# National Institute for Health and Care Excellence

Draft for consultation

# Cerebral palsy in adults

## [F2] Configuration of services: service design access to primary and secondary care

*NICE guideline <TBC>*

*Evidence reviews*

*July 2018*

*Draft for Consultation*

*These evidence reviews were developed by the National Guideline Alliance hosted by the Royal College of Obstetricians and Gynaecologists*

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The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

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# Contents

# Barriers to access to primary and secondary care for adults with cerebral palsy

## Review question

What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

### Introduction

Adults with cerebral palsy have the same health requirements as other adults in terms of screening, diagnosis, monitoring and management, but may have additional requirements and face additional difficulties accessing these services. Barriers may be environmental, organizational, social, or due to complications of Cerebral Palsy. This review question analyses the clinical and cost effectiveness of how services are structured and delivered.

### PICO table

Please see Table 1 for a summary of the mixed method protocol Population, Intervention, Comparison and Outcome (PICO – quantitative), and Population, Interest and Context (PICo – qualitative) characteristics of this review.

**Table 1: Summary of the protocol (PICO table)**

| | |
|---|---|
| Population | **Quantitative population:**<br>• Adults aged 25 years or older with cerebral palsy<br>**Qualitative population:**<br>• Adults aged 25 years or older with cerebral palsy<br>• Primary carers of adults aged 25 years or older with cerebral palsy<br>• Providers of care to adults aged 25 years or older with cerebral palsy |
| Intervention / Interest | **Quantitative:**<br>• Interventions to facilitate access to care services<br>○ Primary care<br>○ Comprehensive therapy services at day care centre level<br>○ Key worker<br>○ Annual review<br>○ Shared information<br>○ Patient held Electronic care records<br>○ Advocacy and health literacy<br>**Qualitative interest**:<br>• Interest in perceived barriers |
| Comparison / Context | **Quantitative comparisons**:<br>• None of these<br>• Each other<br>**Qualitative context**:<br>• Access to primary or secondary care |
| Outcome | **Critical quantitative outcomes:**<br>• Service availability<br>• Utilisation of services |

| | |
|---|---|
| | ○ Secondary care services<br>○ Social care<br>○ Primary care surveillance<br>○ Dental<br>**Critical qualitative themes:**<br>• Perceived barriers or facilitators to health care, for example:<br>○ Personal<br>○ Organisational<br>○ Financial |

For full details see the review protocol in appendix A

## Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual 2014. Methods specific to this review question are described in the review protocol in appendix A and for a full description of the methods see supplementary document C.

Declaration of interests were recorded according to NICE's 2014 conflicts of interest policy from May 2016 until April 2018. From April 2018 onwards they were recorded according to NICE's 2018 conflicts of interest policy. Those interests declared until April 2018 were reclassified according to NICE's 2018 conflicts of interest policy (see Interests Register).

## Clinical evidence

### Included studies

No studies providing quantitative evidence were identified.

A total of 15 qualitative studies were included in this review (Balandin 1997; Balandin 2006; Buzio 2002; Hemsley 2004; Hemsley 2008a; Hemsley 2008c; Hemsley 2008b; Hilberink 2007; Jonsson 2008; Morgan 2014; Mudge 2016; Nieuwenhuijsen 2008; Read 2015; Russell 1993; Sandstrom 2009). Of them 3 used cross-sectional survey study designs (Hilberink 2007; Nieuwenhuijsen 2008; and Russell 1993) , 11 qualitative study designs (Balandin 2006; Buzio 2002; Hemsley 2004; Hemsley 2008a; Hemsley 2008c; Hemsley 2008b; Jonsson 2008; Morgan 2014; Mudge 2016; Read 2015; and Sandstrom 2009), and 1 both cross-sectional survey study and qualitative design (Balandin 1997).

Twelve studies focused on adults with cerebral palsy (number of participants, N=566); 2 studies focused on family caregivers of adults with cerebral palsy (N=12); and 1 study focused on professional carers of people with cerebral palsy (N=6). The majority of included studies collected data by semi-structured interviews or focus groups. The most common data analysis method employed across studies was thematic analysis. With regard to the setting of studies:

- 9 studies were conducted in Australia (Balandin 1997; Balandin 2006; Buzio 2002; Hemsley 2004; Hemsley 2008a; Hemsley 2008c; Hemsley 2008b; Morgan 2014; and Russell 1993)
- 2 studies were conducted in Sweden (Jonsson 2008; and Sandstrom 2009)
- 2 studies were conducted in the Netherlands (Hilberink 2007; and Nieuwenhuijsen 2008)
- 1 study was conducted in New Zealand (Mudge 2016)
- and 1 study was multinational, conducted in the UK, Australia, New Zealand, USA (Read 2015)

Table 2 provides a brief summary of the included studies.

Table 2 provides a summary of the included studies and evidence from these are summarised in the clinical evidence profiles below (Table 3 to Table 14).

See also the literature search strategy in appendix B, study selection flow chart in appendix C and study evidence tables in appendix D.

### Excluded studies

Studies excluded from this systematic review, with reasons for their exclusion, are provided in appendix K.

## Summary of clinical studies included in the evidence review

Table 2 provides a brief summary of the included studies.

**Table 2: Summary of included studies**

| Study | Design | Participants | Outcomes - Themes/categories |
|---|---|---|---|
| Balandin 2007 | • Qualitative<br>• Questionnaire delivered by mail and thematic analysis | • N = 279 Adults with cerebral palsy<br>• Sample age = range: 30-74 years<br>• Male/Female (N) = 136/137<br>• GMFCS 1/2/3/4-5 (N) = N/R<br>• Australia | • Professional attitudes<br>• Health services availability and suitability<br>• Needs perceived from patients<br>• Information - communication needs |
| Balandin 1997 | • Qualitative<br>• Semi-structured interviews and thematic analysis | • N = 10 Adults with cerebral palsy<br>• Sample age = range: 35-61 years<br>• Male/Female (N) = 5/5<br>• GMFCS 1/2/3/4-5 (N) = N/R<br>• Australia | • Role of unpaid/family carers<br>• Professional attitudes<br>• Information - communication needs |
| Buzio 2002 | • Qualitative<br>• Self-administered questionnaire. Data were analysed by means of a descriptive content analysis. | • N = 31 Adults with cerebral palsy<br>• Sample age = range: 20-60 years<br>• Male/Female (N) = 18/13<br>• GMFCS 1/2/3/4-5 (N) = N/R<br>• Australia | • Health services availability and suitability<br>• Professional attitudes<br>• Logistical aspects of obtaining care |
| Hemsley 2004 | • Qualitative<br>• Unstructured interviews (in depth) lasting 1-2 hours, audiotaped and transcribed. | • N = 6 Family carers of adults with cerebral palsy | • Role of unpaid/family carers<br>• Professional attitudes<br>• Logistical aspects of |

| Study | Design | Participants | Outcomes - Themes/categories |
|---|---|---|---|
| | | • Sample age = N/R<br>• Male/Female (N) = 3/3<br>• GMFCS 1/2/3/4-5 (N) = N/A<br>• Australia | obtaining care |
| Hemsley 2008a | • Qualitative<br>• Focus groups and thematic analysis | • N = 6 Adults with cerebral palsy<br>• Sample age = range: 39-58 years<br>• Male/Female (N) = 3/3<br>• GMFCS 1/2/3/4-5 (N) = N/R<br>• Australia | • Role of unpaid/family carers<br>• Professional attitudes |
| Hemsley 2008b | • Qualitative<br>• Focus groups lasting 2 hours and videotaped, transcribed verbatim and analysed for content themes. | • N = 6 Family carers of adults with cerebral palsy<br>• Sample age = range: 32--68 years<br>• Male/Female (N) = 2/4 (5 parents and 1 brother)<br>• GMFCS 1/2/3/4-5 (N) = N/A<br>• Australia | • Role of unpaid/family carers<br>• Logistical aspects of obtaining care |
| Hemsley 2008c | • Qualitative<br>• Focus groups lasting 2 hours and videotaped, transcribed verbatim and analysed for content themes. | • N = 6 Professional carers of people with cerebral palsy<br>• Sample age = range: 27--62 years (mean 43 years)<br>• Male/Female (N) = 1/5<br>• GMFCS 1/2/3/4-5 (N) = N/A<br>• Australia | • Role of unpaid/family carers<br>• Professional attitudes |
| Hilberink 2007 | • Qualitative<br>• Semi structured interviews (open ended questions) along physical examinations. Data were analysed as frequencies by means of descriptive statistics | • N = 54 Adults with cerebral palsy<br>• Sample age = range: 25-36 years<br>• Male/Female (N) = 26/28<br>• GMFCS 1/2/3/4-5 | • Health services availability<br>• Needs perceived from patients<br>• Physical and medical needs |

| Study | Design | Participants | Outcomes - Themes/categories |
|---|---|---|---|
| | | (N) = 15/35/4/17<br>• The Netherlands | |
| Jonsson 2008 | • Qualitative<br>• Both structured and semi-structured interviews. Data were analysed by means a quantitative descriptive analysis. | • N = 16 Adults with cerebral palsy<br>• Sample age = range: 23-61 years (mean 32 years)<br>• Male/Female (N) = 7/9<br>• GMFCS 1/2/3/4-5 (N) = N/R<br>• Sweden | • Role of unpaid/family carers<br>• Professional attitudes<br>• Logistical aspects of obtaining car |
| Morgan 2014 | • Qualitative<br>• Semi structured interviews (open ended questions) and thematic analysis | • N = 6 Adults with cerebral palsy<br>• Sample age = range: 35-52 years (mean 46 years)<br>• Male/Female (N) = 6/0<br>• GMFCS 1/2/3/4-5 (N) = 0/3/3/0<br>• Australia | • Professional attitudes<br>• Health services availability and suitability<br>• Logistical aspects of obtaining care<br>• Needs perceived from patients<br>• Annual review/regular check-up |
| Mudge 2016 | • Qualitative<br>• Face-to-face semi structured interviews with data coded and interpreted by grouping information into categories. | • N = 28 Adults with cerebral palsy<br>• Sample age = range: 37-70 years (mean 47 years)<br>• Male/Female (N) = 14/14<br>• GMFCS 1/2/3/4-5 (N) = 0/5/8/15<br>• New Zealand | • Ageing process<br>• Health Beliefs<br>• Professional attitudes |
| Nieuwenhuijsen 2008 | • Qualitative<br>• Postal questionnaires. Data were analysed by means of descriptive statistics | • N = 29 adults with cerebral palsy<br>• Sample age = range: 16-40 years (mean 28 years)<br>• Male/Female (N) = 19/10<br>• GMFCS 1/2/3/4-5 (N) = 15/4/3/7<br>• The Netherlands | • Education, ageing and socio-cultural characteristics<br>• Health services availability and suitability<br>• Physical and medical needs<br>• Annual review/regular check-up<br>• Information - communication needs |
| Read 2015 | • Qualitative<br>• Open-ended questions within an online survey that was advertised through a | • N = 28 Adults with cerebral palsy<br>• Sample age = | • Health Beliefs<br>• Professional attitudes |

| Study | Design | Participants | Outcomes - Themes/categories |
|---|---|---|---|
| | number of social networking pages aimed at people with CP. | range: 17-58 years (mean 32 years)<br>• Male/Female (N) = 5/22<br>• GMFCS 1/2/3/4-5 (N) = 6/13/6/3<br>• Country (N): UK=15; USA=6; Australia=6; New Zealand=1 | |
| Russell 1993 | • Qualitative<br>• 12 item closed questionnaire and descriptive content analysis | • N = 57 people with cerebral palsy<br>• Sample age =range: 16-50 years<br>• Male/Female (N) =35/22<br>• GMFCS 1/2/3/4-5 (N) =N/A<br>• Australia | • Logistical aspects of obtaining care<br>• Perceived barriers and regularity of dental attendance |
| Sandstrom 2009 | • Qualitative<br>• Semi structured interviews (open ended questions). The data was analysed using qualitative content analysis | • N = 22 Adults with cerebral palsy<br>• Sample age = range: 35-58 years (mean 47 years)<br>• Male/Female (N) = 12/10<br>• GMFCS 1/2/3/4-5 (N) = 0/7/7/8<br>• Sweden | • Health services suitability<br>• Annual review/regular check-up |

*GMFCS: Gross Motor Function Classification System; N: number of participants in study; N/A: not available; N/R: not reported.*

See appendix D for full evidence tables.

## Quality assessment of clinical outcomes included in the evidence review

Three main concepts (i.e. predisposing factors; enabling resources; and factors that indicate a specific need) emerged from the thematic analysis (Figure 1) of the evidence included in the review. The three central concepts of thematic analysis describe conditions that either facilitate or impede healthcare utilisation:

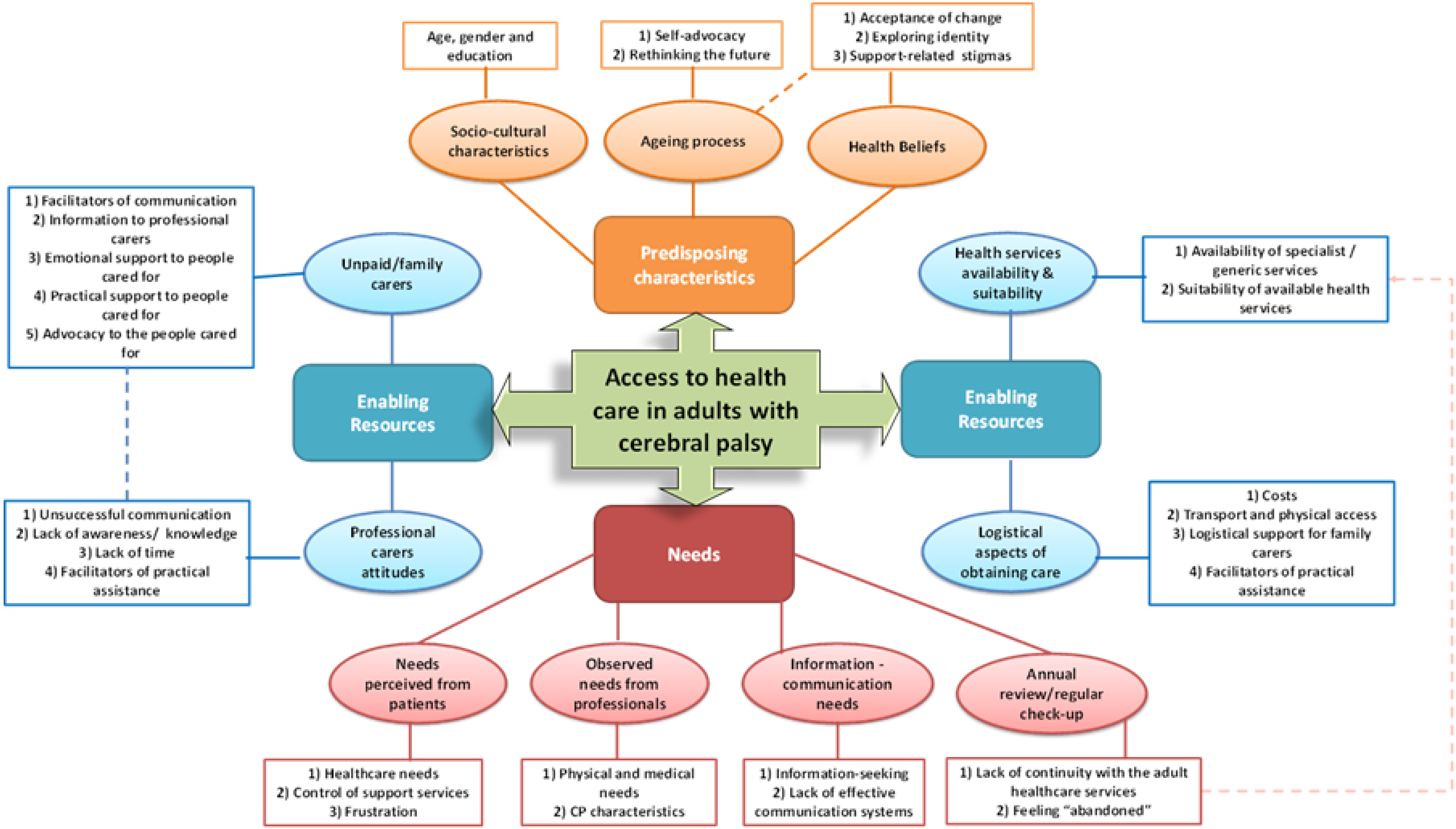
- Predisposing factors are defined as the socio-cultural characteristics of adults with cerebral palsy that are related to their adulthood (i.e. age, gender and education; ageing process; and health beliefs)
- Enabling resources are defined as all the logistical aspects of obtaining care by adults with cerebral palsy (i.e. family carers; professional carers; health services availability and suitability; and logistical aspects of obtaining care)
- Factors that indicate a specific need are defined as the most immediate cause of health service use by adults with cerebral palsy (i.e. needs perceived by patients; needs

observed by professionals; information - communication needs; and need for an annual review/regular check-up)

As shown in the theme map (Figure 1), these concepts have been explored in a number of central themes and subthemes.

# Theme map

## Figure 1: Theme map



## Clinical evidence profile

According to the theme map (Figure 1), the clinical evidence (GRADE-CERQual) profiles for barriers and facilitators to access to primary and secondary care for adults with cerebral palsy are presented in Table 3 to Table 14.

**Table 3: Clinical evidence profile: Predisposing factors of adults with cerebral palsy that are perceived as barriers to access to primary and secondary care: Socio-cultural characteristics**

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| **Sub-theme 1: Age, gender and education** | | | | | | | |
| 1 study | Survey | “*No relations were found between healthcare utilization (i.e. treatment by a rehabilitation physician or physical therapist) and age, gender or level of education of the adults with CP]* [Author quote] | Unclear concerns over methodological limitations[1]. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Major concern over adequacy due to only 1 study included offering thin data.[2] | Very low |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy;*

*1 Evidence was downgraded by 1 due to unclear methodological limitations in the study that contributed to the review findings (no details on data collection and outcome measurement methods)*

*2 Evidence was downgraded by 2 due to adequacy of data, as only one study supported the review’s findings (offering poor data)*

**Table 4: Clinical evidence profile: Predisposing factors of adults with cerebral palsy that are perceived as barriers to access to primary and secondary care: Ageing process**

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| **Sub-theme 1: Self-advocacy** | | | | | | | |
| 2 studies | Qualitative study | Changes with ageing led many participants to reflect on a new or increased need to receive help: *"Now, what is it about families* | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across | Minor concerns over applicability of the findings. | Moderate concern over data adequacy | Low |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *that they don't listen to what you're telling them? I mean, that also is more of a hindrance than your disability"[Adult with CP]*<br>*"I've learnt over the years to not be meek and mild, to actually speak up otherwise you're just going to get sort of forgotten. So you've got to learn even though it's hard, especially if speech is a problem, to actually speak up for yourself or get someone to assist you."* [Adult with CP] *"But what's urgent to you and what's urgent to them often don't meet. So you have to fight, fight, fight."* [Adult with CP] | | studies. | | due to only 2 linked studies offering moderate richness of data.[1] | |
| **Sub-theme 2: Rethinking the future** | | | | | | | |
| 2 studies | Qualitative study | Many participants spoke about their future in terms of long-term goals and aspirations around work, education, family, leisure and sport:<br>*"My fear is it's going to be harder—that's my fear, and I'm going to have some person who comes by and dresses me and puts me together and but…there's this determination there that no, it's not to be that way—I'm going to stay as fit and as mobile as I possibly can till the day I cark it."* [Adult with CP]<br>*"Three of the [adults with CP] stressed in the comments section that they were not experiencing any adverse changes with ageing but rather that they considered* | Substantial concern over methodological limitations.[2] | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[1] | Very low |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *that they had improved as they had grown older"* [authors quote]. | | | | | |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy;*
*1 Evidence was downgraded by 1 due to adequacy of data, as only two studies supported the review's findings (offering thin data)*
*2 Evidence was downgraded by 1 due to moderate methodological limitations in one study that contributed to the findings (Balandin 1997: not clearly reporting the sampling method or relationship between the researcher and participants)*

**Table 5: Clinical evidence profile: Predisposing factors of adults with cerebral palsy that are perceived as barriers to access to primary and secondary care: Health Beliefs**

