-hoc' inclusion became necessary as the limited quantity of literature in this study became apparent. Ridde (2009, p.6) points out that 'post-hoc' inclusion are central to the scoping process it is unlikely that the bases for inclusion can be established from the outset. Included literature was then hand searched by the author ensuring relevance, after which further exclusions were made. This hand searching was necessary as the author was surprised by the amount of articles which claimed, by title, to focus on wheelchair service provision or service delivery, yet ultimately centred on the prescription stage of the process.

Data Analysis

Thematic analysis of the data was completed and key themes emerged. Braun and Clarke's (2006) guidelines for thematic analysis were followed. Themes were quite apparent and emerged quickly from some of the literature while other articles were either quite explicit in their topic, or quite complex with an abundance of themes present; but many that were poorly explored in depth. As Braun and Clarke (2006) point out; the 'keyness' (the perceived importance) of a theme is not necessarily dependent on its quantifiable presence in the literature but can relate to whether it captures something important in relation to the overall research question. In many articles themes emerged that were not the central consideration of that particular article, but were hugely important in terms of wheelchair provision for PNDs. The flexibility of thematic analysis mentioned earlier was crucial in providing the scope for this study to draw out themes in this manner.

Keyword search strategy (See Fig. 1)

A list of keywords was drawn up and a search strategy was created for electronic academic databases and grey literature searches online to achieve as much breadth as possible. For academic databases, the full list of keywords was searched using Boolean operators to maximise the permutations of words scoped. Due to the non-academic nature of many documents pertaining to wheelchair provision, thorough searching of grey literature was necessary. In addition to the electronic databases outline, grey literature from online searches of governmental papers and websites, health service websites, disorder specific organisations and services websites were conducted through Google and Google Scholar.

