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REHABILITATION FOR ADULTS WITH CEREBRAL PALSY

Comprehensive project report

(See separate document for appendices)

Hammel Neurorehabilitation Centre
April 2026

Danish title – Rehabilitering for voksne med cerebral parese

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Preface

Many adults with Cerebral Palsy in Denmark express a feeling of being abandoned in a fragmented healthcare system. Although the majority of people with Cerebral Palsy in Denmark are nowadays adults, no dedicated clinical pathways are available. This and the absence of clinical coordinators hinders the provision of adequate and timely treatment and rehabilitation with the individual and its needs at its centre.

The present report summarises the experiences gained through the project "*Habilitation for Adults with Cerebral Palsy*" conducted at Hammel Neurorehabilitation Centre from 2022 to 2026. The aim of the project was to establish a hospital-based assessment and rehabilitation service for adults with Cerebral Palsy and hence be the first step on a path towards a dedicated clinical pathway. The project was made possible through a benevolent grant from the Elsass Foundation. We are very grateful for the support from the Elsass Foundation throughout the project period.

The present version of the comprehensive project report is a slightly revised version from the project evaluation report delivered to the Elsass Foundation in February 2026. The original version is available upon reasonable request.

I would like to thank all those who have contributed to the present report, especially the clinical CP-team and the enrolled participants, for their interest, commitment, and dedication in improving the healthcare for adults with Cerebral Palsy.

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Summary

Most people with cerebral palsy (CP) in Denmark are adults. Yet, there is still a lack of coordinated and specialised services targeting this group. Many adults experience fragmented care pathways, insufficient coordination, and limited knowledge about CP within the health and social care systems.

The aim of the project "Rehabilitation for Adults with Cerebral Palsy" was to assess the rehabilitation needs, develop a hospital-based, interdisciplinary rehabilitation service for adults with CP, and provide recommendations to inform future services and health policy initiatives. The project was carried out at Hammel Neurorehabilitation Centre between 2022 and 2026 with support from the Elsass Foundation.

The project was grounded in a bio-psycho-social framework based on the WHO's International Classification of Functioning, Disability and Health (ICF) and included interdisciplinary clinical assessments, joint goal setting, rehabilitation pathways, home visits, specialised interventions, and systematic collection of clinical experience. A CP-specific quality database was established, linking administrative data, clinical data, and patient-reported outcomes. The participating adults with CP had substantial comorbidity and a high prevalence of pain, fatigue, and functional impairments across levels of functioning. The rehabilitation pathways were predominantly outpatient and often long-term. Most participants reported high satisfaction with the project clinic, and approximately half of the individual goals were achieved.

The project also identified significant barriers to accessing health and social care services for adults with CP. Based on these findings, concrete clinical and organisational recommendations were developed to address barriers related to the narratives and understanding of CP, health and social policy, financing, service organisation, and recognition of needs. The recommendations include establishing bridging functions and specialised regional services and integrating services into existing structures for people with acquired brain injury.

Overall, the project demonstrates that adults with CP have complex and often overlooked rehabilitation needs that are not adequately addressed in the current healthcare system. A specialised, hospital-based, interdisciplinary approach with a focus on functioning, life stages, and coordinated care pathways is both feasible and meaningful. The report provides a knowledge base for further clinical development, research, and health policy initiatives targeting adults with CP.

Dansk resume

De fleste mennesker med cerebral parese (CP) i Danmark er voksne, men på trods heraf mangler der sammenhængende og specialiserede tilbud målrettet voksne med CP. Mange oplever fragmenterede forløb, og utilstrækkelig koordination og viden om CP.

Formålet med projektet *"Rehabilitering for voksne med cerebral parese"* var at afdække rehabiliteringsbehov, etablere og afprøve et hospitalsbaseret, tværfagligt rehabiliteringsprogram for voksne med CP og generere kliniske erfaringer og anbefalinger, som grundlag for fremtidige kliniske tilbud og sundhedspolitiske initiativer. Projektet blev gennemført på Regionshospital Hammel Neurocenter i perioden 2022–2026 med støtte fra Elsass Fonden. Projektet var forankret i en bio-psyko-social forståelsesramme baseret på WHO's International Classification of Functioning, Disability and Health (ICF) og kombinerede tværfaglige kliniske vurderinger, fælles målfastsættelse, rehabiliteringsforløb, hjemmebesøg, specialiserede interventioner samt systematisk indsamling af kliniske erfaringer. En CP-specifik kvalitetsdatabase blev etableret med kobling af administrative data, kliniske data og patientrapporterede udfald. Projektet viste at deltagerne havde betydelig komorbiditet, høj forekomst af smerter, træthed og funktionsnedsættelser på tværs af funktionsniveauer. Forløbene var overvejende ambulante og langvarige. Størstedelen af deltagerne rapporterede høj tilfredshed med tilbuddet, og omkring halvdelen af de opstillede individuelle mål blev opnået.

I projektet blev der identificeret betydelige barrierer i adgangen til sundheds- og socialydelser for voksne med CP. På baggrund heraf blev der udviklet konkrete kliniske og organisatoriske anbefalinger der kan adressere barrierer relateret til narrativer om og forståelse af CP, sundheds- og socialpolitik, økonomi, organisering af ydelser samt erkendelse af behov. Herunder anbefales det at etablere brobyggende funktioner, specialiserede regionale tilbud og integration i eksisterende organisatoriske strukturer for mennesker med erhvervet hjerneskade.

Samlet viste projektet, at voksne med CP har komplekse og ofte oversete rehabiliteringsbehov, som ikke imødekommes tilstrækkeligt i det nuværende sundhedssystem. En specialiseret, hospitalsbaseret og tværfaglig tilgang med fokus på funktionsevne, livsfaser og sammenhængende forløb er både mulig og meningsfuld. Rapporten udgør et vidensgrundlag for videre klinisk udvikling, forskning og sundhedspolitisk indsats rettet mod voksne med CP.

1. Introduction

This comprehensive project report describes the experiences from the project *"Habilitation*[a] *for Adults with Cerebral Palsy"* conducted from 2022 to 2026 at Hammel Neurorehabilitation Centre with funding from the Elsass Foundation.

The aim of the project was to establish a hospital-based assessment and rehabilitation service for adults with cerebral palsy (CP), grounded in the International Classification of Functioning, Disability and Health (ICF).[1]

The key components described in the protocol for the project are shown in **Table 1** along with a brief description of what was changed during the project period, and where to read more about it in the report.

One key component was the establishment of a database based on individual data from project participants. The collected data is presented in Chapter 2.

Obviously, establishing a new service should aim for evidence-based interventions. However, research-based evidence for the assessment and rehabilitation of adults with CP is limited.[2] Evidence-based clinical practice however draws on three complementary sources of knowledge: research-based evidence, knowledge from clinical experience, and an understanding of patient preferences.[3] The clinical experiences and patient preferences derived from the five-year project period are presented in Chapter 3, whereas Chapter 4 compares the experiences and derived recommendations, with evidence and recommendations from two existing clinical guidelines for adults with CP.[4-20] Chapter 4 also outlines directions for research related to the future clinical setup, where Hammel Neurorehabilitation Centre intends to lead its development and implementation. The clinical setup is described in Chapter 5.

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[a] In *rehabilitation*, the goal is to improve or regain functional abilities following a loss of function e.g. after acquired brain injury. In *habilitation*, the focus is on supporting the development of functions in people with a congenital or early acquired disability, where there may be no previous higher level of function to regain. The term *habilitation* in the project's title reflects that adults with CP differ from those with acquired brain injury. In practice, however, the term rehabilitation is often used to encompass habilitation. It is also the term most commonly used in legislation, health agreements, and international literature on CP Accordingly, rehabilitation is the term used throughout this document.

Table 1. Overview of the key components in the original protocol

	Component in the protocol	Changes and where to read more
The service at Hammel Neuro-center	Hospital-based assessment and rehabilitation service for adults with CP (outpatient; 5-day inpatient rehabilitation; 14-day inpatient rehabilitation)	Primarily outpatient pathways, as inpatient rehabilitation proved highly demanding (financial resources, patients' energy), transfer value of what was learned during inpatient rehabilitation was limited for many patients (p. 56 and Appendices 3 and 5)
	Recruitment by identifying adults with CP through registers, eBoks, and information campaigns across social media, residential facilities, and CP Denmark. Referral though GP and paediatricians at completion of the Danish follow-up program for children and adolescents with cerebral palsy (CPOP)	Identification of individuals through registers and eboks not performed. Adults are referred directly to the project by their GPs (p. 49) No automatic inclusion of 18-year-olds at completion of CPOP. Young adults often do not have a need for assessment and rehabilitation; needs are social-oriented and may be better met by youth mentors (p. 60)
The health care profess-sionals in the project ("The CP team")	A multidisciplinary team	The professional composition of the multidisciplinary team has been specified (Appendix 3)
	Train staff through peer-to-peer training, courses, exchanges, and collaboration with Elsass Foundation and CP Denmark to build a competent interdisciplinary CP team	Peer-to-peer training at residential facilities turned out to be an exchange of experiences between the pedagogical perspective at the residential facilities and the neurorehabilitation perspective on functional ability of the CP team (P. 46, 68) Training additional to the protocol: Youth Mentors 2025; Participation in National conferences; Visits at rehabilitation facilities e.g. Sunaas Sykehus
Data	Build a CP-specific quality database combining data from electronic health records, PROs, and functional measures such as GMFCS and WHODAS.	No changes (Chapter 2)
	Cost effectiveness assessment	Not performed due to lack of relevant regional and municipal procedure and service codes (or the use of them) (p. 40)
	Mapping of potential cross-sectoral cooperation	No changes (Chapter 3.4)
Scaling to national level	Contribute to a pathway program in collaboration with the Danish Health Authority	Not initiated. The need for a Health technology assessment proposed to The Danish Ministry of the Interior and Health (Chapters 3.2 and 3.3)
	Roll out the project in three phases: Year 1 local, Years 2–3 regional, Years 4–5 national	National scaling not performed. Plan for scaling to West Denmark in Chapter 5.

2. The CP Database

This chapter presents the *CP database* developed as part of the project.

The database contains patient administrative and clinical data extracted from the electronic health record (EHR) system and supplemental objective clinical assessment and patient-reported measures collected specifically for the project.

2.1 Administrative framework and data collection

The EHR system at Hammel Neurorehabilitation Centre is integrated in the administrative district of Central Denmark Region, enabling patient administration across all district hospitals. EHR data is staged in a relational data warehouse administered by the districts IT department. The *CP-database* is registered in the Central Denmark Region's internal record of research projects. Data from the database may be used for both quality assurance and research projects after approval from the district council (equivalent to ethical approval). The CP database is managed by a data manager at Hammel Neurorehabilitation Centre, integrated within the project team.

Data is collected through a) the EHR system and b) REDCap electronic data capture tool hosted at Central Denmark Region.[21,22]

Data available through the EHR system is patient administrative information such as outpatient contact types or lengths, administrative and clinical procedure codes and medical history.

Data collected through the REDCap tool is clinical data which is not routinely registered in the EHR (such as the CP classification system measurements or data where EHR use standard templates not matching the aim of the project). Patient-reported information is collected with electronic surveys through REDCap.

Deterministic linkage of data from REDCap and EHR data is possible through the unique national personal identifier number assigned to all residents in Denmark at birth or immigration.

2.2 Choice of measurement tools

The selection of measurement tools was based on a) general validity and relevancy of measurement tools and b) the tools' ability to provide bio-psycho-social information for planning of the patient-centred care. Since the project was planned within the framework of the International Classification of Functioning, Disability and Health,[1] the bio-psycho-social aspect on the concept of functioning was particularly important to capture. Here, especially the holistic perspective on how bodily impairments, and their limiting impact on daily activities and consequently restrictions in societal participation may be mediated by personal and environmental factors. Simultaneously, it was kept in mind to keep the surveys manageable and as little tedious as possible. **Table 2** provides an overview of the selected data and measurement tools.

Table 2. Overview of data collected in the project

Data	Time of collection	Who registered the data and where
Age, education, work, and medical history, information on diet, alcohol, smoking and exercise habits.	Enrollment	Adult with CP in REDcap
Administrative data (contact type and length)	Every contact	Clinicians in EHR
Goal Attainment Scale (to aid understanding and realistic goal setting)	Initial outpatient visit. Evaluated prior to or during the last outpatient visit.	Adult with CP in collaboration with accompanying relatives and clinical staff in REDcap
The five CP classification systems: *Gross Motor Function (GMFCS); Manual Ability (MACS); Communication Function (CFCS); Eating and Drinking Ability (EDACS); Visual Function (VFCS)*	Initial outpatient visits	Clinicians in REDcap
Patient-reported outcome measures: *WHO Disability Assessment Schedule 2.0; (WHODAS); European Quality of Life - 5 Dimensions (EQ5D); Measure of Insights into Cognition (MIC); Multidimensional Fatigue Inventory (MFI)*	1) baseline (i.e. prior to the first outpatient contact), 2) during clinical follow-up (i.e., up to four times; deemed individually by clinical staff based on clinical relevancy), and 3) prior to the termination and evaluation of the outpatient care	Adult with CP in REDcap

Data	Time of collection	Who registered the data and where
Physiotherapeutic assessment: *Action Research Arm Test (ARAT); Balance Evaluation Systems Test (BEStest)*	When clinically indicated	Physiotherapist in REDcap
Occupational therapy assessment: Assessment of Motor and Process Skills (AMPS); Activities of Daily Living Interview (ADL-I); *Sensory Profile; Dysphagia screening; Canadian Occupational Performance Measure (COPM); Mann Assessment of Swallowing Ability (MISA)*	When clinically indicated	Occupational therapist in EHR
Psychological battery measurement tools: *Wechsler Adult Intelligence Scale (WAIS-IV), Rey-Auditory Verbal Learning Test, Visual Object and Space Perception Battery, Beery-Buktenica Developmental Test of Visual-Motor Integration, Behavioural Rating Inventory of Executive Function (BRIEF-V), and Vineland Adaptive Behaviour Scale*	When clinically indicated	Neuropsychologist

2.3 Description of project participants

Eligibility criteria varied throughout the project period for organisational reasons, for example more referrals than clinically possible to meet.
At the time of writing, n = 131 adults with CP had been enrolled in the project clinic; hereof, 81 adults had ended their outpatient treatment course. Most were males (70%) with a median (IQR) age of 31 (23.5-49) years. Approximately one in five had a legal guardian, and half of the adults received help in daily activities through home care or domestic help (**Table 3**).

Nearly three out of four adults reported experiencing pain, and 44% had been hospitalized within the past year (**Table 4**).

Table 3. Characteristics of adults seen in the project clinic

	Total (N=131)
Female Sex	40 (30.5 %)
Age (Median [IQR])	31 [23.5, 49]
Education	
No education/Basic school/High School	90 (68.7 %)
Vocational education	8 (6.1 %)
Higher education	22 (16.8 %)
Missing	11 (8.4%)
Occupation*	
Unemployed or on sickness leave	8 (6.1 %)
Retired	56 (42.7 %)
Working / Studying/ education	40 (30.6 %)
Other	16 (12.2 %)
Missing	11 (8.4%)
Response type	
Self-report	93 (71.0 %)
Missing	12 (9.2 %)
Guardian	
Yes	23 (17.6 %)
Missing	11 (8.4%)
Home Care or Domestic help	
Yes	77 (58.8 %)
Missing	15 (11.5 %)
BMI	
≤ 18.5	21 (16.0 %)
18.5-30	75 (57.3 %)
> 30	15 (11.5 %)
Missing	20 (15.3%)
Physical training	
Free of charge physiotherapy	80 (61.1 %)
Other	31 (23.7 %)
Private/municipality physiotherapy	8 (6.1 %)
Unsupervised training	12 (9.2 %)
Alcohol consumption	
None	76 (58.0 %)
Occasional weekly consumption	44 (33.6 %)
Missing	11 (8.4%)
Smoking habits	
Never smoker	102 (77.9 %)
Former smoker	10 (7.6 %)
Current smoker	8 (6.1 %)
Missing	11 (8.4%)
Satisfactory sleeping pattern	
Yes	48 (36.6 %)
Missing	42 (32.0 %)

*Retired includes employment and support allowance, voluntary early retirement; Other occupations include unpaid work and maternity leave.