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| **Sub-theme 1: Acceptance of change** | | | | | | | |
| 1 study | Qualitative study | Many participants were aware they were experiencing, or would experience, accelerated changes as they got older:<br>*"I think that having a disability and the fact that your body takes such a hiding, for want of a better word, on joints and things over the years because of that disability that the ageing process is probably quicker for someone with a disability than someone who is able bodied."*[Adult with CP]<br>*"I think it's part of ageing; I know everyone who ages slows down but I think people with CP do at a younger age than most people. Mainly, I think, from forcing my body over its physical limits; I* | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Major concern over adequacy due to only 1 study included offering thin data.[1] | Very low |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *think that's the main cause"* [Adult with CP] | | | | | |
| **Sub-theme 2: Exploring identity** | | | | | | | |
| 2 studies | Qualitative study | Changes in their physical capacity and needs prompted reflection on their personal identity (how they saw themselves) and their social identity (how they were perceived by others):<br>*"I've always…been as, if you like, 'normal' as possible and that's the challenge that I'm finding, as I get older, that that kind of perspective is not working anymore. And I don't know how to bridge that gap between "this is who I am" and "this is me with CP."* [Adult with CP]<br>*"I seek support because of my individual needs and requirements independently and not because I identify with other adults with CP."; "If a method of support has been useful to a friend with CP, I would be more likely to try it, but a lot of the support I receive is individualised and necessary for me to perform basic daily tasks*."[Adult with CP] | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[2] | Low |
| **Sub-theme 3: Support-related stigmas** | | | | | | | |
| 1 study | Qualitative study | Many participants believed stigma to be a fundamental reason why adults with CP may not seek the support they need:<br>*"Yes, people with CP do* | Unclear methodological limitations.[3] | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Major concern over adequacy due to only | Very low |

| STUDY information | | Description of Theme or Finding | CERQual Quality Assessment | | | | |
|---|---|---|---|---|---|---|---|
| Number of studies | Design | | Methodological Limitations | Coherence of findings | Applicability of evidence | Adequacy of Data | Overall Confidence |
| | | *experience problems due to stigma. We are often seen as unable to talk for ourselves and we are not given the opportunity to orchestrate our own care needs."*[Adult with CP]<br>*"I do not look like I have "[Cerebral] Palsy". It's a very [unhelpful] label in my case. Because people don't think I should have a blue badge [disabled car parking permit] or use a disabled toilet and they sometimes wonder why I get any help at all."*[Adult with CP] | | | | 1 study included offering thin data.[1] | |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy;*

*1 Evidence was downgraded by 2 due to adequacy of data, as only one study supported the review's findings (offering poor data)*

*2 Evidence was downgraded by 1 due to adequacy of data, as only two studies supported the review's findings (offering thin data)*

*3 Evidence was downgraded by 1 due to potential methodological limitations in one study that contributed to the findings (not clearly reporting the sampling method, or the relationship between the researcher and participants; furthermore this study did not report whether saturation was achieved in terms of data collection or data analysis)*

**Table 6: Clinical evidence profile: Enabling resources of adults with cerebral palsy that facilitate access to primary and secondary care: Unpaid/family carers**

| STUDY information | | Description of Theme or Finding | CERQual Quality Assessment | | | | |
|---|---|---|---|---|---|---|---|
| Number of studies | Design | | Methodological Limitations | Coherence of findings | Applicability of evidence | Adequacy of Data | Overall Confidence |
| **Sub-theme 1: Facilitators of communication** | | | | | | | |
| 5 studies | Qualitative study | Speaking for the Person with CP and CCN: "The *way she walked in and looked at Jeremy and said 'Oh that's right, are you allergic to anything?' you know, those sorts of questions . . I've said 'He doesn't speak.' 'Oh, um, well, ok.'* [Nurse quoted]. *And it was just like, 'This person's there and he* | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Minor concern over data adequacy due to 5 studies offering moderate | Moderate |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *doesn't speak?' [nurse quoted] You know, it was really quite, and I said, 'No he doesn't speak, I have to speak for him, that's why we're here."* [family carer]<br>*"It's a very discrete role, is as [a] translator. Hannah: I think too, is explaining to the staff the level of comprehension the person has. Because quite often people think if their communication is poor, that their understanding is poor also."*[Professional carer]<br>"*The two* [adults with CP] *who were not at all successful [in communicating with nurses] had no access to any form of AAC in the hospital and did not have the support of a caregiver to assist them in communicating or with the interpretation of their communicative attempts* [Author's quote]. | | | | richness of data. | |
| **Sub-theme 2: To give information to professional carers** | | | | | | | |
| 2 studies | Qualitative study | Informing hospital staff of care techniques: *"I mean you guys* [Dianne and Debbie] *know more about your clients, than I would know as a nurse, but the* [family] *carers know more, and they're the ones I talk to when I need to know something.*"[Professional carer] | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[1] | Low |
| **Sub-theme 3: Emotional support to people cared for** | | | | | | | |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| 3 studies | Qualitative study | *"to give you support and to make you feel secure . . . I think to be more of a friend, and give moral support"*[Adult with CP].<br>*"..to (a) reassure and calm the patient: "And [my daughter] was just practically going through the roof trying to breathe, and they're saying "Look we'll have to ventilate her again because she's breathing too hard." It took nearly an hour to convince this guy that she'd be [okay], "Just go away, walk away—I don't want to be rude, but she just needs to relax." And within an hour she was [calm]. It's just, if I hadn't been there, it's frightening."* [Family carer]<br>*"I think it's the [patient's] fear of the nursing staff, and doctors as well … They're somewhere where they don't want to be because they know there is no understanding for them, they know that they won't be able to communicate their needs across, and they're fearful of something else happening to them, that they're not going to — that they don't want to allow to happen."* [Professional carers] | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Minor concern over data adequacy due to 3 studies offering moderate richness of data. | Moderate |
| **Sub-theme 4: Practical support to people cared for** | | | | | | | |
| 5 studies | Qualitative study | Do everything required in relation to providing direct care, (e.g., giving medications, helping with showering or bathing, toileting, | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across | Minor concerns over applicability of the findings. | Minor concern over data adequacy | Moderate |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | meals, and drinks): "*I have learned, that when a person with CP and no speech goes to hospital, is in pain or has any problem or is ill, you actually have to bounce the staff around. You have to say, 'Why are you doing that?' and you have to be there . . . assessing the people that are present and looking after her, and if necessary pushing them around.*" [family carer]<br>Lack of communication, lack of knowledge or experience, and fear could mean that busy hospital staff would be appreciative of any additional support and would not discourage family members from taking on a role in direct care "*Helen: There was an expectation that the [family] carer will be there to do all the care. That was the expectation. To wash, to transfer, to feed … and one of the things they [nurses] said ''Oh their parents come in'' or ''Their home care person comes in and they do the sponging.'' Danielle: Yes, we've had that too*". [Professional carers]<br>"*And because we take more time, when they come over they freak out'*". "*Because we take more time. And they don't know what to do*"[Adult with CP] | | studies. | | due to 5 studies offering moderate richness of data. | |
| **Sub-theme 5: Advocacy to the people cared for** | | | | | | | |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| 2 studies | Qualitative study | "*…Sure, like you need to be the person's champion, you need to be there, and be the voice, and you need to definitely push your opinion across, and say, "Look, look at the whole picture … this is my loved one and the important thing is that they get what they need not just what everybody gets*".[Family carer]<br>*"They're the middle person between the staff in the hospital and the patient. They're the ones there to pass on the information for the client to the nursing staff or the doctors"*[Professional carer] | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[1] | Low |

*AAC: augmentative and alternative communication ; CCN: complex communication needs; CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy;*
*1 Evidence was downgraded by 1 due to adequacy of data, as only two studies supported the review's findings (offering thin data)*

**Table 7: Clinical evidence profile: Enabling resources for adults with cerebral palsy that facilitate access to primary and secondary care: Professional carers attitudes**

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| **Sub-theme 1: Unsuccessful communication** | | | | | | | |
| 5 studies | Qualitative study | "*A lot of people—because she can't speak—a lot of people immediately assume that she's deaf. So they yell at her! [laughs]. But I mean some of them are deaf, but it seems that's their link up—isolate, yell.*"[Family carer]<br>"*Participants* [Adults with CP] | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Minor concern over data adequacy due to 5 studies offering moderate | Moderate |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *expressed helplessness and frustration that neither they, nor their carers, could effectively convey the necessary information about their needs to the large number of different hospital staff involved in care over the period of the hospitalization* [Authors' quote] | | | | richness of data. | |
| **Sub-theme 2: Lack of awareness/ knowledge** | | | | | | | |
| 2 studies | Qualitative study | Eight adults with CP *"stated that they had no faith in the medical profession and that they considered that doctors had no knowledge of CP"* [Author's quote]<br>"*It’s just they seem to see disability and if they haven’t had very much experience of it they seem to go on the offensive [sic]. Like, you know, “I don’t really want to deal with this—it’s not an area that I know about so I’ll walk off and leave it to whoever else is next after me*.” [Adult with CP]<br>*"Some occupational therapists think that they’re god and think that they know it all and think that they’re right and ah no turning around, “Yeah I’m right, you’re wrong, this is how it’s going to be.”*[Adult with CP]<br>"*They don’t know what we are about. They don’t understand"[Adult with CP] "All they see is the disability. They don’t see the person behind it*" | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[1] | Low |

| STUDY information | | | CERQual Quality Assessment | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | [Adult with CP] | | | | | |
| **Sub-theme 3: Lack of time** | | | | | | | |
| 3 studies | Qualitative study | *"But it's very difficult because the staff don't want to listen. They too big a rush rush rush. They don't stop to take time to listen, it's much easier [not to]. I went for three days without food or a shower after major surgery, because the staff just wouldn't listen. So I got on my high horse and told doctor and he made the staff take time to listen, and then it was much easier".* [Adult with CP]<br>*"One barrier participants* [Adults with CP] *reported was that health care personnel were in such a hurry that they seemed to have no time to listen*."[Author quote] | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Minor concern over data adequacy due to 3 studies offering moderate richness of data. | Moderate |
| **Sub-theme 4: Facilitators of practical assistance** | | | | | | | |
| 3 studies | Qualitative study | *"Oh my GP is really cool, because he gets right down to what you've got and he looks after us. He asks you how you've been and what have you been doing and he has a full conversation before he asks you what's wrong."* [Adult with CP]<br>"*Material supports to family carers in the hospital and facilitating collaboration: "There's got to be some kind of teamwork built up between the carer and the staff."[Professional carer]*<br>*"Well maybe when a new shift comes on. Normally the registered nurses go out and introduce themselves, you know,* | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Minor concern over data adequacy due to 3 studies offering moderate richness of data. | Moderate |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *[the family carer needs] to explain to them, what their role is as the carer. You know "This is what I'd like to do, what do you see for this shift?" and just have a discussion.* "[Professional carer] | | | | | |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy; GP: general practitioner.*
*1 Evidence was downgraded by 1 due to adequacy of data, as only two studies supported the review's findings (offering thin data)*

**Table 8: Clinical evidence profile: Enabling resources for adults with cerebral palsy that facilitate access to primary and secondary care: Health services availability & suitability**

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| **Sub-theme 1: Availability of specialist / generic services** | | | | | | | |
| 2 studies | Cross-sectional survey | *"three [adults with CP] stated that they found it impossible to get the speech pathology and physiotherapy that they believed they needed"* [Author's quote]<br>"*Access to generic services was considered difficult by some* [adults with CP]..[Author's quote]<br>Of the 29 adults with CP, 68% visited their physical therapist during the past year, 52% visited their rehabilitation physician during the past year (n= 15 of 29 adults with CP), 32% visited social services during the past year (n=9 of 29 adults with CP), and 28% their occupational therapist (n=8 of | Unclear concerns over methodological limitations.[1] | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[2] | Very low |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | 29 adults with CP). Only 7% of the 54 adults with CP visited their dietican during the past year (n= 2 of 29 adults with CP) | | | | | |
| **Sub-theme 2: Suitability of available health services** | | | | | | | |
| 2 studies | Qualitative study | Being enjoyable, giving effects, being comprehensible, and integrated in daily life were felt as the prerequisites for carrying out physiotherapy and physical activity by adults with CP:<br>(A) Being enjoyable: "*You get away from everything around you at home, so you can totally focus your energy on just training. ( ) And you get away from phones and a lot of mobility service and driving to and fro – you are simply there. "; . . . and preferably enjoyable! . . . It has to be enjoyable and not so laborious, but it's laborious nevertheless.*"[Adult with CP]<br>(B) Giving effect: "*But I found out, as I was at one of those rehabilitation centres ( ), that if you do too much then things backfire. ( ) . . . you find that you get better, but that's up to a certain level ( ) . . . and then things turn around. "; "Well I don't know . . . I don't feel it helps or anything but . . . people round about me say I'm walking more steadily and am not flapping my arms about . . . but I don't know.*"[Adult with CP] | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[2] | Low |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | (C) Being comprehensible: *"Do they mean I'll be like my brother . . . I'll be able to jump and walk ( ) and then you realise things will never really be like that." [Adult with CP]; "I'm more motivated because I know why I'm doing it. I want to try and avoid future problems, so to speak."*[Adult with CP]<br>(D) Being integrated in daily life: *"To be honest, I don't need to do training because I feel my body copes . . . I get enough exercise and I do a lot in my everyday life . . . so I get the exercise I need"* [Adult with CP] | | | | | |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy.*

*1 Evidence was downgraded by 1 due to unclear methodological limitations in one study that contributed to the review findings (Nieuwenhuijsen 2008: no details on data collection and outcome measurement methods)*

*2 Evidence was downgraded by 1 due to adequacy of data, as only two studies supported the review's findings (offering thin data)*

**Table 9: Clinical evidence profile: Enabling resources for adults with cerebral palsy that facilitate access to primary and secondary care: Logistical aspects of obtaining care**

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| **Sub-theme 1: Costs** | | | | | | | |
| 1 study | Qualitative study | *"I mean if someone tells me something, then I'll do it, but I've got to be able to afford it and I've got to be able to get there, and then have the energy to get there and then take off or put on* | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Major concern over adequacy due to only | Very low |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *whatever they want to do and do whatever they say and then get home again and survive"* [Adult with CP]. | | | | 1 study included offering thin data.[1] | |
| **Sub-theme 2: Transport and physical access** | | | | | | | |
| 2 studies | Qualitative study | Difficulties with the physical access of the facility due to inaccessible car parking locations, stair access, or inability to navigate the narrow passageways and doorways: *"All the participants* [Adults with CP] *used the mobility service, but this was perceived as both a facilitator and barrier. It was viewed as a 'necessary evil', a barrier when the vehicles did not arrive on time but a facilitator when they did. For this reason, some avoided the mobility service. ..."* [Author quote]<br>*"People with disabilities can't go to a gym generally because they either can't get there, can't get in the door…"* [Adult with CP] | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[2] | Low |
| **Sub-theme 3: Logistical support for family carers** | | | | | | | |
| 2 studies | Qualitative study | Formal system for provision of accommodation, car parking, meals or refreshments*: "Oh well yeah if they don't, if they decide they don't want to feed me well I've gotta try and, if Tina's, if she's asleep, I'll have to duck down the canteen and grab something"* [family carer]; *"It would be good if you had a—oh well you [to Beth]were lucky you had a room to sleep—but each time I've gone,* | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[2] | Low |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *I've just sat up in a chair all night because there's never a room. And if there is a room it's either on another floor or it's right down the end of the hospital which is useless.*"[Family carer]<br>Improving access to appropriate adaptive equipment might help the family caregiver to position and move the patient safely: *"I said "But I'm just going across there!" And they said "Well you promise me that you will bring it back." Well, I was petrified—I was watching the sling the whole time. I took it to my room at night with me to make sure that it didn't disappear to someone else. And then I took it back when it was all over."* [Family carer] *"While having the equipment helped Beth to position her son, being responsible for the equipment was an additional stress associated with caring in the hospital setting"* [Family carer] | | | | | |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy;*
*1 Evidence was downgraded by 2 due to adequacy of data, as only one study supported the review's findings (offering poor data)*
*2 Evidence was downgraded by 1 due to adequacy of data, as only two studies supported the review's findings (offering thin data)*

**Table 10: Clinical evidence profile: Factors that indicate a specific need of adults with cerebral palsy for access to primary and secondary care: Needs perceived from patients**

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| **Sub-theme 1: Costs** | | | | | | | |
| 1 study | Qualitative study | *"I mean if someone tells me something, then I'll do it, but I've got to be able to afford it and I've got to be able to get there, and then have the energy to get there and then take off or put on whatever they want to do and do whatever they say and then get home again and survive"* [Adult with CP]. | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Major concern over adequacy due to only 1 study included offering thin data.[1] | Very low |
| **Sub-theme 2: Transport and physical access** | | | | | | | |
| 2 studies | Qualitative study | Difficulties with the physical access of the facility due to inaccessible car parking locations, stair access, or inability to navigate the narrow passageways and doorways: *"All the participants* [Adults with CP] *used the mobility service, but this was perceived as both a facilitator and barrier. It was viewed as a 'necessary evil', a barrier when the vehicles did not arrive on time but a facilitator when they did. For this reason, some avoided the mobility service. ..."* [Author quote] *"People with disabilities can't go to a gym generally because they either can't get there, can't get in the door…"* [Adult with CP] | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[2] | Low |
| **Sub-theme 3: Logistical support for family carers** | | | | | | | |
| 2 studies | Qualitative study | Formal system for provision of accommodation, car parking, meals or refreshments*: "Oh well yeah if they don't, if they decide they don't want to feed me well I've gotta try and, if Tina's, if she's* | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked | Low |

| STUDY information | | | CERQual Quality Assessment | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *asleep, I’ll have to duck down the canteen and grab something"* [family carer]; *"It would be good if you had a—oh well you [to Beth]were lucky you had a room to sleep—but each time I’ve gone, I’ve just sat up in a chair all night because there’s never a room. And if there is a room it’s either on another floor or it’s right down the end of the hospital which is useless.*"[Family carer] Improving access to appropriate adaptive equipment might help the family caregiver to position and move the patient safely: *"I said “But I’m just going across there!” And they said “Well you promise me that you will bring it back.” Well, I was petrified—I was watching the sling the whole time. I took it to my room at night with me to make sure that it didn’t disappear to someone else. And then I took it back when it was all over."* [Family carer] *"While having the equipment helped Beth to position her son, being responsible for the equipment was an additional stress associated with caring in the hospital setting"* [Family carer] | | | | studies offering moderate richness of data.[2] | |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy;*
*1 Evidence was downgraded by 2 due to adequacy of data, as only one study supported the review’s findings (offering poor data)*
*2 Evidence was downgraded by 1 due to adequacy of data, as only two studies supported the review’s findings (offering thin data)*

**Table 11: Clinical evidence profile: Factors that indicate a specific need of adults with cerebral palsy for access to primary and secondary care: Needs perceived from patients**

| STUDY information | | | CERQual Quality Assessment | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| **Sub-theme 1: Healthcare needs** | | | | | | | |
| 1 study | Cross-sectional survey | Although 94% adults with CP (n=51 of 54) usually felt healthy, about 25% (n=14 of 54) indicated that their activities were limited by their health problems, and 33% (n=18 of 54) felt worried about their health. | Unclear concerns over methodological limitations.[1] | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Major concern over adequacy due to only 1 study included offering thin data.[2] | Very low |
| **Sub-theme 2: Control of support services** | | | | | | | |
| 1 study | Qualitative study | Maintaining control of their independence and control of any service or therapy provided was highly valued by participants: "*I was offered a carer who was going to come in and help me with my shower and stuff; however, they could only come for six weeks—what's the point of that? I said no thanks…"*[Adult with CP]; "*I had always resisted using anything to help my walking….I wanted to be the one to make a decision about what I used and when"* [Adult with CP] | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Major concern over adequacy due to only 1 study included offering thin data.[2] | Very low |
| **Sub-theme 3: Frustration** | | | | | | | |
| 1 study | Qualitative study | *"It seems as though they put all this effort into children with CP and then give up on us when we become adults!" and "I was really frustrated with what was available to me"*[Adult with CP].<br>*"this is not your life, it's not* | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Major concern over adequacy due to only 1 study included | Very low |

| **STUDY information** | | **Description of Theme or Finding** | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *everybody's life so if it's not everybody's life then why do we have to do it so hard?"* [Adult with CP] | | | | offering thin data.[2] | |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy;*

*5 Evidence was downgraded by 1 due to unclear methodological limitations in the study that contributed to the review findings (no details on the recruitment strategy and outcome measurement)*

*6 Evidence was downgraded by 2 due to adequacy of data, as only one study supported the review's findings (offering poor data)*

**Table 12: Clinical evidence profile: Factors that indicate a specific need of adults with cerebral palsy for access to primary and secondary care: Observed needs from professionals**

| **STUDY information** | | **Description of Theme or Finding** | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| **Sub-theme 1: Physical and medical needs** | | | | | | | |
| 2 studies | Cross-sectional survey | The most frequent conditions were in order pain, joint deformities, vision impairments, speech impairments, swallowing, and medication for epilepsy<br>Adults with CP with pain more frequently consulted their rehabilitation physician compared with adults without pain<br>Adults with CP and lower levels of gross motor functioning visited a rehabilitation physician and a physical therapist more than adults with CP with higher levels of gross motor functioning | Unclear concerns over methodological limitations.[1] | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[3] | Very low |
| **Sub-theme 2: CP characteristics** | | | | | | | |
| 1 study | Cross-sectional survey | More adults with CP with a quadriplegia compared to those with a hemiplegia visited a | Unclear concerns over | Minor concerns over coherence. Data | Minor concerns over | Major concern | Very low |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | rehabilitation physician or physical therapist | methodological limitations.[2] | reasonably consistent within and across studies. | applicability of the findings. | over adequacy due to only 1 study included offering thin data.[4] | |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy;*