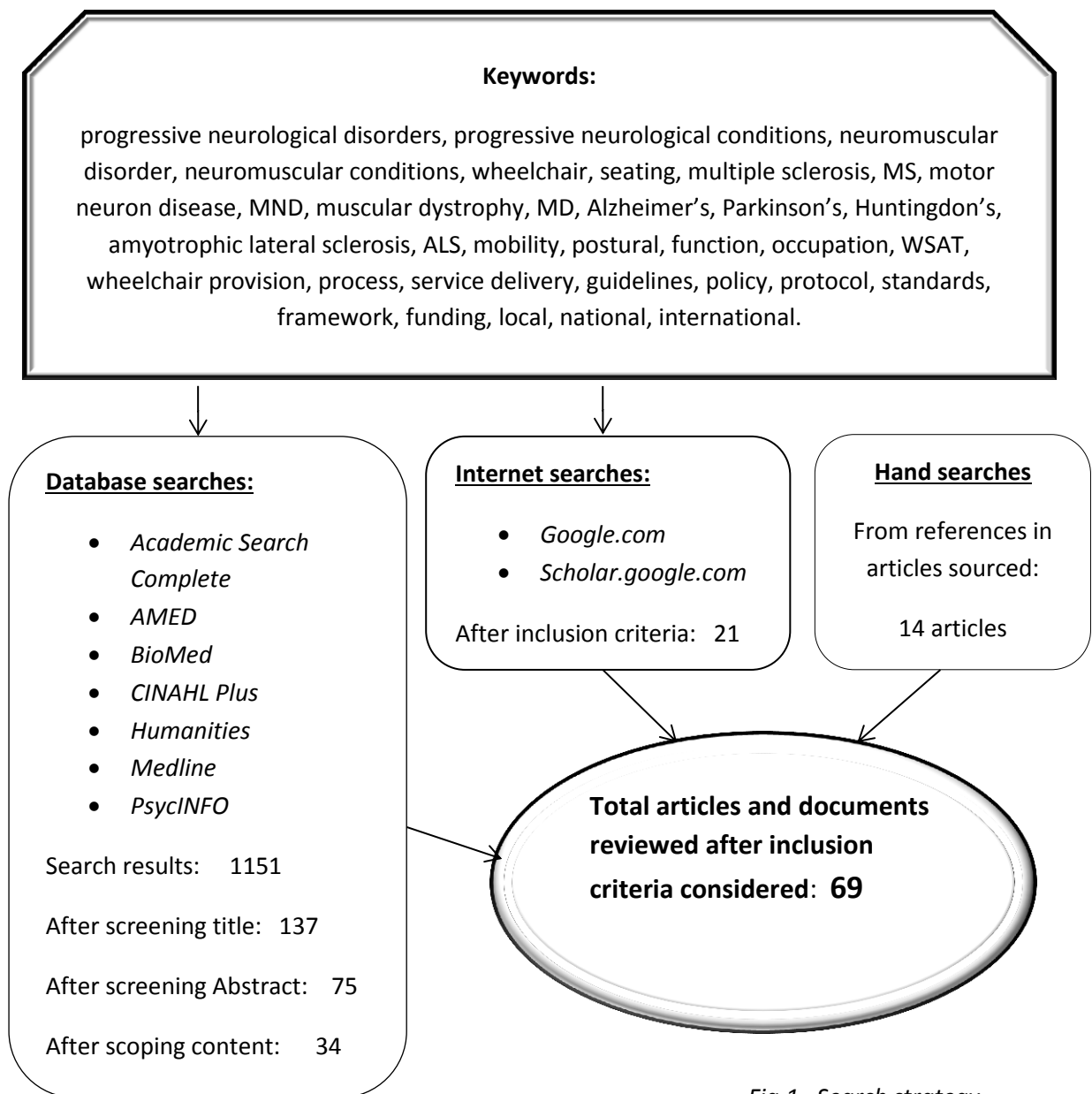


Fig.1 Search strategy

FINDINGS:

The findings from academic databases are described and presented in columns by its main topic and the specific aspect(s) of wheelchair provision to which it relates. The findings cause interest in that many articles which claimed by title to relate to wheelchair provision or service delivery, actually focused on a very specific aspect such as assessment, prescription or user involvement. There was a dearth of literature which focussed on the entire wheelchair provision process for specific PNDs. Development of guidelines or simply use of evidence for practice by occupational therapists will required the extraction of recommendations from a wide range of academic sources in order to best inform wheelchair provision with this population.

Table 2: Findings of academic databases and hand searches

Author	Topic	Wheelchair provision aspect
Ambrosio et al (2007)	Comparisons in mobility device service delivery between MS and SCI	Differences in wheelchair service provision between different disorders
Bardsley (2006)	Overall development of a sustainable service	Assessment, Funding, review, resource Management
Batavia et al (2001)	Anticipating problems in prescribing wheelchairs	Wheelchair prescription, funding, adaptability, maintenance
Batavia and Hammer (1990)	Priority factors of long term WC users with MS, MD, CP	User involvement in wheelchair selection
Bromberg et al (2010)	Timeline for predicting wheelchair use in ALS	Planning, Equipment selection
Brown and Sliwa (2005)	Wheelchair prescription for people with MS	Device selection User involvement
Canning and Sanchez (2005)	Manual v Powered wheelchair for people with MS	Assessment and Device Selection
Clark et al (2004)	Postural support for young people with PNDs	Assessment, prescription
Devitt et al (2004)	Wheelchair use and quality of life in MS	Quality of life outcome measures of wheelchair use in MS
Di Cano	Medicare powered wheelchair provision	Device selection, funding

