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Mobility in Ambulant Adults with Cerebral Palsy — Challenges for the Future

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1. Introduction

Cerebral palsy (CP) is a lifelong cause of disability, with an incidence of around 2 per 1000 people (Himmelmann 2013). It is the most common cause of physical disability in childhood, and children are commonly treated by specialized pediatric services from a broad range of disciplines. Adults with CP are a growing community who are now recognised as outnumbering children 3:1 in some countries (Access Economics 2008). With advances in healthcare, it is now usual for those who walk during childhood to have a relatively normal life expectancy (Strauss, Brooks, Rosenbloom and Shavelle 2008). Over recent times, the need to consider CP as a lifespan, rather than childhood condition has been highlighted, with particular interest in the reported difficulties that emerge during the adult years (Tosi et al. 2009; Morgan and McGinley 2013).

Throughout childhood it is common for much emphasis and resources to be directed at gaining and optimizing walking ability, through a variety of established rehabilitation, medical and surgical interventions. Although around 60% of individuals are able to walk independently or with aids when entering adulthood (Himmelmann 2013), it is common for walking to deteriorate in early and middle adulthood with many young to middle-aged adults describing worsening or loss of walking ability (Morgan and McGinley 2013). The lifespan health challenges faced by this group have been previously poorly described, are arguably still poorly understood, but are now the focus of urgently needed new research directions in CP (Tosi et al. 2009). Many adults with CP commonly develop secondary conditions, such as osteoarthritis (OA), pain, fatigue or falls. Maintaining the ability to walk or maintaining flexible mobility options is important to enable societal participation, maintain employment and retain independence. This chapter provides an overview and exploration of current knowledge of

mobility decline in adults with CP, and considers service provision in the context of lifelong rehabilitation.

2. Current knowledge of mobility decline and associated factors in adults with CP

2.1. Mobility decline and associated factors

Accumulating reports provide clear evidence that many adults with CP experience a decline in walking ability during adulthood. In childhood, understanding of the maturation and change in functional mobility over time has been greatly enhanced by the development of the Gross Motor Functional Classification System (GMFCS) and the reporting of typical 'curves' to reflect motor performance over time (Palisano et al. 1997; Hanna et al. 2009). The recent extension of this data to extend to age 21 suggests that deterioration in function may begin in more impaired children from around age 8 (Hanna et al. 2009). Such similar curves are not yet available for adults, although trends in data from the large studies by Strauss and colleagues suggest a similar profile of decline (Strauss, Ojdana, Shavelle and Rosenbloom 2004; Strauss et al. 2008). A recent systematic review of 16 studies reporting gait decline in adults found variation in the incidence of decline, but with most studies reporting decline affecting around 30% or more of the study participants (Morgan and McGinley 2013). Figure 1 illustrates the proportion of adults who experience decline in walking ability from a selection of studies.
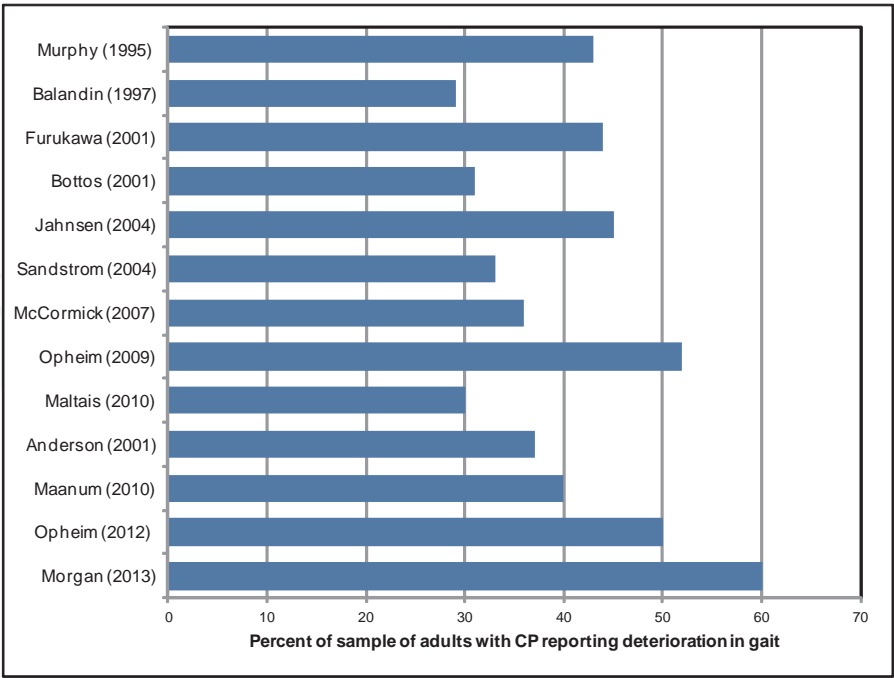

Figure 1. The proportion of adults with CP who experience decline in walking from a range of studies of adults with CP.

A number of studies have now provided insights into factors associated with a higher risk of decline. Unsurprisingly, the most recognised predictor of long term walking function stability is ability during childhood, with age of walking debut associated with likelihood of decline (Bottos et al. 2001; Jahnsen et al. 2004). Similarly, those individuals with poorer gait function requiring the use of gait aids during childhood (GMFCS level III) are more likely to report a deterioration in walking ability, or stop walking entirely (Jahnsen et al. 2003; Opheim, Jahnsen, Olsson and Stangelle 2009). Individuals who are older also appear to be at greater risk of decline. Jahnsen et al (Jahnsen et al. 2004) found that the risk of deterioration progressively increased across age bands from 25 to 45 years, with over 70% of those aged over 45 years reporting a decline in walking. The age of deterioration appears associated with the motor impairment, with the median age of deterioration reported in people with bilateral CP to be 37, compared to 52 in those with unilateral symptoms (Opheim et al. 2009). At even older ages, the potential for more rapid decline may be increased, with around 40% of those walking independently and climbing stairs unassisted at age 60 losing this ability prior to age 75 (Strauss et al. 2004).