Table 4. Self-reported comorbidity and use of health care services

	Total (N=131)
Comorbidity present*	51 (38.9 %)
Use of pulmonary aids**	21 (16.0 %)
Pain	
Yes	90 (68.7 %)
Missing	11 (8.4%)
Pain intensity during the past 2 weeks***	
0-3	20 (15.3 %)
4-7	62 (47.3 %)
8-10	6 (4.6 %)
Missing	43 (32.8%)
Epilepsia	
Yes	22 (16.8 %)
Missing	12 (9.9 %)
Inpatient contact within the past year	
Yes	58 (44.3 %)
Missing	14 (10.7 %)
GP contact within the past year	
Yes	106 (80.9 %)
Missing	14 (10.7 %)
Consultant contact within the past year	
Yes	52 (39.7 %)
Missing	17 (13.0 %)
Brain Scan (ever)	
Yes	68 (51.9 %)
Missing	33 (25.2 %)
Neuropsychologist contact (ever)	
Yes	61 (46.6 %)
Missing	35 (26.7 %)
Fractures (ever)	
Yes	44 (33.6 %)
Missing	22 (16.8 %)

* Comorbidities include pulmonary, gastrointestinal, urinary tract, cardiovascular, other and undetermined
** use of pulmonary aids include tracheostomy, respirator, other aids
*** Pain intensity: 0 = no pain, 10 = worst possible pain

CP classification

Most adults presented with spastic CP (62%). One-third of the adults (36%) could walk without assistive devices (GMFCS ≤ 2); one-fifth (22%) experienced limitations in eating and drinking (EDACS ≥ 3) (**Table 5**).

Table 5. CP classification of included adults

	Total (N=131)
CP type	
Spastic	81 (61.8 %)
Dyskinetic	14 (10.7 %)
Mixed/ ataxic	19 (14.5 %)
Missing	17 (13.0%)
Gross Motor Function (GMFCS)	
1	16 (12.2 %)
2	31 (23.7 %)
3	23 (17.6 %)
4	31 (23.7 %)
5	17 (13.0 %)
Missing	13 (9.9%)
Manual Ability (MACS)	
1	20 (15.3 %)
2	46 (35.1 %)
3	24 (18.3 %)
4	17 (13.0 %)
5	11 (8.4 %)
Missing	13 (9.9%)
Communication Function (CFCS)	
1	40 (30.5 %)
2	24 (18.3 %)
3	17 (13.0 %)
4	31 (23.7 %)
5	6 (4.6 %)
Missing	13 (9.9%)
Eating and Drinking Ability (EDACS)	
1	62 (47.3 %)
2	26 (19.8 %)
3	14 (10.7 %)
4	8 (6.1 %)
5	7 (5.3 %)
Missing	14 (10.7%)
Visual Function (VFCS)	
1	56 (42.7 %)
2	35 (26.7 %)
3	17 (13.0 %)
4-5*	9 (6.9 %)
Missing	14 (10.7%)

*VFCS classification combined to ensure anonymity

CP clinic contacts

Participants were actively enrolled in the project clinic for a median (IQR) of 269 (78-366) days (excluding wait time after visitation). The median (IQR) number of contacts was 11 (4-21) (**Table 6**). The median number of contacts per adult across types were: outpatient 7 (4-13); virtual consultation 5 (2-10), home visit (2 (1-3)).

Table 6. Patient-administrative information

	Total (N=131)
Outpatient status, n (%)	
Open	50 (38.2 %)
Closed	81 (61.8 %)
Number of outpatient contacts*	11 [4-21]
Total number of contacts, n (%)	
Outpatient	1083 (51.7 %)
Home visit	202 (9.6 %)
Virtual consultation	784 (37.4 %)
Inpatient	21 (1.0 %)
First contact planned	6 (0.3 %)
Outpatient treatment length (days)*	269 [78-366]
Wait time from visitation (days)	134 [31-172]
Clinic visit lengths	
Outpatient (hours)	1.4 [0.9-2.0]
Home visit (hours)	1.9 [1.1-2.3]
Virtual consultation (hours)	0.3 [0.2-0.3]
Inpatient (days)	11 [9-11]

*includes only closed outpatient treatment courses

Median [IQR] unless otherwise stated

A total of 29 adults underwent psychological testing, and 86 underwent additional physiotherapeutic assessment (i.e., ARAT or BESTest) (Data not shown).

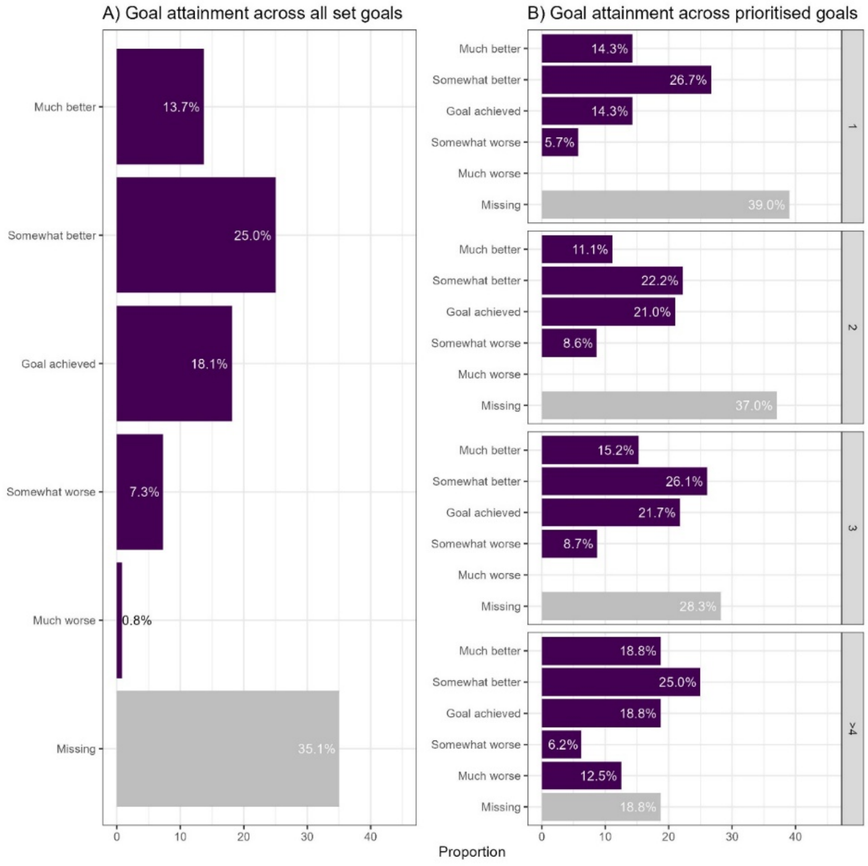
Goal attainment scale and satisfaction with the clinic

From a value-based perspective (i.e. achieving the best personal outcome), based on goal attainment and satisfaction, the project clinic supported the participants in the achievement of their self-determined goals in a satisfactory manner. Most adults were satisfied or very satisfied with the project clinic experience (83%). Most adults reported having gained something or much from the outpatient visits (81%). More than half of the participants rated it very likely to recommend the clinic (**Figure 2**).

Overall, participants rated 57% of their goals as achieved or achieved better than expected. For the primary goal, the proportion of goal achievement or better was 55% (**Figure 1**).

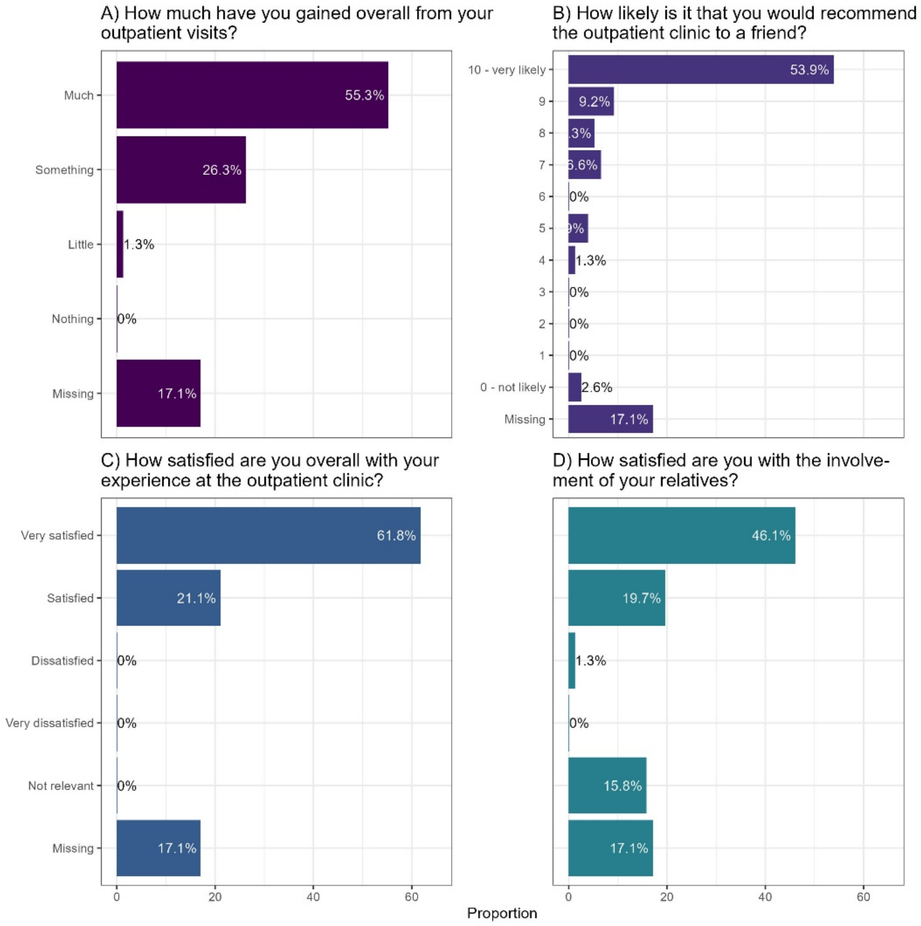
Participants set a median (IQR) of 2 (2-3) goals. Frequently set goals for the Goal Attainment scale concerned: energy/fatigue management, nutrition/ dietary habits, cognition/ communication, physical function/ ambulation, pain, and knowledge on CP. Importantly, response rates to the Goal Attainment Scale were relatively low in the beginning of the project period. Therefore, the clinical staff began to actively remind participants prior to their last visit or to secure time during the last visit to respond to the Goal Attainment Scale.

Figure 1. Goal Attainment Scale



Note: Patients had a median of 2 IQR 2-3 goals; n = 16 patients had >4 goals.

Figure 2. Participants satisfaction with outpatient clinic

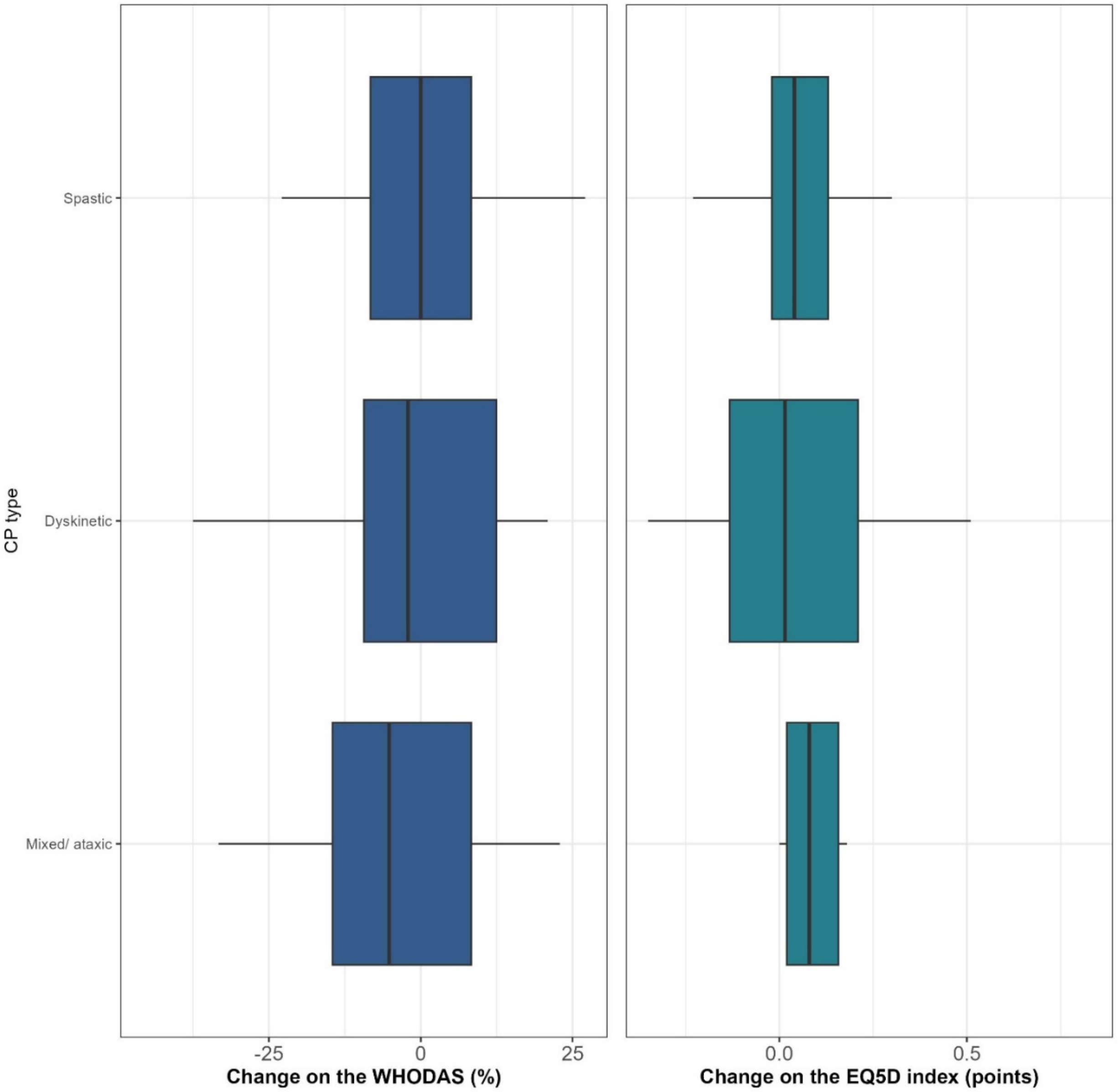


Overall, collecting responses to self-reported data were challenging and demanded repeated reminders.

Patient-reported outcome measures

At baseline, participants reported moderate disability on the WHODAS (median 39.6 IQR [29.2-53.7] percent) and good health-related quality of life on the EQ5D (median index score 0.64 IQR [0.39-0.89]). While the average perceived disability (WHODAS) and quality of life (EQ5D) only changed marginally (**Table 7**), many participants experienced an improvement, but considerable variation was observed (**Figure 3**).

