Ageing with a lifelong condition: The experiences and perception of older people with cerebral palsy.

Kevin Paterson and Nick Watson

Strathclyde Centre for Disability Research
Institute for Health and Wellbeing
University of Glasgow
Glasgow
G12 8RT
Contents

Introduction .................................................................................................................. 3

Methodology .............................................................................................................. 5
  Research framework ............................................................................................... 5
  Ethics/consent ........................................................................................................ 5
  Recruitment and sample ......................................................................................... 5
  Interviews .............................................................................................................. 6
  Analysis .................................................................................................................. 7

Findings .................................................................................................................... 8
  Demographic data .................................................................................................. 8
  The impact of ageing .............................................................................................. 9
  Growing older with CP .......................................................................................... 10

Ageing With Cerebral Palsy: Support and Care ......................................................... 16
  Meeting the changing needs of older people with CP ......................................... 16

Ageing with Cerebral palsy: The role of medical and health professionals .................. 20
  The views of the therapists .................................................................................... 20
  The views of the rehabilitation consultants ....................................................... 22

Closing Comments .................................................................................................. 23
Introduction

The last twenty years or so have seen significant changes for disabled people in general and for people with cerebral palsy (CP) in particular. People with CP previously would have spent much of their lives living in institutions and had little or no contact with mainstream health and social care services, especially services for the care of older people. This is now all changing and people with CP are now living much longer than they did in the past\(^1\). Before the 1950s, few people with CP survived to adulthood, now 65% to 90% of children with CP survive and have a normal life expectancy. Policy changes such the closure of long-stay hospitals, community care and the Self-Directed Support agenda has meant that people with CP are ageing in the community and bringing new needs and wants to service provision.\(^2\).

We currently know very little about what it means to age with CP, how growing older with CP affects people physically, what it is that they want in terms of their social care and support or what it is that is important to them\(^3\). CP is traditionally viewed as a “static”, childhood condition and services and research are based on this\(^4\). Services for people with CP are mainly aimed at children and focus on habilitation rather than rehabilitation. In this research report, based on a project that was commissioned by Capability Scotland and funded by the RS Macdonald Trust we aim to rectify that gap and to explore the experiences of older people with CP and their families and to identify what is important to them.

What we do know about the experience of ageing with CP is that whilst people with the condition age in the same way as non-disabled people (primary ageing), they can also experience accelerated secondary ageing due to the effects of living with a lifelong condition which can bring a range of health and musculoskeletal problems\(^5\). We also know that when people with CP reach adulthood there is a near absence of services for them to access\(^6\). Although there are a range of pediatric services available, there is a lack of knowledge about CP in adulthood among health and social care practitioners\(^7\).

---


The chronic failures of the UK health and social care system in meeting the needs and requirements of an ageing population is well documented. When it comes to serving people ageing with lifelong impairments, the system has even greater failings. Health and social care provision is organised on the basis of distinct “client groups” - services for older people were not initially designed with those ageing with lifelong conditions in mind and those for disabled people were not designed to address issues of ageing - and so when disabled people are “in transition” from one age to another cracks both within and across services become evident.

This project was carried out because the majority of work about ageing with a lifelong impairment and the little research done on ageing with CP originates from outside the UK in North America, Australia and Scandinavia. We need more research into ageing with CP and we need to know about its experience in the UK, and more specifically in Scotland. Do people ageing with CP and other lifelong conditions in Scotland recognise much of the evidence from the literature? The changing policy context, with an increased emphasis on rights and inclusion, ageing in place and anticipatory services, suggests a new approach to older disabled people. We want to hear the views and experiences of older people with CP in the context of present budget realities, the Personalisation service model, Self-Directed Support and the Reshaping Care for Older People agenda.

This research aims to identify the barriers to effective participation as perceived by older people with CP, and ways of overcoming these barriers; identify the health and social care services currently provided for older people with CP; document the kinds and level of support services which older people with CP believe would most effectively meet their needs; ascertain positive experiences of health and social care provision and provide evidence of good practice; document views of service providers and policy makers on the provision for older people with CP; and identify barriers to the provision of services and exploring possibilities for securing additional resources.

---


Methodology

Research framework

The research draws on a life course perspective as it provides a theoretical framework for understanding the influences - individual and environmental - that shape life experience, encompassing agency, identity formation and adaptation over time. A life course approach highlights the multi-layered social contexts in which disabled people live and age, ranging from immediate micro level of family and friends, the meso level of service organisation and provision to the macro level of politics and policy-making that shape personal biographies, and the meanings that individuals ascribe to significant life events and transitions.10

The voices of people ageing with CP were central to this project. Disabled people are experts about their own lives and through documenting their views and feelings and placing those at the centre of the research we were able to explore their experiences of ageing with CP and identify the factors and processes that promote or hinder their social inclusion, how they feel their needs are being met and the extent to which they are receiving the necessary services. These experiences were contextualised with interviews with health and social care providers and practitioners, allowing personal experience to be set within wider professional discourse and practice.