As well as worsening walking function, many previously ambulant adults with CP report stopping walking altogether at a wide range of ages. Often this occurs relatively early in adulthood, in the early 20's and 30's (Morgan and McGinley 2013). For some individuals, it may be that this primarily reflects the inevitable consequence of decline in function, with loss of ability or confidence. Alternatively, for others it may simply reflect their personal choices in response to their current or changing symptoms, environment, life activities, or vocational pursuits. For example, a previously ambulant adult may decide to use a wheelchair to travel greater distances, to save energy for other activities, or for greater time efficiency (Jahnsen et al. 2004). Similarly, individuals may choose strategies to prevent falling and remain safe, for example, electing to use a wheelchair or scooter (Horsman, Suto, Dudgeon and Harris 2010). Conversely, others may choose to stay walking because they view wheelchairs or scooters as compromising their independence (Horsman et al. 2010), and may commence using a gait aid to optimize this choice.

The nature of primary motor symptoms and secondary medical conditions also appear to influence an individual's likelihood of decline. Adults with bilateral syndromes, quadriplegia or choreoathetosis are more prone to report problems than those with hemiplegia with milder deficits, who are likely to walk well until their 50's or beyond (Morgan and McGinley 2013). Similarly, higher levels of pain, higher pain intensity, and higher levels of fatigue are also associated with self-reported deterioration (Morgan and McGinley 2013). Many studies have explored the perceived causes of gait decline from the self-reported perspective of the individual. Reduced balance is the reason most commonly reported as a possible cause, nominated by over 60% of adults in the studies by Jahnsen, Opheim and colleagues (Jahnsen et al. 2004; Opheim et al. 2009). Perceived difficulty with balance is also consistent with the observation by Bottos and colleagues (Bottos et al. 2001) that many individuals experience ''a rising sense of near-falling'' as they age, due to progressive postural instability associated with increased additional weight and other aging factors. Falls or marked insecurity when walking were also cited as causal factors leading to cessation of walking by nine of the 13 people in one

study who stopped walking (Bottos et al. 2001). Figure 2 illustrates many of the common factors self-reported as perceived causes of gait deterioration.
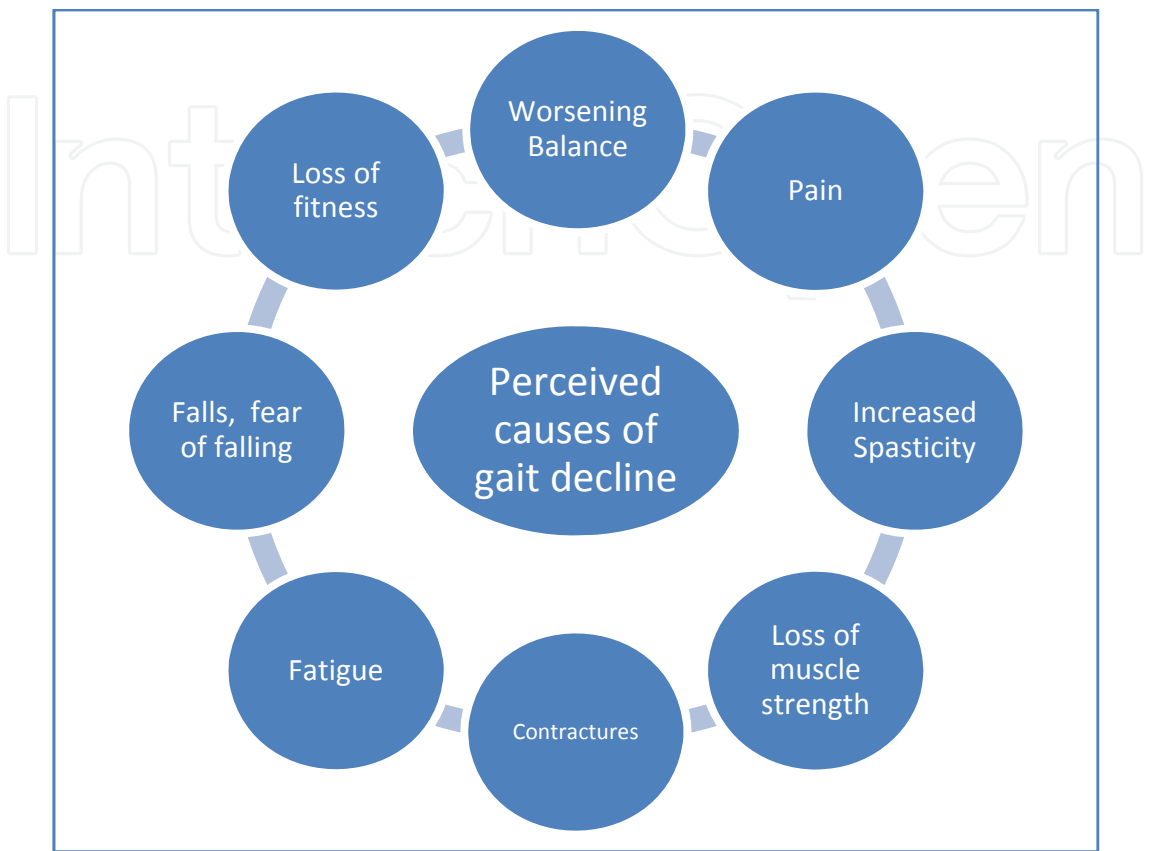
Figure 2. Key self reported factors from adults with CP potentially associated with a decline in mobility

2.2. The nature of gait decline

Gait decline is a multidimensional construct and a great deal of further research is needed to gain a better understanding of the nature of changes experienced by individuals as they age with CP. Adequate walking function is a complex task that requires an individual to success-fully navigate varied environments in order to complete personal goal-directed tasks. Phys-iological changes in any of the systems underpinning motor control or dynamic balance may impact on walking, such as changes in strength, sensation, vision, vestibular function or cognition. Additional symptoms due to secondary conditions such as fatigue, pain, or shortness of breath may also impact on function, as may changes in self-efficacy such as fear of falling or loss of confidence.