Figure 3. Change in perceived disability and quality of life



Note: Based on n = 61 responses. Positive change indicates inprovement.

Table 7. Baseline and follow-up scores across GMFCS

	Total (N=131)	**GMFCS 1** (N=16)	**GMFCS 2** (N=31)	**GMFCS 3** (N=23)	**GMFCS 4** (N=31)	**GMFCS 5** (N=17)	missing (N=13)
Scores (Median [IQR])							
WHODAS (%) (Score range from 0–100, higher scores indicate greater disability)							
Baseline	39.6 [29.2, 53.7]	30.3 [20.8, 35.4]	30.3 [12.5, 39.6]	45.8 [34.3, 52.1]	52.1 [45.8, 62.5]	75 [68.8, 77.1]	25 [25.0, 36.5]
FU	37.5 [22.9, 54.2]	22.9 [18.2, 32.3]	25 [15.6, 32.3]	45.8 [33.4, 52.1]	52.1 [39.6, 64.6]	69.8 [62.0, 81.2]	NA [NA, NA]
EQ5D (index score) (Score range from -0.757 – 1, higher scores indicate better health)							
Baseline	0.64 [0.4, 0.8]	0.83 [0.5, 0.8]	0.805 [0.6, 0.9]	0.66 [0.5, 0.8]	0.41 [0.2, 0.6]	0.28 [0.2, 0.3]	0.76 [0.7, 0.8]
FU	0.68 [0.5, 0.9]	0.84 [0.8, 0.9]	0.84 [0.5, 0.9]	0.77 [0.6, 0.9]	0.52 [0.3, 0.6]	0.42 [0.4, 0.5]	NA [NA, NA]
MIC-SR (point) (Item scores range from 0–12, higher scores indicate more frequent cognitive problems)							
Attention							
Baseline	5.5 [2.8, 9.0]	6 [4.0, 1.0]	6 [3.0, 9.0]	5.5 [4.0, 7.8]	4 [1.0, 9.0]	3 [1.8, 5.5]	4 [3.5, 4.5]
FU	5 [2.0, 7.0]	4 [2.5, 5.5]	5 [3.5, 7.0]	6 [3.5, 8.5]	5 [2.5, 6.0]	1 [0.5, 1.5]	NA [NA, NA]
Executive function							
Baseline	5 [3.0, 7.2]	6 [5.0, 9.0]	5 [3.0, 7.0]	5 [1.2, 7.0]	6 [1.0, 9.0]	3 [2.8, 3.8]	4 [3.0, 5.5]
FU	4 [2.0, 6.0]	4 [2.5, 5.0]	4 [1.5, 6.0]	5 [3.5, 6.5]	4 [3.0, 6.8]	1 [1.0, 1.0]	NA [NA, NA]
Memory							
Baseline	2 [0.8, 6.0]	2 [1.0, 6.0]	3 [1.0, 5.0]	2.5 [0, 4.0]	2 [0, 7.0]	2 [1.8, 2.2]	4 [2.0, 6.5]
FU	2 [1.0, 5.0]	2 [1.5, 2.0]	1 [1.0, 5.5]	3 [1.0, 5.0]	2.5 [0.2, 6.5]	0 [0, 0]	NA [NA, NA]
MFI general (point) (Score range from 4–20, higher scores indicate greater fatigue))							
Baseline	14 [10.0, 16.0]	15 [13.0,16.0]	14 [10.2,16.0]	14 [13.5,17.5]	11.5 [8.5, 16.0]	10 [7.0, 11.0]	15 [13.5,16.5]
FU	13 [10.0,16.0]	14 [8.5, 17.2]	15 [10.5, 17.0]	15 [13.5, 17.0]	11 [8.0, 12.5]	12.5 [11.0,13.8]	NA [NA, NA]
Missing scores (%)							
WHODAS, EQ5D							
Baseline	37 (28.2%)	2 (12.5%)	1 (3.2%)	4 (17.4%)	8 (25.8%)	12 (70.6%)	10 (76.9%)
FU	70 (53.4%)	10 (62.5%)	12 (38.7%)	8 (34.8%)	14 (45.2%)	13 (76.5%)	13 (100%)
MIC-SR							
Baseline	43 (32.8%)	3 (18.8%)	2 (6.5%)	5 (21.7%)	10 (32.3%)	13 (76.5%)	10 (76.9%)
FU	86 (65.6%)	13 (81.3%)	16 (51.6%)	12 (52.2%)	17 (54.8%)	15 (88.2%)	13 (100%)
MFI							
Baseline	39 (29.8%)	2 (12.5%)	1 (3.2%)	4 (17.4%)	9 (29.0%)	12 (70.6%)	11 (84.6%)
FU	72 (55.0%)	10 (62.5%)	12 (38.7%)	8 (34.8%)	16 (51.6%)	13 (76.5%)	13 (100%)

Abbreviations: FU, Follow-up; GMFCS, Gross Motor Function Classification System; WHODAS, WHO Disability Assessment Schedule 2.0; EQ5D, European Quality of Life - 5 dimension; MIC-SR, Measure of Insights into Cognition-Self-reported; MFI, Multidimensional Fatigue Inventory

3. Recommendations

This chapter presents ***experiences gained from the project***, together with a series of ***derived recommendations*** aimed at reducing barriers to access and use of health- and social care services for adults with CP. Both the experiences and recommendations reflect a healthcare perspective.

The chapter is based on a systematic assessment of the project staff's clinical experiences with barriers that prevent adults with CP from having their healthcare needs met within the Danish health- and social care system, as well as on interventions tested during the project.

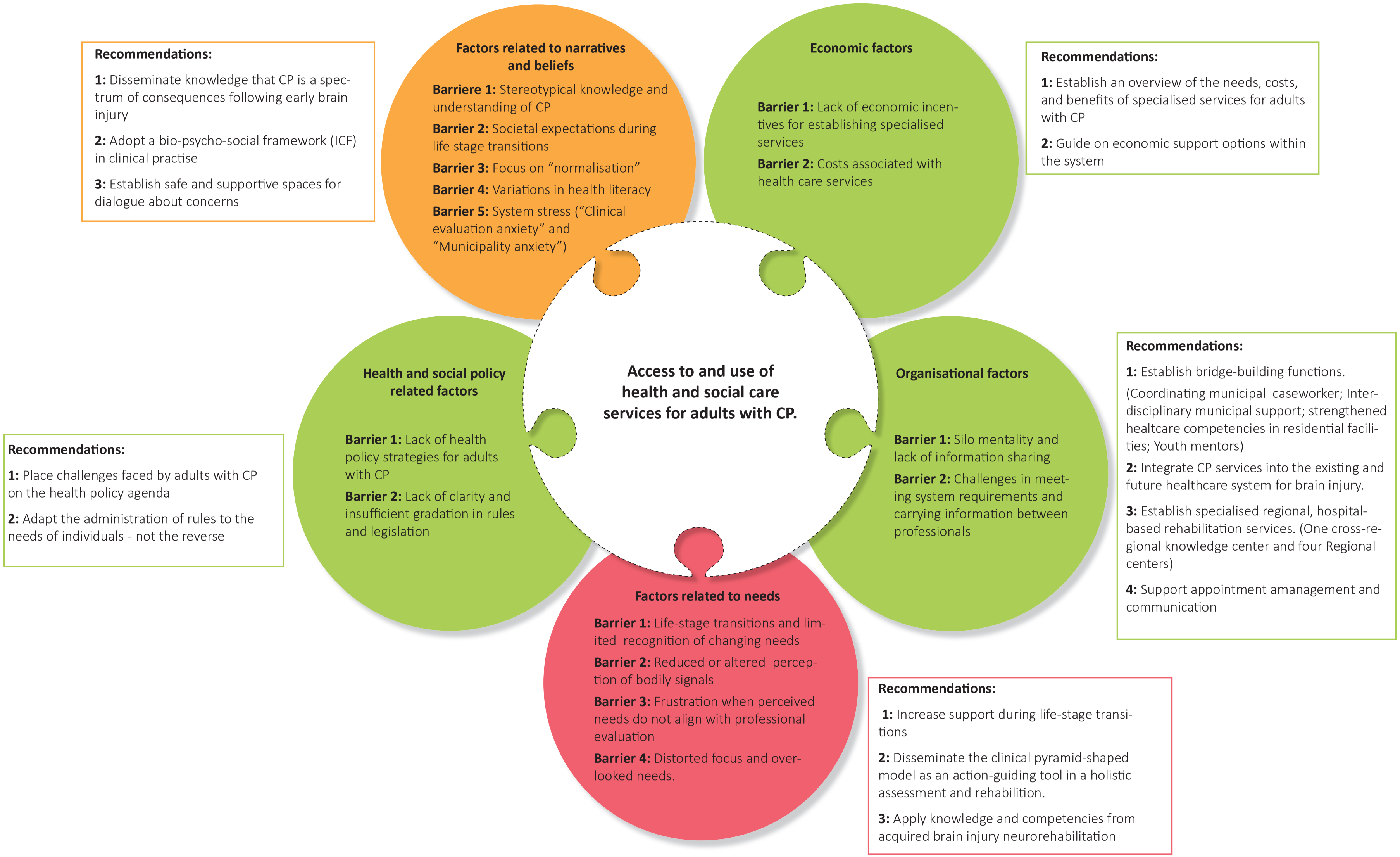
The barriers, the tested interventions, and the derived recommendations are described within three overarching categories that affect the adults' access to and use of health and social care services:

1) Narratives and beliefs
2) Health- and social policy, Economic factors, Organisational factors
3) Needs

The identified barriers and the derived recommendations are illustrated in **Figure 4.** A detailed description is provided in the subsequent sections. Each section outlines the identified barriers and the tested interventions, drawing on cases to illustrate the barriers and how they were addressed within the project. The cases are based on the experiences from the clinical practice but reconstructed and deidentified. Each section concludes with recommendations related to the respective areas.

Finally, a summary table is provided, synthesising key points from each section. The method used to collect and synthesise the clinical experiences is presented in Appendix 1 - separate document.

Figure 4. Identified barriers and derived recommendations



Access to and use of health and social care services for adults with CP.

Factors related to narratives and beliefs

Barriere 1: Stereotypical knowledge and understanding of CP

Barrier 2: Societal expectations during life stage transitions

Barrier 3: Focus on “normalisation”

Barrier 4: Variations in health literacy

Barrier 5: System stress (“Clinical evaluation anxiety” and “Municipality anxiety”)

Recommendations:

1: Disseminate knowledge that CP is a spectrum of consequences following early brain injury

2: Adopt a bio-psycho-social framework (ICF) in clinical practise

3: Establish safe and supportive spaces for dialogue about concerns

Economic factors

Barrier 1: Lack of economic incentives for establishing specialised services

Barrier 2: Costs associated with health care services

Recommendations:

1: Establish an overview of the needs, costs, and benefits of specialised services for adults with CP

2: Guide on economic support options within the system

Organisational factors

Barrier 1: Silo mentality and lack of information sharing

Barrier 2: Challenges in meeting system requirements and carrying information between professionals

Recommendations:

1: Establish bridge-building functions.

(Coordinating municipal caseworker; Interdisciplinary municipal support; strengthened healtcare competencies in residential facilities; Youth mentors)

2: Integrate CP services into the existing and future healthcare system for brain injury.

3: Establish specialised regional, hospital-based rehabilitation services. (One cross-regional knowledge center and four Regional centers)

4: Support appointment amanagement and communication

Factors related to needs

Barrier 1: Life-stage transitions and limited recognition of changing needs

Barrier 2: Reduced or altered perception of bodily signals

Barrier 3: Frustration when perceived needs do not align with professional evaluation

Barrier 4: Distorted focus and overlooked needs.

Recommendations:

1: Increase support during life-stage transitions

2: Disseminate the clinical pyramid-shaped model as an action-guiding tool in a holistic assessment and rehabilition.

3: Apply knowledge and competencies from acquired brain injury neurorehabilitation

Health and social policy related factors

Barrier 1: Lack of health policy strategies for adults with CP

Barrier 2: Lack of clarity and insufficient gradation in rules and legislation

Recommendations:

1: Place challenges faced by adults with CP on the health policy agenda

2: Adapt the administration of rules to the needs of individuals - not the reverse

3.1 Factors related to narratives and beliefs

Factors related to narratives and beliefs refer to the underlying values, cultural norms, and collective or individual conceptions that shape how needs and available services are perceived and may therefore potentially create barriers to adults' access to and use of services.

The identified barriers, tested interventions, and cases illustrating these barriers and how they have been addressed by the project are presented below. The chapter concludes with derived recommendations related to narratives and beliefs.

Barriers

Barrier 1: Stereotypical knowledge and understanding of CP

Identified in the project:

In the past, people with CP were referred to as "spastics" and were often associated with multiple disabilities and intellectual disability. Although the term "spastic" has largely fallen out of use, a simplified and stereotypical understanding of CP may persist in society and the social- and health care system, as people with CP may be perceived either as severely disabled or as having only a motor developmental disorder. At the same time, many people with CP prefer to be seen as having only a motor developmental disorder, which may feed into a narrative of e.g., a "weak" or "uncooperative" leg, and where any potential cognitive challenges are either not considered or considered as a consequence of the physical impairments.

Tested in the project:

Within the project, CP has been conceptualized as a spectrum of consequences following early brain injury. (See case Cecilie below and case Henriette in Chapter 3.5). This understanding has been communicated broadly to people with CP, their relatives, personal care assistants, staff in residential facilities, and health professionals, as described in Chapter 3.5.

Case 1. Cecilie: Understanding CP as a brain injury
Cecilie is a woman her mid-twenties. She is able to walk without assistive devices and does not experience significant challenges related to mobility. She experiences spasticity in her hands. During childhood, Cecilie was enrolled in the CPOP[b]-programme, where the primary focus was on motor development. She has undergone several orthopaedic surgical procedures aimed at optimising her hand function. Cecilie has grown up with a strong belief that intensive training is essential, and she continues to work out almost daily.
Cecilie is currently enrolled in a higher education programme. However, due to limited hand function, she is experiencing challenges in relation to her education.
As part of the project, Cecilie and her companion were introduced to the understanding that CP is a brain injury acquired during pregnancy or in connection with birth, that is, not solely a motor disorder. For Cecilie, this knowledge has resulted in new reflections regarding possible cognitive challenges related to the brain injury. The interdisciplinary team has explained the location of the brain injury and the expected physical and cognitive consequences now and in the future.
Since then, Cecilie has become more reconciled with her diagnosis. After lengthy consideration, she has obtained a job under special employment conditions for people with disabilities. Today, her perspective is no longer that she can do the same as everyone else. Instead, she increasingly takes her disability into account in order to achieve the best possible quality of life and, not least, a sustainable working life.

Barrier 2: Societal expectations during life stage transitions

Identified in the project:

During the transition from childhood to adulthood, families are often met with an expectation from society that parents should step back. Parents of adults with CP may experience that their continued support for their adult child is interpreted as a sign of unhealthy symbiosis. As a result, young people and their families may feel vulnerable in their interactions with public authorities, and based on this, some refrain from seeking help.

Similarly, older adults with CP are met by a society that expects them to hold the same level of functioning as earlier in life, even though people with CP experience a more rapid functional decline than their peers without CP.