Di Marco et al (2003)	Standards for wheelchair prescription	Prescription, outcomes, guidelines
Eberhardt and Finlayson	Wheeled mobility for people with MS	Assessment and Device selection
Eggers et al (2009)	Preliminary Model of Wheelchair Service Delivery	Overall process of wheelchair provision
Fay et al (2004)	Manual wheelchair difficulties in people with MS	Assessment, user satisfaction, evaluation
Fay and Boninger (2002)	Review of mobility devices for MS and appropriate prescription	Waiting times, prescription of WSAT for people with MS
Finlayson and van Denand (2003)	Perspectives of older adults with MS on their loss of mobility	User perspectives on loss of mobility
Hubbard et al (2007)	Distribution and costs of wheelchairs provided by Veterans Health Administration	Selection/Prescription, funding, resource management
Janssens et al (2003)	Expectations of recently diagnosed MS patients around wheelchair dependence	Wheelchair dependency rates of people with MS
Liu et al (2003)	Seating problems and management in DMD	Prescription, outcomes
Michael et al (2007)	Titled seating positioning for neurological impairments	Prescription(positioning), outcomes
Pike et al (2012)	Social and economic issues related to mobility problems in MS	Assessment, timelines, functional impact of MS
Richardson and Frank (2009)	Barriers to WC service delivery for PWC users with MD	Assessment and follow-up/review
Rolfe (2011)	Planning wheelchair provision in MND	Considerations for wheelchair selection, financial restrictions, planning/review times
Samuelsson et al (1998)	Client-centred wheelchair intervention	Device type prescribed
Savage (2005)	Positioning in WC prescription for people with MS	Assessment, Prescription
Souza et al (2010)	Systematic review literature on MS and mobility related assistive technology	Overall service delivery and AT for MS
Taylor (2005)	Ethics in wheelchair decision making	Assessment, prescription, device selection, Funding, User involvement

Trail et al (2001)	Wheelchair selection in Amyotrophic Lateral Sclerosis	Assessment, Device selection, Outcomes
Ward et al (2010)	Powered wheelchair features elected by people with ALS	Wheelchair selection
White and Lemmer (1998)	Key factors required for an effective wheelchair service	Referral procedures, assessment, qualification and training needs
Williams and de Jonge (2012)	The qualifications of OTs for wheelchair prescription	Prescription, training
Visage et al (2013)	Wheelchair service delivery in rural South Africa	Study of implementation of local/national guidelines

Table 3 presents findings resulting from grey literature searches completed through Google and Google Scholar. Similar keywords from the academic search method yielded valuable policy documents and disorder-specific recommendations for management of PNDs. International guidelines were found from organisations such as the World Health Organisation and National Health Service in the UK, the United States, Scotland and Australia. The WHO's (2008) guidelines for wheelchair provision in less resourced countries addresses the design, production, supply and service delivery of manual wheelchairs, in particular for long-term wheelchair users. They do not address wheelchair provision in developed countries such as Ireland, nor can they be applied to people who have constantly changing and complex wheelchair needs such as people with PNDs.

Bardsley (2006) believes that the initial steps in establishing a wheelchair service requires a clear understanding of the population, an analysis of their characteristics and close dialogue with all stakeholders. Best practice guidelines on the overall care management of PNDs were found from disorder-specific organisations, institutes and interest groups such as MD Campaign. However, like the national guidelines found in the UK, USA and Australia, standards or guidelines for wheelchair provision are not implicit. For example, the National Institute for Health and Care Excellence UK (NICE) guidelines on the management of MS recommends the assessment of mobility needs, the provision of appropriate equipment with regular monitoring and adaptation when required. However, there are no recommendations made about timeframes for review or follow-up, funding considerations, training or education, planning for wheelchair and seating intervention or by whom it should be completed.