A wide range of factors may also influence an individual's perception of their own ability. One individual with mild disability may self-report decline due to a reduced ability to walk long distances, or the need to hold a rail during stair walking. A more impaired individual at GMFCS III may reduce their walking activity and rely on a wheelchair to achieve vocational

or recreational demands, yet not perceive a change in walking ability. The accumulation of literature does not offer a comprehensive understanding of how walking changes for adults with CP. Reported common changes include the need for greater assistance, or aids to walk, or the use of a rail on stairs, walking shorter distances or walking only indoors. Other reports suggest that it is common for walking to become slower, unsteadier, and more difficult in varied outdoor terrains. Symptoms such as pain, fatigue, shortness of breath or concern about falling also may be limiting factors (Morgan and McGinley 2013). The nature of walking decline is also challenging to interpret from the literature due to the diversity of outcome measures used in different studies. Measures of walking may capture what the person "does in their daily environment" (performance), what they "can do in their daily environment" (capability), or what they "can do in a controlled standardized environment" (capacity) (Holsbeeke, Ketelaar, Schoemaker and Gorter 2009). Although highly related, these measures are not interchangeable, as capacity and capability may differ and often exceed everyday actual performance. Future longitudinal studies with measures reflecting all three constructs are needed to distinguish and detail objective changes in gait across a range of environmental contexts. These measures could be considered in conjunction with the individual's perceived (self-reported) capabilities, self-efficacy and personal mobility preferences.

Evidence-based knowledge about decline in mobility is markedly limited, and the causes of gait decline are likely to be multifactorial. Current attempts to understand the causes of gait decline are limited by the absence of longitudinal studies that measure gait and provide detailed participant characteristics, preferably from large population based samples. It is also likely that the outcomes of the current generations of adults have been influenced by their treatment during childhood, and may thus vary across age ranges. For example, over the last one to two decades, botulinum toxin therapy, gait analysis to guide surgical planning and single-event multilevel surgery (SEMLS) have been introduced and become standard practice in many specialized tertiary centres. Access to and uptake of these recent treatments may lead to different or better outcomes than in past times. Current and relatively recent cohorts of children may therefore enter adulthood with better limb and joint alignment or different gait ability than cohorts from two or more decades past. Many of the adults who report decline are in their mid 30's to 40's and have likely to have undergone historically different treatment plans to those in current practice. A recent study of outcome after childhood SEMLS surgery guided by gait analysis suggests that gait patterns appear to be largely stable for periods up to 10 years after surgery (Gannotti, Gorton, Nahorniak and Masso 2010). Although promising, it remains uncertain yet whether apparent biomechanical stability of gait patterns will also be accompanied by stable self-reported appraisals of walking. For example, although an individual's gait pattern may remain stable with respect to the kinematic pattern, increasing pain, loss of confidence or falls, or even a change in vocational or recreational demands may lead to an individual walking less, using a gait aid, or preferring to adopt alternative mobility choices. Well designed studies are therefore urgently required to clarify the longer term outcomes of contemporary standard interventions. The greatest and clearest insights will be provided by longitudinal studies of defined cohorts, who have well-detailed treatment records and existing measures of gait biomechanics and function using high quality outcome measurement tools in conjunction with qualitative methods.

3. Fear of falling and falls in CP across the lifespan

3.1. Falls frequency in adults with CP

Difficulty with balance or falls is frequently self-reported by adults with CP as a main reason for changes in mobility throughout adulthood (Opheim et al. 2009; Morgan and McGinley 2013). Identification, early prevention, remediation and monitoring of falls and falls risk factors is now recognised as a standard component of best practice health care in older adults. Surprisingly, there is very little information on falls in adults ageing with CP. Mosqueda (Mosqueda 2004) alarmingly reported that 40% of a cohort of adults with CP (mean age 44 years) fell monthly, and 75% fell at least every two months. More recent literature (Opheim, Jahnsen, Olsson and Stanghelle 2012; Morgan and McGinley 2013) also reported frequent falls experienced by adults with CP, with some reporting two or more falls each week. Falls rates were high, with 80% of ambulant individuals in the study by Opheim falling five or more times in the past year (Opheim et al. 2012) and 68% of those in the prospective study by Morgan falling during a six month period (Morgan and McGinley 2013). For many adults ageing with a disability, falls have been an accepted 'way of life', perhaps regarded as a natural conse-quence of impaired mobility throughout childhood and beyond. However, whereas it may be considered acceptable and common to fall in childhood and adolescence, the physical and social consequences of falling in adulthood become more serious over time, particularly with the potential occurrence of co-morbidities such as osteoarthritis or osteoporosis. For other ambulant adults with CP, falling may be a new development, as a result of the onset of newly acquired mobility and balance decline. Evidence suggests that falls frequency in adults with CP may be as high or higher than other commonly occurring neurological disorders such as Parkinson's disease or stroke (Mackintosh et al. 2005; Pickering et al. 2007).