*1 Evidence was downgraded by 1 due to unclear methodological limitations in both studies that contributed to the review findings (no details on data collection and outcome measurement methods)*

*2 Evidence was downgraded by 1 due to unclear methodological limitations in the study that contributed to the review findings (no details on the recruitment strategy and outcome measurement)*

*3 Evidence was downgraded by 1 due to adequacy of data, as only two studies supported the review's findings (offering thin data)*

*4 Evidence was downgraded by 2 due to adequacy of data, as only one study supported the review's findings (offering poor data)*

**Table 13: Clinical evidence profile: Factors that indicate a specific need of adults with cerebral palsy for access to primary and secondary care: Information - communication needs**

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| **Sub-theme 1: Information-seeking** | | | | | | | |
| 3 studies | Qualitative study<br>Cross-sectional survey | *"119 (43%)* [Adults with CP] *answered that they never read information, 79 (28%) read newspaper articles, 68 (24%) read magazine articles and 57 (20%) read health centre leaflets. "Some [adults with CP] noted in the space 'other' that they gained information from the television or radio programs"* [Author quote].<br>*"A problem in their contacts with authorities could be that they were asked to speak more* | Major concerns over methodological limitations.[1] | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Minor concern over data adequacy due to 3 studies offering moderate richness of data. | Very low |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *clearly, so that participants with speech difficulties avoided ringing them. Such participants considered the mobile phone text message function very facilitative, and used it frequently*" [Author quote] | | | | | |
| **Sub-theme 2: Lack of effective communication systems** | | | | | | | |
| 3 studies | Qualitative study | Adults with CP reflected various physical and psychosocial consequences of difficulties in communicating with professional carers - explaining methods for comfortable positioning, participating in their own diagnoses and health management in the hospital, and gaining access to necessary assistance for: *"When I first went in it was hard because I couldn't make them understand. When I went to bed, they put me on my back, and I don't feel comfortable that way and nobody came until later—I was sad, uncomfortable, and frustrated"* [adult with CP]<br>*"When you are telling them what is the best way to handle you without hurting you or themselves, they just don't hear or listen and you've got to do it their way, and you both find out [their way] is the inappropriate way. They say do no, no, no, you don't know. This last incident with my leg, I could stand up at the foot of the bed and say how to do the footplates, but he didn't put* | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Minor concern over data adequacy due to 3 studies offering moderate richness of data. | Moderate |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *the footplates up and he banged them into my leg that I had the operation on. Another nurse did exactly what I told her and had no problem."*[Adult with CP] | | | | | |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy;*
*5 Evidence was downgraded by 2 due to serious methodological limitations in the all studies that contributed to the review findings*

### Table 14: Clinical evidence profile: Factors that indicate a specific need of adults with cerebral palsy for access to primary and secondary care: Annual review/regular check-up

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| **Sub-theme 1: Lack of continuity with the adult healthcare services** | | | | | | | |
| 2 studies | Qualitative study | *"The physiotherapists change a lot, and you might get a couple of months with one physiotherapist, and then you have to start with another. And that means you're constantly going over your story, so that each of these physiotherapists can get a handle on where you're at.…They can only see you for a short period of time, because their services are in such demand, I feel that you're wasting a lot of time, having to go continually over your story, because that's one session gone"*[Adult with CP]<br>*"It takes a while when you have a disability because they have to get to know the person and the disability and how the disability affects your life. So it's not simple and it will take him [GP] a while to* | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[1] | Low |

| **STUDY information** | | | **CERQual Quality Assessment** | | | | |
|---|---|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of Theme or Finding** | **Methodological Limitations** | **Coherence of findings** | **Applicability of evidence** | **Adequacy of Data** | **Overall Confidence** |
| | | *figure out what he should do and how he should do it*." [Adult with CP] | | | | | |
| **Sub-theme 2: Feeling "abandoned"** | | | | | | | |
| 2 studies | Qualitative study<br>Cross-sectional survey | *"And people seem to forget that…kids grow up and they become adolescents and they become adults. Just because they become adults doesn't mean their condition goes away, it's still there*" [Adult with CP]<br>*"Well, you need someone giving you a jog. It's like going to the dentist. It's easier for the dentist to send out a bit of paper and contact me about a new appointment than for me to ring them, because you receive a bit of paper . . . and you have to do it. ( ) . . . and you get appointments . . . so you don't get forgotten."*[Adult with CP] | Minor concerns over methodological limitations. | Minor concerns over coherence. Data reasonably consistent within and across studies. | Minor concerns over applicability of the findings. | Moderate concern over data adequacy due to only 2 linked studies offering moderate richness of data.[1] | Low |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; CP: cerebral palsy;*

5 Evidence was downgraded by 1 due to adequacy of data, as only two studies supported the review's findings (offering thin data

## Economic evidence

### Included studies

A systematic review of the economic literature was conducted but no studies were identified which were applicable to this review question.

### Excluded studies

No studies were identified which were applicable to this review question.

## Summary of studies included in the economic evidence review

No economic evidence was identified for this review.

## Economic model

This topic was not prioritised for health economic modelling because the topic was concerned with identifying barriers to access rather than considering alternative approaches to providing them. Such topics do not lend themselves well to economic modelling and therefore other topics in the guideline were prioritised.

## Resource impact

No unit costs were presented to the committee as these were not prioritised for decision making purposes.

## Evidence statements

The three central concepts (i.e. predisposing factors; enabling resources; and factors that indicate a specific need) describe conditions that either facilitate or impede healthcare utilisation in adults with cerebral palsy. These themes with subsequent subthemes are interlinked and have been perceived as facilitators or barriers by adults with cerebral palsy, and their carers (either unpaid or paid).

### Predisposing factors

- Very low quality evidence from 1 cross-sectional survey including 29 adults with cerebral palsy showed no relation between healthcare utilisation and age, gender or level of education.
- Low quality evidence from 2 qualitative studies including 34 adults with cerebral palsy reported on the ageing process and the perceived need for self-advocacy and taking control. In particular, these studies showed that changes with ageing led many adults with cerebral palsy to reflect on a new or increased need for help.
- Very low quality evidence from 2 qualitative studies including 307 adults with cerebral palsy reported on the ageing process and the perceived need of rethinking the future. In particular, these studies showed that many adults with cerebral palsy spoke about their future in terms of long-term goals around work, education, family, and sport.
- Very low quality evidence from 1 qualitative study including 28 adults with cerebral palsy reported on health beliefs, with regard to perceived ‘acceptance of change’. In particular, this study showed that many adults with cerebral palsy were aware that as they got older they would experience accelerated changes.
- Low quality evidence from 2 qualitative studies including 56 adults with cerebral palsy reported on health beliefs, with regard to perceived individual and social identity. In

particular, these studies showed that changes in physical capacity and need in adults with cerebral palsy prompted reflection on their personal identity (i.e. how they saw themselves) and their social identity (i.e. how they were perceived by others)

- Very low quality evidence from 1 qualitative study including 28 adults with cerebral palsy reported on health beliefs, with regard to perceived support-related stigma. In particular, this study showed that most adults with cerebral palsy believed stigma to be a fundamental reason why they might not seek the support needed.

**Enabling resources**

- Moderate quality evidence from 5 qualitative studies including 32 adults with cerebral palsy, 12 family and 6 professional carers of adults with cerebral palsy reported on the role of family carers as facilitators of communication between professionals and adults with cerebral palsy. In particular, these studies showed that family carers were fundamental in speaking for the person with cerebral palsy and complex communication needs, and in advocating for the person with cerebral palsy and these needs.
- Low quality evidence from 2 qualitative studies including 6 family carers and 6 professional carers of adults with cerebral palsy reported on the role of family carers as providers of information to professional carers about care techniques for the people cared for.
- Moderate quality evidence from 3 qualitative studies including 6 adults with cerebral palsy, their family carers (n=6), and their professional carers (n=6) reported on the role of family carers as providers of emotional support (for example calm, reassure, and make feel secure) to adults with cerebral palsy.
- Moderate quality evidence from 5 qualitative studies including 22 adults with cerebral palsy, 6 family cares and 6 professional carers of adults with cerebral palsy reported on the role of family carers as providers of practical support (for example giving medications, helping with showering or bathing, toileting, meals, and drinks) to adults with cerebral palsy.
- Low quality evidence from 2 qualitative studies including 6 family carers and 6 professional carers of adults with cerebral palsy reported on the role of family carers as providers of advocacy to adults with cerebral palsy.
- Moderate quality evidence from 5 qualitative studies including 66 adults with cerebral palsy reported on the perceived unsuccessful communication between professionals and adults with cerebral palsy and their family carers.
- Low quality evidence from 3 qualitative studies including 50 adults with cerebral palsy reported on the perceived lack of awareness/knowledge of professionals about the problems associated with cerebral palsy.
- Moderate quality evidence from 3 qualitative studies including 32 adults with cerebral palsy reported on the perceived lack of time of professionals to listen and support adults with cerebral palsy and their family carers.
- Moderate quality evidence from 3 qualitative studies including 44 adults with cerebral palsy and 6 family carers of adults with cerebral palsy reported on the role of professional carers as facilitators of practical assistance to adult with cerebral palsy.
- Very low quality evidence from 2 cross-sectional surveys including 32 adults with cerebral palsy reported on the observed and perceived access to specialist / generic services by adults with cerebral palsy. In particular, these studies showed that access to generic services was considered difficult by some adults with cerebral palsy, and impossible for some specialist services (e.g. speech pathology). The more frequently services visited in the past year were in order: physical therapy; rehabilitation therapy; hydrotherapy/swimming; and occupational therapy. The less frequently specialist visited in the past year was a dietician.

- Low quality evidence from 2 qualitative studies including 28 adults with cerebral palsy reported on service factors perceived as prerequisites for carrying out physiotherapy and physical activity by adults with cerebral palsy (i.e. being enjoyable, giving effects, being comprehensible, and integrated in daily life).

**Factors that indicate a specific need**

- Very low quality evidence from 1 qualitative study including 6 adults with cerebral palsy reported on the cost to access health services. In particular, this study showed that one major concern perceived by adults with cerebral palsy related to the cost associated with accessing the health service, with many people struggling to afford the fees.
- Low quality evidence from 2 qualitative studies including 22 adults with cerebral palsy reported on their perceived transport and physical barriers (for example. car parking locations, stair access, or inability to navigate the narrow passageways and doorways) to access health services.
- Low quality evidence from 2 qualitative studies including 12 family carers of adults with cerebral palsy reported on the logistical support needed by family carers of adults with cerebral palsy for accessing health services (for example. a formal system for provision of accommodation, car parking, meals or refreshments, access to the patient's medical charts, and practical access to patients). In particular, these studies showed that improving logistical support may help the family carer to support the patient safely and effectively.
- Very low quality evidence from 1 cross-sectional survey including 54 adults with cerebral palsy reported on the healthcare needs perceived by these people. In particular, this study showed that most adults with cerebral palsy usually felt healthy, about 25% indicated that their activities were limited by their health problems, and 33% felt worried about their health.
- Very low quality evidence from 1 qualitative study including 6 adults with cerebral palsy reported on their perceived needs of maintaining control (in terms independence) and to manage any service/therapy provided.
- Very low quality evidence from 1 qualitative study including 6 adults with cerebral palsy reported on the frustration (leading to fatigue) they felt when seeking appropriate and timely health services.
- Very low quality evidence from 2 cross-sectional surveys including 83 adults with cerebral palsy reported on the healthcare needs observed by their professional carers. In particular, these studies showed that the most frequent conditions were (in order): pain, joint deformities, vision impairments, speech impairments, swallowing, and medication for epilepsy. Adults with cerebral palsy with pain more frequently consulted their rehabilitation physician compared with adults without pain. Adults with cerebral palsy and lower levels of gross motor functioning visited a rehabilitation physician and a physical therapist more than adults with cerebral palsy with higher levels of gross motor functioning
- Very low quality evidence from 1 cross-sectional survey with including 83 adults with cerebral palsy reported on the relations between healthcare utilisation and cerebral palsy clinical features. In particular, this study showed that more adults with cerebral palsy with a quadriplegia compared to those with a hemiplegia visited a rehabilitation physician (or a physical therapist).
- Very low quality evidence from 3 studies (2 qualitative studies, and 1 cross-sectional survey) including 83 adults with cerebral palsy reported on their perceived ways of information seeking. In particular, these studies showed that sources of information for adults with cerebral palsy and their carers include newspaper articles, magazine articles and health centre leaflets. Some adults with cerebral palsy gained information from the television or radio programs. Many people had the perception that a problem in their contacts with authorities could be that they were asked to speak more clearly, so that adults with cerebral palsy with speech difficulties avoided ringing them. Such adults with

cerebral palsy considered the mobile phone text message function very facilitative, and used it frequently.

- Moderate quality evidence from 3 qualitative studies including 16 adults with cerebral palsy and 6 family carers of adults with cerebral palsy reported on the lack of effective communication systems (leading to difficulties in communicating with professional carers – for example explaining methods for comfortable positioning, and gaining access to necessary assistance) perceived by these people.
- Low quality evidence from 2 qualitative studies including 28 adults with cerebral palsy reported on the perceived lack of continuity between paediatric and adult health services (and the extended time required to establish a therapeutic relationship).
- Low quality evidence from 2 studies (1 qualitative study, and 1 cross-sectional survey) including 35 adults with cerebral palsy reported the feeling of “abandonment” by the health service since becoming an adult.

## Recommendations

F1.7 Recognise and address barriers to accessing primary and secondary care for adults with cerebral palsy. These may include:

- personal barriers, such as:
  - communication difficulties between the adult and healthcare professionals
  - mental health-related factors such as depression, anxiety
  - lack of an advocate (for example, a family member, carer or friend) if needed
  - social and emotional factors such as fear of stigma, lack of motivation and exhaustion
- physical barriers, such as:
  - inadequate physical access to buildings
  - difficulties with transport
- organisational barriers, such as:
  - lack of availability of appropriate equipment (for example, hoists and wheelchair weighing scales) and adequate changing and toilet facilities
  - inadequate time given in appointments, for example, to allow for hoisting and dressing.

F1.8 When an adult with cerebral palsy is admitted to hospital, the staff should always offer advocacy, health and personal care (toileting, washing, nutrition and hydration) even if the person has a family member, carer or advocate there to support them.

F1.9 Provide information about national screening services (for example breast, colon and cervical cancer screening) to adults with cerebral palsy.

## Rationale and impact

### Why the committee made the recommendations

The evidence showed that adults with cerebral palsy experience many obstacles to equal access to services. Some of the barriers identified by the evidence are highlighted in the recommendations to help raise awareness among healthcare professionals. The committee agreed that healthcare professionals should ensure that any barriers are addressed to enable equitable access to services and provide timely care. This will improve quality of life and health outcomes for adults with cerebral palsy.

The committee also noted that access to services may be limited for adults with cerebral palsy who need practical support and advocacy. There was some evidence that lack of an advocate could disadvantage people, especially when they are admitted to hospital. The evidence also showed that some adults with cerebral palsy reported that when they are admitted to hospital family members were expected to act as their carers. The committee agreed that it should not be assumed that family members should provide personal care in a healthcare setting and that advocacy and health and personal care should always be offered to people when they are admitted to hospital.

Based on their knowledge and experience, the committee noted inequalities in access to national screening programmes for adults with cerebral palsy. They agreed that increasing awareness would help to improve uptake of these services. The committee acknowledged that there may be other barriers to screening, for example providing breast screening for women in wheelchairs, especially those with limited upper body strength, but they noted that interventions to improve screening services was outside of the scope of the guideline.

### Impact of the recommendations on practice

The recommendations on access to services reinforce legislation and best current practice.

## The committee's discussion of the evidence

### Interpreting the evidence

#### *The outcomes that matter most*

The committee considered the individual opinions and views about barriers or facilitators and the themes emerging from these to be the critical outcomes. As they considered the evidence was likely to be qualitative in nature for this review the perspective of service users was felt to be the most important factor for decision making.

#### *The quality of the evidence*

moderate quality.  The main concerns with regards to the quality of the evidence were selection bias and recruitment bias, lack of thematic saturation and lack of verification of findings.

The committee discussed that none of the studies included adults with cerebral palsy from England and Wales and were uncertain whether their findings were applicable and generalisable to all adults with cerebral palsy in the UK because international services differ in how they are provided.

The committee thought that, due to the uncertainty about methodological quality and data saturation on many of the findings in this review, the evidence should be interpreted with caution.

#### *Benefits and harms*

The committee noted, based on the evidence, that adults with cerebral palsy perceive many factors as barriers to access health and social care services. Identification and removal of these barriers to access wherever possible should improve health outcomes in this group and promote equality. The committee therefore recommended that these personal, physical, and organisational factors should be recognised and addressed. These also included social, infrastructure, service provision and communication between professionals and the adult with cerebral palsy and such barriers should be identified to determine what level of support is required. The evidence showed that many barriers were consistently reported by adults with cerebral palsy as causing problems. They agreed that when recognised, these factors must be managed by health professionals, in order to foster the access to health and social care services of adults with cerebral palsy. The committee discussed the evidence that adults with cerebral palsy often felt disadvantaged and therefore they recommended that barriers to primary and secondary care are removed to promote inclusivity. The lack of an an advocate where necessary for the adult with cerebral palsy, and lack of understanding of cerebral palsy by healthcare professionals were other themes that emerged from the evidence and were considered by the committee as potential impeding factors to access services. The committee noted that this could particularly be a problem for adults with cerebral palsy and complex needs who are admitted to hospital.

The committee acknowledged, based on the evidence, that showed that adults with cerebral palsy who were admitted to hospital experienced that family members were expected to act as their carers and advocates. . They would therefore not get the staff support and care that should be provided and carers may not always willing or able to give such support. The committee therefore decided that it was important to raise awareness so that advocacy and health and personal care should always be offered to people when they are admitted to hospital that .

The committee noted, based on their knowledge and experience, that informing adults with cerebral palsy about national screening programmes would help to reduce access inequalities in this group. The committee thought it was important to make healthcare professionals aware of this, therefore recommended provision of information about national screening services to adults with cerebral palsy to promote equal access. This would mean that more adults with cerebral palsy who may have a condition, for example cervical or breast cancer, would be treated in a timely manner and that this would therefore improve health outcomes.

### Cost effectiveness and resource use

The committee noted that no relevant published economic evaluations had been identified and no additional economic analysis had been undertaken in this area. They agreed that these recommendations were unlikely to have a significant resource impact as most of the costs are already being incurred.

### Other factors the committee took into account

The committee discussed the rights for disabled people that are legally binding under the Equalities act (2010) and the UN Convention on the Rights of Persons with Disabilities. These describe requirements for access to services to enable adults with disabilities to live as autonomously as possible. The committee highlighted to particular articles related to access: Article 9 of the UN Convention specifically outlines the rights to accessibility which state ‘*To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility….’.* Article 25 on the topic of ‘Health’ states ‘*Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation*’. The committee’s recommendations are intended to reinforce this legislation.