Ethics/consent

Ethical approval was sought and gained from the School of Social and Political Science’s Ethics Committee at the University of Glasgow. All research participants were provided with full information about the nature of the study and what taking part would involve. Informed consent was sought from all participants. Participants were told that they had the right to withdraw from the project at any time without giving a reason.

Recruitment and sample

People with CP

In total, 26 people with CP - 14 men and 12 women - were recruited and interviewed for the research. Recruitment took place through Capability Scotland, CILs, network contacts and snowballing. Individuals were sought who were 55 years old and over. There has been considerable debate about when the ageing process ‘begins’, and whether it starts earlier for disabled people. To try and clarify this, the Department of Health (2001) stated that it should be assumed to start earlier, at around 50 years old, particularly in terms of people with the learning difficulties. There are issues specific to people with Down’s syndrome, in particular their susceptibility to dementia. To address this, the Joint Lothian Older Adults with Learning Disability Group have included adults with learning difficulties over 50 years old and adults with Down’s syndrome over 40 years old.

The participants represent the diverse experiences of people ageing with CP across Scotland. Ages range from 55 to 70+ years old, apart from one participant who is 46 years old. We opted to interview the younger individual because she had recently chosen to live in a care home and she was also keen to participate in the research along with her companions. Participants are single, in relationships, widowed, divorced and are parents and grandparents. Some live in urban areas whilst others live in more rural locations. 11 individuals live in care homes, 3 individuals employ their own support and 12 individuals have previously worked. Some are former long-stay hospital patients, while others have lived in the community all their lives. Some have formal support, while others rely on informal support or none at all.

Health and social care providers and practitioners

The views of people ageing with CP were supplemented with those of health and social care providers and practitioners: Local Authorities, rehabilitation consultants and physiotherapists. All 32 Local Authorities in Scotland were contacted by letter and asked how they were approaching the issue of increasing life expectancy of disabled people, whether they recorded numbers of older people with a lifelong condition (in particular CP) and have they, or are they intending to, implement procedures/polices in relation to this. 18 Local Authorities replied to the letter, providing a variety of responses and detail. A second letter was sent out to those Local Authorities who did not reply to the initial letter. Those Local Authorities who supplied information were contacted to request a telephone interview with the relevant persons about provision for older people with lifelong conditions and 10 interviews were conducted. These included a Manager of Social Care and Health, a Senior Manager of Community Care Locality Services, a Strategic Planning and Commissioning Officer (Physical & Complex Disabilities), a Manager of Adults and Community Care Services, a Senior Planning Officer, a Service Manager of Older Adult Services, a Service Manager of Care Management Social Care and Wellbeing and 2 Association of Directors of Social Work representatives.

Rehabilitation Consultants were contacted across Scotland to request an interview about ageing with CP and 1 face-to-face interview and 3 telephone interviews were conducted. (Neuro) Physiotherapists were contacted across Scotland to request an interview about ageing with CP and 4 telephone interviews were conducted.

Interviews

Interviews with people with CP were semi-structured and took place where they lived. Interviews were designed to be flexible to allow for the insights derived from ongoing analysis. Broad themes were covered with each participant, but they were able to focus on those issues that they saw as the most important. Participants were encouraged to discuss their past and present lives, their thoughts about growing older, the help that they received now and in the past, how they felt about the services and support they received and how they thought health and social care provision could be improved. Individuals were active participants in the research process, shaping both the content and direction of the research as they identify practices, processes and places which are important to them.
Interviews with health and social care providers and practitioners were also semi-structured and were designed to be flexible to allow for the insights derived from ongoing analysis. Informants were asked about their awareness of increasing numbers of older people with lifelong conditions, the services they provided to disabled people as they age, the implementation of new procedures/policies and the development of health and social care provision.

**Analysis**

Transcribed interviews were analysed using a thematic approach. Data was categorised into a series of themes and sub-themes identifying issues and topics of particular importance to participants.
Findings

Demographic data -

At the outset of this project one of our aims was to try and quantify the number of older people with CP living in Scotland. There is, unfortunately no national data base that can answer this question and neither do Local Authorities or Health Boards routinely collect such data. All the Local Authorities we contacted reported that they felt that there had been an increase in number of older people with CP but none were able to back up these claims with figures. Interviews with Local Authorities and responses to questions we sent to them at the outset of the project suggest that whilst this is a recognised area of need and that they are aware of increased numbers of older people with lifelong conditions this is based on anecdotal rather than quantifiable data. When representatives from the Local Authorities were asked to justify this claim some referred to statistics drawn from the Scottish Consortium for Learning Disability’s database eSAY, the latest version of which reports that since 2003 the number of people with a learning disability in Scotland has increased from 1,777 to 2,419. However, whilst these figures suggest a general trend they relate solely to people with a learning disability and do not include people with CP.

The message from health and medical professionals was more mixed. One therapist claimed that he now saw double the number of people ageing with CP that he saw 10 years ago and he estimated that he was now seeing 24 such people per year. Another therapist felt that there had been no increase such referrals and reported only seeing 22 people ageing with CP in the last 8 years. Medical professionals were also divided on this issue, with some claiming that the number had increased and others feeling that it had remained static over the years.