3.2. Falls consequences in adults with CP

The common consequences of falls in older adults include minor soft tissue injuries (55%), with fractures or lacerations and fractures requiring hospitalization occurring less frequently (5-10%) (Nevitt, Cummings and Hudes 1991). Much less is known about the injuries incurred by falls experienced by adults with CP. For this group, falls have been reported as less likely to result in minor soft tissue injuries, possibly due to the greater integrity of soft tissue compared to older adults (Morgan and McGinley 2013). However, the rate of serious injuries is equivalent, around 10% (Morgan and McGinley 2013), with fractures and serious lacerations requiring medical attention evident. Furthermore, the functional consequences and outcome of serious injuries in adults with CP may be significant. For example, a fractured wrist may result in an inability to use a gait aid, dress and shower independently, or use a wheelchair for longer distances. It is likely that the consequences of falls in the older adult – fractures, soft tissue injuries, fear of falling, plus costs and resources associated with hospital admissions, carer requirements, rehabilitation and supported accommodation (Watson, Clapperton and Mitchell 2010) – may be similar to those experienced by ambulant adults with CP.

It is recognized that individuals with other neurological conditions and older adults typically reduce their activities as a consequence of a fall (Pieterse et al. 2006). Similarly, older people

who fall frequently implement changes post-fall such as seeking assistance with shopping (Murray, Hill, Phillips and Waterston 2005), or bathing. Adults with CP appear less likely to change their activities as a result of a fall (Morgan and McGinley 2013), possibly due to habituation to long-standing falls, or reduced focus on risk taking behavior.

3.3. Fear of falling

Fear of falling is increasingly recognised as a serious consequence of falls in the healthy older adult. In older adults, falling predicted poorer physical health, greater negative emotions and less physical activity due to self-imposed restriction (Ruthig et al. 2007). For adults ageing with a physical disability, any potential limitation in physical activity is undesirable. Eighty-two percent of adults with multiple sclerosis who reported fear of falling, admit to subsequent physical activity restriction (Peterson, Cho and Finlayson 2007). The Falls Efficacy Scale-International (FES-I) is an instrument to assess level of 'concern' about falling, a term closely related to fear (Yardley et al. 2005), and has been found to be predictive of falls in longitudinal research (Delbaere et al. 2010). Recent research has indicated that moderate fear of falling is experienced by ambulant adults with CP (Opheim et al. 2012; Morgan and McGinley 2013), according to the FES-I, at a level equivalent or higher than that reported in elderly people who were treated for fall related fractures (Nordell, Andreasson, Gall and Thorngren 2009), and ambulant adults with stroke or Parkinson's disease (Faria, Teixeira-Salmela and Nadeau 2009; Allen et al. 2010). Interestingly fear of falling appears not to be related to falls frequency (Morgan and McGinley 2013) or the presence of recent mobility decline in adults with CP. This may reflect longstanding awareness of balance and mobility dysfunction that is different to the more recently acquired balance decline in older adults or those who have acquired health conditions.

3.4. Falls risk assessment

Recommended protocols now exist for the assessment of falls and balance dysfunction in older adults with the inclusion of a battery of objective measures (e.g. timed up and go (TUG), 10 metre walk test), and the use of standardised assessment tools to identify level of falls risk. Performance on these measures can assist prescription of targeted rehabilitation, and imple-mentation of falls risk reduction strategies. Although these tools are not typically used in CP management, they have been extensively used in other older adult and disabled populations to describe and define falls risk (Berg, Wood-Dauphinee, Williams and Gayton 1989; Podsiadlo and Richardson 1991; Russell et al. 2008).

A recent study used the FROP-Com (Falls Risk in Older People – community) risk assessment tool to appraise falls risk in adults with CP (Morgan and McGinley 2013). The FROP-com was developed as a tool to evaluate falls risk in community dwelling older people (Russell et al. 2008). The majority of adults with CP who fell were considered at 'mild risk' of future falls, according to their FROP-com scores (Russell et al. 2008), considerably underestimating their ongoing falls risk. Currently available tools such as the FROP-com, developed to identify multifactorial risk factors typically present in older people such as multiple medications, footwear and continence, appear to lack sensitivity in identifying falls risk factors in adults

with CP. For example, in the study by Morgan and McGinley (Morgan and McGinley 2013), no adults with CP demonstrated problems with footwear, in contrast to 70% of people who fell and 50% of people who did not fall in an elderly cohort (Murray et al. 2005). The evidence to date suggests that ambulant adults with CP who fall do not have higher falls risk factors (as identified by current risk 'tools') than those who do not fall (Morgan and McGinley 2013).

3.5. Interventions to reduce falls risk in adults with CP: An evidence gap

Effective falls prevention has the potential to prevent injury, improve quality of life, and decrease the likelihood of subsequent fear of falling and activity restriction. Published clinical practice guidelines on the prevention of falls in older adults have summarised effective interventions to address single or multifactorial causation. For example, strength and balance re-training, tai chi, medication review and management of Vitamin D deficiency may be advocated to address risk factors in older adults experiencing falls (Campbell and Robertson 2007). Similar interventions have been trialed and evaluated in Parkinson's disease and stroke (Pickering et al. 2007; Batchelor et al. 2012) but not as yet in adults ageing with CP. A systematic review reported that structured exercise programmes may increase habitual physical activity levels in people with CP, however none to date have evaluated the impact on falls (Bania, Dodd and Taylor 2011). Although it is tempting to assume that effective interventions applied to older adults or adults with acquired neurological dysfunction may apply to adults with CP, there is no evidence to support this proposal. Many adults with CP begin to fall, or increase their falling behaviour as a result of age-associated mobility decline. Falls consequences can have significant impact on physical, social and economic outcomes. Current falls risk assessment tools appear to have limited application to adults ageing with CP. Adults with CP who seek health services to address mobility decline are typically not provided with comprehensive falls prevention or falls risk reduction strategies. Practitioners working with adults with CP need to consider falls management as an essential component of care.