Table 3: Grey Literature findings

Title	Focus
WHO Guidelines on the provision of manual wheelchairs in less-resourced settings (2008)	Access to wheelchairs, Policy planning, Wheelchair design/production, Service delivery, Training, User involvement
Health Care Standards for Wheelchair Services Under the NHS (2005) – United Kingdom	Access to services, Referrals, Assessment, Prescription, Supply, Handover, Maintenance, Training, Documentation
NHS Scotland Wheelchair and Seating Services – Draft Clinical Standards (2011)	Assessment, Follow-up/Review, Equipment management, Quality/Service management, Target timelines, Evidence base
Rehabilitation Appliances Program (RAP) National Guidelines – Australia (2012)	National guidelines for assistive technology with specific guidelines on customised manual and powered wheelchairs, pressure relieving and reclining chairs.
Rehabilitation Engineering & Assistive Technology Society of North America (RESNA) Wheelchair Service Provision Guide	Guidelines/framework for overall wheelchair service provision – Referral, Assessment, Design, Education, Funding/Procurement, Fitting/Training/Delivery, Follow-up Maintenance/Repair, outcome Measurement
Wheelchair Provision for Children and Adults with Muscular Dystrophy and other Neuromuscular Conditions – Best Practice Guidelines (2011)	Access, Assessment, Planning, Seating and posture issues, Clinical management impact on wheelchair provision
UK Best Practice Guidelines for Wheelchair Provision for Children and Adults with Neuromuscular Conditions (2011)	Muscular Dystrophy led guidelines on planning appropriate wheelchair provision for MD and other neuromuscular conditions.
National Institute for Health and Care Excellence (NICE) 2003 Multiple Sclerosis CG8	Management of MS in primary and secondary care – advice to NHS on condition management and treatments they should receive
National Institute for Health and Care Excellence (NICE) 2011 Motor Neuron Disease CG105	The use of non-invasive ventilation in the management of motor neurone disease
National Institute for Health and Care Excellence (NICE) 2006 Parkinson’s CG35	Overall diagnosis and management of PD in primary and secondary care
Association for the Advancement of Assistive Technology in Europe (2003)	Position paper on assistive devices service delivery in Europe

A limited number of studies (3) were found which map out recommendations for wheelchair planning in specific disorders. Rolfe (2012) outlines the average number of months between which various wheelchair types are required for a person with MND (see Fig. 2). Awareness of studies like these from wheelchair providers working with people with PND's will be crucial in planning appropriate wheelchair provision. The development of national condition-specific guidelines highlighting such timelines may lead to improved services for this population. Similar studies outlining timelines for predicted wheelchair use were also found for Amyotrophic Lateral Sclerosis (Bromberg et al 2010) and Multiple Sclerosis (Mhyr et al 2001).

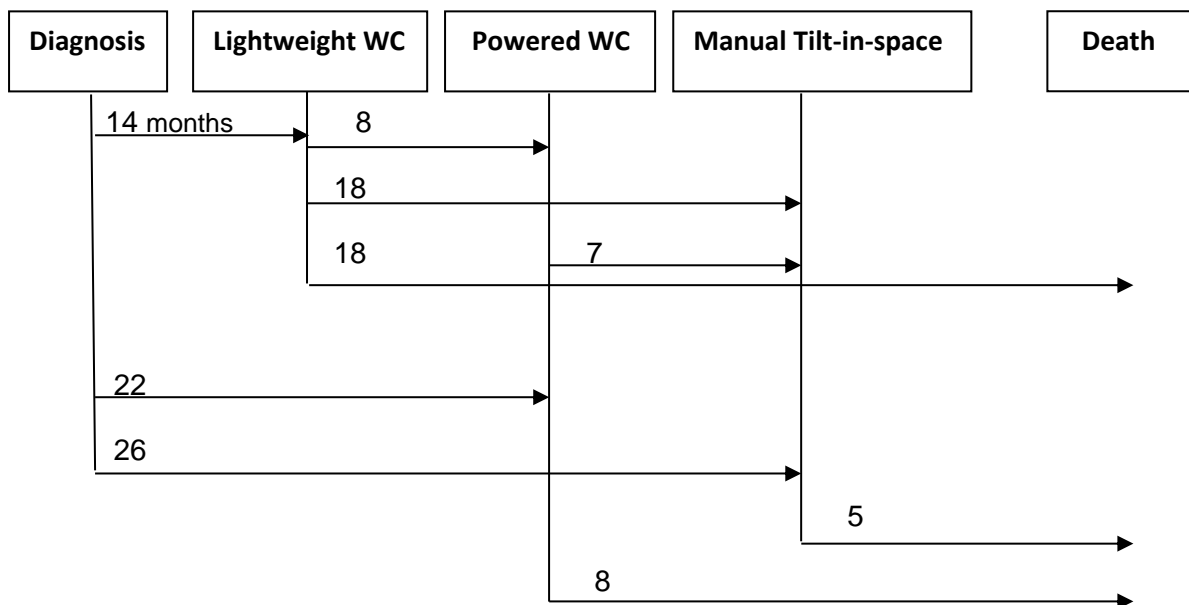


Fig 2: Average months between issuing of different types of wheelchair in MND from diagnosis to death (Rolfe 2012)