Tested in the project:

The project’s communication of CP as a spectrum of consequences following early brain injury has contributed to adjusting societal expectations during life

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[b] CPOP is The Danish Cerebral Palsy Follow-up Program. It is a combined follow-up program and national clinical quality database that aims to monitor and improve the quality of health care for children with cerebral palsy.

stage transitions, for example through communication at network meetings with schools and municipalities (See case Jakob). See also the section on life stage transitions in Chapter 3.5.

Case 2. Jakob: Societal expectations during life stage transitions
Jakob is a young adult and lives with his family. He is currently enrolled in an educational programme for young people with special needs. When Jakob turned 18, his parents were no longer invited to participate in meetings and planning at the school, and the existing dialogue regarding Jakob's support needs stopped.
As a result, the demands and tasks assigned to Jakob at school, including work placement periods, were not conveyed to his parents. Similarly, the school was not informed about increasing distress and frequent emotional reactions at home, particularly related to feelings of stress based on school tasks.
As a result, the school assessed Jakob as being more capable than he actually was, and the teachers believed that Jakob was being overprotected by his parents.
The CP team participated in a joint network meeting. At the meeting, the extent of Jakob's brain injury and the level of support he requires in everyday life in order to avoid significant distress were explained.

Barrier 3: Focus on "normalisation"

Identified in the project:

Many adults with CP reported having grown up with the understanding that targeted training can optimise functional ability, and that effort and determination can compensate for functional impairment. When functional ability gradually declines with age, many believe that this is because they have not trained sufficiently. In this way, individuals implicitly assume responsibility for the deterioration, and this self-blame may lead to feelings of guilt and shame. At the same time, many adults reported having grown up with a strong desire to be perceived as "*normal*" and to demonstrate that they can manage "*despite*" their CP. This focus may make it difficult to accept the need for assistance and the use of assistive devices, such as a wheelchair. For many, this is experienced as a personal defeat and as a threat to their identity. The desire for normality, combined with feelings of guilt and shame, may indicate that some people with CP postpone or avoid seeking help and support, even when the need is clearly present.

In addition to this, health services for children and adolescents with CP often focus on normal motor development. As a result, this approach may fail to equip the child or adolescent, as well as their surroundings, with strategies for managing the consequences of CP across the life course, and this may contribute to the challenges encountered in adulthood.

Tested in the project:

The project's communication of CP as a spectrum of consequences following early brain injury has contributed to reducing misunderstandings related to perceived demand for normality. For example, the CP team has repeatedly observed a marked sense of relief among adults with CP when, after seeing their brain scan, they come to understand the cause of their functional impairment: that they are not personally to blame for it, and that the injury is visible on the scan. This realisation often helped to challenge previous explanatory narratives regarding the cause and to place the individual's functional ability in a more realistic perspective.

Another contribution to the changed perspective is the project's foundation in a bio-psycho-social framework.[1] This approach, together with the conceptualisation of CP as a brain injury, has been systematically communicated to people with CP, their relatives, personal care assistants, staff in residential facilities, and health professionals. This approach has helped shift the focus away from an ambitious "normalisation" of bodily functions towards a more practical focus on everyday functioning (See case Emma).

The ICF perspective is integrated into the pyramid-shaped clinical model (**Figure 6**, Chapter 3.4) and in the interdisciplinary clinical status report (Appendix 4 - separate document) both of which was developed in connection with the project.

Case 3. Emma: Shifting focus from "normalisation" to everyday functioning.

Emma is in her thirties, lives alone, and is in full-time employment. She attended mainstream school, and completed a higher education programme, without any special accommodations. She describes her academic performance as very average, which has been frustrating for her, as she invested all her time in homework and schoolwork. Emma wanted to perform on equal terms with everyone else. Her everyday life is carefully planned in order to make it manageable. All practical tasks are carried out during weekends, and very limited time and energy is available for social activities.

During her clinical pathway at the CP clinic, Emma is encouraged to view her functional limitations as more than "just" spasticity. Among other things, she gains insight into how fatigue, cognitive challenges, and poor sleep quality also play a significant role in how she functions in her daily life and at work. Besides this, Emma becomes aware of the importance of environmental factors, including that changes and adaptations can be made to the way her workplace and home are organised in order to better accommodate her needs. She realises that she is no longer able to work full time and initiates an assessment process for a subsidised employment scheme [Danish: Fleksjob]. She states that this process has not been easy for her, but sees value in the trade-off of having more energy for social activities and quality of life.

Barrier 4: Variations in health literacy

Identified in the project:

Many adults with CP and their relatives experience difficulties in understanding the health-related consequences of CP and how these are linked to functioning. They have lived with, for example, fatigue or pain throughout their lives and therefore experience these as given conditions rather than as issues that can be addressed and acted upon.

Below, three examples are presented to illustrate difficulties in understanding the health-related consequences of CP, and how these difficulties become barriers to seeking and receiving health care services.

Cognitive function and fatigue: Many people may have limited knowledge and understanding of what cognitive functions are. Some misunderstand cognitive challenges as being synonymous with low intellectual ability. At the same time, many find it difficult to understand and act upon fatigue as a direct consequence of CP. For example, many adults are reluctant to include rest periods during the day, even when experiencing pronounced fatigue, as this does not align with the self-image they aim to maintain.

The CP team also encountered adults who e.g., due to limited comprehension overstated their capabilities leading to a reduction or withdrawal of needed support and services.

Spasticity and pain: Many adults with CP may need practical knowledge about spasticity, how it specifically affects them, and that it can be alleviated and managed. In addition to this, many have difficulty linking their desire for functioning (to be able to do the same as before) with aging-related decline. Many adults may have become accustomed to their condition, making it difficult to recognise these problems as something that could potentially be alleviated or treated. As a result, some do not seek help for the assessment of increasing pain.

Dysphagia and underweight: Many adults experience difficulties in recognising underweight as a consequence of dysphagia, and how this is related to energy levels and functioning. Some hold the belief that food with a modified texture lacks flavour. Relatives may be reluctant to change the texture of food, as meals also represent an important social context, or because they, as parents, experience satisfaction in being able to provide something for their child (training eating skills). There may also be an understanding that it is "a pity" if the adult is not offered the same food as everyone else. Finally, there is often considerable resistance to the insertion of a PEG tube, particularly among relatives, as this is perceived as a loss of quality of life.

Tested in the project:

The project's communication of CP as a spectrum of consequences following early brain injury, together with the project's use of the ICF as a conceptual framework, has contributed to increasing health literacy among people with CP. Health literacy is a personal factor that influences functioning,[1] and the CP team has therefore focused on strengthening health literacy among people with CP through education on how CP may manifest in different individuals. This has been achieved by offering learning experiences that support understanding of the relation between CP and functioning (See Case Marianne.) See also section on distorted focus, Chapter 3.5.

Case 4. Marianne: Strengthening health literacy through education and learning experiences
Marianne is in her thirties. Her movement pattern is characterised by involuntary movements, and all selective movements are uncoordinated. This results in significant challenges with chewing and swallowing food. Marianne frequently experiences aspiration, which causes severe coughing. She experiences respiratory problems for several months at a time and uses a great deal of energy when eating, which leads to exhaustion and prevents her from completing meals.

Marianne is sceptical about assessing her eating and drinking difficulties, as she could not envision a life with a feeding tube. However, Marianne agreed to both an assessment and a trial of foods with textures different from those she was accustomed to. The assessments showed that there was no indication for tube feeding. It became clear that she used significantly less energy when eating foods with modified texture and swallowed the food more efficiently. Most surprisingly to Marianne, puréed or gratin-style food tasted both better and more flavourful, as her tongue no longer pushed the food directly into the pharynx or out of the oral cavity, but instead allowed her to actually taste the food. She stated that she would never have believed this had she not experienced it herself through practical trials.

Today, Marianne is less frequently ill than she was previously. She now primarily eats gratin-style food. Through the clinical evaluation, it was therefore possible to increase not only Marianne's health literacy, but also her mealtime satisfaction.

Barrier 5: System stress ("Clinical evaluation anxiety" and "Municipality anxiety")

Identified in the project:

For many adults, hospital admission is associated with previous negative experiences with the system. Many adults with CP and their families experience "municipality anxiety" – an often-well-founded fear that their current municipal support and services may be reduced, as well as a general sense of insecurity and unease in their interactions with the municipality. This concern may result in adults refraining from moving to a different municipality or from applying for necessary interventions, such as medication or a power-assisted wheelchair unit, due to fear of jeopardising their existing support arrangements.

Some adults believed that cognitive difficulties equate to low intellectual ability and therefore declined an indicated cognitive evaluation due to the fear of social consequences. This fear was pronounced for adults receiving services under the 'BPA' scheme (user-controlled personal care assistance for people with substantial and long-term physical or mental impairments) due to the demand of assuming the role of work leader (see case Martin).

Several adults have expressed a desire for rapid treatment (such as morphine for pain management in order to maintain previous levels of functioning), while refusing clinical evaluation due to *fear of what the examinations might reveal and the potential consequences* (such as surgery or a serious diagnoses). This resistance may be shaped by *explanatory models in which the cause of symptoms is attributed to insufficient training or incorrect use of assistive devices*, rather than ageing or long-term consequences of CP.

Tested in the project:

Early in the project, rehabilitation pathways based on hospital admission were included. While hospital admissions have not been omitted in principle, the associated challenges (e.g., unknown environment, past negative experiences), led us to primarily provide rehabilitation through outpatient pathways - see Chapter 3.4. By meeting adults in the outpatient clinic over longer clinical pathways, and by intentionally prioritising relational work, the CP team created a safe space in which individuals can openly discuss their concerns and previous experiences with the system. The team has approached anxiety with understanding and acknowledged the barriers they experience. This approach has made it possible to uncover how an apparent "no, thank you" to a clinical evaluation or an offered intervention often conceals an underlying fear or worry, for example of losing current support or worsening their collaboration with the municipality. These efforts have been successful in most cases, but not always (see Cases Marianne and Karsten below).

Case 5. Martin: Municipality anxiety

Martin is his twenties and has significant physical limitations in daily life. He receives daily support. Martin has not undergone a cognitive assessment in adulthood. For several years, he has experienced considerable psychological strain.

As part of the project, Martin wished to gain greater insight into his cognitive resources and barriers in order to better understand himself and his reactions in everyday life. However, he was concerned that a neuropsychological assessment could lead the municipality to withdraw his support arrangement. As a result, the assessment was not carried out. Instead, he participated in advisory conversations based on already available information.

This illustrates a broader problem: adults with cerebral palsy may refrain from acquiring knowledge that could be beneficial for them in terms of receiving appropriate support and using optimal strategies in daily life, due to fear that such assessments might jeopardise the daily assistance they depend on.

Case 6. Karsten: System stress
Karsten is in his late fifties and has a long history of negative experiences within the municipal system, accompanied by considerable frustration. He has lived in several Danish municipalities and reports adverse experiences in all of them. Karsten is sceptical about the CP clinic.
During the initial review of his medical history, it quickly becomes apparent that important clinical data, such as blood test results, are missing. Karsten is anxious about anything related to medical examinations and refuses most. He does not want to receive test results unless positive findings can be guaranteed. Several aspects of his medical history indicate that serious underlying conditions may be present and that blood test would likely lead to further examinations. While efforts were made to build the necessary foundation of trust with Karsten, these efforts were unfortunately not successful, and the clinical pathway was therefore discontinued.

Case 7. Marianne: Clinical evaluation anxiety
As described in case 4, Marianne is assisted with eating and frequently experiences aspiration, which causes severe coughing. She uses a great deal of energy when eating, leading to exhaustion and preventing her from completing meals.
She has consistently refused to engage in discussions about her eating and drinking difficulties, as she cannot envision a life with a feeding tube. Marianne asked us not to pursue this issue.
After a few meetings and the establishment of a trusting alliance with Marianne, however, she agreed to both an assessment and a trial of different food textures. Subsequently, Marianne herself articulated that her beliefs on food and drinks had been very black-and-white, and that her anxiety about being advised to have a feeding tube made it impossible for her to think in terms of graded solutions.
Through the project, it was thus possible to address Marianne's clinical evaluation anxiety.

Recommendations

Recommendation 1: Disseminate knowledge that CP is a spectrum of consequences following early brain injury

Knowledge that CP should be conceptualised as a spectrum of consequences following early brain injury should be disseminated in society, within the health care system, and among adults with CP and their relatives. This may contribute to reducing stigmatisation and misunderstandings related to life stage transitions and functioning and thereby reduce the barriers that limit adults with CP from accessing relevant health care services. Furthermore, this may contribute to adults with CP being met in an acknowledging and supportive manner, both in the social care and health care system.

Recommendation 2: Adopt a bio-psycho-social (ICF) framework in clinical practice

In clinical practice, CP should be conceptualised within a bio-psycho-social framework (ICF)[1] to ensure a holistic approach. This may help shift the focus of both the health care system and the individual away from expectations of “normalising” failing body functions, and the associated feelings of guilt and shame, towards a more genuine approach to everyday functioning, with an emphasis on meaningfulness and well-being. Furthermore, this approach may contribute to strengthening health literacy among both adults with CP and healthcare professionals.

Recommendation 3: Establish safe and supportive spaces for dialogue about concerns

Health professionals should acknowledge that adults with CP navigate a complex system characterised by multiple barriers, where previous experiences with healthcare services and municipal case management may influence trust in public authorities. An open and acknowledging approach may help reveal that resistance to offered services often conceals an underlying anxiety about losing existing support. Creating safe spaces requires time and intentional relational work.

3.2 Health and social policy related factors

Health and social policy factors refer to the authoritative decisions and regulations that shape the organisational conditions for adults' access to and use of health and social care services. These factors include legislation and political initiatives at all administrative levels, as well as requirements related to quality improvement within the health care system. Below, the identified barriers, tested interventions, and cases illustrating these barriers and how they were addressed by the project are presented. The chapter concludes with the derived recommendations related to health and social policy factors.

Barriers

Barrier 1: Lack of health policy strategies for adults with CP

Identified in the project:

Only a few national initiatives concerning CP exist, and these are directed exclusively towards children (the national clinical quality database CPOP,[23] collaboration agreements with the regions in relation to CPOP,[24] and an outdated clinical guideline for physiotherapy and occupational therapy for children and adolescents with CP[25]). For adults with CP, there are no national initiatives. The following are currently lacking:

- A Health Technology Assessment (HTA) to describe the overall needs and costs related to CP
- A neurological medical specialty plan[26] in which CP is included
- Health and Collaboration Agreements to ensure that adults with CP can access appropriate specialised treatment
- Care pathway descriptions defining coherent pathways for adults with CP
- Clinical guidelines to support and guide health care professionals including general practitioners working with adults with CP

Tested in the project:

In 2023, the CP team, together with CP Denmark and the Elsass Foundation, presented the project to a member of the Danish Parliament during a visit to

Hammel Neurorehabilitation centre. Furthermore, in connection with a meeting at the Ministry of Interior Affairs and Health in 2024, the development of an HTA for this area was proposed. The meeting was initiated by external partners who had contacted the Ministry. The team and Hammel Neurorehabilitation centre have not received further communication from the Ministry since then.

Finally, an initial meeting was held with CP Denmark and the Elsass Foundation to initiate the development of a joint health policy strategy for the adults with CP. It was decided that CP Denmark takes responsibility for direct political advocacy. Going forward, work will continue developing a joint health policy strategy, also including this present project’s recommendations.

Barrier 2: Lack of clarity in interpretation and insufficient gradation in rules and legislation

Identified in the project:

Participants in the project often spend considerable time and energy trying to clarify their income support options (such as flexible employment, retirement benefits, disability student grants) and available support services. They lack guidance on how to navigate the system and to apply for and receive relevant forms of support.