4. Common musculoskeletal disorders that impact on mobility

Adults living with CP are at risk of developing or worsening secondary musculoskeletal conditions as they get older. In ambulant adults with CP these secondary conditions often contribute to functional decline, consequently reducing independence with activities of daily living, participation in the community, social interactions and psychological wellbeing. The emergence and changing nature of secondary musculoskeletal conditions reflects the contemporary recognition of CP as a condition in which the brain lesion itself is static and non-progressive but accompanied by secondary musculoskeletal problems, which typically *do progress*. The functional impact of CP therefore can be changing and dynamic across the lifespan, and thus evidence based knowledge to develop and evaluate interventions that limit or prevent secondary health conditions are urgently needed. Some of the most commonly reported musculoskeletal conditions include pain, osteoarthritis and fatigue. Specific evidence of the prevalence and impact of these and other musculoskeletal symptoms is gradually building, yet currently limited in detail, often poorly differentiates between adults who are

ambulant and those who are more functionally impaired, and remains primarily based upon cross-sectional samples of convenience.

Pain is very common in the lifelong experience of living with CP, with estimates of prevalence of any type or site of pain ranging to over 80% (Turk, Geremski, Rosenbaum and Weber 1997; Schwartz, Engel and Jensen 1999; Jahnsen, Villien, Stangelle and Holm 2004). Acute and chronic pain both occur, with reportedly nearly one third of adults with CP incurring chronic pain (Jahnsen et al. 2004). Pain is the most consistent musculoskeletal disorder reported by adults living with CP (Turk et al. 1997) and is proposed to be directly linked to age and increased inactivity (Vogtle 2009), with deterioration of functional skills found to be significantly associated with chronic pain (Jahnsen et al. 2004). Notably, pain was also the physical symptom most frequently associated with CP by a survey of rehabilitation physicians (Hilberink et al. 2007). Reported pain locations varied widely but commonly include the back and neck, along with the hips, knees and feet. Pain often affects multiple body areas, with a large longitudinal study finding that it was typical to experience pain at multiple sites, with a median of three locations identified (Opheim, Jahnsen, Olsson and Stanghelle 2011). Pain was reported by many individuals to be worsened by overexertion and fatigue and improved by rest, physiotherapy, or participation in exercise (Schwartz et al. 1999; Jahnsen et al. 2004; Opheim et al. 2011).

The relationship between pain presence, location and an individual's level of function is not yet well understood, although data from two studies suggests no association between pain and GMFCS level (Sandstrom, Alinder and Oberg 2004; Hilberink et al. 2007). This may be expected as it is likely that many individuals experience pain, but perhaps due to different profiles of physical symptoms. For example, back pain may be related to a severe postural deformity or scoliosis in a non-ambulant person, or to excessive movement and joint load in an ambulant person. Adults with CP who walk tend to have excessive pelvic tilt and a larger range of lumbar rotation during gait, which is likely to contribute to or possibly exacerbate low back pain, potentially leading to lumbar spondylolysis (Harada et al. 1993; Opheim et al. 2011). The accumulating toll of weight bearing on joints with abnormal alignment, including cavus feet, knee deformities and displaced hips can in the long term also lead to the onset of pain in the affected joints during ambulation. In unilateral CP, it is also suggested that asymmetry in motor control could lead to overuse of the non affected side, ineffective recruitment of available muscles and asymmetrical joint loading further contributing to back pain (Opheim et al. 2011). Of interest, however, a study by Opheim and colleagues (Opheim et al. 2011) did not find there to be a correlation between the number of pain sites and psychological health in this population. This may be reflective of life long experience of pain from childhood onwards, possibly resulting in better coping strategies in comparison to general public.

Other musculoskeletal disorders in adults with CP can be classified as deformities and they too have the potential to impact on an individual's ability to walk. Relatively common musculoskeletal deformities include subluxations or dislocations of the hip, structural abnormalities of the foot/feet, patella alta, pelvic asymmetry/obliquity and contractures of various muscle groups (Gajdosik and Cicirello 2001). Hip subluxation or dislocation is an

acquired condition resulting from muscle imbalance, persistent bony mal-alignment and altered patterns of weightbearing, affecting an estimated 18% to 59% of individuals with CP (Root 2009). It is unknown what proportion of adults with CP who walk have abnormal hip joint structure, but it is well recognised as a common factor causing many adults to stop walking due to the development of painful joint degeneration. A number of small case series studies have emerged that outline surgical interventions for hip joint misalignment and degeneration, with individuals reporting improved pain and walking function after surgery (Root 2009; Shroeder et al. 2009). A follow up study of 16 ambulatory adults 10 years after hip arthroplasty found that this surgery can provide long-term pain relief and improved function, albeit with a higher complication rate than in non-CP individuals (Shroeder et al. 2009). Patella alta is another relatively common condition in ambulatory adults with CP, often associated with longstanding anterior knee pain or a crouch gait pattern. Stress fractures and pain can occur due to the underdeveloped and poorly aligned patella, in conjunction with altered tendon structure. Surgical interventions including distal femoral extension osteotomy and patella tendon surgery are now common during adolescence (Novacheck, Stout, Gage and Schwartz 2009), but the long term outcomes of such interventions in adulthood are unknown.