In the next sections we draw on our interviews with older people with CP, with health and medical professionals and with representatives from social care and local authorities as we discuss what it is like growing older with CP. We start with a discussion on the physical aspect of ageing and then move on to look at how ageing with CP affects medical and social care and support.

**The Impact of ageing:**

In this first data section we examine what our research participants had to say about the experience of ageing from a physical perspective. We explore people’s views on both primary ageing, that is the gradual and inescapable process of bodily deterioration that takes place throughout life and secondary ageing, the process that results from the impact of living with a condition\(^{12}\). As we stated earlier, much of the research to date has focussed on biomedical changes and the physical effects of ageing with CP\(^{13}\). In contrast to that earlier work we, where appropriate, explore how some of the physical changes experienced by those we spoke to impacted on their psycho-emotional and social wellbeing and how their social environment interacted with the ageing process.

The first key point we wish to make is that as people age their condition and the level or extent of their impairment changes and that changes associated with secondary ageing are a very important and significant part of growing older with CP. They affect their lives in a number of ways and people experienced a change in what it is that they could and could not do:

> Everything just gets harder as you get older and I’m getting pains in my legs that I never had. Now I might turn and it’s like a cramp just for about 5 or 10 seconds but it kind of stops you in your tracks you know, even just turning and I’ve obviously pulled a muscle or something and things like that but it does definitely get harder and my energy levels are not as good,

There is evidence that the physical changes associated with secondary ageing experienced by people ageing with CP are unanticipated by individuals, their family and the medical profession and that this can lead to a period of anxiety and stress. People are unprepared for the secondary effects of ageing with CP and there is a general lack of knowledge about the process.

While people with a lifelong condition experience primary ageing in the same way as their non-disabled peers, lifelong musculoskeletal disuse or overuse by people with CP can mean that they experience a range of other symptoms such as pain, osteoarthritis, muscle tightness, joint problems and fatigue. As Gordon neatly put it

> We wear out quicker. There’s no doubt about it.

Ageing was not just physical but also psychological and it affected people’s ability to concentrate:

> I’m slowing down these days and my concentration is weakening and that annoys me greatly. (Walter)


It is clear that Cerebral Palsy is, contrary to popular belief, not a static condition, it is a condition that changes and these changes can, for some be dramatic. CP is a long term, lifelong, condition yet it is the static or non-progressive element of the description that has dominated both professional and lay knowledge about CP. The injury to the brain may be non-progressive, but the musculoskeletal effects of the condition on an individual are not fixed over the life course and can change as the individual ages. Traditionally, CP has been considered a childhood condition which required therapeutic and other medical and social intervention and there are a range of health and social services available for children with CP until they reach eighteen years old. After this period of habilitation, individuals with the condition are thought to be ‘finished’ with therapy (as their condition is static) and hence a similar range of rehabilitation services for adults is not in place. CP in adulthood is, according to many of those we spoke to, a “Cinderella” issue among health care practitioners and social care providers. There are only very few health and social support services available to people ageing with CP and there are few if any dedicated solely to their needs.

This leads us to the second key point we wish to make in this respect which is that problems associated with ageing with CP are not widely recognised and that support services are neither aware of nor do not plan for the consequences of CP as a long term condition. For many of those we spoke to this was the first time they had been asked what it was like to age with CP and how it was affecting them both in terms of their physical needs and their social needs. Few if any health or social care professionals had approached them about the subject. So one of the few professionals we spoke to who recognised this told us:

*I think that cerebral palsy, in general, in health perspective is just viewed as a static condition and you either have it or you don’t… you’re not unwell with it… unless you have profound disability and there might be a risk of infections but… but even, my neurology colleagues were not really aware of this.*

Consultant neurologist.

These two factors combine and reinforce each other and the outcome is that services for older people with CP are neither appropriate nor are they helping to meet their needs. These two key findings frame this research report and are central to the experience of growing older with CP.

**Growing older with CP**

Far from being a stable condition and one that disappeared after they reached the age of eighteen, which is, our research would suggest, how services view the condition, the effects of CP are constantly changing and this is a process that increases as people age. As people got older they started to use a range of assistive devices, including wheelchairs, walkers, crutches and other mobility aids, and they required more assistance in performing activities associated with daily living. These “ageing effects” are central to the physical experience of ageing for people with CP - they are, for some, the drivers of the ageing experience.
Our research participants spoke about the following physical changes that they associated with ageing with CP:

**Physical**

- Walking and balance issues;
- Using a wheelchair full time;
- Using crutches / rollator;
- Increased tiredness;
- Weight bearing issues;
- Musculoskeletal problems, eg. muscle stiffness / tightening, shoulder, hip and knee problems, brittle bones;
- Pain;
- Bladder problems;
- Osteoporosis;
- Changes in ability to use speech and language and becoming a user of Augmentative and Alternative Communication (AAC);
- Cellulitis;
- Hypertrophic spondylitis;

Whilst people could not ignore these changes that they were experiencing and the new barriers they faced it is important to point out that they were not always overwhelmed by them and that many people were leading happy and successful lives. They may have been irritated, unhappy, frustrated about both the physical changes associated with ageing and the lack of appropriate support, but they were still, in the main, happy and very active socially.