The CP team finds that rules and legislation lack gradation and contain such a broad scope for interpretation that they lead to uncertainty in everyday practice. It is as if a shared “moral compass” is missing in the interpretation of rules and legislation, and economic considerations sometimes appear to drive decisions - both at the system level, where access to funding and support seems dependent on current budget constraints, and at the individual level, where relatives risk becoming financially dependent on caring for their child.

Furthermore, the team finds that the distinct expert terminology used by municipal caseworkers and health professionals, respectively, may be difficult to understand across professional groups. In practice, this means that many young people and adults with CP are left with limited options, and services that are not tailored to their needs. This also applies to other adults with different types of disabilities.

Examples related to the field of education

Young adults with CP often require *reduced study hours in higher education*, but obtaining approval to study part-time may be challenging (see Case Lise below). The requirement of a minimum of 23 hours per week to be eligible for *student financial support* (Danish Students' Grants and Loans Scheme §22, subsection 2 [SU-bekendtgørelsen]) may prevent them from utilising their competencies and result in them ending up in unskilled employment or on disability pension (see Case Rasmus below). The team also encountered young adults who, despite stress reactions and the need for sick leave, remained enrolled in their studies to avoid losing their income, even though other income support options may be available in the system.

Students may apply for a *mentor scheme or Special Educational Support* (Consolidation Act on Special Educational Support at Higher Education §2, punkt 2 [Bekendtgørelse af lov om specialpædagogisk støtte ved videregående uddannelser m.v.]), but not until the educational programme has formally commenced. However, young adults with CP often require support before the programme commences, to plan their education programme and clarify opportunities for and extent of later support, including support during potential internship periods. Younger adults with CP may receive support from an *educational guidance counsellor* when choosing upper secondary education (Consolidation Act on Municipal Support for Young People under 25 [Bekendtgørelse af lov om kommunal indsats for unge under 25 år]), but these counsellors do not necessarily have knowledge of CP, and the guidance and support provided may therefore become general or counterproductive.

Examples related to the field of employment

The team encountered several adults who face challenges related to rules and regulations in the labour market (e.g., Working Environment Act [Arbejdsmiljøloven]) (see Case Emma, Chapter 3.1). This is also consistent with a recent study from Aalborg University showing that flexible and relevant jobs are lacking for people with CP who have a medium-cycle or long-cycle higher education.[27]

Examples related to daily living support

In general, there is considerable variation in the services an individual may be granted, including variations in how responsibility for payment is interpreted (see Case Søren, Chapter 3.3), and the documentation requirements that must be met to receive a service (see Case Andy below).

Rules in the *BPA scheme* (personal assistance scheme for people with disabilities; Social Services Act § 96 [Serviceloven]) lead to uncertainties in other areas - such as when applying for assistive devices that could otherwise strengthen independence. Individuals worry that assistive devices which increase independence may result in a reduction or loss of their BPA scheme altogether. Some therefore refrain from seeking relevant support out of concern that rules or support in one area may negatively affect other areas.

The requirement to fulfil the role of work leader within the BPA scheme may lead some adults to pay privately for a cognitive evaluation by a neuropsychologist who already knows them. Although such an evaluation is clinically relevant, privately financed assessments are not always recognised as valid documentation by public authorities.

Rules for *companion schemes* within home care or residential settings (Social Services Act § 97 [Serviceloven]) state that companions may not assist with practical tasks, including, for example, toilet visits. As a result, a companion scheme, which is the common alternative to a BPA scheme for those assessed as unable to fulfil the work leader role, often results in significantly reduced personal freedom and quality of life compared with a BPA scheme arrangement.

Furthermore, the level of *support for developing digital competencies* varies across municipalities, even though communication with public authorities is increasingly digitised. Many adults with CP have limited competencies to manage and navigate in this system.

Examples related to training

Rules for *free of charge physiotherapy* (Health Act §140a [Sundhedsloven]; Consolidation Act on free of charge Physiotherapy §12 [Bekendtgørelse om vederlagsfri fys]) mean that people with CP are only eligible for the scheme if their CP condition include a "severe physical disability", even though they may still have difficulties independently seeking, engaging in, and structuring workout and training. In the project, 39% of participants were not included in the free of charge physiotherapy scheme (**Table 3**, Chapter 2). Besides this, there is also substantial variation in the content and extent of free of charge physiotherapy, which the team believe cannot be explained by individual needs. For example, some may receive supervised training twice a week and an offer for warm-water pool training, while others only receive a weekly session consisting of 20 minutes of passive movement.

Examples related to the transition from childhood to adulthood

Rules related to the *transition from child to adult* (Children's Act §122 & 123 [Barnets Lov]) are managed differently across municipalities, and families often lack support to navigate the system on the adult level. If parents are not aware of the requirement to apply for digital power of attorney or guardianship - for example, because the municipality did not inform them at their 17½-year meeting - young people who lack the necessary digital competencies risk losing access to communication and collaboration with public authorities.

Additionally, some parents who have received compensation for lost earnings for many years are not aware that the scheme ends when the child turns 18. The end of the scheme may provide an opportunity to return to working life, but support may be needed to facilitate this process. In some cases, municipalities do not fulfil their formal responsibility to prepare the transition from child to adult, when the young person moves from legislation under the children and youth area to being covered by Social Services Act [Serviceloven]. During the project, the team has encountered young adults whose municipal support ceased entirely when they turned 18, without an assessment of whether the young adult may be entitled to other forms of support under provisions such as Social Services Act [Serviceloven].

<u>Tested in the project:</u>
The CP team includes a social worker who often coordinated patient pathways during the project enrolment period - similar to the role of brain injury coordinators within the field of municipal brain injury services (see Case Viggo below). She assisted adults in clarifying income support options and available services and supported them in navigating the municipal system. With her extensive knowledge of legislation, insight into which information municipal caseworkers require, and what should be included in written reports, she has played a central role in ensuring coherent pathways. Besides this, she assisted the CP team in understanding and navigating the system.

The CP team participated in network meetings with various municipal representatives and the municipal assessment unit to ensure that municipal services are adjusted to adults' needs. The interdisciplinary status report on functioning that has been prepared for all participating adults in the project (see template in Appendix 4 (in Danish) - separate document) and has often been used to inform municipal caseworkers about support needs before such meetings. The aim has been to contribute to a trust-based dialogue and to translate the needs of adults with CP into accessible language for municipal caseworkers. These efforts have been successful in most cases, but not always (see Case Andy below).

Case 8. Lise: Studying part-time

Lise is in her twenties. She uses an electric wheelchair and has severe motor impairments and uses communication aids. She is enrolled in a university programme. Prior to the commencement of her studies, she contacted the student guidance service for advice on the possibility of studying part-time due to her need for extended time for communication and pronounced fatigue. Lise is asked to obtain a medical statement for use in the university's assessment. However, the medical statement is rejected twice by the university, because her functional impairments are not sufficiently described. On this basis, Lise contacts the CP team for professional support. The CP team prepares a supplementary clinical note. The note outlines, among other things, the relationship between cerebral palsy and increased energy use due to sustained muscle activity, pain, and fatigue, as well as the impact of motor and communicative challenges on cognitive load and study endurance. Additionally, fatigue is described as a well-known and well-documented issue among adults with CP. The clinical note is attached to the medical statement from the GP, after which the university approves Lise's application to complete the programme part-time.

Case 9. Rasmus: Applying for disability pension

Rasmus has used an electric wheelchair since he was a child and requires lifting equipment for all transfers. He receives 24-hour assistance. He is referred to the CP team due to declining functional ability.

When Rasmus turned 18, he was encouraged to apply for disability pension. However, Rasmus wanted to pursue education and employment, and he therefore declined. Since then, he has repeatedly discontinued educational programs due to stress, depression, and severe pain. He received student grant support during the periods in which he was enrolled in education. Now he is concerned about his future income. He does not believe he can apply for disability pension, as he previously declined, and he does not know where to seek assistance. The CP team's social worker arranges a meeting the municipal Job Centre, in which the social worker participates alongside Rasmus. The municipal caseworker receives medical documentation from the CP team regarding Rasmus's health status through the interdisciplinary status report on functioning. Rasmus is quickly granted disability pension, as the municipality considers it unpromising to attempt to develop his work capacity.

Case 10. Andy: Documentation requirements to apply for support

Andy is his forties and has significant cognitive difficulties, challenges with emotional regulation, dysarthria and mild dysphagia. He requires assistance with all basic activities. His carers agree that his current housing arrangement is unsuitable. The CP team's recommendation is a housing arrangement with continuous health and social-pedagogical support, such as a residential facility with 24-hour staffing. Although Andy's practical care needs are well-documented, the municipality also requires documentation of his social-pedagogical needs, including evidence that these needs cannot be met in his own home. The municipality proposes that Andy documents his social-pedagogical needs in a form over a 24-hour period. This task is impossible for Andy, both due to motor impairments and cognitive challenges. The CP team described Andy's difficulties extensively in a written interdisciplinary status report and assumed that this report documented his social-pedagogical needs (although not using the term "social-pedagogical need"). Besides this, the CP team's social worker participated in meetings with various municipal representatives and clarified the descriptions and recommendations. The municipal caseworker subsequently asked Andy's carers to document their observations in writing as evidence of the social-pedagogical needs. Later the application for residential placement is rejected, stating that enhanced coping skills support in Andy's own home has not yet been attempted.

The case illustrates the difficulty of translating the needs of adults with CP into the language used in municipal case processing. It also shows how challenging it may be to determine whether the municipal assessment process has the ability or intention to use, for example, the interdisciplinary status report as valid documentation of support needs.

Case 11. Viggo: Coordinating the support options
Viggo, a man in his thirties, has lived in different municipalities during adulthood. He now lives alone in a rented apartment without any daily support. Viggo finds it difficult to communicate with the municipality, and is frequently demoralised after meetings or interactions. He feels rejected and experiences that his applications for support never succeed, which means that he has desisted from seeking assistance. The occupational therapist and the social worker visit Viggo in his home together with a municipal assessor. Following this visit, the municipality grants daily household aid (e.g., cleaning & laundry), and a housing support is subsequently established for Viggo. He recalls that he previously received additional expenses benefits* (e.g., extra laundry costs), but he is unsure why it stopped. The occupational therapist and social worker aid Viggo in the application for reinstatement, which is subsequently granted. The case illustrates the coordinating function provided by the project's social worker during the period in which the participant was affiliated with the project.

*As of September 1st 2025, the additional expenses will be replaced by a new compensation benefit (Social Services Act § 100 [Serviceloven]).

Recommendations

Recommendation 1: Place challenges faced by adults with CP on the health policy agenda

Draw attention to unmet needs and significant barriers - for example with reference to the examples and cases presented in this report. Relevant actors are CP Denmark (patient perspective), Elsass Foundation (financial capacity), and Hammel Neurorehabilitation Centre (clinical expertise).

Professional societies, including the Danish Neurological Society and the Danish Society for Neurorehabilitation, may support this agenda by providing scientific legitimacy and a clear professional voice in public and health policy debates.

The vision is the development of national strategies for adults with CP, embedded within the existing rules and structures for acquired brain injury (See Chapter 3.4).

Recommendation 2: Adapt the administration of rules to the needs of individuals - not the reverse

This applies broadly to legislation in *the children and youth area, the field of education, the field of employment*, Health Care Act [Sundhedsloven] *and* Social Services Act [*Serviceloven*]. Examples under "Identified in the project" can be used to articulate this need.

To ensure that services are tailored to the adult with CP, there is a need for trust-based dialogue between the adult with CP and municipal caseworkers. In many cases, there will be a need for a coordinating caseworker with greater insight into CP, for example a brain injury coordinator (see Chapter 3.4).

There is a particular need in the transition from child to adult, where the young person moves from child legislation to adult legislation. Contact with Youth Mentors is a potential source of additional support (see Chapter 3.5).

Finally, it is essential to translate the needs of adults with CP into a language that is accessible to municipal caseworkers. The interdisciplinary status report developed in this project is a possible tool for this purpose (Appendix 4, separate document).

3.3 Economic factors

Economic factors refer to the financial resources available at the societal level to pay for health care services, which may create barriers to access and use of such services. These factors include incentives for providing services as well as individuals' personal resources to pay for services.

The identified barriers, tested interventions, and cases illustrating these barriers and how they were addressed by the project are presented below. The chapter concludes with the derived recommendations related to economic factors.

Barriers

Barrier 1: Lack of economic incentives for establishing specialised services

Identified in the project:

The project staff's knowledge on rehabilitation for adults with CP is based on experiences from the externally funded project. Currently, there is no comprehensive overview of the needs of adults with CP, nor of the societal costs and benefits associated with establishing a specialised service for adults with CP. Without such an overview, there is no clear economic incentive to establish a service for adults with CP.

Tested in the project:

A collaborating municipality designated as a partner for analysing this project's costs and benefits, stated that there is no overview of the municipal services provided to people with CP. The CP team furthermore found that documentation in the regional EHR system lacks relevant clinical procedure codes that could be used for a health economic analysis.

The CP team suggested to the Ministry of Interior Affairs and Health that a Health Technology Assessment be developed for this area – see details in Chapter 3.2.

Barrier 2: Costs associated with health care services

Identified in the project:

Many participants in the project experience difficulties in obtaining *funding from the municipality or the region* for treatments that improve quality of life, such as Transanal Irrigation (TAI), a treatment for chronic constipation. If the individual cannot afford private payment, the lack of funding may lead to discontinuation of an effective treatment (see case Søren below).

Many adults also spend significant effort applying for support for small but necessary expenses (for example sheets, weighted blankets, and positioning cushions), as such items are generally not granted within the system.

*Co-payments for health care services and transport cost*s are also challenging for many people (for example transport costs related to training and treatment sessions). Furthermore, people with CP often require specialised dental care, which ordinary dental clinics cannot provide, such as a lift to transfer them into the dental chair or treatment under general anaesthesia in cases of severe spasticity. Access to specialised dental care requires municipal approval, but user fees of up to approximately 2,000 DKK may prevent some adults from seeking the necessary treatment.

Tested in the project:

The project's social worker has helped individuals gain an overview of available support options, their rights, as well as where and how to apply correctly. In some cases, individuals have been advised to apply for personal grants to cover expenses that are not funded within the public system.

Case 12. Søren: Costs associated with health care services

Søren is a middle-aged permanent wheelchair user. With aging, Søren has experienced a marked decline in functional ability, including chronic constipation symptoms causing discomfort, flatulence, and odour issues. As a result, Søren increasingly avoids social activities. The CP team undertook a comprehensive assessment of his symptoms and jointly with Søren tested various medical and lifestyle interventions. By using a transanal irrigation (TAI) system, Søren was able to maintain satisfactory bowel function, and reduce odour issues and discomfort. Subsequently, Søren experienced a marked improvement in his quality of life and regained confidence to resume social activities. Nevertheless, the financing of TAI proved to be a significant challenge, as he did not have the financial means to pay for the product himself:

- If TAI was classified as a treatment, the regional health authority was responsible for covering the cost, but only if deemed indicated after further specialist examination.
- If TAI was classified as an assistive device, Søren could apply for municipal funding.
- If neither the region nor the municipality acknowledged the need, Søren would have to pay for the TAI himself

The CP team ultimately issued a specialist referral for Søren for a dedicated examination indicating his needs. Søren is currently awaiting an appointment.

Recommendations

Recommendation 1: Establish an overview of the needs, costs, and benefits of specialised CP services

Such an overview - for example as part of a Health Technology Assessment (HTA) of a dedicated service for adults with CP - may underline the incentives for the development of dedicated services for people with CP, while highlighting values such as improved quality of life. An HTA would thus provide the foundation for the health policy process described in Chapter 3.2.