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# Appendices

## Appendix A – Review protocols

Review protocols for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

**Table 15: Review protocol for F2 Barriers to access to primary and secondary care for adults with cerebral palsy**

| Field (based on PRISMA-P) | Content |
|---|---|
| Review question | What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy? |
| Type of review question | Mixed method quantitative and qualitative |
| Objective of the review | This review aimed to identify factors that make it more difficult (or easier) for adults with cerebral palsy to access healthcare services. |
| Eligibility criteria – population | **Quantitative population:**<br>• Adults aged 25 years or older with cerebral palsy<br>**Qualitative population:**<br>• Adults aged 25 years or older with cerebral palsy<br>• Primary carers of adults aged 25 years or older with cerebral palsy<br>• Providers of care to adults aged 25 years or older with cerebral palsy |
| Eligibility criteria – intervention(s) | **Quantitative:**<br>• Interventions to facilitate access to care services<br>○ Primary care<br>○ Comprehensive therapy services at day care centre level<br>○ Key worker<br>○ Annual review<br>○ Shared information<br>○ Patient held Electronic care records<br>○ Advocacy and health literacy |

| Field (based on PRISMA-P) | Content |
|---|---|
| | **Qualitative**:<br>• Perceived barriers |
| Eligibility criteria – comparator(s)/control | **Quantitative comparisons**:<br>• None of these<br>• Each other<br>**Qualitative context**:<br>• Access to primary or secondary care |
| Outcomes and prioritisation | **Critical quantitative outcomes:**<br>• Service availability<br>• Utilisation of services<br>  o Secondary care services<br>  o Social care<br>  o Primary care surveillance<br>  o Dental<br>**Critical qualitative themes:**<br>• Perceived barriers or facilitators to health care, for example:<br>  o Personal<br>  o Organisational<br>  o Financial |
| Eligibility criteria – study design | • Mixed methods studies<br>• Cohort studies<br>• Case series<br>• Qualitative studies |
| Other inclusion exclusion criteria | Community, residential, primary and secondary care. UK and non-UK studies. ( Non UK studies from high income countries according to WHO criteria) |
| Proposed sensitivity/sub-group analysis, or meta-regression | In the presence of heterogeneity, the following subgroups will be considered for sensitivity analysis:<br>Population subgroups:<br>  o GMFCS level I to III vs GMFCS level IV and V |

| **Field (based on PRISMA-P)** | **Content** |
|---|---|
| | ○ SES<br>Cognitive impairment In the presence of heterogeneity, the following subgroups will be considered for sensitivity analysis:<br>Population subgroups:<br>○ GMFCS level I to III vs GMFCS level IV and V<br>○ SES<br>○ Cognitive impairment |
| Selection process – duplicate screening/selection/analysis | A random sample of the references identified in the search will be sifted by a second reviewer. This sample size will be 10% of the total, or 100 studies if the search identifies fewer than 1000 studies. All disagreements in study inclusion will be discussed and resolved between the two reviewers. The senior systematic reviewer or guideline lead will be involved if discrepancies cannot be resolved between the two reviewers. |
| Data management (software) | STAR was used to sift through the references identified by the search<br>Microsoft Excel was used for data extraction and thematic-analysis |
| Information sources – databases and dates | Embase 1974 to present, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present, PsycINFO 1806 to present |
| Identify if an update | Not an update |
| Author contacts | For details please see the guideline in development web site. |
| Highlight if amendment to previous protocol | For details please see section 4.5 of Developing NICE guidelines: the manual 2014 |
| Search strategy – for one database | For details please see appendix B. |
| Data collection process – forms/duplicate | A standardised evidence table format will be used, and published as appendix D (clinical evidence tables) or H (economic evidence tables). |
| Data items – define all variables to be collected | For details please see evidence tables in appendix D (clinical evidence tables) or H (economic evidence tables). |
| Methods for assessing bias at outcome/study level | Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual 2014<br>The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/. |

| **Field (based on PRISMA-P)** | **Content** |
|---|---|
| Criteria for quantitative synthesis | For details please see section 6.4 of Developing NICE guidelines: the manual 2014. |
| Methods for quantitative analysis – combining studies and exploring (in)consistency | For details please see the methods in supplementary document C. |
| Meta-bias assessment – publication bias, selective reporting bias | For details please see section 6.2 of Developing NICE guidelines: the manual 2014. |
| Confidence in cumulative evidence | For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual 2014. |
| Rationale/context – what is known | For details please see the introduction to the evidence review. |
| Describe contributions of authors and guarantor | A multidisciplinary committee developed the evidence review. The committee was convened by the National Guideline Alliance (NGA) and chaired by Dr Paul Eunson in line with section 3 of Developing NICE guidelines: the manual 2014.<br>Staff from the NGA undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods in supplementary document C. |
| Sources of funding/support | The NGA is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists. |
| Name of sponsor | The NGA is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists. |
| Roles of sponsor | NICE funds NGA to develop guidelines for those working in the NHS, public health and social care in England |
| PROSPERO registration number | Not applicable |

*CERQual: Confidence in the Evidence from Reviews of Qualitative research; GRADE: Grading of Recommendations Assessment, Development and Evaluation; GMFCS, gross motor function classification system;; NICE: National Institute for Health and Care Excellence; NGA: National Guideline Alliance; RCT: randomised controlled trial; RoB: risk of bias; ; SES: socioeconomic status.*

# Appendix B – Literature search strategies

Literature search strategies for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

**Database: Medline & Embase (Multifile)**

Database(s): Embase 1974 to 2018 March 22, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present, PsycINFO 1806 to August Week 4 2017

**Table 16: Last searched on 22/03/2018**

| # | Searches |
|---|---|
| 1 | exp Cerebral Palsy/ use prmz |
| 2 | exp cerebral palsy/ use oemezd |
| 3 | exp Cerebral Palsy/ use psyh |
| 4 | ((cerebral or brain or central) adj2 (pal* or paralys#s or pares#s)).tw. |
| 5 | cerebral palsy.ti,ab. |
| 6 | little? disease.tw. |
| 7 | ((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) adj5 spastic*).tw. |
| 8 | ((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) adj3 ataxi*).tw. |
| 9 | or/1-8 |
| 10 | limit 9 to english language |
| 11 | limit 10 to (adult <18 to 64 years> or aged <65+ years>) use oemezd [Limit not valid in Ovid MEDLINE(R),Ovid MEDLINE(R) In-Process,PsycINFO; records were retained] |
| 12 | limit 10 to "all adult (19 plus years)" [Limit not valid in Embase,PsycINFO; records were retained] |
| 13 | 12 use prmz |
| 14 | limit 10 to adulthood <18+ years> [Limit not valid in Embase,Ovid MEDLINE(R),Ovid MEDLINE(R) In-Process; records were retained] |
| 15 | 14 use psyh |
| 16 | or/11,13,15 |
| 17 | exp Aging/ or exp Ambulatory Care/ or exp "Attitude of Health Personnel"/ or exp Choice Behavior/ or exp Communication/ or exp Community Health Services/ or exp Consumer Behavior/ or exp Decision Making/ or exp Disability Evaluation/ or exp Educational Status/ or exp Family Health/ or exp Patient-Centered Care/ or exp Professional-Family Relations/ or exp Health Knowledge, Attitudes, Practice/ or exp Health Planning/ or exp Health Services/ or exp Health Status/ or exp Health Status Disparities/ or exp Health Services Accessibility/ or exp Health Policy/ or exp "Delivery of Health Care"/ or exp Women's Health/ or exp Attitude to Health/ or exp "Patient Acceptance of Health Care"/ or exp Help-Seeking Behavior/ or exp Insurance, Hospitalization/ or exp Patient Readmission/ or exp Hospitalization/ or exp Family Practice/ or exp Logistic Models/ or exp "Surveys and Questionnaires"/ or exp "Outcome and Process Assessment (Health Care)"/ or exp Primary Health Care/ or exp Quality Indicators, Health Care/ or exp "Quality of Health Care"/ or exp Treatment Refusal/ or exp Patient Compliance/ or exp Counseling/ or exp Medication Adherence/ or exp Behavior Therapy/ or exp Mobility Limitation/ or exp Mental Health Services/ or exp "Health Services Needs and Demand"/ or exp Needs Assessment/ or exp Community Mental Health Services/ or exp Health Services Research/ or exp Outpatients/ or exp Personal Autonomy/ or exp Physical Fitness/ or exp "Referral and Consultation"/ or exp "Physical and Rehabilitation Medicine"/ or exp Rehabilitation Centers/ or exp Rehabilitation/ or exp Personal Satisfaction/ or exp Insurance Coverage/ or exp Self Care/ or exp Public Policy/ or exp "Severity of Illness Index"/ or exp Social Adjustment/ or exp Social Isolation/ or exp Social Support/ or exp Socioeconomic Factors/ or exp Student Dropouts/ or exp Policy/ or exp Disabled Persons/ or Physicians/st [Standards] |
| 18 | 17 use prmz |
| 19 | exp aging/ or exp daily life activity/ or exp ambulatory care/ or exp health personnel attitude/ or exp interpersonal communication/ or exp community care/ or exp consumer attitude/ or exp disability/ or exp family health/ or exp family centered care/ or exp family nursing/ or exp patient care/ or exp attitude to health/ or exp health status/ or exp health disparity/ or exp decision making/ or exp social support/ or exp adaptive behavior/ or exp help seeking behavior/ or exp patient attitude/ or exp cooperation/ or exp educational status/ or exp health behavior/ or exp social aspect/ or exp hospitalization/ or exp independence/ or exp primary medical care/ or exp health insurance/ or exp patient referral/ or exp medical specialist/ or exp health care access/ or exp hospital/ or exp statistical model/ or exp outcome assessment/ or exp health care quality/ or exp quality control/ or exp medication compliance/ or exp walking difficulty/ or exp health service/ or exp health care need/ or exp needs assessment/ or exp "organization and management"/ or exp health services research/ or exp mental health service/ or exp health care organization/ or exp health care delivery/ or exp outpatient care/ or exp personal autonomy/ or exp rehabilitation medicine/ or exp fitness/ or exp physician/ or exp patient referral/ or exp rehabilitation care/ or exp rehabilitation/ or exp life satisfaction/ or exp satisfaction/ or exp patient |

| # | Searches |
|---|---|
| | satisfaction/ or exp public health service/ or exp financial management/ or exp income/ or exp health care policy/ or exp insurance/ or exp self care/ or exp "severity of illness index"/ or exp social adaptation/ or exp social isolation/ or exp socioeconomics/ or exp school dropout/ or exp questionnaire/ or exp health care planning/ or exp wellbeing/ or exp women's health/ or exp treatment refusal/ or exp patient compliance/ or exp counseling/ or exp policy/ or exp disabled person/ |
| 20 | 19 use oemezd |
| 21 | exp aging/ or exp outpatient treatment/ or exp health knowledge/ or exp health attitudes/ or exp mental health personnel/ or exp health education/ or exp knowledge level/ or exp primary health care/ or exp health care services/ or exp health personnel/ or exp health personnel attitudes/ or exp disabilities/ or exp choice behavior/ or exp communication skills training/ or exp augmentative communication/ or exp communication barriers/ or exp interpersonal communication/ or exp communication/ or exp communication skills/ or exp health care delivery/ or exp health service needs/ or exp community mental health services/ or exp "quality of care"/ or exp community services/ or exp health care utilization/ or exp health/ or exp mental health services/ or exp community health/ or exp health care policy/ or exp hospitals/ or exp consumer behavior/ or exp disability evaluation/ or exp education/ or exp family/ or exp decision making/ or exp patients/ or exp treatment planning/ or exp client centered therapy/ or exp client satisfaction/ or exp client attitudes/ or exp caregivers/ or exp therapist attitudes/ or exp health disparities/ or exp government policy making/ or exp health insurance/ or exp stigma/ or exp health care seeking behavior/ or exp treatment compliance/ or exp hospital admission/ or exp family physicians/ or exp item response theory/ or exp questionnaires/ or exp surveys/ or exp treatment effectiveness evaluation/ or exp treatment refusal/ or exp compliance/ or exp counseling/ or exp behavior therapy/ or exp physical activity/ or exp physical mobility/ or exp needs assessment/ or exp hospitalized patients/ or exp health care costs/ or exp hospitalization/ or exp outpatients/ or exp autonomy/ or exp "independence (personality)"/ or exp well being/ or exp "activities of daily living"/ or exp physical fitness/ or exp professional referral/ or exp professional consultation/ or exp rehabilitation/ or exp rehabilitation centers/ or exp life satisfaction/ or exp satisfaction/ or exp health insurance/ or exp self-care skills/ or exp self-management/ or exp "severity (disorders)"/ or exp social adjustment/ or exp social isolation/ or exp social support/ or exp socioeconomic status/ or exp disability laws/ or exp "disabled (attitudes toward)"/ or exp disability discrimination/ |
| 22 | 21 use psyh |
| 23 | (barrier* or limit* or access* or utili* or need* or exclusion* or exclude* or inclusion or include* or well?being or isolat* or support* or service* or health or service* or work* or educat* or financ* or leisure or recreat* or cultur* or social or adjust* or earn* or insurance or challeng* or satisf* or rehabilitat* or fitness or sport* or care* or plan* or independen* or disparit* or attitud* or family?centred or contact* or time* or consult* or insufficien* or participat* or connect* or discriminat* or stigma or inequalit* or policy or policies or knowledge or equipment* or information* or communicat* or interact* or appointment* or examination* or space or treatment room* or wheelchair* or visual aid* or assist* or physical therap* or dental* or wellness or legislative or government).ti,ab. |
| 24 | ("Health and Social Care Act" or "Care Bill").ti,ab. |
| 25 | 18 or 20 or 22 or 23 or 24 |
| 26 | 16 and 25 |
| 27 | conference abstract.pt. use oemezd |
| 28 | letter.pt. or LETTER/ use oemezd |
| 29 | Letter/ use prmz |
| 30 | EDITORIAL/ use prmz |
| 31 | editorial.pt. use oemezd |
| 32 | NEWS/ use prmz |
| 33 | exp HISTORICAL ARTICLE/ use prmz |
| 34 | note.pt. use oemezd |
| 35 | ANECDOTES AS TOPIC/ use prmz |
| 36 | COMMENT/ use prmz |
| 37 | CASE REPORT/ use prmz |
| 38 | CASE REPORT/ use oemezd |
| 39 | CASE STUDY/ use oemezd |
| 40 | (letter or comment* or abstracts).ti. |
| 41 | or/27-40 |
| 42 | RANDOMIZED CONTROLLED TRIAL/ use prmz |
| 43 | RANDOMIZED CONTROLLED TRIAL/ use oemezd |
| 44 | random*.ti,ab. |
| 45 | or/42-44 |
| 46 | 41 not 45 |
| 47 | ANIMALS/ not HUMANS/ use prmz |
| 48 | ANIMAL/ not HUMAN/ use oemezd |
| 49 | exp ANIMALS, LABORATORY/ use prmz |
| 50 | exp ANIMAL EXPERIMENTATION/ use prmz |

| # | Searches |
|---|---|
| 51 | exp MODELS, ANIMAL/ use prmz |
| 52 | exp RODENTIA/ use prmz |
| 53 | NONHUMAN/ use oemezd |
| 54 | exp ANIMAL EXPERIMENT/ use oemezd |
| 55 | exp EXPERIMENTAL ANIMAL/ use oemezd |
| 56 | ANIMAL MODEL/ use oemezd |
| 57 | exp RODENT/ use oemezd |
| 58 | (rat or rats or mouse or mice).ti. |
| 59 | or/46-58 |
| 60 | 26 not 59 |

## Database: Cochrane Library

**Table** 17**: Last searched on 22/03/2018**

| ID | Search |
|---|---|
| #1 | MeSH descriptor: [Cerebral Palsy] explode all trees |
| #2 | ((cerebral or brain or central) N2 (pal* or paralys?s or pare?s)) |
| #3 | ((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) N5 spastic*) |
| #4 | ((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) N3 ataxi*) |
| #5 | #1 or #2 or #3 or #4 |
| #6 | MeSH descriptor: [Delivery of Health Care] explode all trees |
| #7 | MeSH descriptor: [Health Services Administration] explode all trees |
| #8 | MeSH descriptor: [Models, Organizational] explode all trees |
| #9 | MeSH descriptor: [Logistic Models] explode all trees |
| #10 | MeSH descriptor: [Community Health Services] explode all trees |
| #11 | MeSH descriptor: [Health Services Research] explode all trees |
| #12 | MeSH descriptor: [Health Services Accessibility] explode all trees |
| #13 | MeSH descriptor: [Health Education] explode all trees |
| #14 | MeSH descriptor: [Health Care Rationing] explode all trees |
| #15 | MeSH descriptor: [Health Personnel] explode all trees |
| #16 | MeSH descriptor: [Attitude of Health Personnel] explode all trees |
| #17 | MeSH descriptor: [Patient Care Team] explode all trees |
| #18 | MeSH descriptor: [Health Status Indicators] explode all trees |
| #19 | MeSH descriptor: [Health Status] explode all trees |
| #20 | MeSH descriptor: [Health Status Disparities] explode all trees |
| #21 | MeSH descriptor: [Health Planning] explode all trees |
| #22 | MeSH descriptor: [Rehabilitation Centers] explode all trees |
| #23 | MeSH descriptor: [Physical and Rehabilitation Medicine] explode all trees |
| #24 | MeSH descriptor: [Aging] explode all trees |
| #25 | MeSH descriptor: [Rehabilitation] explode all trees |
| #26 | MeSH descriptor: [Continuity of Patient Care] explode all trees |
| #27 | MeSH descriptor: [Professional-Family Relations] explode all trees |
| #28 | MeSH descriptor: [Primary Health Care] explode all trees |
| #29 | MeSH descriptor: [Patient Acceptance of Health Care] explode all trees |
| #30 | MeSH descriptor: [Quality of Health Care] explode all trees |
| #31 | MeSH descriptor: [Quality Indicators, Health Care] explode all trees |
| #32 | MeSH descriptor: [Quality of Life] explode all trees |
| #33 | MeSH descriptor: [Mental Health Services] explode all trees |
| #34 | MeSH descriptor: [Health Services Needs and Demand] explode all trees |
| #35 | MeSH descriptor: [Needs Assessment] explode all trees |
| #36 | MeSH descriptor: [Community Mental Health Services] explode all trees |
| #37 | MeSH descriptor: [Public Policy] explode all trees |
| #38 | MeSH descriptor: [Health Policy] explode all trees |

| ID | Search |
|---|---|
| #39 | MeSH descriptor: [Standard of Care] explode all trees |
| #40 | MeSH descriptor: [Professional Practice] explode all trees |
| #41 | MeSH descriptor: [Utilization Review] explode all trees |
| #42 | MeSH descriptor: [State Medicine] explode all trees |
| #43 | MeSH descriptor: [Social Support] explode all trees |
| #44 | MeSH descriptor: [Social Work] explode all trees |
| #45 | MeSH descriptor: [Health Knowledge, Attitudes, Practice] explode all trees |
| #46 | MeSH descriptor: [Educational Status] explode all trees |
| #47 | MeSH descriptor: [Student Dropouts] explode all trees |
| #48 | MeSH descriptor: [Employment] explode all trees |
| #49 | MeSH descriptor: [Financing, Government] explode all trees |
| #50 | MeSH descriptor: [National Health Programs] explode all trees |
| #51 | MeSH descriptor: [Referral and Consultation] explode all trees |
| #52 | MeSH descriptor: [Hospitalization] explode all trees |
| #53 | MeSH descriptor: [Disability Evaluation] explode all trees |
| #54 | MeSH descriptor: [Disease Management] explode all trees |
| #55 | MeSH descriptor: [Disabled Persons] explode all trees |
| #56 | MeSH descriptor: [Severity of Illness Index] explode all trees |
| #57 | MeSH descriptor: [Transportation of Patients] explode all trees |
| #58 | MeSH descriptor: [Patient Preference] explode all trees |
| #59 | MeSH descriptor: [Outcome and Process Assessment (Health Care)] explode all trees |
| #60 | MeSH descriptor: [Activities of Daily Living] explode all trees |
| #61 | MeSH descriptor: [Self Care] explode all trees |
| #62 | MeSH descriptor: [Ambulatory Care] explode all trees |
| #63 | MeSH descriptor: [Home Care Services] explode all trees |
| #64 | MeSH descriptor: [Complementary Therapies] explode all trees |
| #65 | MeSH descriptor: [Recreation] explode all trees |
| #66 | MeSH descriptor: [Leisure Activities] explode all trees |
| #67 | MeSH descriptor: [Age Factors] explode all trees |
| #68 | MeSH descriptor: [Life Style] explode all trees |
| #69 | MeSH descriptor: [Transition to Adult Care] explode all trees |
| #70 | MeSH descriptor: [Socioeconomic Factors] explode all trees |
| #71 | MeSH descriptor: [Social Adjustment] explode all trees |
| #72 | MeSH descriptor: [Social Isolation] explode all trees |
| #73 | MeSH descriptor: [Aftercare] explode all trees |
| #74 | MeSH descriptor: [Physical Therapy Modalities] explode all trees |
| #75 | MeSH descriptor: [Choice Behavior] explode all trees |
| #76 | MeSH descriptor: [Counseling] explode all trees |
| #77 | MeSH descriptor: [Communication] explode all trees |
| #78 | MeSH descriptor: [Consumer Behavior] explode all trees |
| #79 | MeSH descriptor: [Decision Making] explode all trees |
| #80 | MeSH descriptor: [Family Health] explode all trees |
| #81 | MeSH descriptor: [Family Practice] explode all trees |
| #82 | MeSH descriptor: [Women's Health] explode all trees |
| #83 | MeSH descriptor: [Attitude to Health] explode all trees |
| #84 | MeSH descriptor: [Patient Acceptance of Health Care] explode all trees |
| #85 | MeSH descriptor: [Help-Seeking Behavior] explode all trees |
| #86 | MeSH descriptor: [Insurance, Hospitalization] explode all trees |
| #87 | MeSH descriptor: [Patient Readmission] explode all trees |
| #88 | MeSH descriptor: [Hospitalization] explode all trees |
| #89 | MeSH descriptor: [Surveys and Questionnaires] explode all trees |
| #90 | MeSH descriptor: [Treatment Refusal] explode all trees |
| #91 | MeSH descriptor: [Patient Compliance] explode all trees |

| ID | Search |
|---|---|
| #92 | MeSH descriptor: [Medication Adherence] explode all trees |
| #93 | MeSH descriptor: [Behavior Therapy] explode all trees |
| #94 | MeSH descriptor: [Mobility Limitation] explode all trees |
| #95 | MeSH descriptor: [Outpatients] explode all trees |
| #96 | MeSH descriptor: [Personal Autonomy] explode all trees |
| #97 | MeSH descriptor: [Physical Fitness] explode all trees |
| #98 | MeSH descriptor: [Personal Satisfaction] explode all trees |
| #99 | MeSH descriptor: [Insurance Coverage] explode all trees |
| #100 | MeSH descriptor: [Physicians] explode all trees and with qualifier(s): [Standards - ST] |
| #101 | barrier* or limit* or access* or utili* or need* or exclusion* or exclude* or inclusion or include* or well?being or isolat* or support* or service* or health or service* or work* or educat* or financ* or leisure or recreat* or cultur* or social or adjust* or earn* or insurance or challeng* or satisf* or rehabilitat* or fitness or sport* or care* or plan* or independen* or disparit* or attitud* or family?centred or contact* or time* or consult* or insufficien* or participat* or connect* or discriminat* or stigma or inequalit* or policy or policies or knowledge or equipment* or information* or communicat* or interact* or appointment* or examination* or space or treatment room* or wheelchair* or visual aid* or assist* or physical therap* or dental* or wellness or legislative or government or "Health and Social Care Act" or "Care Bill" |
| #102 | {or #6-#101} |
| #103 | #5 and #102 |