Osteoarthritis is also a common cause of pain for patients with CP and typically has an earlier onset in this population group when compared to the non CP population (Gajdosik and Cicirello 2001). It is thought that the altered joint loading patterns in childhood due to delayed weight bearing and altered muscle activity can lead to poor joint integrity and irreversible damage to the articular cartilage of the joint surface, consequently developing early onset OA, predominantly seen in the hip, knee and feet (Carter and Tse 2009). No large sample population data exists to indicate how common OA is, and who is affected. It is likely that the joint distributions and severity of OA may vary between ambulant and non-ambulant adults, and may also relate to the movement disorder type. Some studies report the incidence of hip OA to be as high as in 59% of non-ambulant adults living with CP (Boldingh et al. 2005). Individuals with more severe CP are thought to develop OA at a higher rate, as reduced weight-bearing and restricted range of motion does not provide sufficient cyclic loads to different areas of the hip that is needed to maintain cartilage (Carter and Tse 2009). Another study found clinical evidence of OA in 27% of young adults with CP between the age of 15 and 25, occurring more commonly in those who could walk (Cathels and Reddihough 1993). Population based studies to investigate the occurrence of OA with radiological confirmation are needed to determine the prevalence of this common debilitating secondary condition.

Fatigue is also common in adults with CP and potentially associated with both decline in walking or adoption of alternate mobility choices. Adults with CP reported significantly more physical fatigue than the general population, with fatigue levels associated with pain and deterioration of functional skills (Jahnsen, Villien, Stangelle and Holm 2003). In a recent study of mostly ambulant adults with CP, 20% of the sample was fatigued and a further 41% were severely fatigued (Van der Slot et al. 2012). Of concern, there was a high prevalence and relatively frequent co-occurrence of chronic pain, fatigue, and depressive symptoms (Van der Slot et al. 2012).
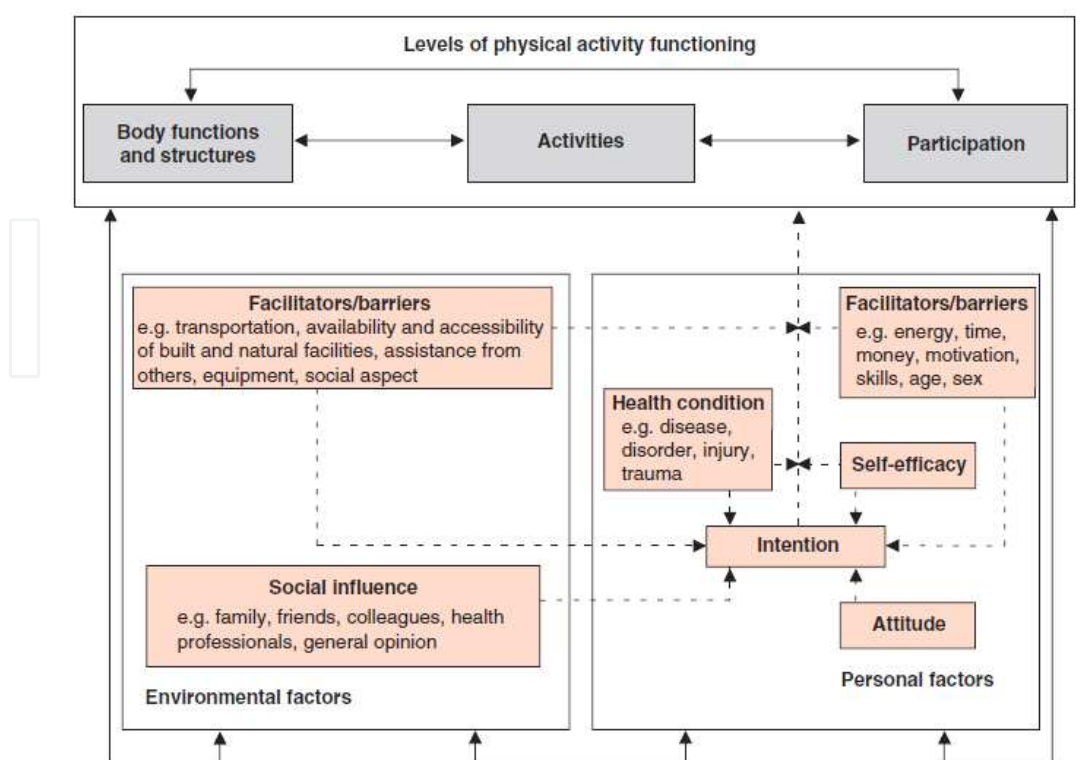
5. Physical activity

Physical activity is important for health and wellbeing across the lifespan and is an important part of healthy aging. Strong evidence has linked participation in regular moderate-intensity physical activity to a wide range of health and social benefits. Physical activity is particularly important for those living with a chronic disability such as CP, in order to maintain long term health and to prevent secondary complications of disability. Chronic conditions that cause mobility problems are known to place individuals at greater risk of inactivity (Ashe, Miller, Eng and Noreau 2009) increasing the likelihood of developing long-term negative health consequences such as cardiovascular disease or poor bone density (Carlon, Taylor, Dodd and Shields 2013). As individuals with CP age and become less active, they may also be at greater risk of lifestyle-related diseases, such as diabetes mellitus or obesity. Encouraging physical activity (PA) is important for health promotion, and may have beneficial effects on secondary conditions and on functional independence, social integration, and well being (Buffart et al. 2009).

Being active across the life span can pose additional challenges for those with physical disability. Evidence has shown that children with CP engage in significantly lower levels of habitual physical activity than their peers, and less than recommended guidelines (Carlon et al. 2013). Relatively few studies have examined physical activity of adults with CP. Most studies suggest that this group have lower levels of physical fitness and are less active than able bodied peers (Nieuwenhuijsen et al. 2011), with the exception perhaps of those with mild unilateral deficits (van der Slot et al. 2007). Data from a larger study by Jahnsen et al (Jahnsen et al. 2003) also suggests that physical activity may decline over time, with many inactive individuals reporting a reduction/cessation of physical activity over recent years. Those who were physically active were found to demonstrate a reduction in risk of mobility decline, with deterioration in gait associated with higher odds ratio for inactivity (Maltais, Dumas, Boucher and Richards 2010). Of particular interest, a recent systematic review found preliminary evidence suggesting that exercise and online support programmes can increase habitual physical activity in people with CP (Bania et al. 2011).