These physical changes were accompanied by a range of social changes, including:

**Social**

- Feeling more vulnerable.
- Being less able to manage tasks without assistance;
- Finding tasks take longer and use more energy to complete;
- Decreased concentration;
- Risk of falling when transferring;
- Requiring assistance into bed via a hoist;

Several of those we spoke to talked about what they saw as the similarities that they felt existed between what they were experiencing as they grew older with CP and post-polio syndrome. They also talked about how there is much more recognition about the effects of post-polio, of ageing with polio and the extensive range of services available to people living with the effects of polio. We were told for example that there is an online register which you can look up of consultants and other health service professionals who have an interest in post-polio, whereas in contrast acquiring information about consultants in Scotland who have an interest in ageing with CP is extremely difficult. We were told how even where people had
directly contacted charities and organisations that work with people with CP they had been told that there were no such services and did not receive any advice.

**Change in mobility**

Changes in mobility – specifically walking and balance – was a recurrent theme in the research. Most of those we spoke to who could in the past walk and had some ability to stand now no longer could. Carrying out physical tasks and activities had become more difficult as they aged and required more time and took more energy to perform. Falling over became much more of a frequent and grave occurrence for people and now when they fell it was much more serious problem. Not only were they more likely to break bones but even when serious injury did not result it was difficult to get straight back up off the floor as they had done when they were younger.

These changes were perhaps to be expected, what was most surprising was the age at which these changes occurred. When we initially planned this research we decided to interview people aged 55 and over, following advice from the Department of Health and Lothian Health Board\(^\text{14}\) on how best to define older people with a lifelong condition. We expected that by selecting this age range we would be able to talk to people as they were going through the physical changes associated with ageing. What we found was that for most people these changes had already begun to happen some time ago, and they told us that they had started noticing differences in their capacity by their mid thirties and that it was during their forties and into their fifties that the most significant changes took place. Physiotherapists said that individuals with CP who came to see them with musculoskeletal problems were typically in their thirties, forties and fifties and the average age was between 35 and 45 years old. There are of course exceptions at both ends of this age range. This is discussed more fully in the section on health care professionals below.

The one change that people were usually able to pinpoint was the time when they began using a wheelchair full time or other mobility aid and the circumstances that led up to this transition. For some it was a gradual change in walking and balance which led to a point where their mobility was being compromised to such an extent that using a wheelchair or mobility aid was the only solution. As Robert told us:

> *I was falling all over the place; my walking was really getting bad…, so I ended up in a wheelchair…*

Evelyn described a similar pattern:

> *I noticed I was getting worse about 12, 13 years ago and I just kept carrying on but I knew myself I would really need to address it and then I kept falling and then the fear of falling, you know like getting up and down a high pavement, even now with crutches it’s still difficult if there’s no dip that you can get, even with the crutches it is difficult but on my own, without them now it would be impossible.*

\(^{14}\) Joint Lothian Learning Disability Strategy Review 2007
For others, the transition to using a wheelchair was more rapid, occurring either as the result of an illness, a fall and/or a stay in hospital. Calum, for example described how roughly 11 years ago he just woke one morning and was unable to walk, the result of what he believed to be a virus. He says that, at the time, it was very hard to get additional help or therapy and that this impacted on his wife and his family and they all had to provide him with more help and support, including his young children. This upset him greatly. Derek talked about losing his ability to walk following a fall which resulted in a badly fractured femur and a damaged hip joint. Olive described how, up until four years ago she could still walk using walking sticks but during a three month stay in hospital because of problems with her feet and toes she lost the ability to walk, an event she described as “….just one of these things I suppose...”.

Whilst many of those we spoke to talked about the different ways that they lost the ability to walk all shared one similar experience, a lack of services or therapy to help them try and regain the ability to walk or to keep walking before they reached a crisis point. They were all told that they should walk and that walking was much better for them in terms of their health but they did not receive the practical help, advice and therapy to do so.

It is however important to point out that whilst many people expressed concern at losing the ability to walk and felt that the shift to a wheelchair was a major problem others, on reflection, were more sanguine about the outcome. People talked about how much safer they felt and that the use of mobility aids, rather than restricting their opportunities actually enhanced them. As Walter argues:

> But it was a blessing in disguise. When I did walk with a walking aid, I couldn't go for a pleasurable stroll, too tiresome. But now I thoroughly enjoy getting around on my motorised wheelchair whether it's in the city or down the coast. Yes it's a very true saying, 'every cloud has a silver lining'.

And Evelyn said:

> I should have done it [use crutches] years ago because it has made life so much easier and given me a lot more freedom 'cause I can go places now and I know even in a crowd I can manage better because I've got the support of my crutches, you know, and I've found people more accommodating as well....