These comprehensive and disorder-specific timeline above can be compared and contrasted with national recommended guidelines for wheelchair provision such as those found in Table 4. While Rolfe (2012) sets out a timeline for the wheelchair needs of MND, the National Health Service in the UK have produced generalised guidelines for response times for wheelchair provision. While a valuable resource in general terms, they are non-specific to any population and as such, are not helpful in planning wheelchair provision in PND, or indeed in people with other complex needs.

Table 4: NHS guidelines for timeframes for each stage of wheelchair provision

Stage	Response time
Referrals	
- All referrals will be screened by.....	2 working days
- Referrals acknowledged to referrer.....	2 working days
- Incomplete referrals returned in.....	2 working days
From receipt of referral to assessment.....	15 working days
From prescription to delivery	
- Locally held stock.....	15 working days
- Orders from manufacturers.....	30 working days
- Made to measure.....	30-65 working days
Non-emergency repairs.....	3 working days
Emergency Repairs/Responses.....	24 hours
Deliveries.....	5 working days
Collections.....	5 working days

It appears from the findings that while published academic studies have been conducted into the wheeled mobility needs of people with PNDs and the proposed timeframes for intervention, this information and recommendations has not translated into national guidelines for wheelchair provision for this population. Instead, only generic and arguably vague guidelines for the overall wheelchair provision process exist. Several common factors emerged which can help explain barriers to appropriate wheelchair provision in PNDs.

The themes that emerged from thematic analysis of the above findings were: disorder-specific guidelines, funding and system-level factors, review times and planning ahead, resource management, adequate training and the development of national guidelines.

Discussion:

Disorder-Specific guidelines

The findings of this study has highlighted the unique and varied wheelchair and seating needs of each PND. While generalised guidelines on wheelchair provision may ensure a

person receives a wheelchair in a timely manner for example, there is no one-size-fits-all approach to standards of practice for PNDs. The development of disorder-specific guidelines will offer an evidence-based platform for therapists to work from to ensure effective and appropriate provision. A very limited number of publications and grey literature documents were found which offer evidence and guidelines on specific conditions. Ward et al (2010, p.270) outline the types of wheelchair people with ALS/MND are likely to need during the course of their condition and highlight basic essential features such as; tilt, recline, powered elevating leg rests, air or gel cushion, height adjustable gel or contoured arm rests, soft head rest and seatbelt. Other features such as a seat elevator, swing away joystick and attendant controlled joystick are commonly required for this population in later stages and should be considered. Knowledge of these requirements by a therapist prior to assessment would be hugely beneficial in planning wheelchair provision for this population.

Unlike static disabilities such as spinal cord injury, the unpredictable and progressive nature of PND's can make wheelchair selection complicated (Brown and Sliwa 2005) and as such, the findings suggest that guidelines are crucial in the selection process. Rolfe's (2012) study on wheelchair provision in Motor Neuron Disease mapped out the timeline for the different types of wheelchairs used by people during the course of their illness (see Fig. 3). Evidence like this should be incorporated into any guidelines that may be developed for MND to ensure their needs are met not reactively, but in a planned manner. Analysis of the literature highlighted common issues which influence and impact upon the planning of disorder-specific provision and further called for the development standards and guidelines.