The determinants of regular physical activity in this group have not been well defined. To describe factors associated with PA in people with a physical disability, van der Ploeg et al. (van der Ploeg, van der Beek, van der Woude and van Mechelen 2004) proposed the Physical Activity for People with a Disability (PAD) model (Figure 3). This model explicitly considers the determinants of physical activity within the context of the environmental factors and personal factor components of the International Classification of Function model. The PAD model highlights the importance of social influence and environmental barriers and facilitators, including factors such as support and opinions of family, friends and healthcare professionals, and transport, access and assistance provision where needed. Within the personal factors component, key behavioural factors such as self-efficacy, intention and attitude are considered, in conjunction with the health condition. This framework is highly relevant to adults with CP, but as yet the determinants have not yet been explored in a comprehensive nor systematic manner.

Figure 3. The Physical Activity for people with a disability (PAD) model; Van der Ploeg et al. 2004 [reproduced with permission]

Limited knowledge has identified some factors that inform factors within the PAD model. Jahnsen et al found that age and mildness of severity were significantly associated with regular physical activity (Jahnsen et al. 2003). Of particular interest, the strongest predictor of physical activity was a factor called "learnt personal responsibility for personal health". The most frequently reported motivational factor in relation to physical activity was improvement or preservation of health, and the most frequently reported reason for not being physically active was lack of initiative and motivation (Jahnsen et al. 2003). Some knowledge is also available from a wider study of young people with a range of physical disabilities including CP, suggesting that barriers to physical activity included attitude and motivation. In addition, lack of energy, existing injury or fear of new injuries, limited physical activity facilities, and lack of information appeared to be barriers. Facilitators of engagement in PA included fun and social contacts, as well as improved health and fitness (Buffart et al. 2009). Further detailed studies are needed to identify and explore the range of personal and environmental factors that influence PA in adults with CP.

6. Health care services for adults with Cerebral Palsy

Adults with chronic but changing health conditions such as CP require access to appropriate health services across the lifespan, to provide support to individuals to optimize function and

health related quality of life. Health promotion is defined as 'activities directed toward increasing the level of well-being and actualizing the health potential of individuals, families, communities and societies' (Pender 1987). Health promoting behaviours, in contrast to disease management strategies, may be ongoing activities that become an integral part of one's life such as physical exercise, nutritional eating, stress management, stopping smoking. Absence of illness or disability is not a pre requisite for health; therefore individuals living with a disability can be considered 'healthy'. Of concern, health care providers may perceive that people with disabilities are 'sick', contributing to people with disabilities thinking of them-selves as passive participants in their own health care, rather than as individuals responsible for, and contributing to, their well-being. In a more collaborative model of rehabilitation, a partnership paradigm is advocated where the clinician has expertise regarding disability management and the care-seeker (e.g. adult with CP) has expertise about their own life. This is consistent with components of broader approaches of models of care to support self management in those who live with chronic disease or chronic health conditions (Bodenheim-er, Wagner and Grumbach 2002). This approach emphasizes self care, and promotes an active, independent and informed attitude towards lifelong rehabilitation. This direction is consistent with a shift from a focus on a 'medical' to a 'participation' model.

6.1. Lifelong access to expert health care

Adults with CP may experience both diagnosis-related and ageing-related health consequen-ces (Svien, Berg and Stephenson 2008; Peterson, Gordon and Hurvitz 2013). As described earlier in this Chapter, many adults with CP experience new onset of symptoms such as muscle fatigue and weakness, pain, spasticity and contracture, joint dislocation or skin breakdown. Relative inactivity can result in further health related concerns such as premature sarcopenia and obesity (Peterson et al. 2013). Furthermore, adults with CP may experience psychosocial issues, as well as secondary biomedical concerns, related to their disability (Horsman, Suto, Dudgeon and Harris 2010). Medical management for co-morbidities can also result in health concerns. For example, some medications to treat epilepsy can cause osteopenia. The incidence of other diseases in adults with CP is also acknowledged to be higher than age matched comparisons; e.g. an increased incidence of cancer, chronic obstructive airways disease, pneumonia, and bowel obstruction. It has been suggested that a decreased verbal ability to convey symptoms and a reduced tendency to access regular health screening may contribute to the rise in disease incidence in this population (Svien et al. 2008). Adults with disabilities such as CP need lifelong, but not necessarily continuous, access to health and rehabilitation services to meet their changing needs and enable them to make informed choices to address any health problems that arise (Field, Scheinberg and Cruickshank 2010).

6.2. Transition from paediatric to adult health services

In the childhood of an individual with CP, there is often a supportive health facility and/or therapy organization, which is readily accessible and staffed with competent professionals. It is usual for children with CP and their families to frequently have long relationships with their therapists and medical team, who are knowledgeable and dedicated to providing services for

children with CP. Although some children may become less engaged with the requirement for ongoing physiotherapy and rehabilitation services throughout adolescence, there are still a range of functional activity options available, and ready access to rehabilitation professionals as and when required.