With the loss of mobility other changes in physical capacity could follow. One area of particular concern was the ability to weight bear and in particular its affect on the ability to transfer to and from a wheelchair. This was a major issue for some of our participants. Neil, for example described how he had gradually lost the ability to transfer in and out of his chair and, at first every now and then his leg would give away as he transferred and he would fall. Initially this happened once a month or so and he was able to rely on informal support provided by neighbours. As he aged further he started to fall more regularly and he could no longer rely on this informal level of support and after calling on “anyone from the police to NHS 24 to God knows what” he had to set up a formal arrangement with sleepovers and he now employs Personal Assistants to help with his social support.
Ageing with CP meant that things “get harder to do”, people lived with more pain and had to learn new ways of doing things. Changes in physical capacity meant that people could no longer do the things that they used to do and used to take for granted, such as cooking, cleaning, DIY, home maintenance and other activities. People told us how they ‘need a lot more care and a lot of help with toileting, most things’ (Douglas). This often resulted in feelings of frustration and irritation, especially where this help and support is not provided, a relatively common occurrence, as we describe later in the report.

Ageing also impacted on people’s ability to take part in social activities, as Douglas described:

Also there are very few places I would go on my own now and would always want to take someone with me and of course to say that when at a time of cut backs and all the rest there’s a danger that all the social activity, which 15 years ago I took for granted is in fact going to disappear and so on….

Ageing with CP impacted on the working life of a number of people who had been able to find employment as they had to take early retirement on health grounds in their 40s and 50s. Gordon told us:

I couldn’t carry on anymore… when I went to my GP and I just said to him “Look I’ve got to do something - I’ve got to stop…” and he says “Well if you’re saying that, I’ve no hesitation in writing you a line…” because he says “I know what you’re like…”

It would however be too simple to ascribe the feelings of frustration solely to the ageing process for, as the quotes above shows, many of the changes associated with ageing with CP can be ameliorated by good health and social care and other support, an issue we cover in more detail in the next section. Robert for example felt that if he had received better medical treatment earlier, he would have been able to work for up to 10 years longer instead of taking early retirement.

Some of the people we spoke to were also keen to point out that all people change as they get older and that this was not particular to disabled people but something universally experienced. Julia says:

…I feel that even able bodied people as they get older they begin to not be as quick at things and not be able to do the things that they were able to do and that can frustrate them, like… When my mother began not to be able to see all that well and couldn’t read a paper well – that really got her frustrated. And I think for anybody – able bodied or disabled – unless an ‘able’ bodied person is physically fit and able then I think that we all have a wee bit of going downhill unfortunately

It is undeniably true that change is part and parcel of ageing. It is normal and although those we spoke to are experiencing an accelerated form of change this cannot be used to separate them out from their non-disabled peers. However, this point notwithstanding, physical changes associated with ageing with CP can be complicated and can impact on what people
can and can not do and on their feelings and their emotional wellbeing, Neil neatly summed up the experience of ageing with a lifelong impairment when he stated:

*It's like somebody that's not got a disability but you've still got limitations, you might not, you can run a mile but you know that you're not going to be able to climb Ben Nevis right, so you'll run a mile but not climb Ben Nevis. In the past, before I was deteriorating with the cerebral palsy I knew my limits and worked within my limits so what happens is when you do deteriorate to the extent that I have, you have to re-educate yourself again and really it's a sense like as though you've not had a disability before compared to the level of disability now. You know if that kind of makes any sense but that's the way I've kind of approached it, because you've had to start again. It has not made me give up but you still have to start again.*

Having examined the impact of ageing on people with CP in the next section we move on to look at the provision of social care and social support to people as they age and to document our informants views of the care and support they receive.
Ageing with Cerebral Palsy; Support and Care

This section examines what Local Authorities had to say on the delivery of care to older people with CP and what those who received the support had to say about it. It examines the sources of support and care received and people’s thoughts and feelings about it. Our participants received assistance and support in a variety of different ways. Some were in receipt of Direct Payments and employed their own PAs, others lived in care homes and had Key Workers, while others used care agency services or relied on care and support directly provided by their Local Authority.

All of the older people that we spoke to raised issues around both support and care they received and the care providers and other support services. People talked about a general dissatisfaction with care providers and expressed concern about their lack of control, choice and autonomy in the way in which that care and support was delivered. Many participants also expressed antagonism towards social workers and other social service professionals. These views, whilst important are not directly related to ageing and may be found in many groups of disabled people when asked to comment on their care. We have therefore opted to concentrate in this report on views on social care and social support that are directly relevant to the ageing process. The focus of this section of the report is not about their general satisfaction of care and support services but about how their changing needs have been met, or, as is the case for many for those we spoke to, not met.

We also include in this section data drawn from our interviews with Local Authorities and explore how they responded to some of the critiques of care and support identified by older people with CP. This section of the report opens with an overview of their views on the services they deliver.