Recommendation 2: Guide on economic support options within the social care system

There is a substantial need for guidance, otherwise financial constraints may become a barrier to receiving necessary treatment and adequate support. Adults with CP should be offered assistance from a coordinating caseworker with insight into municipal and regional support options, as recommended in Chapter 3.4. The caseworker should provide an overview of income support options, and where such applications should be directed.

3.4 Organisational factors

Organisational factors refer to the structural conditions within the healthcare and social sectors that may create barriers to adult's access to and use of services. These includes, among other things, the organisation of the system, its capacity, coordination, accessibility, staffing, and workflows.

Below, the identified barriers, tested interventions, and cases that illustrate these barriers and how the project has addressed them are presented. The chapter concludes with the derived recommendations related to organisational factors.

Barriers

Barrier 1: Silo mentality and lack of information sharing

Identified in the project:

The system often lacks the necessary flexibility to accommodate the complex and changing needs of people with CP, as hospital departments, general practice, and municipal services in both the health and social sectors are governed by the tasks and routines within each individual department and area (silo mentality). Besides this, many adults experience inadequate information exchange between professionals, for example between general practitioners (GPs), hospitals, and municipal actors, because their IT systems are not compatible. Consequently, many experience an expectation that they themselves must carry information between professionals – this is described in more detail in Barrier 2.

There is therefore a lack of services that can coordinate across sectors. The intentions of the *Healthcare Reform 2024* to strengthen coherence in the healthcare system through cross-sectoral, standardised, and individually tailored initiatives point towards a potential future solution to the silo mentality problem. However, the Healthcare Reform mainly focuses on initiatives targeting major chronic disease groups and older adults.[28] In this context, CP constitutes a relatively small target group. A key lesson from the project is therefore the need to embed initiatives within existing structures in the healthcare system. Integrating initiatives for people with CP within the brain injury structures, requires discussion in regional collaboration forums (for example, Central Denmark Region's Brain Injury Council), where hospital leadership, municipal social directors, and municipal clusters/health councils work to strengthen cross-sector collaboration between hospitals and municipalities.

Below are examples of silo mentality and lack of communication between professionals as observed in the project. However, many of these issues also apply to other adults with different types of disabilities.

Examples from hospitals

- Adults with CP often do not have *treatments* initiated or do not receive adequate treatment:
    - Many adults cannot independently participate in clinical evaluations and therefore do not fit into the established routines within relevant departments, for example completing a fluid chart in connection with a urological clinical evaluation (See Case Karin).
    - Specialised treatment such as Botulinum Toxin injections is currently limited to typically 10–20 minutes per session performed by a single physician, with little or no knowledge of the cognitive and complex issues that may make treatment difficult to carry out in practice. There is rarely the opportunity for interdisciplinary follow-up to assess the effect and adjust the dose over time. There are also long waiting times, often up to several years, for assessment in relation to treatment with a baclofen pump.
- Many people with CP have significant comorbidities and therefore often require hospital contacts. However, there may be a *lack of coordination between departments*, resulting in adults being scheduled for multiple appointments at the same time or for appointments placed so closely together that they are unable to participate.

- Children with CP are followed through the dedicated *CPOP* follow-up programme but lose this support in the healthcare system once they turn 18. Hereafter, general practitioners usually assume treatment and follow-up responsibility.

Examples from general practice

- *Limited consultation time* makes it difficult to conduct a comprehensive medical history and prioritise coexisting conditions.
- There is often a *lack of specific knowledge*, both about CP and about opportunities for consultation with specialists in the field (See case Michael).
- There are *limited options for referring patients to relevant clinical evaluations and specialised services,* partly because referrals for these specialised evaluations must be issued by specialist doctors, and partly due to long waiting times for specialised services.

Examples from the municipal sector

- It is not possible to obtain a comprehensive interdisciplinary clinical evaluation, and difficult to access monodisciplinary assessments:
  - Cognitive assessment by a *psychologist* depends on municipal prioritisation and often only available in connection with job capacity assessment processes.
  - Collaboration with a *dietitian*, for example in cases of underweight or overweight, is difficult to establish as CP falls outside the dietitian's target group.
  - Referral to *occupational therapy*, for example in relation to guidance on optimising daily activities (eating), is often not possible, as occupational therapy is typically only offered as part of a rehabilitation plan following hospital discharge.

- People with CP often have *many caseworkers* within the municipality (for example one in the Adult Disability Department, one in the Job Centre, one in the vehicle unit [if granted a car], one in home care services, one for housing adaptations [if they require adjustments in the home]), but they appear to rarely collaborate on initiatives, even though the individual's needs are interconnected and require coordination.
- Many experiences *high turnover among caseworkers*, preventing any single caseworker from gaining a proper understanding of the respective adult's needs.
- Many experience a *lack of communication between residential facilities and day activity services*, meaning that environments and support in the activity service are not aligned or adjusted when changes occur for the adult (See case Miriam).
- Some health-related conditions stay undetected because personal care assistants, staff in *BPA schemes, and residential facilities* not necessarily have an education in healthcare and are therefore not formally trained to identify risk factors or initiate preventive measures (see case Poul).
- In some municipalities, preparation for the *transition from childhood to adulthood* is insufficient, with young people moving from child regulations to Social Services Act. The team encountered young people whose municipal support ceased when they turned 18.
- *Free of charge physiotherapy* services are often not tailored to the complex needs of people with CP, as areas such as assistive devices, environmental factors, 24-hour interventions, positioning, and body alignment are rarely addressed. These findings align with a recent survey where adults request individual treatment plans and diagnosis-specific competencies in the free of charge physiotherapy scheme.[29]

Tested in the project:

In the project, the CP team explored the possibility of receiving support from *brain injury coordinators*, but this is not possible, as CP currently falls outside the coordinators' target group. The CP team also explored the possibility of obtaining a *rehabilitation plan*[c] (a key cross-sector document for people with acquired brain injury), but people with CP do not automatically receive such a plan, as CP does not stem from a newly acquired injury.

The project, however, has largely functioned as a bridge-building initiative, ensuring that the adults' individual needs, and the professional assessment of these, guide the selection and organisation of interventions, rather than the tasks and routines of different sectors, departments and professionals.

Below, this is described using the clinical pathway illustration (**Figure 5**) and the pyramid-shaped model for clinical work (**Figure 6**). A description of the outpatient function and the interdisciplinary team can be found in Appendix 3 - separate document.

Clinical pathway from recruitment to completion

Figure 5 illustrates the bridge-building functions across sectors and departments. These include:

- Preparation of a comprehensive medical history: information is gathered across sectors and departments and used for pathway planning.
- Preparation of an interdisciplinary clinical evaluation status report (Appendix 4 - separate document). The report has typically been shared prior to meetings with municipal representatives to inform about support needs.
- Coordination of cross-sector collaboration and network meetings, corresponding to the role undertaken by brain injury coordinators in the field of acquired brain injury.
- Sending the interdisciplinary status report with points for follow-up to general practice.

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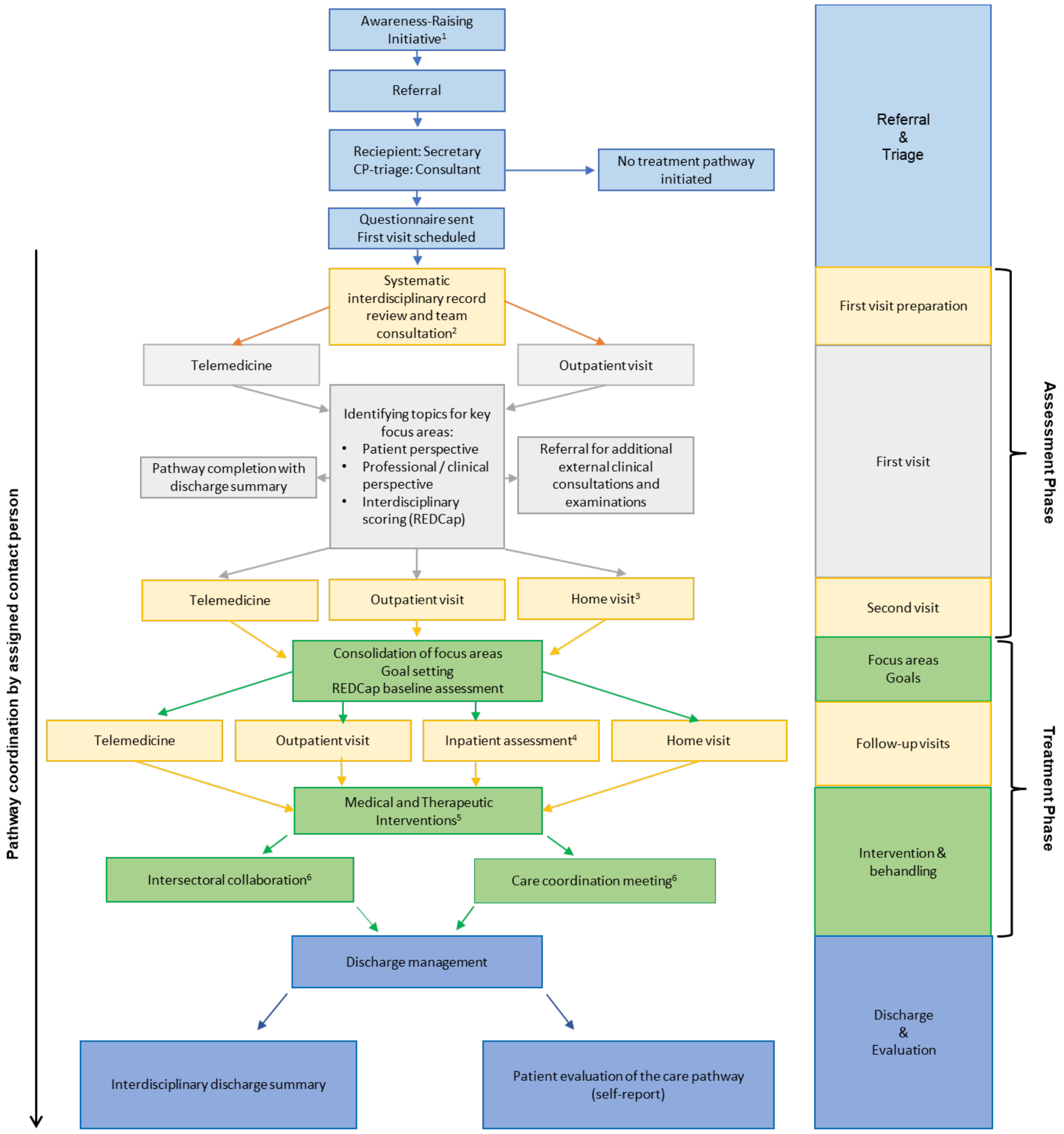
[c] A rehabilitation plan is a binding plan for the continued rehabilitation and training after hospitalization. It is prepared by the hospital and regulated by Sundhedsloven § 140 [Danish Health Act]. The interdisciplinary team in the municipality uses the rehabilitation plan in the communication with the municipality and thereby can provide specific services targeted to the citizen's individual needs

Figure 5. Clinical pathways in the project



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[1] *In the initial phase, dissemination was carried out primarily through "CP Danmark" (social media posts, etc.), and referrals were often based on the user's knowledge of the project. Currently, recruitment takes place via announcements on the Hammel Neurocenter website and LinkedIn. GPs and hospital physicians are by now familiar with this opportunity.*

[2] *In Denmark, healthcare professionals have access to the patient's complete electronic health record, allowing reconstruction of previous healthcare contacts, examinations, interventions, comorbidities, and medication history throughout the current care pathway.*

[3] *Home visits support home-based assessment, improve ecological validity of assessments, and allow evaluation of the home environment, assistive devices, and daily routines.*

[4] *In exceptional cases, inpatient assessments are conducted.*

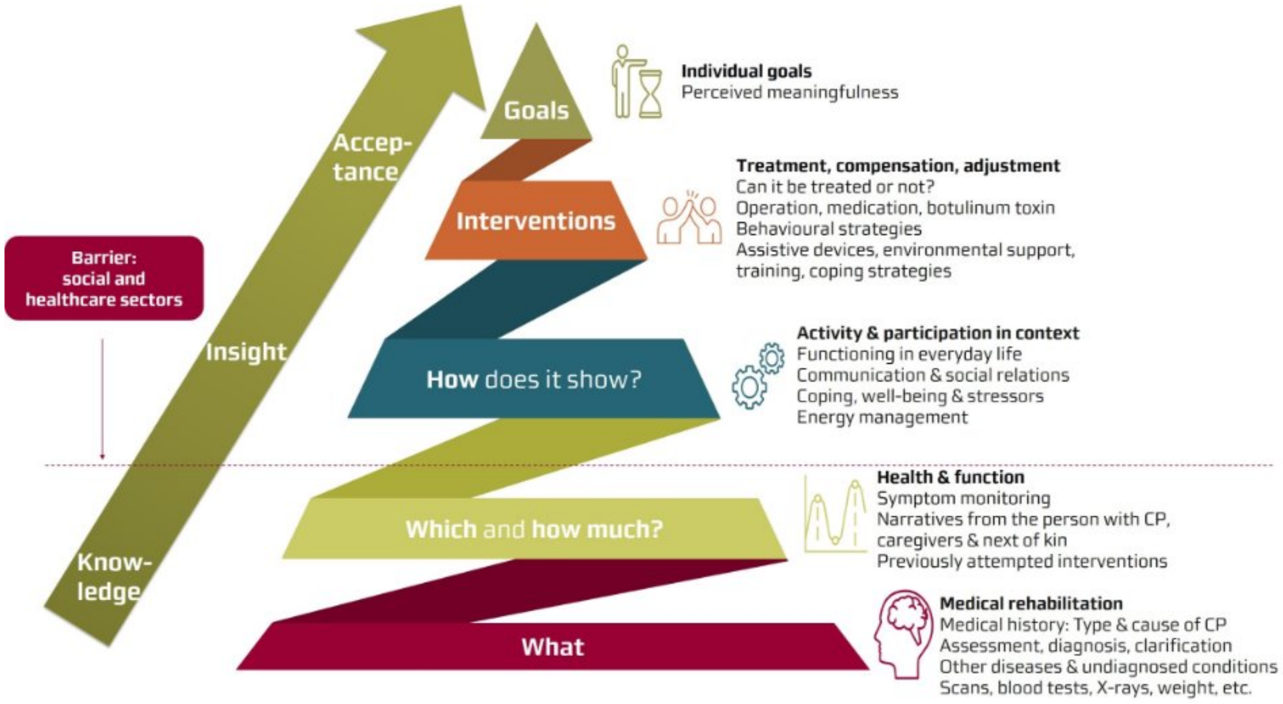
[5] *Specific interventions are initiated, e.g., physiotherapy-based training, occupational therapy with a focus on energy management and fatigue, and nursing interventions addressing bladder and bowel management or spasticity management, including treatment with botulinum toxin where indicated. At the same time, an interdisciplinary clinical status report is prepared.*

[6] *Social workers are actively involved in the care process. A care coordination meeting is a key instrument used to bring together the patient, relatives, and relevant professionals from different sectors (e.g. hospital, municipal services, social services) to support shared understanding, coordination, and planning.*

The pyramid-shaped model for clinical work

The pyramid-shaped model for clinical work (**Figure 6**) illustrates the holistic approach of the clinical pathway, based on the adult's individual needs and the interdisciplinary clinical evaluation.