For an adult with CP who seeks health services, it is not immediately obvious where to turn. As a result, many young adults with CP experience a 'vacuum' after leaving paediatric rehabilitation (Ng, Dinesh, Tay and Lee 2003). A lack of adequate care, together with changes in social role and in environmental expectations as they grow into adulthood, may result in unmet (health) needs of adults with physical disabilities (Ng et al. 2003). Over the last ten years or so, 'transition clinics' have been established in many countries in an attempt to bridge the gap between paediatric and adult services. Most commonly, these clinics cater for those with chronic illness or disability in the 16 to 25 age group. A variety of literature has described the optimal design of these transition services to provide adult health care for adolescents and young adults with disability, such as adequate preparation, flexible timing, care coordination, transition clinic visits, and interested adult-centred health care providers (Binks, Barden, Burke and Young 2007). The importance of an adult system that includes multidisciplinary teams that are central to the care of people with CP and other lifelong health conditions is also stressed (Bakheit et al. 2009; Field et al. 2010) with evidence that a team approach is more likely to enhance participation in society of young people with physical disabilities (Bent et al. 2002).

6.3. Challenges in accessing adult health services

Despite this knowledge, specialized health services for adults with CP are widely reported to be extremely limited (Bent et al. 2002; Ng et al. 2003; Field et al. 2010), and despite an increase in funding of transition services (Field et al. 2010), remain fragmented and challenging to navigate. The health care services that are publicly accessible to most adults with a chronic disability are frequently limited in scope, or perceived by users as inadequate and staffed by practitioners with limited knowledge and skills in disability care (Sandstrom 2007). A common experience by adults with CP is frustration with health service type and availability, facility access, staff turnover, and lack of engagement with their needs. With an attempt to increase access by driving disability services into 'community accessible models' (such as dieticians and therapists within the community health sector), the development of experience and expertise in disability by health practitioners has been limited. For example, a paediatric physiotherapist may have an exclusive caseload of children with CP with mentoring and advice readily available from colleagues within a specialist tertiary paediatric hospital, a defined career pathway within the health service, and access to professional development within the paediatric disability area. In contrast, a physiotherapist working in a community health centre may provide services to a wide variety of adults ranging from those post fracture or knee replacement, to elderly people post fall, to those recovering from stroke, and only see a few adults with CP each year. Knowledge of who are the 'experts' in management of adults with CP, and hence who to seek advice from, is frequently unclear both to adults with CP and the health practitioner community.

Health services for adults with developmental disability are frequently accessed and provided in an ad-hoc manner by many different organisations each with their own criteria for defining who receives health services and support and the nature of any services and support provided. Adults with CP reportedly use specialty health-care and rehabilitation services less, and emergency room care more, than their non-CP peers (Tosi et al. 2009). Anecdotally, adults with CP who present to their general medical practitioner (GP) following a fall may be referred to 'geriatric' (>65 years) services such as Falls and Balance Clinics as their GP cannot identify where alternate suitable services may be located. Tosi and colleagues (Tosi et al. 2009) reported that few medical facilities are prepared to treat adults with developmental disabilities, and adults with CP needing surgery may find themselves in paediatric environments, where personnel have not been trained in adult care. As a result, overall care is often fragmented and does not address the complex physical and psychosocial issues of adults with CP with any continuity. Horsmann and colleagues (Horsman et al. 2010) reported that decisions regarding allocation of health and support services to those living with CP are often flawed, as such decisions are viewed from an exclusively medical model rather than a participation model. For example most self-assessments by adults with disabilities identified taking part in leisure activities as a priority (participation model) whereas most social service agency assessments considered only basic health needs (medical model) when determining eligibility for hired caregivers (Horsman et al. 2010). As a result, adults with CP may be provided with unwanted or unsuitable health and support services.

6.4. An ideal model for health service delivery for rehabilitation

Effective service development for rehabilitation for adults with CP at any age requires a detailed knowledge of the likely health issues experienced by this population across the lifespan and a robust evidence base upon which to base recommendations and management. Goldstein, Chairman of the Cerebral Palsy International Research Foundation, in 2009 urged a move to a system of health services to maximise life-long functioning of people with disabilities rather than to just a new health care environment. Reddihough and colleagues (Reddihough et al. 2013) however are hopeful that the introduction of a National Disability Insurance Scheme in Australia will assist in improving the physical and social outcomes of adults with CP in this country. The scheme aims to optimise opportunities for people with disabilities to participate in the social and economic life of the community. People with disabilities will be empowered to use their own funding packages to purchase the equipment and associated therapy they require for optimal independent function and participation, while health services will be required to provide therapy that responds to health concerns and needs. However, in order to achieve a seamless rehabilitation service across the lifespan of disability, health practitioners urgently require upskilling and training to be able to deliver evidence based interventions for adults with CP experiencing functional and mobility decline at any age. Furthermore, adults with CP require information in order to make informed choices about health interventions.

Ambulant adults with CP have ongoing health needs to address age-related changes associated with their disability. Despite a growing body of evidence describing persistent unmet health

needs experienced by adults with CP little appears to have changed regarding this issue. Adults with CP continue to report frustration with service type and availability, facility access, staff knowledge and skills, staff turnover, and lack of engagement with their needs. A more effective, equitable and accessible system of health care for this population is urgently needed.

6.5. Summary

Many adults with CP face challenges with declining mobility and the emergence of secondary musculoskeletal conditions as they age. Decline in walking and falls are common, potentially comprising activity, participation and health-related quality of life. Carefully constructed longitudinal studies of population-based samples are needed to evaluate and characterise the prevalence and impact of mobility decline. Evidence to guide clinical practice is currently extremely sparse. CP-specific interventions to address mobility decline and falls need to be developed and evaluated in rigorous randomised controlled trials. Similarly, the development of interventions for the secondary conditions of OA, pain, fatigue and reduced physical activity warrant similar consideration. Current healthcare services for adults with CP currently lack the evidence-based knowledge needed to develop and implement best practice clinical guidelines.

Acknowledgements

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