Funding and System-level factors

Eggers et al's (2009) model of wheelchair provision in the United States draws attention to the "system-level factors" which influence service delivery and ultimately the appropriateness of wheelchairs provided. These factors include administration and funding, standards, policies and regulations. Through the identification of factors that can lead to huge disparities in wheelchair provision, providers can intervene and reduce such disparities. White and Lemmer (1998) further argue that a person receiving an appropriate chair is not solely dependent on a therapist's skill in assessment but highly reliant on the operational policies of the wheelchair service.

Greer et al (2012) also found that wheelchair providers must balance what type of chair they feel the client requires as result of assessment, with what they are likely to be granted funding for. This may result in a person receiving a chair that is not appropriate for their needs. The development of a voucher system in Ireland, such as that which exists in the USA and UK, should be considered for the funding of wheelchairs for those who may or may not qualify for free healthcare or those who may be able to contribute something towards the purchase of an appropriate chair, instead of joining a long waiting list or receiving a more affordable and inappropriate chair. Batavia et al (2001) point out that provision of inappropriate wheelchairs leads to abandonment of chairs and huge financial wastage.

Review Times and Planning Ahead

A report from Muscular Dystrophy Ireland (2009) showed that 47% of their clients experienced delays in receiving essential mobility equipment, with 18 of their clients having to wait more than a year for recommended mobility devices. Bardsley (2006) reports that review, reassessment and maintenance are the essential elements of any service to ensure wheelchairs continue to meet user's needs and the absence of standards or guidelines perpetuates inappropriate provision. The National Health Service (NHS) in the United Kingdom have developed minimum national standards for the provision of wheelchair services for people with long-term mobility problems and associated postural needs. Developed in response to huge variations in wheelchair prescription, funding and staffing which existed across many geographical areas. One of the most useful aspects of the standards is the recommended minimum required response times for each stage of the wheelchair provision process (See Table 4). An argument can be made that a similar document is necessary in Ireland in order to ensure users' needs are met in a timely manner and to ensure equality in services across conditions or geographical areas.

Di Marco et al (2003) found no existing standards of practice for wheelchair prescription and highlighted the need for development of clinical guidelines for periodic follow-up following wheelchair provision. They discovered that follow-up was not a structured practice, varied hugely from area to area and was dependent on the user initiating a review if required. Di Marco et al (2003) concluded that three months following wheelchair issue was an appropriate time for the initial follow-up, allowing the user to fully experience the chair in

their own environment and how it performs based on their needs. A second review was recommended after 12 months. Likewise, the NHS Scotland Seating and Wheelchair services (2011) argue that wheelchair users with complex and changing require periodic, planned reviews to ensure that their needs are anticipated and responded to on a continuous basis to reduce avoidable complications of inadequate mobility or postural support. They advise that the frequency of review should not be outlined in general terms, but determined from one individual to the next, dependent on the progressive nature of their disorder.

Rolfe's (2012) study on wheelchair provision in motor neuron disease draws attention to the challenge of delays in supplying wheelchairs, which when eventually provided are no longer appropriate for the client due to a deterioration in their condition. Rolfe (2012) argues that if a client with MND's needs can be more accurately predicted then therapists can better plan wheelchair intervention and have the chair the person is likely to need available for them. In ALS, death usually occurs 3-5 years after onset and Trail et al. (2001) further recommends the proactive planning of a first wheelchair for this population due to the rapid progression and long waiting times associated with wheelchair provision. Realistically, having a chair ready and available for each person is not feasible but forward planning based on evidence based information on the likely needs of an individual will shorten waiting times and ensure a person's participation in society is not disrupted.

Krizak (2003) notes that a wheelchair is the catalyst to increased independence and social integration, but it is not an end in itself. The need for regular and planned review was found to be crucial in determining the continued appropriateness of a wheelchair for this population. Cotter et al. (2011) argue that it is essential to think and plan ahead and consider the future needs of a client with a progressive disorder. Both current and future long-term wheelchair requirement should be considered at each assessment. Cotter et al (2011) further draw attention to the fact that people with PNDs can be reluctant to accept seating changes and it is worth using products that can 'grow' or be easily adapted. For example children with muscular dystrophy can rapidly deteriorate and this, combined with their natural growth can cause postural problems. Delays with wheelchair assessment, funding and provision can sometimes mean that by the time the child receives the wheelchair it may no longer be suitable (Gowran 2011). This is simply unacceptable in a

developed country like Ireland and the establishment of a sustainable system; led by evidence-based guidelines are necessary in this regard.