## Database: Web of Science

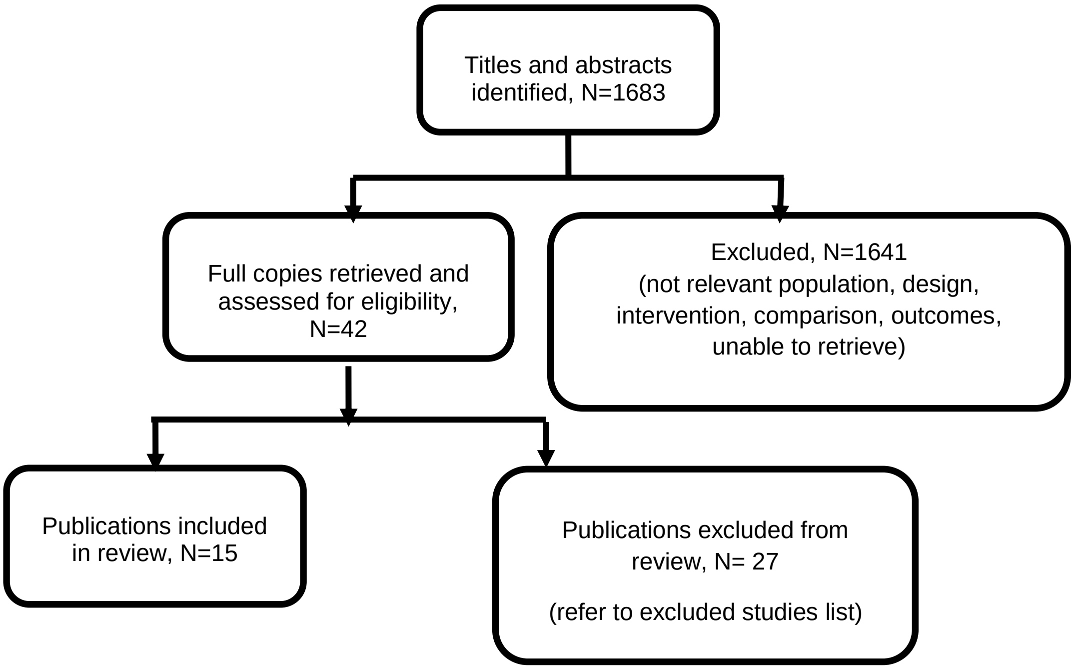
**Table** 18**: Last searched on 22/03/2018**

| #4 | (#3) AND LANGUAGE: (English) |
|---|---|
| #3 | #2 AND #1 |
| #2 | ts=barrier* or ts=limit* or ts=access* or ts=utili* or ts=need* or ts=exclusion* or ts=exclude* or ts=inclusion or ts= include* or ts=well?being or ts=isolat* or ts=support* or ts=service* or ts=health care service* or ts=work* or ts=educat* or ts=financ* or ts=leisure or ts=recreat* or ts=cultur* or ts=social or ts=adjust* or ts=earn* or ts=insurance or ts=challeng* or ts=satisf* or ts=rehabilitat* or ts=fitness or ts=sport* or ts=care* or ts=plan* or ts=independen* or ts=disparit* or ts=attitud* or ts=family?centred or ts=contact* or ts=time* or ts=consult* or ts=insufficien* or ts=participat* or ts=connect* or ts=discriminat* or ts=stigma or ts=inequalit* or ts=policy or ts=policies or ts=knowledge or ts=equipment* or ts=information* or ts=communicat* or ts=interact* or ts=appointment* or ts=examination* or ts=space or ts=treatment room* or ts=wheelchair* or ts=visual aid* or ts=assist* or ts=physical therap* or ts=physiotherapy* or ts=dental* or ts=wellness or ts=legislative or ts=government |
| #1 | ts=cerebral palsy |

# Appendix C – Clinical evidence study selection

Clinical evidence study selection for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

**Figure 2: Flow diagram of clinical article selection for access to care review**



# Appendix D – Clinical evidence tables

Clinical evidence tables for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

**Table 19: Studies included in the evidence review for access to care**

| Study details | Participants | Methods | Outcomes and Results | Comments |
|---|---|---|---|---|
| **Full citation**<br>Balandin, S., Hemsley, B., Sigafoos, J., Green, V., Communicating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs, Applied Nursing Research, 20, 56-62, 2007<br>**Ref Id**<br>586391<br>**Country/ies where the study was carried out**<br>Australia<br>**Study type**<br>Qualitative study/survey<br>**Aim of the study**<br>The aims of this research were to explore patterns of access to a variety of specific health care services among people with chronic or disabling conditions, focusing on factors that predict access to services.<br>**Study dates**<br>Publication date: 1997<br>**Source of funding**<br>Not reported | **Sample size**<br>N = 279 Adults with CP<br>**Characteristics**<br>Sample age = range: 30-74 years<br>Male/Female (n) = 136/137*<br>GMFCS 1/2/3/4-5 (n) = N/R<br>**Inclusion criteria**<br>1) aged 30 years + ; 2) cognitively able to complete the questionnaire themselves<br>**Exclusion criteria**<br>N/R (see inclusion criteria) | **Context & sample selection**<br>Participants were recruited via 2 organizations providing services to individuals with CP: Australian Cerebral Palsy Association, and an anomisous organization in New South Wales. All individuals respondent with the inclusion criteria were contacted.<br><br>**Data collection & analysis**<br>Questionnaire delivered by mail (4 sections - demographic information, information on health, health care and respondents' perceptions of their own ageing process) | **Themes/categories**<br><br>**Professional attitudes**<br>".. *medical profession was criticised by* 17 [adults with CP] ..*Eight adults with CP "stated that they had no faith in the medical profession and that they considered that doctors had no knowledge of CP*" [Author's quote]. "*Three [adults with CP] noted their disgust at not being treated as an adult by doctors: "some doctors pat you on the head and feed you peanuts!"* [adult with CP]. *There was a general call for recognition of the need to have doctors specialised in working with adults with CP and sonlte [adults with CP] noted that they would like to find such a doctor but had so far been unsuccessful* [Author's quote].<br>**Health services availability and suitability**<br>*"three [adults with CP] stated that they found it impossible to get the speech pathology and physiotherapy that they believed they needed*" [Author's quote].<br>**Needs perceived from patients**<br>There were mixed concerns raised about health problems in the future: "*nine* [adults with CP] *stated that they had already started to experience increased aches, pains and stiffness...* | **Limitations (CASP- checklist for qualitative studies)**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes<br>• **Q2** Was a qualitative methodology appropriate? - Yes<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? - Unclear<br>• **Q5**: Were the data collected in a way that addressed the research issue? - Yes<br>• **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear<br>• **Q7**: Have ethical issues been taken into consideration? - No<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes<br>• **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - No<br>**Overall quality:** Low<br><br>**Other information**<br>*6 unclassified |

| Study details | Participants | Methods | Outcomes and Results | Comments |
|---|---|---|---|---|
| | | | *Three of the* [adults with CP] *stressed in the comments section that they were not experiencing any adverse changes with ageing but rather that they considered that they had improved as they had grown older"* [authors quote].<br>**Information - communication needs**<br>In response to questions seeking information on what material [adults with CP] read to gain information: 119 (43%) [Adults with CP] answered that they never read information, 79 (28%) read newspaper articles, 68 (24%) read magazine articles and 57 (20%) read health centre leaflets. "*Some [adults with CP] noted in the space 'other' that they gained information from the television or radio programs*" [authors quote]. | |
| **Full citation**<br>Balandin, Susan, Morgan, John, Adults with cerebral palsy: What's Happening?, Journal of Intellectual and Developmental Disability, 22, 109-124, 1997<br>**Ref Id**<br>675421<br>**Country/ies where the study was carried out**<br>Australia<br>**Study type**<br>Qualitative study<br>**Aim of the study**<br>The aims of this qualitative research were to explore the hospital experiences of adults with cerebral | **Sample size**<br>N = 10 Adults with CP<br>**Characteristics**<br>Sample age = range: 35-61 years<br>Male/Female (n) = 5/5<br>GMFCS 1/2/3/4-5 (n) = N/R<br>**Inclusion criteria**<br>1) adults with CP (age not specified); 2) with CCN (complex communication needs); 3) hospitalised since 2/3 years; 4) able to complete the interviews themselves | **Context & sample selection**<br>Participants were recruited via a non-government organization that provides a range of services to patients with CP. No further details were provided in the paper<br><br>**Data collection & analysis**<br>Semi-structured interviews lasting about 1 hour conducted at the Participants' workplace or residence | **Themes/categories**<br><br>**Role of unpaid/family carers**<br>"*The two* [adults with CP] *who were not at all successful [in communicating with nurses] had no access to any form of AAC in the hospital and did not have the support of a caregiver to assist them in communicating or with the interpretation of their communicative attempts*" [Author's quote]. "*One* [adult with CP] *reported that his communication with the nurses in the hospital was always successful because his mother acted as an interpreter for him*" [Author's quote]<br><br>**Professional attitudes**<br>Adults with CP identified situations in which nurses did not have time to stop and communicate or spoke over the patient to the caregiver: "*People like to* | **Limitations (CASP- checklist for qualitative studies)**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes<br>• **Q2** Was a qualitative methodology appropriate? - Yes<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? - Yes<br>• **Q5**: Were the data collected in a way that addressed the research issue? - Yes<br>• **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear<br>• **Q7**: Have ethical issues been taken into consideration? - Yes<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes<br>• **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - |

| Study details | Participants | Methods | Outcomes and Results | Comments |
|---|---|---|---|---|
| palsy and CCN to identify communication barriers and effective communication strategies between these patients and nurses.<br>**Study dates**<br>Publication date: 2006<br>**Source of funding**<br>Not reported | **Exclusion criteria**<br>those who 1) did not have an intellectual disability and 2) had a functional method of communication | | *be in their comfort zone, but if third person comes in [to the interaction], because people like to speak in their comfort zone, they talk to the third person—and I'm blocked out, because I can't speak as fast. I believe they're not aware that this is happening*."[Adult with CP]. Adults with CP reported that gaining the nurse's attention was a common difficulty encountered in the hospital: *"I can't complain, but one night they woke me up and gave me a needle; it came out and there was a lot of blood [and] they never came back to clean me up—I couldn't reach the buzzer so I went back to sleep"*[Adult with CP].<br>**Information - communication needs**<br>Adults with CP perceived that the lack of an effective communication system limited their ability to successfully initiate a message when they wanted or needed to communicate with nurses: "*When you are telling them what is the best way to handle you without hurting you or themselves, they just don't hear or listen and you've got to do it their way, and you both find out [their way] is the inappropriate way. They say no, no, no, you don't know. This last incident with my leg, I could stand up at the foot of the bed and say how to do the footplates, but he didn't put the footplates up and he banged them into my leg that I had the operation on. Another nurse did exactly what I told her and had no problem."*[Adult with CP]<br>Physical and psychosocial consequences of difficulties in communicating with the nurses in the hospital - (1) explaining methods for | Unclear<br>**Overall quality:** Moderate<br>**Other information**<br>None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
|---|---|---|---|---|
| | | | comfortable positioning, (2) participating in their own diagnoses and health management in the hospital, and (3) gaining access to necessary assistance for or explaining methods of basic care (e.g., mealtimes, toileting, personal care, and showering or bathing): "*When I first went in it was hard because I couldn't make them understand. When I went to bed, they put me on my back, and I don't feel comfortable that way and nobody came until later—I was sad, uncomfortable, and frustrated*" [adult with CP] | |
| **Full citation**<br>Buzio, A., Morgan, J., Blount, D., The experiences of adults with cerebral palsy during periods of hospitalisation, Australian Journal of Advanced Nursing, 19, 8-14, 2002<br>**Ref Id**<br>416121<br>**Country/ies where the study was carried out**<br>Australia<br>**Study type**<br>Qualitative study<br>**Aim of the study**<br>The aim of this qualitative research was to explore the experiences of adults with CP during inpatient admission to a number of public hospitals<br>**Study dates**<br>Publication date: 2002 | **Sample size**<br>N = 31 Adults with CP<br>**Characteristics**<br>Sample age = range: 20-60 years<br>Male/Female (n) = 18/13<br>GMFCS 1/2/3/4-5 (n) = N/R<br>**Inclusion criteria**<br>1) adults with CP; 2) aged 20-70 years; 3) admitted at Sidney public hospital min the last 2 years; 4)provided with informed consent<br>**Exclusion criteria**<br>N/R (see inclusion criteria) | **Context & sample selection**<br>Participants were recruited at the hospital setting of the study<br><br>**Data collection & analysis**<br>17 item self-administered questionnaire developed based on a literature review and anecdotal information from study's participant and their family carers. Data were analysed by means of a descriptive content analysis. | **Themes/categories**<br>**Level of care required:**<br>23% (n=7) respondents reported being asked by hospital staff for information about their disability specific needs, as a part of the admission process.<br>**Level of care received:**<br>Majority of the respondents (>60% of all disability categories except medication) felt the disability specific needs were never, almost never or only sometimes met by the hospital staff.<br>When asked how hospital staff could have better met these needs, three main themes emerged:<br>• Increased staff knowledge of cerebral palsy<br>• Increased skills required to care for people with disabilities and<br>• Increased staff patience when caring for people with cerebral palsy<br>Verbatim: *"Taking time for the person with CP to relay the message they're trying to get across; staff to listen when* | **Limitations (CASP- checklist for qualitative studies)**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes<br>• **Q2** Was a qualitative methodology appropriate? - Yes<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? - Yes<br>• **Q5**: Were the data collected in a way that addressed the research issue? - Yes<br>• **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear<br>• **Q7**: Have ethical issues been taken into consideration? - Yes<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes<br>• **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - No<br><br>**Overall quality:** Unclear<br><br>**Other information** |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| **Source of funding**<br>Not reported | | | *person with CP tells them the best way to assist."*[adult with CP]<br>Not all were unhappy.<br>Verbatim *"They certainly looked after me; I found the staff.. very well advised and I had no problems"* [adult with CP]<br>**Staff Knowledge:**<br>87% (n=27) of respondents felt that the hospital staff had some degree of knowledge and /or skill deficit when caring for people with cerebral palsy. Hospital staff, particularly nurses, were often perceived as ignorant of how to provide appropriate care to a person with cerebral palsy.<br>Verbatim: *"They had no/little idea, were asking house staff all the time; most staff don't know much about cerebral palsy. The condition is a mystery and so are the needs."* [adult *with CP]*<br>**Staff Attitude:**<br>*"The hospital staff were mostly pleasant but they just didn't have a clue about people with cerebral palsy and they seemed as though they did not want to know either."* [adult with *CP]*<br>**Communication:**<br>There was a positive correlation between people who were unable to communicate verbally and dissatisfaction with care received. Of 15 respondents unable to communicate, all reported they were not specifically asked about their disability needs on admission to hospital.<br>**Physical Environment:**<br>35%(n=11) respondents indicated they had difficulty physically accessing the hospital environment, mainly due to slippery floors or limited access in | None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| | | | bathrooms and bedrooms. This made mobilisation within the hospital environment dangerous or difficult, although one respondent reported having trouble getting into the hospital from the car park.<br>**Discharge Planning:**<br>55%(n=16) respondents reported some degree of discharge planning by the hospital prior to discharge. This ranged from asking the person if they would cope at home to arranging community nurse follow up. The remaining 45%(n=15) indicated that the discharge planning was not discussed with them during their stay. | |
| **Full citation**<br>Hemsley, Bronwyn, Balandin, Susan, Without AAC: The Stories of Unpaid Carers of Adults with Cerebral Palsy and Complex Communication Needs in Hospital, AAC: Augmentative and Alternative Communication, 20, 243-257, 2004<br>**Ref Id**<br>656887<br>**Country/ies where the study was carried out**<br>Australia<br>**Study type**<br>Qualitative study<br>**Aim of the study**<br>The aim of this qualitative research was to explore how unpaid carers experienced caring for adults with | **Sample size**<br>N = 6 Family carers of adults with CP<br>**Characteristics**<br>Sample age = N/R<br>Male/Female (n) = 3/3<br>GMFCS 1/2/3/4-5 (n) = N/A<br>**Inclusion criteria**<br>1) family carers who had cared for adults with CP with CCN; 2) in hospital; 3) hospital stay within the past 2 years<br>**Exclusion criteria**<br>N/R (see inclusion criteria) | **Context & sample selection**<br>Participants were recruited at the hospital setting of the study<br>**Data collection & analysis**<br>Unstructured interviews (in depth) lasting 1-2 hours, audiotaped and transcribed. Questions asked by the first author were not standard across the interviews, but arose in response to information gathered during each interview. | **Themes/categories**<br>**Role of unpaid/family carers**<br>Giving instructions to hospital staff, complaining on behalf of their son or daughter, or pushing the hospital staff to carry out particular activities**: "** *I have learned, that when a person with CP and no speech goes to hospital, is in pain or has any problem or is ill, you actually have to bounce the staff around. You have to say, 'Why are you doing that?' and you have to be there . . . assessing the people that are present and looking after her, and if necessary pushing them around*." [family carer]; "*If we hadn't have been there, then Jeremy wouldn't have received the care that he did . . . people don't understand him . . . he can't tell anybody, 'Hey scratch my back', or you know, 'I've got a headache' or anything like that, so you wouldn't know whether or not he does have anything else [more serious] wrong with him*." [family carer]<br>Direct care to the persons they | **Limitations (CASP- checklist for qualitative studies)**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes<br>• **Q2** Was a qualitative methodology appropriate? - Yes<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? - Unclear<br>• **Q5**: Were the data collected in a way that addressed the research issue? - Yes<br>• **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear<br>• **Q7**: Have ethical issues been taken into consideration? - Unclear<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes<br>• **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - Yes<br>**Overall quality:** Unclear |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| cerebral palsy and complex communication needs in the absence of a functional communication systems in hospital.<br>**Study dates**<br>Publication date: 2004<br>**Source of funding**<br>None | | | supported while they were in the hospital: ''*I usually get up very early in the morning, and go and attend to Jeremy, and feed him and we shower him, look after him the whole time until late at night*,'' [family carer]<br>Assisting with Communication:" *Oh, well, various. Mostly you'll find in emergency, any help they can get they'll appreciate it. When they're on the ward, different story. You get some good ones. You get some that obviously resent you being there, but I never let that bother me. I mean if they say, 'You'll have to leave' and I'll say, 'No, I'm staying' and I'll see what they'll do about it. And as I've said I haven't been thrown out yet, but I've come close a number of times."* [family carer]<br>Speaking for the Person with CP and CCN: *" The way she walked in and looked at Jeremy and said 'Oh that's right, are you allergic to anything?' you know, those sorts of questions . . I've said 'He doesn't speak.' 'Oh, um, well, ok.'* [nurse quoted]. *And it was just like, 'This person's there and he doesn't speak?'* [nurse quoted] *You know, it was really quite, and I said, 'No he doesn't speak, I have to speak for him, that's why we're here*." [family carer]<br>facilitating the development of more effective communication over the period of the hospital stay: "*You see Natalie cannot communicate with the nurses as they are not familiar with reading her communication . . . I tell them, from the word go I explain to them, that Natalie will need a pillow under here or that, and I always tell every nurse that Natalie will tell you if she's uncomfortable. And I said, she* | **Other information**<br>None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| | | | *will have difficulty telling you how to make her comfortable, but you have to keep trying positions until she says yes. That's all you have to do. When you say Is that okay? Is that okay? and she will grunt or she will smile, and if she smiles, keep on that pathway*." [family carer]<br>**Professional attitudes**<br>Unsuccessful communication between the nurse and the person with CP and CCN: "*A lot of people—because she can't speak—a lot of people immediately assume that she's deaf. So they yell at her! [laughs]. But I mean some of them are deaf, but it seems that's their link up—isolate, yell*."[Family carer]<br>Some nurses lacked confidence in working with people with CP and CCN, and were therefore, reticent to interact directly with them.: *"They wouldn't have been confident enough [to talk to Mel] unless they've handled people with disability before. And it is difficult to go up to a person with disability, you don't even know if they can hear, you don't know whether they can understand, but you do know that they can't speak, so you know? You've gotta be a certain type of person that will take that on."*[Family carer]<br>**Logistical aspects of obtaining care**<br>Family carers of adults with CP felt that having unlimited access to the patients was an important way to improve the hospital experience for all concerned: *"I would go to the hospital with Natalie when she gets admitted. And then I will stay with her until she gets settled. And then I'll stay with her until probably late at night. And then I* | |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| | | | *would come back at five or six in the morning . . . and I say, 'Look Natalie is going to have to have someone here as much as possible. And it's gonna benefit you, as much as anybody else, so, can you acknowledge that?' And I said, 'The only people that will do this and I tell them, will be me, her [relative], her* [relative], *and somebody, a singular person, from the* [disability service]." [family carer]<br>no formal system for provision of accommodation, car parking, meals or refreshments: "*Oh well yeah if they don't, if they decide they don't want to feed me well I've gotta try and, if Tina's, if she's asleep, I'll have to duck down the canteen and grab something*" [family carer]<br>lack of recognition of both the importance of their role and the inconvenience and discomfort associated with the lack of amenities: "*Moira: The thing that really gets me is, I find myself out on the street, at 12.30 in the morning in the middle of Saturday night, having to get to my car, because she'd been admitted during visiting hours, so I hadn't been able to get a park . . . so I find myself out on the street after midnight to walk to the car. So I did a pink panther, every time a car went past, I'd hide behind a pole, they think, 'Who's this old lady out here?' They might pop me over, grab my bag*." [family carer] | |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| **Full citation**<br>Hemsley, B., Balandin, S., Togher, L., 'We need to be the centrepiece': adults with cerebral palsy and complex communication needs discuss the roles and needs of family carers in hospital, Disability & Rehabilitation, 30, 1759-71, 2008<br>**Ref Id**<br>339760<br>**Country/ies where the study was carried out**<br>Australia<br>**Study type**<br>Qualitative study<br>**Aim of the study**<br>The aims of this qualitative research were to explore the family caregivers' views on what supports are needed by family caregivers of adults with CP providing care in the hospital setting<br>**Study dates**<br>Publication date: 2008<br>**Source of funding**<br>Not reported | **Sample size**<br>N = 6 Adults with CP<br>**Characteristics**<br>Sample age = range: 39-58 years<br>Male/Female (n) = 3/3<br>GMFCS 1/2/3/4-5 (n) = N/R<br>**Inclusion criteria**<br>1) adults with CP (age not specified); 2) with CCN (complex communication needs); 3) hospitalised at least 2/3 days in the last 3 years; 4) able to complete the interviews themselves<br>**Exclusion criteria**<br>N/R (see inclusion criteria) | **Context & sample selection**<br>Participants were recruited at the hospital setting of the study<br><br>**Data collection & analysis**<br>Focus groups with the a) use of ACC systems (i.e. speech generating devices, communication boards, and dysarthric speech with speech interpreters); b) the moderator being familiar with the communication methods of participants with an additional role of clarifying and repairing unclear messages | **Themes/categories**<br><br>**Role of unpaid/family carers**<br>To do everything : "*Because the hospital staff are too busy. They are running around*" [Adult with CP]. "*And because we take more time, when they come over they freak out'".* *"Because we take more time. And they don't know what to do"*[Adult with CP].<br>Emotional support: "*to give you support and to make you feel secure . . . I think to be more of a friend, and give moral support*"[Adult with CP].<br>Advocacy: "*Rory commented that the carer's presence acted as a signal to hospital staff 'for the able people to be more nice to us.*"[Adult with CP]<br>Communication support: "*participants* [Adults with CP] *relied on family carers for support in communication because hospital staff lacked knowledge and experience in caring for people with CP and CCN* [Authors' quote]<br>**Professional attitudes**<br>Attitudes of hospital staff: "*Yeah they're frightened. They don't know what to do*" [Adult with CP]; "I *feel they make themselves busy*".[Adult with CP]; "*They don't know what we are about. They don't understand*"[Adult with CP]<br>Important for the patient to develop more confidence and assertiveness in advocating for their own needs in hospital: "...*But it's very difficult because the staff don't want to listen. They too big a rush rush rush. They don't stop to take time to listen, it's much easier [not to]. I went for three days without food or a shower after major surgery, because the staff just wouldn't listen. So I got on my high* | **Limitations (CASP- checklist for qualitative studies)**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes<br>• **Q2** Was a qualitative methodology appropriate? - Yes<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? - Unclear<br>• **Q5**: Were the data collected in a way that addressed the research issue? - Yes<br>• **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear<br>• **Q7**: Have ethical issues been taken into consideration? - Yes<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes<br>• **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - Yes<br><br>**Overall quality:** Moderate<br><br>**Other information**<br>None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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|  |  |  | *horse and told doctor and he made the staff take time to listen, and then it was much easier*"[Adult with CP] |  |
| **Full citation**<br>Hemsley, Bronwyn, Balandin, Susan, Togher, Leanne, Professionals' views on the roles and needs of family carers of adults with cerebral palsy and complex communication needs in hospital, Journal of Intellectual and Developmental Disability, 33, 127-136, 2008<br>**Ref Id**<br>445411<br>**Country/ies where the study was carried out**<br>Australia<br>**Study type**<br>Qualitative study<br>**Aim of the study**<br>The aims of this qualitative research were to explore the views of hospital and disability service staff on the roles and needs of family carers of adults with CP and complex communication needs in hospital<br>**Study dates** | **Sample size**<br>N = 6 Professional carers of people with CP<br>**Characteristics**<br>Sample age = range: 27--62 years (mean 43 years)<br>Male/Female (n) = 1/5<br>GMFCS 1/2/3/4-5 (n) = N/A<br>**Inclusion criteria**<br>1) professional carers who had cared for adults with CP with CCN; 2) in hospital; 3) within the past 2 years<br>**Exclusion criteria**<br>N/R (see inclusion criteria) | **Context & sample selection**<br>Participants were recruited at the hospital setting of the study<br><br>**Data collection & analysis**<br>Focus groups lasting 2 hours and videotaped, transcribed verbatim and analysed for content themes. | **Themes/categories**<br><br>**Role of unpaid/family carers**<br>Emotional support and reassurance: "*I think it's the [patient's] fear of the nursing staff, and doctors as well … they just tend to not speak to the client themselves, they just totally ignore them, thinking that "Well obviously, they don't know anything, they don't understand, they're mostly likely deaf", like you [Hannah] said, "They're dependent, they can't speak for themselves, they have no opinions of what is going to happen to them now don't realise that there is this gigantic fear factor for the client. That person is scared. Helen: [nods] Mmm. Debbie: They're somewhere where they don't want to be because they know there is no understanding for them, they know that they won't be able to communicate their needs across, and they're fearful of something else happening to them, that they're not going to — that they don't want to allow to happen.*" [Professional carers]<br>A role in supporting communication: "*Heath: It's a very discrete role, is as [a] translator. Hannah: I think too, is explaining to the staff the level of comprehension the person has. Because quite often people think if* | **Limitations**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes<br>• **Q2** Was a qualitative methodology appropriate? - Yes<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? - Unclear<br>• **Q5**: Were the data collected in a way that addressed the research issue? - Yes<br>• **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear<br>• **Q7**: Have ethical issues been taken into consideration? - Yes<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes<br>• **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - Yes<br><br>**Overall quality:** Moderate<br><br>**Other information**<br>None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| Publication date: 2008<br>**Source of funding**<br>Not reported | | | *their communication is poor, that their understanding is poor also*."[Professional carer]<br>A role in mediation, protection and advocacy: "*They're the middle person between the staff in the hospital and the patient. They're the ones there to pass on the information for the client to the nursing staff or the doctors*"[Professional carer].<br>Informing hospital staff of care techniques: "*I mean you guys* [Dianne and Debbie] *know more about your clients, than I would know as a nurse, but the* [family] *carers know more, and they're the ones I talk to when I need to know something.*"[Professional carer]<br>Providing care within the hospital culture: "*Heath: Well something like surgical ward, where, the list starts happening, your vision goes "Right I've gotta get this list happening". So there's this production line that goes … Danielle: You're thinking more of your IVs [intravenous lines] and everything else*." [Professional carers]<br>The family carer's role in providing direct care - *There was consensus across the group that the combination of these difficulties (lack of communication, lack of knowledge or experience, and fear) meant that busy hospital staff would be appreciative of any additional support and would not discourage family members from taking on a role in direct care "Helen: There was an expectation that the [family] carer will be there to do all the care. That was the expectation. To wash, to transfer, to feed … and one of the things they [nurses] said "Oh their parents come in" or "Their home care* | |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| | | | *person comes in and they do the sponging.'' Danielle: Yes, we've had that too*". [Professional carers]<br>**Professional attitudes**<br>Material supports to family carers in the hospital and facilitating collaboration: *"There's got to be some kind of teamwork built up between the carer and the staff."*[Professional carer]<br>*"Well maybe when a new shift comes on. Normally the registered nurses go out and introduce themselves, you know, [the family carer needs] to explain to them, what their role is as the carer. You know ''This is what I'd like to do, what do you see for this shift?'' and just have a discussion*. "[Professional carer]<br>Support in adapting to the culture of care on the ward - participants discussed the importance of family carers developing an understanding of the culture of care in a particular hospital ward: *"It's almost like understanding the anthropology of how this little piece* [of the hospital] *works*. [Gestures ''box'' with hands.] … *They* [carers] *need an orientation to the activity, in terms of the roles and responsibilities of the whole thing*." [Professional carer]<br>Increasing capacity of staff to provide care: "*We're working to build up a relationship with the nursing staff on the ward that the person's going to and having meetings with the staff, so they get to know this person, before they actually go in for their operation*." [Professional carer] | |
| **Full citation**<br>Hemsley, Bronwyn, Balandin, Susan, | **Sample size**<br>N = 6 Family carers of adults | **Context & sample selection**<br>Participants were recruited at the hospital setting of the study | **Themes/categories**<br><br>**Role of unpaid/family carers** | **Limitations**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| Togher, Leanne, Family caregivers discuss roles and needs in supporting adults with cerebral palsy and complex communication needs in the hospital setting, Journal of Developmental and Physical Disabilities, 20, 257-274, 2008<br>**Ref Id**<br>656888<br>**Country/ies where the study was carried out**<br>Australia<br>**Study type**<br>Qualitative study<br>**Aim of the study**<br>The aims of this qualitative research were to explore what adults with CP and complex communication needs perceive to be the role of the family carer in hospital, and what they perceive would improve the hospital experience for themselves, the family carer and hospital staff.<br>**Study dates**<br>Publication date: 2008<br>**Source of funding**<br>Not reported | with CP<br>**Characteristics**<br>Sample age = range: 32--68 years<br>Male/Female (n) = 2/4 (5 parents and 1 brother)<br>GMFCS 1/2/3/4-5 (n) = N/A<br>**Inclusion criteria**<br>1) family carers who had cared for adults with CP with CCN; 2) in hospital; 3) within the past 2 years<br>**Exclusion criteria**<br>N/R (see inclusion criteria) | **Data collection & analysis**<br>Focus groups lasting 2 hours and videotaped, transcribed verbatim and analysed for content themes. | Reassure and calm the patient: "*And* [my daughter] *was just practically going through the roof trying to breathe, and they're saying "Look we'll have to ventilate her again because she's breathing too hard." It took nearly an hour to convince this guy that she'd be* [okay], "*Just go away, walk away—I don't want to be rude, but she just needs to relax." And within an hour she was [calm]. It's just, if I hadn't been there, it's frightening."* [Family carer]<br>Help with communication: "*The thing is too I think they see people in a wheelchair and they immediately think that they don't have a brain*" [Family carer]<br>Advocate for the patient, including protecting him or her from harm and monitoring decisions made in relation to his or her medical care: "*My daughter hasn't moved for thirty years, so I hardly felt that Heparin was necessary, so I said "What are you giving her?" "Heparin." "Why? Well I don't think that's necessary." "Sorry doctor's orders." "Well send the doctor to me and we'll discuss it." "Sure, like you need to be the person's champion, you need to be there, and be the voice, and you need to definitely push your opinion across, and say, "Look, look at the whole picture … this is my loved one and the important thing is that they get what they need not just what everybody gets*".[Family carer]<br>Give information to hospital staff: "*There are so many people in the hospital, you never have the same people come, there are people coming in and out, all different shifts and everything, and they don't seem to* | • **Q2** Was a qualitative methodology appropriate? - Yes<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? - Unclear<br>• **Q5**: Were the data collected in a way that addressed the research issue? - Yes<br>• **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear<br>• **Q7**: Have ethical issues been taken into consideration? - Yes<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes<br>• **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - Yes<br><br>**Overall quality:** Moderate<br><br>**Other information**<br>None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| | | | *pass the message on … a nurse will come in, she won't know a thing about what you've told the previous nurse*."[Family carer]<br>Do everything (e.g., giving medications, helping with showering or bathing, toileting, meals, and drinks): "*On the wards, say if she's busting to go to the [toilet]… you're not allowed to use—something you do all the time, at home—the sling, to lift, a hoist. You're not allowed to do that on the ward, you have to wait 'til a nurse, or the wards person comes to help you, and you might be there for four hours … They won't let you, because of this O H & S… We just close the door and just do it ourselves. And then, they come up, and they don't mind, they think "Oh thank god she's done it I don't have to do it myself." " When we went into the main ward they have the centre desk and they had the rooms around. He was lucky to get a room on his own, so I just closed that door and I stayed the nights and did whatever I had to do for him, with the toilet and everything else.*"[Family carer]<br><br>**Logistical aspects of obtaining care**<br>Participants also focused upon what could be improved to help them in their roles: "*It would be good if you had a—oh well you [to Beth]were lucky you had a roomto sleep—but each time I've gone, I've just sat up in a chair all night because there's never a room. And if there is a room it's either on another floor or it's right down the end of the hospital which is useless*."[Family carer]<br>Supportive Hospital Policies: "*You can't pick up the chart and read, 'Oh* | |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| | | | *yes she’s had her six am medications’… It’s locked away in a cupboard. I find that difficult. That’s one of the reasons we stopped going to the wards."[Family carer] \|\|\|\| Access to Adaptive Equipment Participants indicated that improving access to appropriate adaptive equipment might help the family caregiver to position and move the patient safely: "I said “But I’m just going across there!” And they said “Well you promise me that you will bring it back.” Well, I was petrified—I was watching the sling the whole time. I took it to my room at night with me to make sure that it didn’t disappear to someone else. And then I took it back when it was all over*." [Family carer] "; “*While having the equipment helped Beth to position her son, being responsible for the equipment was an additional stress associated with caring in the hospital setting*" [Family carer] | |
| **Full citation**<br>Hilberink, S. R., Roebroeck, M. E., Nieuwstraten, W., Jalink, L., Verheijden, J. M. A., Stam, H. J., Health issues in young adults with cerebral palsy: Towards a life-span perspective, Journal of Rehabilitation Medicine, 39, 605-611, 2007<br>**Ref Id**<br>357283<br>**Country/ies where the study was carried out**<br>The Netherlands | **Sample size**<br>N = 54 Adults with CP<br>**Characteristics**<br>Sample age = range: 25-36 years<br>Male/Female (n) = 26/28<br>GMFCS 1/2/3/4-5 (n) = 15/35/4/17<br>**Inclusion criteria**<br>1) diagnosis of CP; 2) aged 25-36 years; 3) cared at the rehabilitation centre in The Hague; 4) willing to participate | **Context & sample selection**<br>Participants were recruited at the rehabilitation centre setting of the study<br><br>**Data collection & analysis**<br>**S**emi structured interviews (open ended questions) along physical examinations. Data were analysed as frequencies by means of descriptive statistics | **Themes/categories**<br><br>**Health services availability**<br>Of the 54 adults with CP:<br>• 32% visited their rehabilitation physician during the past year:<br>• 57% had physical therapy ;<br>• 28% hydrotherapy/swimming;<br>• 15% occupational therapy.<br>• 6% of the 54 adults with CP visited their dietician during the past year.<br>**Needs perceived from patients**<br>Of the 54 adults with CP:<br>• 94% usually felt healthy;<br>• 25% indicated that their activities were limited by their | **Limitations (Newcastle Ottawa quality assessment scale - adapted for cross sectional studies)**<br><br>• **Selection**: Low risk of bias<br>• **Comparability**: not applicable<br>• **Outcome**: Unclear risk of bias<br><br>**Overall quality:** Unclear<br><br>**Other information**<br>None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| **Study type**<br>Cross-sectional study/survey<br>**Aim of the study**<br>The aims of this qualitative research were to explore which impairments and health problems were present in a sample of adults with CP; to assess the utilization of healthcare by adults with CP to explore associated factors; and to establish which conditions rehabilitation physicians in adult rehabilitation care recognize as CP-related.<br>**Study dates**<br>Publication date: 2007<br>**Source of funding**<br>Sophia Fund of Sophia Rehabilitation in The Hague, the Netherlands and Erasmus MC – University Medical Centre Rotterdam, the Netherlands | **Exclusion criteria**<br>N/R (see inclusion criteria) | | health problems;<br>• 33%felt worried about their health.<br>**Physical and medical needs**<br>The most frequently conditions were in order:<br>• pain (59%, n=32 of 54);<br>• joint deformities (15-57%, n=8-31 of 54);<br>• vision impairments (22%, n=12 of 54);<br>• speech impairments (20%, n= 11 of 54);<br>• swallowing (19%, n=10 of 54);<br>• nd medication for epilepsy (17%, n=54).<br>Adults with pain more frequently consulted their rehabilitation physician compared with adults without pain [OR = 4.9 (95% CI 1.2–20.1)]<br>“A large decrease in the utilization of healthcare is observed after discharge from paediatric rehabilitation." [data no shown] | |
| **Full citation**<br>Jonsson, G., Ekholm, J., Schult, M. L., The International Classification of Functioning, Disability and Health environmental factors as facilitators or barriers used in describing personal and social networks: a pilot study | **Sample size**<br>N = 16 Adults with CP<br>**Characteristics**<br>Sample age = range: 23-61 years (mean 32 years)<br>Male/Female (n) = 7/9<br>GMFCS 1/2/3/4-5 (n) = N/R<br>Diagnosis (n): - | **Context & sample selection**<br>Participants were recruited at the rehabilitation centre setting of the study, and were selected at random.<br><br>**Data collection & analysis**<br>Both structured and semi-structured interviews, lasting about 1.5 hours and conducted at the place of residence. The interview guide included seven demographic questions and 22 structured | **Themes/categories**<br><br>**Role of unpaid/family carers**<br>73% adults with CP (n=22 of 30) felt their ‘immediate and extended family’ network that gave physical or social support: “*the participants received support and help with personal care, cooking, housework and managing their financial affairs, during weekends when there were vacancies in the staff group and when visiting the parental* | **Limitations (CASP- checklist for qualitative studies)**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes<br>• **Q2** Was a qualitative methodology appropriate? - Yes<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? - Yes<br>• **Q5**: Were the data collected in a way that addressed the research issue? - No |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| of adults with cerebral palsy, International Journal of Rehabilitation Research, 31, 119-29, 2008<br>**Ref Id**<br>340202<br>**Country/ies where the study was carried out**<br>Sweden<br>**Study type**<br>Qualitative study<br>**Aim of the study**<br>The aim of this qualitative research was to explore the social networks involved in the everyday lives of adults with CP. A further aim was to describe how far these adults experienced the contacts within these networks as facilitators or barriers.<br>**Study dates**<br>Publication date: 2008<br>**Source of funding**<br>Not reported | Diplegia= 11; -Tertraplegia= 1; -Dyskinesia= 4<br>**Inclusion criteria**<br>1) resident in Stockholm County; 2) had an extensive functional disability judged by whether they were confined to a wheelchair, entirely/partly indoors and entirely outdoors; 3) no documented mental retardation; 4) understanding of the Swedish language; 5) and the ability to put forward their views themselves.<br>**Exclusion criteria**<br>N/R (see inclusion criteria) | questions: 'Support and Relationships'; 'Attitudes'; 'Service, Systems and Policies' .Data were analysed by means a quantitative descriptive analysis. | *home. Many perceived help from parents as a barrier, in that they were being overprotected*" [Author quote]<br>**Professional attitudes**<br>All the participants (30 of 30) experienced health professionals as facilitators.<br>Barriers: *they did not get the help they wished for or that they noted shortcomings in the staff's knowledge of the participant's CP damage. One barrier participants reported was that health care personnel were in such a hurry that they seemed to have no time to listen. A number of participants stated that it could be hard to make themselves understood to the health care providers, and that on such occasions the staff elected to talk with the personal assistant instead.* [Author quote]<br>**Logistical aspects of obtaining care**<br>Transport services: "*All the participants used the mobility service, but this was perceived as both a facilitator and barrier. It was viewed as a 'necessary evil', a barrier when the vehicles did not arrive on time but a facilitator when they did. ….*"[Author quote] | • **Q6**: Has the relationship between researcher and participants been adequately considered? – No<br>• **Q7**: Have ethical issues been taken into consideration? - Yes<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes<br>• **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - Unclear<br><br>**Overall quality:** low<br><br>**Other information**<br>None |
| **Full citation**<br>Morgan, P., Pogrebnoy, D., McDonald, R., Health service experiences to address mobility decline in ambulant adults ageing with cerebral palsy, Journal of Intellectual & Developmental Disability, 39, 282-289, 2014 | **Sample size**<br>N = 6 Adults with CP<br>**Characteristics**<br>Sample age = range: 35-52 years (mean 46 years)<br>Male/Female (n) = 6/0<br>GMFCS 1/2/3/4-5 (n) = 0/3/3/0<br>**Inclusion criteria** | **Context & sample selection**<br>Participants were recruited via a number of organizations providing services to individuals with CP. All individuals respondent with the inclusion criteria were contacted.<br><br>**Data collection & analysis**<br>Semi structured interviews (open ended questions) lasting 1 hour conducted in a mutually convenient location. The interview was | **Themes/categories**<br>**Professional attitudes**<br>Health service accessed perceived as unsatisfactory due to perceived inadequate expertise and knowledge of those providing the service: *"I was in pain and there was just nowhere I could go and nothing I could do to address it. The only thing that was really on offer for me was painkillers and that was completely inappropriate for what my needs were."* [Adult with | **Limitations**<br>**Limitations (CASP- checklist for qualitative studies)**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes<br>• **Q2** Was a qualitative methodology appropriate? - Yes<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? - No<br>• **Q5**: Were the data collected in a way that |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| **Ref Id**<br>675543<br>**Country/ies where the study was carried out**<br>Australia<br>**Study type**<br>Qualitative study<br>**Aim of the study**<br>The aims of this qualitative research were to explore the experience and impact of health service access to address mobility change in adults ageing with CP<br>**Study dates**<br>Publication date: 2014<br>**Source of funding**<br>Monash University Peninsula Campus | 1) adults living in the community with CP; 2) of any subtype; 3) aged 35 – 65 years; 4) at GMFCS–Extended and Revised Level I–III<br>**Exclusion criteria**<br>1) cognitive impairment precluding the ability to participate in a conversation; 2) and informed consent not provided | organized as follows: a-Experiences in adult health services; b-Suitability of health services accessed; c-Barriers and facilitators to health service access; and d- perceptions of efficacy of any strategies/interventions offered to address mobility and balance changes. | CP]<br>lack of engagement with the service due to perceptions of insufficient skills: “*to tell you the truth, I can’t be bothered telling my whole life story to someone who doesn’t have the skills to help me*”[Adult with CP]; "“*it is tiring and somewhat frustrating having to tell my whole life story to physiotherapists who I don’t feel have the training to be able to help individuals like me*”[Adult with CP]; “*my physio has been fantastic for my back pain, it is much better now but she says that she doesn’t know enough about CP to be able to help me further*”[Adult with CP]<br>**Health services availability and suitability**<br>Suitability of available health services - Participants commented on a perceived lack of suitability of what was offered in general by the service: “*Unfortunately community-based services are not well set up to effectively treat people with a neurological condition*”[Adult with CP]. Some felt that the specific treatment proposed was not appropriate for their overall condition and needs: "*I know what it’s like to be singled out, I know what it’s like to be stared at, commented on, there’s no way I was joining a mainstream Pilates program where it can be potentially quite competitive almost. There was just no way. I didn’t have confidence in my own ability*"[Adult with CP]; "*I found it difficult to keep the program up on my own. I would have been more successful had I been involved in a structured program where I have to attend weekly—this way I have a commitment and there is a greater* | addressed the research issue? - Yes<br>• **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear<br>• **Q7**: Have ethical issues been taken into consideration? - Yes<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes<br>• **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - Unclear<br>**Overall quality:** low<br>**Other information**<br>None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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|  |  |  | *chance I would get it done*"[Adult with CP]<br>**Logistical aspects of obtaining care**<br>Health service costs and transport - : "*So what I'm finding frustrating is…I said I wanted to go to Hydro, because Hydro helps with pain and so forth. I got to go twice, and the physiotherapist said "oh, you're so self-sufficient. You don't need to come anymore. You can just go off and do it yourself." And I really liked going to the group, because it was a set time, and I could book a taxi at that time, and once it's booked in, you know they're going to come and get you, and take you back."* [Adult with CP] ; "*I mean if someone tells me something, then I'll do it, but I've got to be able to afford it and I've got to be able to get there, and then have the energy to get there and then take off or put on whatever they want to do and do whatever they say and then get home again and survive"* [Adult with CP].<br>Difficulties with the physical access of the facility due to inaccessible car parking locations, stair access, or inability to navigate the narrow passageways and doorways: "*People with disabilities can't go to a gym generally because they either can't get there, can't get in the door…*" [Adult with CP]<br>**Needs perceived from patients**<br>Frustration: ""*It seems as though they put all this effort into children with CP and then give up on us when we become adults!" and "I was really frustrated with what was available to me"[Adult with CP].* \|\|\|\| *"this is not your life, it's not everybody's life so if it's not everybody's life then why do we have* |  |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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|  |  |  | *to do it so hard?*" [Adult with CP]<br>Perceived control - Maintaining control of their independence and control of any service or therapy provided was highly valued by participants: "*I was offered a carer who was going to come in and help me with my shower and stuff; however, they could only come for six weeks—what's the point of that? I said no thanks…"[Adult with CP]; "I had always resisted using anything to help my walking.…I wanted to be the one to make a decision about what I used and when*" [Adult with CP]<br>The need for self-advocacy: Participants described an ongoing need for self-advocacy to optimise health service access, type, and delivery: "*But what's urgent to you and what's urgent to them often don't meet. So you have to fight, fight, fight." [Adult with CP]; "Because a lot of physiotherapists don't actually think that somebody with mild CP is worth their time, that's the reality. There's so much about our condition that it's like "why bother, they're up on their feet, they've got a job, they're contributing, they're paying taxes.*" [Adult with CP]<br>The need to take ownership for wellbeing: "I *found I had to learn a lot myself and now feel like I know enough. I do my own research as well*"[Adult with CP]<br>**Annual review/regular check-up**<br>Lack of continuity with the adult health service providers, and the extended time required to establish a therapeutic relationship, which negatively impacted on time available for treatment: "*The physiotherapists change a lot, and you might get a* |  |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| | | | *couple of months with one physiotherapist, and then you have to start with another. And that means you’re constantly going over your story, so that each of these physiotherapists can get a handle on where you’re at.…They can only see you for a short period of time, because their services are in such demand, I feel that you’re wasting a lot of time, having to go continually over your story, because that’s one session gone*"[Adult with CP]; "*It takes a while when you have a disability because they have to get to know the person and the disability and how the disability affects your life. So it’s not simple and it will take him [GP] a while to figure out what he should do and how he should do it*." [Adult with CP]<br>Feeling “abandoned” by the health service since becoming an adult: “*And people seem to forget that…kids grow up and they become adolescents and they become adults. Just because they become adults doesn’t mean their condition goes away, it’s still there*” [Adult with CP] | |
| **Full citation**<br>Mudge, S., Rosie, J., Stott, S., Taylor, D., Signal, N., McPherson, K., Ageing with cerebral palsy; What are the health experiences of adults with cerebral palsy? A qualitative study, BMJ Open, 6 (10) (no pagination), 2016<br>**Ref Id**<br>587201<br>**Country/ies where the** | **Sample size**<br>N = 28 Adults with CP<br>**Characteristics**<br>Sample age = range: 37-70 years (mean 47 years)<br>Male/Female (n) = 14/14<br>GMFCS 1/2/3/4-5 (n) = 0/5/8/15<br>Diagnosis (n): - Diplegia= 2; - Hemiplegia= 5; - | **Context & sample selection**<br>Participants were recruited via non-governmental CP organisation, advertisements on disability services web sites and a paid advertisement in a rural community newspaper. All individuals respondent with the inclusion criteria were contacted.<br><br>**Data collection & analysis**<br>Face-to-face semi structured interviews lasting 2 hours were undertaken with data systematically | **Themes/categories**<br><br>**Ageing process**<br>Taking charge of help - Changes with ageing led many participants to reflect on a new or increased need to receive help: *"Now, what is it about families that they don’t listen to what you’re telling them? I mean, that also is more of a hindrance than your disability*"[Adult with CP]; "*I need some, some things done for me but that’s different from “I need to be taken care of”. I don’t need 24 hour care, I* | **Limitations (CASP- checklist for qualitative studies)**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes<br>• **Q2** Was a qualitative methodology appropriate? - Yes<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? – Yes<br>• **Q5**: Were the data collected in a way that addressed the research issue? - Yes<br>• **Q6**: Has the relationship between researcher and participants been adequately considered? - |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| **study was carried out**<br>New Zealand<br>**Study type**<br>Qualitative study<br>**Aim of the study**<br>The aims of this qualitative research were to explore experiences of ageing in the context of CP; and to explore participants' experiences in healthcare encounters and to consider how health services could be improved to assist health and well-being across the adult lifespan.<br>**Study dates**<br>Publication date: 2016<br>**Source of funding**<br>New Zealand Lottery Health Research Grant (265357) | Quadriplegia= 18;<br>- unspecified= 3<br>**Inclusion criteria**<br>1) adults with CP aged 35 years or older; 2) who had lived in NZ for 15 years or more<br>**Exclusion criteria**<br>1) unable to understand or communicate in English; 2) unable (with assistance) to take part in an interview | coded and interpreted by grouping information into categories. Following exploratory questions around the participant ' s current situation, questions focused on the participant ' s experiences of ageing in the context of CP and experiences with health and disability services. | *don't need people making decisions for me, I don't need people putting me on programmes where I can go and socialise because I can go down the [pub] and do that*."[Adult with CP]; *"I've learnt over the years to not be meek and mild, to actually speak up otherwise you're just going to get sort of forgotten. So you've got to learn even though it's hard, especially if speech is a problem, to actually speak up for yourself or get someone to assist you."* [Adult with CP]<br>Rethinking the future: *"My fear is it's going to be harder—that's my fear, and I'm going to have some person who comes by and dresses me and puts me together and but…there's this determination there that no, it's not to be that way—I'm going to stay as fit and as mobile as I possibly can till the day I cark it.*" [Adult with CP]; "*Mum ran out of puff. When I played [sport] I needed a full time carer…no other carer available so that job also fell to Mum to fit into my 24 hour care. I am still unable to get other assistance so I am not able to access [my sport] anymore*." [Adult with CP]<br>**Health Beliefs**<br>Acceptance of change -: "*I think that having a disability and the fact that your body takes such a hiding, for want of a better word, on joints and things over the years because of that disability that the ageing process is probably quicker for someone with a disability than someone who is able bodied*."[Adult with CP]; "*I think it's part of ageing; I know everyone who ages slows down but I think people with CP do at a younger age than most people. Mainly, I think, from forcing my body* | Unclear<br>• **Q7**: Have ethical issues been taken into consideration? - Yes<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes<br>• **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - Unclear<br><br>**Overall quality:** Moderate<br><br>**Other information**<br>None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| | | | *over its physical limits; I think that's the main cause*"[Adult with CP]<br>Exploring identity: *"I've always…been as, if you like, 'normal' as possible and that's the challenge that I'm finding, as I get older, that that kind of perspective is not working anymore. And I don't know how to bridge that gap between "this is who I am" and "this is me with CP*." [Adult with CP]; "*It's an interesting dichotomy for me because, you know, I'm, I'm in my nature I'm successful but I'm not a, you know, I'm also, I'm, I'm what's the word? I'm, I am irresponsible and I'm disabled (laughs). You know, and I enjoy that about me but I'm at the point now, because of my CP, and probably because of my age, but I think my CP is making me think about this stuff*" [Adult with CP]; "*I just think when you get into your 40s you're in this really neat time of your life where you just don't worry so much like you did when you were 20 and 30—you just think, well I don't care, I need this so I'm going to make it happen. I now don't worry so much about my body image as I did when I was that age say, you know, and so that, that's something else I don't worry about anymore so maybe I've got more energy to put into the "I need this to happen so how can I make it happen?"*[Adult with CP]<br>**Professional attitudes**<br>Experiences with health professionals were mixed - positive: "*Oh my GP is really cool, because he gets right down to what you've got and he looks after us. He asks you how you've been and what have you been doing and he has a full conversation before he asks you what's wrong*." [Adult with CP] | |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| | | | Negative experiences: "*[The neurologist] tested my reflexes and stuff… and, you know, I was under a lot of stress at the time but I just, I just felt like I didn't have a relationship—it was like he didn't see me and I wanted him to see me*."[Adult with CP]; "*I got so um anxious and panicked, I was panicking that I had to go into hospital. But when, but when I got into hospital they didn't want to know about my um my panic attacks, they discovered there was something wrong with my bowel. And I was in there because I was panicking, having panic attacks and they never did anything about that part. They just, they just concentrated on the bowel."[*Adult with CP];<br>Interacting with health professionals: "*It's just they seem to see disability and if they haven't had very much experience of it they seem to go on the offensive [sic]. Like, you know, "I don't really want to deal with this—it's not an area that I know about so I'll walk off and leave it to whoever else is next after me*. [Adult with CP]"; "*Some occupational therapists think that they're god and think that they know it all and think that they're right and ah no turning around, "Yeah I'm right, you're wrong, this is how it's going to be*."[Adult with CP] | |
| **Full citation**<br>Nieuwenhuijsen, Channah, van der Laar, Yvette, Donkervoort, Mireille, Nieuwstraten, Wilbert, Roebroeck, Marij E., Stam, Henk J., Unmet needs and health care utilization in young | **Sample size**<br>N = 29 adults with CP<br>**Characteristics**<br>Sample age = range: 16-40 years (mean 28 years)<br>Male/Female (n) = 19/10 | **Context & sample selection**<br>Participants were recruited at the 2 rehabilitation centres setting of the study. All individuals respondent with the inclusion criteria were contacted.<br><br>**Data collection & analysis**<br>Postal questionnaires on unmet | **Themes/categories**<br>**Education, ageing and socio-cultural characteristics**<br>No relations were found between healthcare utilization (i.e. treatment by a rehabilitation physician or physical therapist) and age, gender or level of education of the adults with CP (ρ [rho-Spearman's rank correlation | **Limitations (Newcastle Ottawa quality assessment scale - adapted for cross sectional studies)**<br><br>• **Selection**: Low risk of bias<br>• **Comparability**: not applicable<br>• **Outcome**: Unclear risk of bias<br><br>**Overall quality:** Moderate |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| adults with cerebral palsy, Disability and Rehabilitation: An International, Multidisciplinary Journal, 30, 1254-1262, 2008<br>**Ref Id**<br>445381<br>**Country/ies where the study was carried out**<br>The Netherlands<br>**Study type**<br>Cross-sectional study/survey<br>**Aim of the study**<br>The aims of this survey research were to explore the unmet needs and utilization of health care of adults with CP and to explore relations between unmet needs, health care utilization and subject characteristics<br>**Study dates**<br>Publication date: 2008<br>**Source of funding**<br>Netherlands Organization for Health Research and Development (grant: 1435.0011) and Children's Fund Adriaanstichting (KFA grant: 01.08.06) | GMFCS 1/2/3/4-5 (n) = 15/4/3/7<br>Diagnosis (n): - Diplegia= 7; - Hemiplegia= 8; - Quadriplegia= 14<br>**Inclusion criteria**<br>1) adults with CP, aged 16-40 years; 2) admitted at the paediatric or adult department of a rehabilitation centre in the Netherlands<br>**Exclusion criteria**<br>1) severe learning disabilities (IQ<70); 2) inadequate language comprehension to fill out the questionnaires; 3) additional diagnosis with lasting effects on motor functioning | needs and health care utilization were sent to all eligible subjects. Data were analysed by means of descriptive statistics | coefficient] not statistically significant for any variable)<br><br>**Health services availability and suitability**<br>Of the 29 adults with CP:<br>• 68% visited their physical therapist during the past year (n= 20 of 29 adults with CP)<br>• 52% visited their rehabilitation physician during the past year (n= 15 of 29 adults with CP)<br>• 32% visited social services during the past year (n=9 of 29 adults with CP)<br>• 28% their occupational therapist (n=8 of 29 adults with CP)<br>• 7% of the 54 adults with CP visited their dietican during the past year (n= 2 of 29 adults with CP)<br><br>**Physical and medical needs**<br>Relations were found between adults with CP characteristics and utilization of health care services:<br>• Adults with CP lower levels of gross motor functioning visited a rehabilitation physician and a physical therapist more than participants with higher levels of gross motor functioning (ρ [rho-Spearman's rank correlation coefficient] = 0.44 and 0.55 with a p-value< 0.05 respectively [rehabilitation physician, physical therapist]).<br>• Similar results were found for the orthopaedist, | **Other information**<br>None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
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| | | | occupational therapist and speech therapist (data not reported).<br>More adults with CP with a quadriplegia compared to those with a hemiplegia visited a rehabilitation physician or physical therapist (data not reported)<br>**Annual review/regular check-up**<br>Of the 29 adults with CP:<br>• 69% (n=20) mentioned to "Getting more physiotherapy" and "discontinuity between paediatric and adult care<br>**Information - communication needs**<br>79% of the study sample (n= 22 of 29 adults with CP) reported at least one unmet need for information (e.g., information on complications of CP, on consequences of CP and on causes of CP) | |
| **Full citation**<br>Read, S. A., Morton, T. A., Ryan, M. K., Negotiating identity: a qualitative analysis of stigma and support seeking for individuals with cerebral palsy, Disability & Rehabilitation, 37, 1162-9, 2015<br>**Ref Id**<br>416418<br>**Country/ies where the study was carried out**<br>UK, Australia, New zeland, USA<br>**Study type**<br>Qualitative study<br>**Aim of the study**<br>The aim of this | **Sample size**<br>N = 28 Adults with CP<br>**Characteristics**<br>Sample age = range: 17-58 years (mean 32 years)<br>Male/Female (n) = 5/22<br>GMFCS 1/2/3/4-5 (n) = 6/13/6/3<br>Country (n): UK=15; USA=6; Australia=6; NZ=1<br>**Inclusion criteria**<br>N/R<br>**Exclusion criteria**<br>N/R | **Context & sample selection**<br>No details were given on the recruitment process.<br><br>**Data collection & analysis**<br>Open-ended questions within an online survey that was advertised through a number of social networking pages aimed at people with CP. The survey took between 30–45 minutes to be completed, and was articulated in 4 sections: 1- demographic m information; 2- support received to access health services; 3- perceived stigma in receiving support to access services; 4- personal importance of their identity as an adult with CP, and the extent to which they saw themselves primarily as an individual or in more social terms; 5- | **Themes/categories**<br><br>**Health Beliefs**<br>The majority of participants were aware of the stigma associated with their condition and believed stigma to be a fundamental reason why adults with CP may not seek the support they need:" *stigma has always been a barrier to many of us because of our CP"*[Adult with CP]; "*Yes, people with CP do experience problems due to stigma. We are often seen as unable to talk for ourselves and we are not given the opportunity to orchestrate our own care needs.*"[Adult with CP Acknowledging they needed to access desired support: "*I feel the fact that I need so much support marks me out as different from other people*."[Adult with CP]; " *I feel that we have to battle* | **Limitations (CASP- checklist for qualitative studies)**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes<br>• **Q2** Was a qualitative methodology appropriate? - Yes<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? - Unclear<br>• **Q5**: Were the data collected in a way that addressed the research issue? - Yes<br>• **Q6**: Has the relationship between researcher and participants been adequately considered? - Yes<br>• **Q7**: Have ethical issues been taken into consideration? - Unclear<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes |

| Study details | Participants | Methods | Outcomes and Results | Comments |
|---|---|---|---|---|
| qualitative research was to explore how adults with CP construct their personal and social identities in the face of stigma when support seeking.<br>**Study dates**<br>Publication date: 2015<br>**Source of funding**<br>Economic and Social Research Council studentship (Grant: ES/J50015X/1). | | to describe whether this social identity influenced their personal support-seeking behaviour. | *to receive this support . . . because each time I try to access support I have to justify myself*" [Adult with CP]; "*I do not look like I have "[Cerebral] Palsy". It's a very [unhelpful] label in my case. Because people don't think I should have a blue badge [disabled car parking permit] or use a disabled toilet and they sometimes wonder why I get any help at all.*"[Adult with CP]<br>In order to access desired support, adults with CP had to incorporate their social identity as similar to other disabled people, which led to stigmatization through feelings of difference to the non-disabled: "*I seek support because of my individual needs and requirements independently and not because I identify with other adults with CP.*" [Adult with CP]; "*If a method of support has been useful to a friend with CP, I would be more likely to try it, but a lot of the support I receive is individualised and necessary for me to perform basic daily tasks.*"[Adult with CP]; "*I find myself in an advocate/advisor role - informing other younger people about types of services they may be able to access.";* *"it is important to me to share my struggles with the hope of saving others from struggles as well.*" [Adult with CP]<br>**Professional attitudes**<br>Providers had a general lack of awareness of the problems associated with CP .. .. As a consequence, they had to acknowledge inappropriate attitudes towards them and their ability: "*I hate [how] people have to be explained to about my* [disability]"[Adult with CP]; "*I* [find] | - **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - Unclear<br>**Overall quality:** Unclear<br>**Other information**<br>None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
|---|---|---|---|---|
| | | | *people's attitudes towards CP frustrating"; "GP's do not understand what hemiplegia* [a specific type of CP] *is - there is not enough awareness of it - I find myself having to explain it to medical professionals who look at me confused* (sic)"[Adult with CP] | |
| **Full citation**<br>Russell, G. M., Kinirons, M. J., A study of the barriers to dental care in a sample of patients with cerebral palsy, Community Dental Health, 10, 57-64, 1993<br>**Ref Id**<br>340990<br>**Country/ies where the study was carried out**<br>UK<br>**Study type**<br>Cross-sectional study/survey<br>**Aim of the study**<br>The aim of this survey research was to explore the potential barriers to dental care in adults with CP.<br>**Study dates**<br>Publication date: 1993<br>**Source of funding**<br>Health and Social Care in Northern Ireland (HSC) | **Sample size**<br>N = 57 people with CP*<br>**Characteristics**<br>Sample age =range: 16-50 years<br>Male/Female (n) =35/22<br>GMFCS 1/2/3/4-5 (n) =N/A<br><br>**Inclusion criteria**<br>1) People with cerebral palsy 2) >16 years of age 3) Those attending day facilities at the study setting.<br>**Exclusion criteria**<br>1) Adults with cerebral palsy in mainstream education 2) Adults with cerebral palsy in regular employment | **Context & sample selection**<br>Participants were recruited at the day facilities setting of the study in Northern Ireland.<br>**Data collection & analysis**<br>12 item closed questionnaire completed with help of member of staff | **Themes/categories**<br>**Perceived barriers to dental care:**<br>• 30% reported no barriers<br>• 23% reported one barrier<br>• 25% reported two barriers<br>• 22% reported three or more barriers<br>• 30%(n=17) reported anxiety/fear<br>• 30%(n=17) indicated the need to be accompanied<br>• 26%(n=15) did not like/want dental treatment<br>• 19% (n=11) reported difficulty getting into surgery/chair<br>• 19% (n=11) reported difficulties with transport<br>• 19% (n=11) reported difficulties with communication<br>• 18% (n=10) feared that the dentist won't understand their disability<br>• 14% (n=8) experienced difficulty with cooperation<br>• 9% (n=5) did not know a suitable dentist<br>• 5%(n=3) perceived cost as a barrier<br><br>**Perceived barriers and regularity of dental attendance :**<br><br>Regular Attendance (n=34) | **Limitations (Newcastle Ottawa quality assessment scale - adapted for cross sectional studies)**<br>• Selection:<br>1) Representativeness of the sample: *(all subjects)<br>2) Sample Size: Not justified<br>3) Non respondents: * (response rate is satisfactory)<br>4) Ascertainment of exposure: **<br>• Comparability: Not applicable<br>• Outcome:<br>1) Assessment of outcome: * self report<br>2) Statistical test: *appropriate for the measurement of association<br><br>**Overall quality:** *****<br><br>**Other information**<br>*only 23 of the 57 included people was aged more than 25 years (the 41% of the study sample, 59% of people were aged 16--25 years) |