Meeting the Changing Needs of Older People with CP

One of the key themes that emerged from our interviews with representatives from Local Authorities was a general lack of knowledge about the potential problems people with CP face as they age which, in its turn, resulted in a lack of concern about whether the needs of this particular group were being met. There is, our data would suggest, an unpreparedness of social and health services to meet the needs of older people with CP, or other groups of people with a long term condition. Whilst some medical and health professionals recognised that there were issues particular to this group and there was a need to provide such specialist services, there were few if any actually available. The social care needs of older people with CP, according to most of the Local Authorities, would be adequately met through normal day to day policies and practices. Only one out of the ten authorities we spoke to expressed some concern on this issue. It was felt that as a result of strategic developments and initiatives variously described as ‘individualised planning’, ‘person centred planning’, ‘ageing in place. ‘personalised care packages’ and ‘anticipatory care planning’ the needs of this group, and other similar groups, would be fully met. There was no need to identify or develop specific, targeted packages. The Reshaping of Care for Older People agenda and the promotion of enablement, re-enablement and independence together with partnership working and co-production were seen as key here. People from the Local Authorities that we
spoke to were generally fairly confident in the adequacy of their services to meet the needs of people ageing with CP.

A small number of older people with CP we spoke to agreed with this general sentiment and were, in the main, happy with the care and the support they received. Much of this satisfaction however was based on people comparing their situation now to a time in the past and everybody we spoke to described how much better things were now than they had been previously. Walter, for example described how at 63 years old he had moved out of a care home and into his own flat which “turned out to be the best move ever made”. He was now receiving much more care and attention and had more autonomy and freedom and was much happier. Most of the participants who were care home residents expressed a great deal of satisfaction about their living and support arrangements. They felt that the care homes of today were much better than the institutions they had been in the past. They all had their own person centred care plan which set out their needs and wants and they had good and close relationships with their Key Workers. However, during the process of the interviews it became clear that activities and choices were dependent staffing levels and resources rather than what they wanted to do. Sometimes their requests could not be accommodated or had to be deferred because there was not enough staff on site and they often had to take part in group activities which they might have preferred not to.

The vast majority of people we spoke to had a lot of concerns about the way that their care and support was delivered. They felt that their needs were not understood and that social care services did not know how best to help them or to meet their changing needs as they aged:

*Individually some do, eh, as a whole the managers haven’t the slightest idea, they haven’t a clue what CP is, they haven’t a clue now on it and any support outside old age support and they try to put you in that category, and you’ve got to fight on to, at times, to get out of it. Which is still possible but it’s pretty difficult. But basically now I find that with any agency that I come into contact with thinks in terms of care of the elderly and tries to put you in that category and I’m not getting near that and I don’t really want to get it.* (Douglas)

The situation is further complicated for people ageing with CP as it is seen as a “static, but not unchanging” condition. People felt that their changing needs were not taken account in service planning and that their support was inadequate on a number of grounds. First, and perhaps most importantly there was a general feeling that services tended to be reactive rather than proactive and that there is no planning ahead. Additional needs are we were told by many were reacted to only when the demand became critical and that you have to “kick them if you require any urgent help”. They also felt their own opinions were often not given the status that they should be, Olive’s comments were typical:

*Well, I’m not in favour with having a social worker because they tell me what to do and I don’t need told what to do... I know better than them what to do*

Another key problem people identified was the way that care and support was delivered. Care had become task focussed and the processes that surround it was ignored. This meant
that people often felt lonely. Morag for example told us how, following the closure of the hostel where she had lived for over 20 years she moved into a flat on her own. Her support workers were only allocated for short periods each day to carry out specific tasks such as help with cooking or toileting. They did not have any time to spend with her to assist her to get out and about or to talk to her and whilst her care needs were met she felt lonely. After a short period she opted to move back into residential care.

Many people described how as they had grown older their needs had changed but that the social care they were offered had not changed to reflect this. Margaret for example told us how she now finds her day centre too big and noisy and that she would like, as she puts it, to “retire” but is unable to do so because there is no funding available that could provide her with care and support in her own home. We were told how the day centres and the activities were focussed on supporting younger people and they did not reflect their needs or wants. Also as they had aged getting up at 7am every day was becoming very demanding and the repetition boring and that they would have liked to have been able to do something else but there was no funding to enable this to happen. People also told us that whilst the day centres they went to were now no longer suitable for them, the alternative care of the elderly day centres that some had been offered were also not suitable as these tended to be for people with dementia, people with whom they shared little in common.

At the root of many of these problems some felt was an inherent ageism in both the delivery of care to older people and also the activities they were offered:

\[ \text{The perception within social care as you get older, your social needs are less and it’s okay to be sitting in a chair and around a wall, around the 4 walls of a room, that’s okay for elderly people and it’s not okay for young vibrant adults as they need to be out and about but for older people it is okay to provide a pulley and a chair and feed them at one end and wipe them at the other and that’s all you need….we need to look at what is it that social care is for, what is social care for? (Robert)} \]

One Local Authority representative pointed out that this could also happen to young disabled people and it is difficult to disentangle ageism and disablism.

The threat of residential care was a great fear among those who had previously experienced life in care homes:

\[ \text{I often wondered if I would end up back in residential care because I fear that as well. I don’t want to end up in one because I was in residential care when I was young, (Robert)} \]

People who had once lived in care homes described how much better their life was now compared to what it was. The Local Authorities were, in the main very keen to promote community living and had put in place policies and practices that ensured that they maximise people’s independence and enabled them to live in the community for as long as possible. However whilst the aim was to keep people at home, some local authorities apply a ‘de-facto’ cost ceiling for care of older people. This is set at roughly the equivalent of the COSLA agreed rate for residential care. This means in practice that provided the safety and security
of an individual can be assured and that their support needs can be met for less than a specified amount their care will be provided fully in the community. If, however, the costs rise above that limit Local Authorities will consider pursuing residential care as an option. When this happens the Local Authorities aimed, where possible, to place the individual in a residential home as close as possible to their original home. However this was not always achievable, especially in the more rural communities and often people were located in homes distant from their own locality.