Resource management

Access to an appropriate wheelchair may not be dependent upon therapist skill, waiting lists or funding arrangements. White and Lemmer (1998) highlight the importance of the management of stock within the wheelchair provision process to ensure all unused chairs are returned for reuse. Batavia and Hammer (1990) highlight the importance of the flexibility and ease of maintenance as key factors in wheelchair provision. Retrofitting of attendant controlled joysticks, headrests and lateral supports are all common requirements in PNDs when people lose capacity to control their chair independently or develop postural difficulties. The early provision of a chair that can take these adaptations can save undue stress for users and carers while saving money for the service (Batavia and Hammer 1990). The resource management of wheelchair services in Ireland are currently ad-hoc at best and highly dependent on month-to-month funding restrictions and determined by which enterprise has obtained the rights to manage the health service's stock. A service which matched the appropriate chair to the person instead of the person being matched to an existing chair is necessary to ensure positive outcomes for individuals. The huge level of abandonment of chairs was studied by Mortensen and Miller (2008, p.171) who stressed that on top of funding considerations, the experience and level of therapist training was crucial in the provision of an appropriate chair.

Adequate Training

Little is currently known about whether or not occupational therapists are incorporating current evidence or guidelines into their practice (Williams and de Jonge 2010). In their publication on policy and planning to implement sustainable wheelchair provision, the World Health Organisation (WHO) insist that national health services are responsible for ensuring the adequate training of all personnel involved in wheelchair provision. The Association for the Advancement of Assistive Technology in Europe (2003) also calls for greater competencies of professionals involved in wheelchair provision. There is some debate in the literature about the recommended qualifications of wheelchair providers. Considering the specialised seating needs of people with PNDs, Williams and de Jonge

(2010) pose the question about whether or not occupational therapists are suitably qualified as the chief providers in wheelchairs to this population. Several studies have highlighted the lack of undergraduate training in wheelchair provision (White and Lemmer 1998, Silcox 1995). Brownlee et al (2011) point out that there is little evidence of wheelchair and seating training within course outlines for any of the undergraduate or postgraduate occupational therapy and physiotherapy courses in the Republic of Ireland.

Ward et al (2010) outlines the complex nature of ALS and MND and suggests the importance of input from an entire specialised team of professionals with knowledge of the condition during wheelchair prescription. The WHO, in partnership with the United States Agency for International Development has developed a wheelchair service training package for different levels of personnel involved in the provision of wheelchairs. An intermediate level training package is available for people involved in providing wheelchairs for those with poor postural control such as people with PNDs. However, this is an online training resource and there is undoubtedly a need for compulsory training at undergraduate and postgraduate level.

Development of national guidelines

The WHO urges national authorities and wheelchair providers to develop and adopt national standards which are needed to address the issues of quality of service delivery and personnel training. WHO also offer its own guidelines as a starting point in development of countries own national standards. Furthermore, the NHS Scotland has encouraged wheelchair providers to use their guidelines in the development of local or national wheelchair provision standards. The standards are explicit in the identification of user involvement in the process, acceptable waiting times and they emphasise the need for planned seating reviews for users, an area crucial for people with PNDs and indeed other population such as children and older people.

None of the documents referred to in this study provide a comprehensive framework for planning appropriate wheelchair provision for people with PNDs. However, combining the information and strategies collectively will undoubtedly assist in the development of disorder-specific guidelines. With this information on hand there is little excuse for the absence of national standards on wheelchair provision for people with PNDs.