| Study details | Participants | Methods | Outcomes and Results | Comments |
|---|---|---|---|---|
| | | | 8 reported anxiety<br>10 expressed need to be accompanied<br>5 disliked treatment<br><br>Irregular Attendance(n=23)<br>9 reported anxiety<br>7 expressed need to be accompanied<br>10 disliked treatment<br>There was only a weak and statistically insignificant relationship between admission of anxiety and need to be accompanied as potential barriers and the regularity of dental attendance. Dislike of dental treatment as a barrier was significantly more likely to be reported by irregular attenders. | |
| **Full citation**<br>Sandstrom, K., Samuelsson, K., Oberg, B., Prerequisites for carrying out physiotherapy and physical activity - experiences from adults with cerebral palsy, Disability & Rehabilitation, 31, 161-9, 2009<br>**Ref Id**<br>437111<br>**Country/ies where the study was carried out**<br>Sweden<br>**Study type**<br>Qualitative study<br>**Aim of the study**<br>The aims of this qualitative research were to explore how adults with CP experience physiotherapy and | **Sample size**<br>N = 22 Adults with CP<br>**Characteristics**<br>Sample age = range: 35-58 years (mean 47 years)<br>Male/Female (n) = 12/10<br>GMFCS 1/2/3/4-5 (n) = 0/7/7/8<br><br>**Inclusion criteria**<br>1) adults with CP aged 35+ years; 2) GMFCS level II–IV<br>**Exclusion criteria**<br>1) GMFCS level I, V | **Context & sample selection**<br>Participants were recruited from 5 counties in Sweden and selected by rehabilitation professionals who had knowledge of the population.<br><br>**Data collection & analysis**<br>Semi structured interviews (open ended questions), informal and lasting between 45-90 minutes. Interviews were tape-recorded and transcribed verbatim. The data was analysed using qualitative content analysis | **Themes/categories**<br>**Health services suitability**<br>Being enjoyable, giving effects, being comprehensible, and integrated in daily life were felt as the prerequisites for carrying out physiotherapy and physical activity by adults with CP:<br>• Being enjoyable: "*You get away from everything around you at home, so you can totally focus your energy on just training. ( ) And you get away from phones and a lot of mobility service and driving to and fro – you are simply there.* "*; . . . and preferably enjoyable! . . . It has to be enjoyable and not so laborious, but it's laborious nevertheless.*"[Adult with CP];<br>• Giving effects - *The experienced effects of physical activity could vary: "But I found out, as I was at one of those rehabilitation centres ( ), that if you do too much then things backfire. ( ) . . . you find that you get better, but that's up to a* | **Limitations (CASP- checklist for qualitative studies)**<br>• **Q1** Was there a clear statement of the aims of the research? - Yes<br>• **Q2** Was a qualitative methodology appropriate? - Unclear<br>• **Q3** Was the research design appropriate to address the aims of the research? - Yes<br>• **Q4** Was the recruitment strategy appropriate to the aims of the research? - Yes<br>• **Q5**: Were the data collected in a way that addressed the research issue? - Yes<br>• **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear<br>• **Q7**: Have ethical issues been taken into consideration? - Yes<br>• **Q8**: Was the data analysis sufficiently rigorous? - Yes<br>• **Q9**: Is there a clear statement of findings? - Yes<br>• **Q10**: - Is valuable the research in terms of generalizability of its findings and conclusions? - Unclear<br><br>**Overall quality:** Moderate |

| Study details | Participants | Methods | Outcomes and Results | Comments |
|---|---|---|---|---|
| physical activity in a perspective from childhood to adulthood; and how personal and environmental factors influence possibilities for physiotherapy and physical activity.<br>**Study dates**<br>Publication date: 2009<br>**Source of funding**<br>Norrbacka-Eugenia Foundation, Stockholm; The Swedish Association of persons with neurological Disabilities; The Swedish Association of Registered Physiotherapists/Section of Neurology. | | | *certain level. . and then things turn around*. "[Adult with CP]; "*Well I don't know . . . I don't feel it helps or anything but . . . people round about me say I'm walking more steadily and am not flapping my arms about . . . but I don't know*."[Adult with CP]<br>• Being comprehensible - "*Do they mean I'll be like my brother . . . I'll be able to jump and walk ( ) and then you realise things will never really be like that." [Adult with CP]; "I'm more motivated because I know why I'm doing it. I want to try and avoid future problems, so to speak*."[Adult with CP];<br>• Being integrated in daily life - *In adulthood, the relation between time-consuming daily living and physical training can be difficult and many hindrances must be limited: "To be honest, I don't need to do training because I feel my body copes . . . I get enough exercise and I do a lot in my everyday life . . . so I get the exercise I need*" [Adult with CP]; "*And then it's hard to do things yourself. Managing movements and so on . . . and at home, with my husband for example, he's so tall and. . .. ( ). Where can you go to train? You can't do it in bed. He'd break his back"*.[Adult with CP]<br>**Annual review/regular check-up**<br>Barriers related to the structure in healthcare and rehabilitation. The experience of a vacuum after leaving the paediatric rehabilitation was | **Other information**<br>None |

| Study details | Participants | Methods | Outcomes and Results | Comments |
|---|---|---|---|---|
| | | | managed in different ways: "*nobody has the time to find out how the body feels . . . and what kind of incorrect load it is*"[Adult with CP]; "*The difficult thing I've felt, it's having been too well to get help and not well enough to manage completely on my own, so you sort of end up between two stools*";[Adult with CP]<br>Even though the informants want to have continuity in their contacts with healthcare, they are most often offered insufficient or no follow-up in adulthood: "*Well, you need someone giving you a jog. It's like going to the dentist. It's easier for the dentist to send out a bit of paper and contact me about a new appointment than for me to ring them, because you receive a bit of paper . . . and you have to do it. ( ) . . . and you get appointments . . . so you don't get forgotten*."[Adult with CP] | |

*AAC: augmentative and alternative communication; CASP: critical appraisal skills programme; CP: cerebral palsy; GMFCS: Gross Motor Function Classification System; N: number of participants in study; N/R: not reported;*

# Appendix E – Forest plots

Forest plots for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

There are no forest plots for this topic.

# Appendix F – GRADE tables

GRADE tables for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

See full GRADE-CERQual in the body of the evidence review.

# Appendix G – Economic evidence study selection

Economic evidence study selection for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

No economic evidence was identified.

# Appendix H – Economic evidence tables

Economic evidence tables for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

No economic evidence was identified for this review.

# Appendix I – Health economic evidence profiles

Health economic evidence profiles for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

No economic evidence was identified for this review.

# Appendix J – Health economic analysis

Health economic analysis for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

This is not applicable because no economic analysis was conducted for this review.

# Appendix K – Excluded studies

Clinical and economic lists of excluded studies for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

## Clinical studies

**Table 20: Excluded clinical studies for access to care**

| **Excluded studies – F2 What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?** | |
|---|---|
| **Study** | **Reason for Exclusion** |
| Bagatell, N., Chan, D., Rauch, K. K., Thorpe, D., "Thrust into adulthood": Transition experiences of young adults with cerebral palsy, Disability and Health Journal, 10, 80-86, 2017 | This study evaluates transition to adulthood, the gradual change in roles and responsibilities, is identified as a challenging time for adolescents and young adults with physical disabilities, including those with cerebral palsy |
| Balogh, R., McGarry, C., McMorris, C., Lake, J., Dobranowski, K., Wilton, A., Fehlings, D., Bayley, M., Lunsky, Y., Chronic diseases and healthcare utilization in persons with cerebral palsy and intellectual disabilities, Journal of Intellectual Disability Research, 60, 633-633, 2016 | Conference abstract - not enough information to assess the risk of bias and the applicability of the study findings |
| Beatty, P. W., Hagglund, K. J., Neri, M. T., Dhont, K. R., Clark, M. J., Hilton, S. A., Access to health care services among people with chronic or disabling conditions: patterns and predictors, Archives of Physical Medicine & Rehabilitation, 84, 1417-25, 2003 | No population - This aim of this survey research were to explore health and health care issues pertinent to adults with CP in Australia; to explore issues of access to information and to investigate the perceptions on ageing process. Only 11% of the overall study participants were adults with CP (110 out 800) |
| Bjorquist, E., Nordmark, E., Hallstrom, I., Parents' Experiences of Health and Needs When Supporting Their Adolescents With Cerebral Palsy During Transition to Adulthood, Physical & Occupational Therapy in Pediatrics, 36, 204-16, 2016 | No relevant population and aim - The aim of this study was to observe of how parents of adolescents with CP experience their own health and wellbeing and their needs for support during the adolescents transition to adulthood. Included people: parents of 10 adolescents with CP aged 17-18 years |
| Boucher,N., Dumas,F., Maltais,D.B., Richards,C.L., The influence of selected personal and environmental factors on leisure activities in adults with cerebral palsy, Disability and Rehabilitation, 32, 1328-1338, 2010 | No relevant - this study examined the influence of selected personal and environmental factors on leisure participation in adults with CP |
| Buran, C. F., Sawin, K., Grayson, P., Criss, S., Family needs assessment in cerebral palsy clinic, Journal for Specialists in Pediatric Nursing: JSPN, 14, 86-93, 2009 | No relevant population - this study included parents of children with CP |
| Dambi, J. M., Jelsma, J., The impact of hospital-based and community based models | Not relevant study population - this quasi-experimental trial included children with CP |

| Excluded studies – F2 What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy? | |
|---|---|
| **Study** | **Reason for Exclusion** |
| of cerebral palsy rehabilitation: a quasi-experimental study, BMC Pediatrics, 14, 301, 2014 | (aged 0.5-12 years) |
| Darrah, J., Magil-Evans, J., Adkins, R., How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery, Disability and Rehabilitation, 24, 542-549, 2002 | No relevant population - this study included 49 adolescents (13 - 15 years) and 39 young adults (19 - 23 years) with CP and their families. This paper was also included in the CG “Cerebral Palsy in Children” |
| Darrah, J., Magill-Evans, J., Galambos, N. L., Community services for young adults with motor disabilities A paradox, Disability and Rehabilitation, 32, 223-229, 2010 | No relevant - this study evaluated the contribution of educational, employment, transportation, and assured income service programs to the successful transition to adulthood of young persons with motor disabilities in young adults with CP |
| Elrod, C. S., DeJong, G., Determinants of utilization of physical rehabilitation services for persons with chronic and disabling conditions: an exploratory study, Archives of Physical Medicine & Rehabilitation, 89, 114-20, 2008 | Not relevant study population - this survey research trial included in total 451 adults with chronic and disabling conditions (CP; multiple sclerosis; spinal cord injury). Of the overall sample size only 22% were adults with CP |
| Frisch, D., Msall, M. E., Health, functioning, and participation of adolescents and adults with cerebral palsy: a review of outcomes research, Developmental Disabilities Research Reviews, 18, 84-94, 2013 | Not relevant review of literature - references has been checked |
| Jahnsen, R., Villien, L., Aamodt, G., Stanghelle, J. K., Holm, I., Physiotherapy and physical activity - Experiences of adults with cerebral palsy with implications for children, Advances in Physiotherapy, 5, 21-32, 2003 | This survey research does not contain any data (quantitative or qualitative) about access to healthcare services |
| Kibele, A., Llorens, L. A., Going to the source: the use of qualitative methodology in a study of the needs of adults with cerebral palsy, Occupational Therapy in Health Care, 6, 27-40 14p, 1989 | No relevant to the PICO - this qualitative study suggested guidelines for occupational therapy practice |
| Kroll,T., Beatty,P.W., Bingham,S., Primary care satisfaction among adults with physical disabilities: the role of patient-provider communication, Managed Care Quarterly, 11, 11-19, 2003 | No population: people with CP are only 55 out of 195 overall study sample (28%) |
| Lariviere-Bastien, D., Majnemer, A., Shevell, M., Racine, E., Perspectives of adolescents and young adults with cerebral palsy on the ethical and social challenges encountered in healthcare services, Narrative Inquiry in Bioethics, 1, 43-54, 2011 | No relevant population - this study included 10 adolescents with CP aged 14-25 years. This paper was also included in the CG “Cerebral Palsy in Children” |
| Lewis, D., Fiske, J., Dougall, A., Access to special care dentistry, part 8. Special care dentistry services: seamless care for people in their middle years - part 2, British Dental Journal, 205, 359-71, 2008 | No relevant study design - narrative overview of the literature (references have been checked) |
| Linroth, R., Meeting the needs of young | No relevant study design and study |

| Excluded studies – F2 What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy? | |
|---|---|
| **Study** | **Reason for Exclusion** |
| people and adults with childhood-onset conditions: Gillette Lifetime Specialty Healthcare, Developmental Medicine & Child Neurology, 51 Suppl 4, 174-7, 2009 | population - this paper is a case study describing how "Gillette Specialty Healthcare" developed a program to meet the specialty-care outpatient and in-patient needs of children with C and other serious congenital disabilities as they made the transition to early adulthood |
| Liptak, G. S., Health and well-being of adults with cerebral palsy, Current Opinion in Neurology, 21, 136-42, 2008 | No study design - narrative overview of the literature (references have been checked for relevant papers) |
| Mackeith, R. C., Bax, M. C., Assessment, training and employment of adolescents and young adults with cerebral palsy. 2. What facilities are needed, Cerebral palsy bulletin, 3, 135-8, 1961 | No relevant study design - narrative overview of the literature (references have been checked) |
| Mir, G., Tovey, P., Asian carers' experiences of medical and social care: The case of cerebral palsy, British Journal of Social Work, 33, 465-479, 2003 | No relevant population and aim - The aim of this study was to observe of how parents of adolescents with CP experience their own health and wellbeing and their needs for support during the adolescents transition to adulthood. Included people: parents of 10 adolescents with CP aged 17-18 years |
| Morgan, M. R., Assessment, training and employment of adolescents and young adults with cerebral palsy. 3. Facilities now available, Cerebral palsy bulletin, 3, 139-44, 1961 | No relevant study design - narrative overview of the literature (references have been checked) |
| Morgan, P., McDonald, R., McGinley, J., Perceived cause, environmental factors, and consequences of falls in adults with cerebral palsy: A preliminary mixed methods study, Rehabilitation Research and Practice, 2015 (no pagination), 2015 | No relevant to the PICO - this qualitative study reported falls frequency, falls precipitators, and consequences (physical and psychosocial) and the relationship of falls to age for a group of ambulant adults with CP |
| Neri, M., Kroll, T., Understanding the consequences of access barriers to health care: Experiences of adults with disabilities, Disability and Rehabilitation: An International, Multidisciplinary Journal, 25, 85-96, 2003 | No relevant population - this study included 10 adults with CP (out of the 30 people with disabilities enrolled - the 33%) |
| Ng, S. Y., Dinesh, S. K., Tay, S. K., Lee, E. H., Decreased access to health care and social isolation among young adults with cerebral palsy after leaving school, Journal of Orthopaedic Surgery, 11, 80-9, 2003 | No relevant population - this study included 149 young adults with CP aged 15-22 years |
| Overeynder, J. C., Turk, M. A., Cerebral palsy and aging: A framework for promoting the health of older persons with cerebral palsy, Topics in Geriatric Rehabilitation, 13, 19-24, 1998 | No relevant to the PICO question: this study does not focus on access to care in adults with cerebral palsy |
| Young, N. L., Steele, C., Fehlings, D., Jutai, J., Olmsted, N., Williams, J. I., Use of health care among adults with chronic and complex physical disabilities of childhood, Disability & | No relevant study design and study population - this paper is a retrospective descriptive study, using a health services analysis approach and reporting only rates |

| **Excluded studies – F2 What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?** | |
|---|---|
| **Study** | **Reason for Exclusion** |
| Rehabilitation, 27, 1455-60, 2005 | of usage of healthcare services. It includes 345 adults with chronic / complex physical disabilities of childhood origin aged 19 -27 years (mean age 21 years). Only 188 of these were people with CP |
| Zwicker, J., Zaresani, A., Emery, J. C. H., Describing heterogeneity of unmet needs among adults with a developmental disability: An examination of the 2012 Canadian Survey on Disability, Research in Developmental Disabilities, 65, 1-11, 2017 | This is a cross-sectional study reporting on the unmet employment, education and daily needs of adults with developmental disabilities, including people with autism spectrum disorder and CP in Canada, to inform policy development. As such this study has been excluded (since data on barriers/facilitators to access to primary and secondary care for adults with cerebral palsy were not reported) |

1 *CG: Clinical guideline; CP: cerebral palsy; PICO: population intervention comparison outcomes*

## 2 Economic studies

3 No economic evidence was identified for this review.

4

5

# Appendix L – Research recommendations

Research recommendations for review question F2: What service configuration and what interventions can facilitate access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?

No research recommendation was made for this topic.