Figure 6. The pyramid-shaped model for clinical work[d]



The model should be read from bottom to top. Based on the model, the CP team has:

- Established an overview of the adult's medical history by gathering information from hospitals, the GP, and (with user consent) the municipality. This has made it possible to distinguish between previously attempted initiatives and areas that still require clinical evaluation or intervention.
- Offered a comprehensive interdisciplinary clinical evaluation, as well as referral for supplementary assessments which are integrated into the overall interdisciplinary evaluation.

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[d] Adapted from 30. Rasmussen AC, Nielsen JF, Nielsen JB, Severinsen KE, Honoré H. [How adults with cerebral palsy are treated]. *Ugeskr Laeger* 2025; **187**(9).

- Offered to establish contact with and between relevant professionals, including guidance to the adult’s free of charge physiotherapist, communication of functional ability and support needs to municipal departments, and contact to youth mentors.
- Offered specialised interdisciplinary treatment and rehabilitation (see Chapter 3.5).

Case 13. Poul: Silos in the municipality

Poul lives in a residential facility. He is now an older man and has several secondary complications, including severely reduced cognitive function and limited ability to communicate. Staff has observed that Poul has developed agitated behaviour, especially during meals. In addition, it has become increasingly difficult to position him correctly in his wheelchair. The pedagogical staff is puzzled about the change in behaviour.

Poul undergoes an interdisciplinary clinical evaluation by the CP team, in collaboration with staff from his residential facility. It becomes clear that Poul experiences pain when his right hip is moved or touched. An Xray reveals that his hip is completely dislocated. It is expected that this will cause significant pain. After the correcting surgery, Poul’s behaviour gradually changes – he shows more enjoyment during meals and can be positioned more easily in the wheelchair. He also becomes able to verbally express pain experiences, as the “background noise” (the constant pain sensation) has now been removed.

The case illustrates the importance of healthcare follow-up and ongoing monitoring. In residential facilities with limited healthcare resources, there is increased risk of overlooking harmful health conditions, which creates a barrier to prevention, early identification, monitoring, and treatment, as well as collaboration with the GP or residential facility physician.

Case 14. Miriam: Lack of information exchange

Miriam, a woman in her twenties, lives in a residential facility. She is underweight and has significant feeding difficulties. The residential facility staff assists her during all meals, both physically and motivating her to complete meals. Four days a week, Miriam attends an activity-based day programme. Here, the mealtime assistance is not available, and Miriam therefore often returns home without having eaten.

In the project, the CP team addressed the day programme’s lack of support during meals, and a collaborative agreement was made to ensure that Miriam now receives daily support during meals. The team also prepared presentation slides with recommendations regarding meals, which were reviewed with and provided to Miriam’s caregivers.

Case 15. Karin: Specialised clinical evaluation and treatment

Karin is in her late twenties and primarily relies on a manual wheelchair in daily life. Karin is employed and leads an active and independent life. She contacts her GP due to pronounced urinary urgency, including individual episodes of urinary incontinence. The GP refers Karin to a specialist. In the specialist clinic Karin is instructed to complete a fluid and voiding diary for at least three days, measuring fluid intake and urine output. Karin experiences significant difficulties in conducting the measurements and completing the diary. The task becomes overwhelming and burdensome, and she develops feelings of guilt and shame for not being able to meet the requirements of the clinical evaluation. Consequently, Karin does not attend the planned follow-up appointment at the clinic.

In the project, Karin is met through a person-centred, resource-oriented approach that takes her level of functioning, daily life, and overall strain into account. The clinical evaluation of her urinary symptoms is resumed in an adapted format to make the task more manageable. Based on the adapted diary, Karin’s description of her symptoms, and her own preferences medical treatment is initiated. After a few weeks, Karin experiences a marked reduction in urgency.

The treatment significantly improves her quality of life and gives her confidence for participation in social activities.

Case 16. Michael: Challenges in general practice
Michael attended public school and is now enrolled in a higher education. Michael experiences a significant decline in his functioning. He shows depressive symptoms, has major difficulties initiating and carrying out activities, and attention difficulties. Michael's friend and flatmate also express his concern. Michael contacts his GP, who refers him to a psychologist for assessment. The psychologist notes Michael's CP and discusses with him whether the brain injury might contribute to his symptoms. Both Michael and his GP had been unaware of the potential connection.
In the project clinic, Michael meets an interdisciplinary team which initiates a holistic clinical evaluation. It becomes evident that Michael has linguistic and executive cognitive functioning difficulties. Within the project, the CP team subsequently initiated relevant support: professionals who coordinated the interdisciplinary efforts and ensured a holistic approach. This case illustrates how challenges in general practice may lead to symptoms being assessed in isolation without relating them to his underlying neurological condition. This leads to a risk of delayed or insufficient treatment and a lack of support for coping.

Barrier 2: Challenges in meeting system requirements and carrying information between professionals

Identified in the project:

Contact issues: For some adults with CP, a Digital Post (E-boks) appointment notification is not sufficient and must be supplemented with SMS, email, and contact with relatives. Several adults are also exempt from Digital Post and receive letters by regular mail, which may be delayed, fail to arrive, or remain unopened.

Appointment issues: Many adults with CP find it difficult to manage appointments or meeting the requirements associated with assessment, clinical evaluation, and treatment, such as:

- Keeping a diary of pain or medication side effects
- Completing forms documenting support needs
- Being admitted for inpatient assessment

There may be multiple reasons for this, but ultimately it means that the adult does not receive a systematic evaluation of symptoms, treatment effects, and support needs.

Carrying information between professionals: The lack of information exchange between professionals (see Barrier 1) means that there is an expectation, that the adult must personally carry information between professionals. For many adults with CP, it is challenging to communicate a condition or symptom, and to pass on information between professionals. In addition, dysarthria and cognitive-communication impairments make it difficult for many to express oneself clearly and retain key information. Familiar communication strategies often do not work when meeting new professionals who are not familiar with their communication style. At the same time, some adults have limited insight into their own symptoms and limitations and therefore attend appointments alone, which further increases the risk of misunderstandings and incomplete transfer of essential information (See Case Liva). Furthermore, companions such as personal care assistants or staff from residential facilities may also lack knowledge about CP and the specific symptoms at hand and may therefore be unable to support the adult effectively.

<u>Tested in the project:</u>

- *Adapted communication and contact within the project:*
  The CP team allocated time to identifying the best way to contact each individual adult and continuously adjusted communication modes to minimise missed appointments and misunderstandings.
- *Support to attend appointments:* Various forms of support were implemented to ensure attendance, including:
    - Involvement of relatives or municipal housing support workers.
    - Home visits when attending in person was overwhelming for the adult, ensuring that clinical evaluation and interventions were also accessible to those unable to attend the clinic (see case Anne).
    - The project identified and documented situations in which adults lack the prerequisites for successfully meeting the necessary requirements for municipal case processing (see Case Mona, Chapter 3.2).

- *Support to carry information between professionals:*

  The CP team:
    - Offered adults concrete and simple tools to aid structure, overview, and shared understanding in communication with professionals.
    - Highlighted the importance of bringing a companion, who knows the adult well, to clinical evaluations and assessments.
    - Accompanied adults to appointments to support their understanding of the information provided.
    - The interdisciplinary status report, which was prepared for all adults in the project, also assisted them in carrying information between professionals.
- *Choice of outpatient pathways as the primary intervention:*

  A substantial proportion of adults found it difficult to benefit from inpatient admissions in new and unfamiliar environments. Some inpatient pathways had to be discontinued because the adult became overstimulated and developed sleep disturbances. In addition, several adults found it difficult to transfer newly learned skills into daily life. Those who benefited from inpatient admission achieved comparable outcomes in the outpatient service, sometimes supplemented with home visits. Consequently, the project primarily offered longer-term outpatient pathways, often with a high number of contacts (median 11 cf. **Table 6**, Chapter 2).

  From a health-economic perspective, outpatient care pathways also represent a cost-effective and efficient approach. For example, nearly three adults can be treated in a structured outpatient setting with 11 interdiciplinary contacts for the cost of one inpatient episode (see results from a break even analysis in appendix 5 - separate document)

Case 17. Anne: Setting requirements on the adult's terms

Anne is in her early twenties, has developed severe anxiety and finds it extremely difficult having appointments or leaving home. She wishes guidance that may support her in improving her well-being. However, contact with healthcare professionals and caseworkers increases Anne's anxiety. Anne is discouraged and does not feel acknowledged in her meetings with healthcare professionals and caseworkers. Anne experiences cognitive challenges and often misunderstands information, which increases her anxiety symptoms. Meetings are therefore often too complex for her to participate in.

In the project, Anne's pathway was adapted to avoid strain. She authorised close relatives to participate in meetings on her behalf, including collaborative meetings with the municipality. Clinical evaluation and guidance primarily took place through home visits in her known and safe environment. All communication between the CP team and Anne took place with a trusted companion present. It was crucial for the pathway that sufficient time was scheduled between appointments, and that a gradual approach was used, allowing for rapport to be built and improvements in daily well-being to emerge. A standardised, time-limited pathway within the healthcare system would likely have exacerbated the severe anxiety Anne was facing.

Case 18. Liva: Challenges in carrying information

Liva, a woman in her mid-thirties, is enrolled in several hospital-based outpatient clinics, encompassing regular outpatient and telephone follow-ups. Liva has good communication abilities and attends appointments without a support person. While she has a helper driving her to appointments, he is usually asked to wait outside.

The CP team finds that Liva is burdened and stressed by managing the large number of appointments. Errors and double bookings occur, in which Liva misses important appointments. Besides this, Liva struggles to remember or convey important information regarding her treatment to her helper.

During the pathway in the CP clinic, the team becomes aware of the strain Liva experiences in acting as the sole information carrier. The CP team discusses with her the importance of maintaining ownership and control over her own life. At the same time, the team also explains how normal it is for most people to have additional support and companions present for important conversations and recommend this to her. Subsequently, Liva, her helper and the CP team develop a management and communication strategy for future appointments, including her helper as companion during appointments.

Recommendations

Recommendation 1: Establish bridge-building functions

These functions should connect the "silos" within the Danish system, both across sectors (hospital, municipality, and general practice) and within each sector. These functions also improve the options available to GPs to meet the needs of adults with CP. The overall aim is that interventions are guided by the individual adults' needs and professional clinical assessment. Suggested bridge-building functions are listed below.

- *A coordinating municipal caseworker* ensuring coherence and overview across social and health-related interventions. The function may be entail existing *brain injury coordinators* or other municipal resource persons.

- *Outreach municipal support*, for example through an interdisciplinary municipal team, which can ensure access to necessary assistive devices and daily support when adults are unable to seek help themselves.
- *Strengthening healthcare-related competencies* among staff in residential facilities and municipal home support functions.
- *Youth Mentors* who can support young people during the vulnerable transition from childhood to adulthood (see Chapter 3.5)
- *Specialised regional, hospital-based neurorehabilitation services* (see Recommendation 3 and Chapter 5)

Recommendation 2: Integrate CP services into the existing and future healthcare system for brain injury

CP services integrated into existing services for people with acquired brain injury, as well as new services established as part of the implementation of the Healthcare Reform within the field of brain injury include access to:

- Brain injury coordinators
- Rehabilitation plans
- Follow-up by a physiotherapist and/or occupational therapist who is part of an interdisciplinary team
- Specialised regional, hospital-based neurorehabilitation services (see Recommendation 3 and Chapter 5)

This requires that the field is placed on the health-policy agenda (cf. recommendations in Chapter 3.2).

Recommendation 3: Establish specialised regional, hospital-based neurorehabilitation services

Specialised CP services inspired by the organisation of services following acquired brain injury include:

1) *A cross-regional knowledge centre* with the capacity to conduct *interdisciplinary expert assessments* following referrals from the regional centres.

2) *Regional CP centres in all four regions*, located at rehabilitation hospitals or units, and staffed by interdisciplinary teams.

A proposed setup for Western Denmark is outlined in Chapter 5.

It is recommended that *referrals to the regional centres* are formalised, so that referrals do not depend on the individual adult's own knowledge. Instead referrals should become an integrated and well-known aspect of clinical practice (**Figure *5***).

It is recommended that services are primarily delivered on an *outpatient basis,* as many adults may not benefit from inpatient admissions in new and unfamiliar environments (See Barrier 2).

It is recommended that these centres have a particular focus on *life-stage transitions* and provide needs-based services (cf. experiences related to life-stage transitions Chapters 3.1 and 3.5).

Recommendation 4: Support appointment management and communication

To ensure attendance at health care consultations, Digital Post notifications should be supplemented with text messages, email, and contact to relatives.

To support communication with professionals it is often necessary to:

- Allocate additional time for consultations.
- Ensure that the adult brings a companion who knows them well.
- Equip adults with communication aids, (concrete and simple tools that can aid structure and keeping an overview).
- Provide structured information-sharing between professionals so responsibility does not rest with the adult.

- Close and individualised support for monitoring processes, for example through frequent structured conversations and the use of visual or digital aids.
- Prioritise outpatient, long-term pathways rather than inpatient stays

3.5 Factors related to needs

Needs related factors refer to the aspects that either the individual or health professionals consider require an intervention. These include both perceived needs and evaluated needs, each of which may create barriers to access to and use of services.

Perceived needs concern the individual adult’s own understanding of their health condition, while e*valuated needs* represent the professional evaluation of the adult’s need for support.

Below, the identified barriers, tested interventions, and cases illustrating these barriers and how they were addressed by the project are presented. The chapter concludes with the derived recommendations related to needs related factors.

Barriers

Barrier 1: Life stage transitions and limited recognition of changing needs

<u>Identified in the project:</u>

Life stage transitions represent vulnerability for adults with CP. Adults with CP are often expected to identify their own needs during these transitions, take the initiative to seek help, and apply independently for relevant assistive devices and support.

Life stage transitions that are particularly sensitive include:

- The transition from adolescence to adulthood, including moving away from home, entering education, and entering the labour market.
- The transition into adult life, such as establishing a family, entering employment, children leaving home, or divorce.
- The transition into older age, where individuals may experience the loss of a partner or a decline in functional ability.

In general, signs of ageing occur earlier and more prominently in adults with CP than in peers. Many participants in the project were not prepared for this premature decline in functional ability. Many adults do not associate the decline with reduced "reserve capacity" commonly seen in CP, nor with the circumstance that ageing reduces the functional limits. In turn, many adults interpret the premature decline as insufficient training or incorrect use of assistive devices (see also Chapter 3.1).

The CP team does not find that turning 18, or ending follow-up in the CPOP programme, per se generates a continued need for specialised CP service for everyone. Yet, support in navigating legislation and regulations in the child-to-adult transition may be a worthwhile offer for everyone (see Chapter 3.2).
In our experience, very few young adults did seek support themselves; instead, their parents pursued a continued follow-up within the healthcare system. Those young adults' who were enrolled in the project clinic were typically describing social or activity-related needs which may be addressed through, e.g., a Youth Mentor. Presently, Youth Mentors is a neuro-specialist service for young people with a brain injury in Central Denmark Region. The youth mentors focus on identity formation, social networks, and life as a young adult with a disability, aiming to support everyday functioning and participation in meaningful social interactions. Nevertheless, healthcare needs may change as life circumstances change (e.g., start of or stopping an education).

Tested in the project:

A focus on life stage transitions has been an integrated part of the project's interventions. Special focus has been placed on the transition from adolescence to adulthood, ensuring that both the young adults and their parents have been supported (See Case Anne). Parents and personal care assistants have been included as central resources, given their crucial importance for overall daily functioning. Furthermore, the project has addressed ageing in CP and the need for adjustments in daily life as functioning declines over time, for example as a consistent element in the project's psychoeducation (See case Carsten).