Calum was one of those caught up in this dilemma. As a result of ageing he now requires 24hr support but cannot get this funded in his own home and has been told that he will only get the level of support he needs if he agrees to move into a care home, something he is adamant that he does not want to do. His home support situation has been compounded by his local authority which is now cutting the funding for his day attendance at the home (due to price rises) from 5 days a week to only 2 half sessions a week. He is now faced with the option of either living without the care and support he needs or moving into a care home.

The role of the family

Much of the previous research on ageing with a lifelong condition has highlighted the centrality of parents and other family members in providing support and care and how this can become destabilised as the family support network ages\textsuperscript{15}. In our sample we did not find many instances of family members as primary carers. This may have been due to the particular characteristics of our cohort of participants as many of those we spoke to were former residents of long-stay hospital or former or current care home residents. If they had lived with their parents or family it was only when they were much younger. Mary, for example, had lived with her mother until she became ill and died, but has been a care home resident for 27 years, others had moved into residential care as children or young people. However even those who had lived their whole lives in the community and had grown up in their parental home did not rely on their family for care or support. A number of participants were in very close contact with their family and regularly met up with their parents (if they were still alive), their siblings and other relatives. They regularly went out with them or visited their homes. Some also received secondary support and assistance from siblings but this was very much on an informal, ad hoc basis. Other participants did not mention their family at all or said they had little contact with living family members for personal reasons or practical difficulties with travelling. Some people provided assistance to their disabled partners or care for their elderly relatives. Julia, for example, gave up work after 22 years partly to help in the care of her elderly mother who was ill and did not want to be at home alone. She acted as her mother’s carer until she died.

Ageing with Cerebral palsy: The role of medical and health professionals

In this section we describe the role of health and medical care in the lives of older people with CP. We draw on the data we collected from interviews with physiotherapists and occupational therapists and with hospital consultants. The data are presented from both groups separately but one thing that is clear is that this is an area that is only now been recognised by these professionals as a problem and one that is not yet fully understood or catered for. Most of the services provided by this sector focus on habilitation and are targeted at younger people, so one of the consultants told us:

[Older people with CP] has only recently begun to be talked about, maybe in the last five years has that really begun to be a topic of conversation other than just purely administrative – you know, ‘it is now time – this patient is now 65 he should no longer be in my ward, he should be in your ward.’ Beyond that – the issue of approaching that transition properly is nowhere near as developed as the conversation is about younger age transition.

A point reinforced by a second neurologist;

There is masses of research on childhood cerebral palsy… if there are major works on adults with cerebral palsy emerging… I don’t think that I am familiar with them

This was a point very strongly endorsed by many of the older people we spoke to. This section of the report opens with the views of the physiotherapists we spoke to and then moves on to look at the views and opinions of the medical consultants.

The views of the therapists

The physiotherapists we interviewed were much more open about the deficiencies of service provision than either Local Authority representatives or rehabilitation consultants. All those we spoke to currently worked or had previously worked with people ageing with Cerebral Palsy and all felt that there are few if any specialist services dedicated to meet their needs. They said that the individuals with CP who came to see them were typically in their thirties to fifties and were usually those who had ‘coped well’ with their condition and were now reporting problems with walking and increased pain. Most of their clients had faced very few problems since their late teens and had only had very limited contact with specialist neurology services since leaving school but were now facing increased musculoskeletal problems as they aged. These were, according to the therapists, due to a range of factors including their gait, the way that they sat, or their wheelchair seating position all of which placed strain on the body. Prior to their problems the individuals had been generally just ‘getting on with life’. In childhood and through into adolescence they may have received quite good care and support through paediatric services but in the transition to adulthood they had become ‘lost’ to the services. As a result they rarely received any advice and this coupled with what they described as young people’s more ‘carefree’ approach to health
management and lack of concern about the future they tended to stop following any form of ‘maintenance regime’. A combination of such circumstances can, according to the therapists, lead to premature physical ageing, as one therapist told us:

*I get the impression, with a few of them that I have spoken to, they tend to let their regimes go, they tend to enjoy the fact that they have…em…the ability to do what they want, when they want and, yeah, don’t really think too much about the exercises or the stretches and it’s normally when the…I see…em… people come to me in their 30’s when they are starting to feel that things aren’t quite going the way thing were and, kind of…em… musculoskeletal system and neurological system are, kind of, taking its toll on their bodies and they are struggling to be either up right walking or they are struggling to be able to carry out their activities that they were doing previously…*

The therapists felt that many people with CP stopped doing the exercises and stretches that they may have been forced into doing at school, by their parents or by paediatric services and that this may be part of the problem.