Conclusion:

This study has shown that evidence exists on the wheeled mobility needs of specific progressive neurological disorders, yet guidelines and standards on how wheelchair provision for these same populations should be planned and carried out is sparse. There is consensus in the literature of the functional and occupational impact of an inappropriate wheelchair for people with PNDs and the importance of the development of guidelines.

The McColl (1986) report highlighted the poor standards of wheelchair prescription and assessment in the UK which led to countless people receiving inappropriate wheelchairs. The recommendations included in the report are believed to have provided the framework for the latest NHS Standards for Wheelchair Services that would follow several years later. In Ireland no such governmental report has been completed but recent studies such as Gowran (2013) has brought the issue of a lack of sustainable system of wheelchair provision in Ireland into focus.

The WHO (2008) is clear that imperative to planning and implementing an appropriate wheelchair provision system is the adoption of minimum national standards on service delivery. The different aspects of wheelchair provision have been highlighted and the impact that each aspect can have on appropriate wheelchair provision in PNDs argued. It appears from the literature that before disorder-specific guidelines can be developed; there is an urgent need for general national standards to be created. The WHO urge the development of these standards in order to address the issues associated with wheelchair provision such as waiting times, funding, personnel training and service delivery. They encourage the use of the WHO's own published guidelines as a starting point in developing standards.

The development of guidelines in other countries such as the NHS Scotland's (2011) wheelchair and seating clinical standards document sets out a recommended set of standards for each aspect of service provision with its own geographical area, but insists that this model is suitable for use in other geographical locations. To date no such guidelines have been developed, adopted or even promised by the national health service in Ireland. While an absence of guidelines, standards or policy remains, health professionals involved in wheelchair provision continue daily to intervene in provision of wheelchairs with PNDs

without a recommended framework to guide their practice. Such an absence surely perpetuates the disjointed and ad hoc manner in which wheelchair services in Ireland currently operates. There must also be an obligation for stakeholders in the provision of assistive devices to strive for appropriate policy and guidelines in this area to ensure that an effective, transparent and sustainable system of wheelchair provision is developed in Ireland. Other than the work of Gowran et al (2011) and Gowran (2013), this study failed to identify any other Irish literature calling for the development of the aforementioned guidelines.

Other research has shown the need for timely assessment, a sustainable system of funding, efficient resource management and regular and planned reviews of this population's wheelchair and seating needs. The need for specialised training for wheelchair providers was also identified to ensure evidence-based effective planning for complex disorders, yet this is another area that has been neglected both in the literature and in clinical practice. An extremely limited number of national guidelines and standards for appropriate wheelchair provision exists but each one of these found during this study existed outside of an Irish context. Education and training for Irish occupational therapists is limited and the developing of guidelines and standards for wheelchair provision on a clinical level and on a broader organisational level are imperative in ensuring appropriate wheelchair provision for people with PNDs.

As the primary professional involved in wheelchair provision; the implications for occupational therapy practice in Ireland are serious. The evidence which outlines the complex needs of people with PNDs and the impact on inappropriate provision cannot be ignored. By doing so is contradictory to the evidence-based practice towards which the profession strives. If it is indeed the case that occupational therapists are undereducated and hampered by the lack of guidelines and standards; by continuing to practice within an inadequate system of wheelchair provision is cause for concern.

This study highlights the need for further research in many key areas of wheelchair provision. Little is known about the clinical experiences of Irish therapists currently involved in wheelchair and seating provision. Information from occupational therapists' point of view on their training requirements and their perceived knowledge and skills in the area of

wheelchair provision for PNDs would be invaluable in the future development of any guidelines. The impact that funding and system-level factors is having on appropriate wheelchair provision needs to be discovered from an Irish perspective to establish if, like several international studies suggest, many people with PNDs are receiving inappropriate chairs and are suffering occupation disruption and deprivation. The development of standards and guidelines in wheelchair provision may have a positive impact on the current barriers to appropriate and sustainable provision by placing an obligation on the state and services to ensure timely and effective wheelchair and seating provision for people with PNDs.

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