However they also felt that people with CP did age prematurely and even in those who carried on with the exercise regime once they reached 35 - 40 years old, there does appear to be a deterioration of physical function.

The problems of older people with CP is not generally well understood outside physiotherapy and only selectively understood within the service and the physiotherapists we spoke to stated the type of service people get is ‘a bit like roulette’. It depends on the knowledge of their GP or their consultant. People can go “all round the houses” and whilst some might find the right therapist who can assist with the problems they are experiencing others are not so fortunate.

Physiotherapists stated that they believed rehabilitation and therapy service provision was not adequate to meet the needs of people ageing with CP. There are only limited resources and staffing available and many rehabilitation units do not have out-patient physiotherapy services, due mainly to funding and concerns about creating new demand. There was a general consensus among the therapists that they could do a lot more and whilst there is a big push to get patients out of physiotherapy service and self-managing their condition at home, the number of out-patient sessions a person with CP receives is down to the strength of physiotherapist in arguing for their caseload. There is a strong policy drive towards promoting self-management of long term conditions however physiotherapists could not recall CP being recognised as a long term condition in the reams of documents and memos they receive so is not covered under the Lifelong Condition Policy.
The Views of Rehabilitation Consultants

Findings from rehabilitation consultants present mixed perspectives on whether ageing with CP is an issue of concern. Some consultants recognise the need for more research in this area and some even suggest that there is a need for specialist services focusing on the needs of people ageing with CP. Others however do not see evidence of such a cohort of older people existing as a population experiencing unmet need and were stridently unconcerned. They also all felt that relative to other older disabled people, older people with CP would represent a very small cohort and their needs would not be widely recognised.

Some of the consultants did talk about the biomechanical problems that people with CP have and how, as they aged, this would increase their tendency towards increased musculoskeletal problems. There was also a suggestion that medical services aimed at people ageing with CP would not be funded and developed without evidence that there is unmet need but without a register this is difficult. Moreover, there is the suggestion that older people with CP are not part of an established and vocal lobby group like younger people with CP and people with other conditions are. This means that they have few, if any advocates and that without lobbying services for this group are unlikely to improve.
Closing Comments

Before concluding this document we feel that it is important to point out that the majority of the older people with CP we talked to were very active and claimed they were ‘enjoying life to the full’. Most were out every day and/or evenings doing something recreational or involved with another activity. They attended day centres and art classes, went on holiday, went to the pub, cinema and the theatre, did voluntary work and were board members of disability organisations. As William told us: “I only see my wife at night time and the only time I spend with my wife is at the weekends as she’s got a busy [life] and I’ve got a busy life.”

The fact that disabled people - even those who use a high level of support and assistance - have a packed social life is not a shock. However, it does challenge the notion of “successful ageing” and ‘healthy’ older people portrayed in gerontology literature and ‘western’ culture, where the premise has been the absence of ‘chronic illness and disability’. “Active ageing” for disabled people is often impeded because of a lack of appropriate support or because of the controlling influence of others rather than the existence of age-related changes.16

Wanting to “grab every opportunity when it comes” was a common refrain from participants who were former long-stay hospital patients. Some participants intimated said that their childhood prognosis was so negative that they were not expected to live into adulthood. For them actually growing old was a bonus. It should be noted that this does not negate the additional physical and support issues mentioned by many participants that accompany the ageing process, but it is a reminder of how much life expectancy has changed for many disabled people.

In concluding this report we feel that there are two key issues that need to be stressed; first, as people with CP age their impairment, that is the extent to which they are affected by CP, changes and second, services and support for people does not recognise or take account of these changes. CP is seen as a static, nonprogressive condition as are their needs. This means that many people with CP face increasing problems as they age and this need is not acknowledged. Older people with CP are, our research would suggest, leading more difficult lives than they would do if social care was better managed. Even in organisation dedicated to helping people with CP ageing with the condition is rarely mentioned and there are no services dedicated to this target group. Generic services are not suitable and do not meet their needs if, as is usually the case, they are not responsive. People are trapped and rely on generic services because there is no alternative.

Their health needs are also going unmet and health care also fails to take account of their changing needs. All of the emphasis on transition for this group is focused on the transition experienced by young people as they leave school and move into adulthood, little attention is

paid to the needs of people as they age. CP should be viewed as a lifelong condition and should be treated in the same manner as other long term conditions. Hospitals and Health Boards should draw up plans to ensure that the health needs of this groups are met at all stages of the lifecourse, not just childhood or when they leave school.

Older people with CP are a group with few advocates and they represent a marginalised group within two already marginalised populations, older people and disabled people. Most of the policy initiatives in this area are aimed at older people who acquire an impairment in later life with little attention paid to the needs of disabled people as they age. Our research would suggest that despite the passing of anti-discrimination legislation, including legislation that outlaws discrimination against older people, and many other changes in disability policy little has changed since Gerry Zarb’s and Mike Oliver’s earlier work on ageing with a disability in which they asked in their conclusion if older disabled people had a right to expect more in the future. Our research would suggest that even with that right they are still not getting the support and care that they should expect and face a continuingly uncertain future.