Case 19. Anne: The transition from adolescence to adulthood,
Anne is young woman who lives with her parents. She experiences poor well-being, including anxiety, which affects her daily life. Anne has given up on pursuing higher education as she always felt pressured in school. Anne prefers to withdraw completely to avoid demands being placed on her. She has no contact with the municipality.
During the project, efforts focus on improving Anne's wellbeing in daily life. Home visits are carried out, with one of her parents always present. Anne participates in a graded evaluation process focusing on how CP affects her everyday life, on assistive devices, and on income support options. Anne is guided in applications for income support and other relevant daily support she is eligible for. Anne states that she feels understood by healthcare professionals for the first time. Likewise, she begins to develop a positive outlook on life and actively plans her future. She states that she could not have imagined this was possible based on her previous experiences in the healthcare system.

Case 20. Carsten: Age-related decline in functional ability
Carsten is middle-aged and has only received little aid during his life. Over the years, he experiences marked decrease in certain body functions, including walking, neglect and constant bowel discomfort. In addition, he increasingly experiences mental challenges, including fatigue, attention problems, and organising activities throughout the day. He now uses a wheelchair permanently and receives assistance for all transfers. These challenges affect his mood, and he wishes to improve his physical condition through training, hoping this will also improve his cognition, fatigue, and mood.
The CP team examined Carsten to exclude newly emerged conditions. A set of goals was then developed in collaboration, including gaining more knowledge about CP, especially ageing with CP and age-related functional decline. Throughout Carsten's pathway, there was an ongoing dialogue and focus on energy management and balancing daily activities, with an emphasis on prioritising meaningful activities. By participating in group sessions, Carsten met other adults with CP in similar situations. A key element was also to provide information about ageing and CP to his friends and family, several of whom had grown increasingly concerned and puzzled by his declining cognitive capacity.

Barrier 2: Reduced or altered perception of bodily signals

Identified in the project:

Many adults with CP have never experienced, what most perceive as, "having a normal body". Many adults may ignore or not recognise bodily signals or symptoms manifest in an atypical way. Reduced or altered perception of bodily signals may entail that the need for help is neither felt nor recognised. As a result, classical descriptions of how symptoms present themselves often cannot be used to identify symptoms in adults with CP.

Examples:

- Many adults experience increasing *pain* over time but do not seek help for evaluation. They often become accustomed to the pain and have difficulty describing it, both in terms of localisation and type. Some find it difficult to answer whether they have pain, while others have heightened sensitivity. For example, 79% of participants reported having pain at the start of the project (**Table 4**, Chapter 2).

- Many adults experience extensive *fatigue* but may find it difficult to accept or recognise its manifestations. As a result, fatigue often goes undiagnosed and unmanaged (see Case Asta).
- Many experiences *sensory challenges* which make it difficult to sense, interpret, or react to bodily signals. Some respond strongly or aggressively to noisy environments, loud noises, or touch. Especially when communications skills are limited, adults have difficulty articulating their experiences. Here, personal care assistants often become the ones who observe and interpret reactions (which can be complex and difficult to understand).

Tested in the project:

The project's pyramid-shaped clinical model[30] (Figure 6, Chapter 3.4) has guided clinical evaluation:

- All reports of changes were taken seriously, without expecting that adults would be able to provide detailed evaluations of symptoms such as pain, fatigue, or other bodily sensations.
- The CP team supplemented self-reported information with observations from care staff and relatives.
- Objective examinations such as Xray and blood tests were conducted, which in some cases helped explain e.g., aggressive behaviour (See case Poul, Chapter 3.4 and case Lotte below).
- Patient reported measures from the first questionnaire were used to assess the degree to which the adult's own perception aligned with observations from the CP team. For example, sometimes the adults or their relatives disagreed with the clinical staff with regards to the observed and perceived level of functioning e.g., independent walking ability. Besides this, the

questionnaire responses were also used to clarify how symptoms presented themselves (see Case Asta).

The project allocated substantial time to build rapport, as bio-psycho-social symptoms may only be meaningfully identified once a trusting and respectful relationship has been established. Examples of this work include:

- Focusing on listening actively to the adult's story at the first meeting and taking them seriously. As a result, the first outpatient contact did not always include clinical examinations and tests.
- Follow-up phone calls to ask how things were going.

Relational work has been integrated into all testing and evaluation situations, as well as during psychoeducation

Case 21. Lotte: Reduced perception of bodily signals

Lotte is a woman in her forties who works fulltime and has an active family life. Lotte attends a follow-up appointment in the CP-clinic and describes numerous diffuse symptoms her GP could not help her with. When describing the symptoms to her GP several times, she has been sent home under the assumption that she had influenza. Lotte has now had symptoms for two months and appears pale and fatigued. Lotte is apparently not well compared to her usual state. The CP-team conducts a detailed questioning, taking all symptoms seriously, and reviews her case history again. Blood tests reveal an alarmingly low haemoglobin level. The information is passed on to her GP, who takes over further treatment.

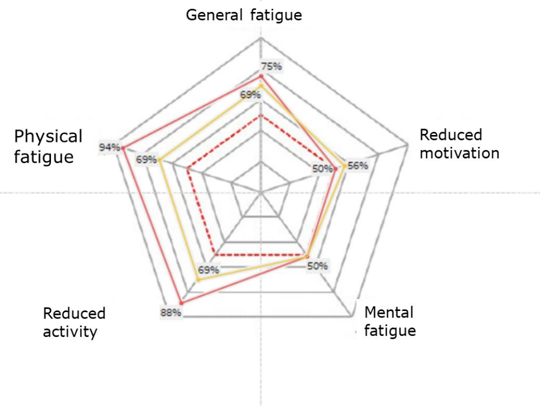
In this case, having a trusting relationship and knowledge of Lotte, including her medical history and her manner of describing symptoms, were crucial for identifying and managing a serious condition in time.

Case 22. Asta: Fatigue

Asta is an elderly woman who has experienced marked changes in functioning over the past decade. Until recently, she had an active lifestyle, including employment, travelling, and social activities. Asta now becomes fatigued more easily, which particularly affects her walking, and ability to maintain overview in daily life. Asta does not adapt her daily activities to the fatigue, does not rest during the day, and tries to maintain all the activities she has always valued, including her work.

At the beginning and end of her patient pathway, Asta completed a self-assessment of daily fatigue using the Multidimensional Fatigue Inventory (MFI). The MFI results are illustrated in the spiderweb chart below. The innermost red dashed line shows the normative fatigue level among adults. Asta's fatigue level at the start of the pathway (yellow) and at the end (red) of the pathway are also shown. The MFI indicates pathological fatigue levels, based on various aspects.

Self-assessment and daily registration of fatigue symptoms can be very effective and illustrative for understanding fatigue, which may be experienced as diffuse and invisible. The MFI tool and illustration were used in psychoeducation to help Asta understand what fatigue is and how it affects her daily activities and functioning. Asta became increasingly aware of signs of fatigue and how she could prioritise activities in daily life. At the end of the pathway, Asta shows higher fatigue levels likely reflecting increased awareness and that she is now better able to detect and recognise signs of fatigue.



Barrier 3: Frustration when perceived needs do not align with professional evaluation

Identified in the project:

Frustration may arise when perceived needs do not align with the clinical evaluation. This misalignment may shift the focus away from the remainder of the patient pathway. For example, some individuals wanted strong analgesic medication to enable pain-free walking, while the clinical evaluation was to refer to an orthopaedic surgeon for potential hip surgery. Others wanted to work on energy management, although the clinical evaluation indicated the demand for other priorities first. There were also requests for referrals and treatments, even when such evaluations had already been conducted. Often frustration may mask fear of what examinations may reveal or the perceived failing of explanatory models related to insufficient training (see Chapter 3.1)

Tested in the project:

The project's pyramid shaped clinical model[30] (**Figure 6**, Chapter 3.4) has guided clinical evaluation:

- The core principle of identifying the base of the pyramid (clinical evaluation with medical history and diagnostic imaging) as a prerequisite for subsequent rehabilitation: Although this evaluation may be unpleasant or frightening, the CP team has experienced significant relief among most adults with CP after being aided in gaining insight to and understanding the causes and consequences of CP.

- The model helped the CP team maintain focus on professional reasoning, including in situations where individuals express frustration (See case Katja).

Case 23. Katja: Frustration when perceived needs do not align with the professional evaluation
Katja is in her late forties and is deeply frustrated with the municipal and healthcare system, based on her negative experiences. She experiences a decline in physical capacity, pronounced fatigue, and other diffuse symptoms indicating chronic complications. She insists the sole focus of the pathway being physical functioning and energy management. Katja disagrees with the CP-team's suggestion of supplemental examinations to guide the clinical pathway, especially with regards to uncover the cause of the diffuse symptoms.
The CP-team does not consider it appropriate to focus on her preferred areas in isolation before a thorough evaluation has been completed. Katja decides to end her pathway and is asked to see her GP about the symptoms.
Here, the pyramid-shaped clinical model supported the CP team in maintaining a professional perspective on the needed evaluation for a holistic approach towards the perceived and assessed needs. Unfortunately, Katja ended her clinic pathway before a trusted relationship could be built.

Barrier 4: Distorted focus and overlooked needs

Identified in the project:

Although multimorbidity and a premature decline in functioning are highly prevalent among adults with CP, specific and changing needs are frequently overlooked in clinical practice. The reasons for this may include lack of knowledge about CP as a brain injury as well as the organisational challenges (see Chapters 3.1 and 3.4).

Examples of distorted focus and overlooked needs

- **Focus on motor functions instead of overall everyday functional ability.** The Gross Motor Function Classification System (GMFCS) is used as a guideline for determining support needs for children with CP in the CPOP follow-up programme. However, GMFCS does not represent the individual's functioning - neither for children nor for adults - because it only captures body function and activities within specific domains.

Cognitive functioning, for example, is not included in GMFCS, and the classification does not include daily activity (other than walking mode) and participation, or how personal factors and environmental factors affect functioning. Even adults classified as GMFCS level 1 may struggle in everyday life. For example, 50% of the project participants classified as GMFCS 1 had a WHODAS score of 30 or above, which indicates at least moderate disability (**Table 7**, Chapter 2). Many adults also shift GMFCS level over time, yet this is not followed systematically, and necessary support is therefore often lacking. The CP team has encountered many adults who have not previously discussed how everyday life is working or which daily activities are meaningful for them.

- **Cognitive functions are frequently overlooked** as a contributing factor to challenges in daily life, education, and employment. Cognitive difficulties vary across individual adults, but as a group, difficulties are seen across all cognitive domains, including executive functioning. Many experiences loss of cognitive abilities with ageing, combined with declining physical function (See Case Henriette).
- **Basic health problems are often overlooked** in clinical practice and by personal care assistants who are not trained to recognise health-related challenges (see Chapter 3.4).
    - Many adults experience *bladder and bowel problems* (urge incontinence, chronic constipation) but are rarely evaluated in general practice. Standard constipation treatments (promotility agents) are often ineffective for people with CP (See case Ulrik).
    - *Dysphagia* is common but frequently overlooked, despite increasing the risk of malnutrition and respiratory infections. The CP team has encountered many adults with severe dysphagia who continue to eat regular food because they had never been made aware (see Case Marianne, Chapter 3.1.)

  - Many have untreated *nutritional challenges*:
    - Obesity (BMI>30) for example when cognitive challenges hinder an active lifestyle (12% of the adults in the project (**Table 3**, Chapter 2)).
    - Underweight (BMI<18.5) often due to dysphagia (16% of the adults in the project (**Table 3**, Chapter 2)).
    - Vitamin deficiencies (particularly low vitamin D) are also often overlooked with symptoms (muscle weakness, difficulty concentrating) often being misinterpreted as neurological deterioration.
  - *Fatigue* is also highly prevalent, with many adults not being evaluated for its underlying causes. In the project, many adults displayed signs of pathological fatigue (median baseline Multidimensional Fatigue Inventory general score of 14, where 20 is the highest level) (**Table 7**, Chapter 2 + see Case Asta).
  - *Spasticity* is highly prevalent, but many adults lack awareness of options to alleviate and manage spasticity. Spasticity is not followed up in usual clinical practice. When individuals seek help from their GP due to pain, these symptoms are often explained simply as “due to CP”. GPs are often unaware that pain may be caused by spasticity and that it can be alleviated and managed (See case Karl).
  - *Osteoporosis* is not monitored systematically, and adults with reduced weightbearing (for example those who become permanent wheelchair users) therefore do not receive timely and appropriate treatment, despite being at increased risk of osteoporosis.
- **Comorbidity is often overlooked**, either because adults with reduced bodily awareness do not seek help, or because health professionals interpret symptoms as being ‘simply’ CP-related.

Tested in the project:

All interventions were grounded in a holistic understanding of human functioning, in line with the ICF framework[1] and the team's pyramid-shaped clinical model[30] (Figure 6, Chapter 3.4), in which personal health and well-being, potential comorbidities and individual goal setting for the pathway are integral components.

Below, the central interventions, *Interdisciplinary evaluations*, *Education and psychoeducation*, and *Targeted training*, are presented. An overview of the outpatient clinic, the interdisciplinary team and their respective roles can be found in Appendix 3 (separate document).

Interdisciplinary evaluations (outpatient clinic and/or home visits)

The CP team has made extensive use of interdisciplinary evaluations to assess needs in everyday life. These evaluations include besides medical tests, physiotherapy and occupational therapy evaluations as well as neuropsychological assessments of cognitive functions (**Table 2**, Chapter 2). These evaluations are particularly important during life stage transitions to ensure appropriate expectations and reduce the risk of stress reactions. In some cases, these evaluations were supplemented with home visits to assess the adult's daily life in order to establish appropriate expectations and reduce the risk of overload reactions. Overall, 10% of the contacts were home visits (**Table 6**, Chapter 2).

Education and psychoeducation

A common individual goal for the adults' pathways in the project was to obtain knowledge on CP (cf. The Goal Attainment Scale – see Chapter 2). The CP team has widely disseminated knowledge about CP as a spectrum of consequences following early brain injury, the concept of a holistic understanding of functioning, and how conditions such as dysphagia, incontinence, constipation, spasticity, and cognitive difficulties may present themselves in adults with CP. Modes of teaching include:

- Formalised psychoeducation, covering fixed topics such as ageing, pain, fatigue, cognition, bowel and blader difficulties. Presentation slides have been developed for teaching targeted at adults with CP, their relatives, and staff (see example of a slide on spasticity in Appendix 2 (separate document)). Adults with CP received teaching through group-based and/or individual psychoeducation. The groups were composed based on age and an assessment of the participants' abilities to engage in a social setting. Individual psychoeducation focused on general understanding, followed by how challenges manifest for the specific person.
- Individual psychoeducation for relatives. Group teaching was declined because tailored teaching was needed to explain how CP presents itself in their specific family member.
- Individual and/or general teaching for personal care assistants and staff at 13 residential facilities, delivered in the adult's home, at the residential facility, or online.
- Network meetings with municipalities often included teaching aimed at adapting municipal services.
- Courses and Webinars for adults with CP, their relatives, and health professionals in cooperation with CP Danmark, Elsass Foundation, and Transitionsklinikken[e]
- Podcasts,[31,32] and various professional,[33-38] and scientific articles and presentations.[30,39]
- Presentations at diverse national professional conferences.

Targeted training

Common goals of the adults with CP in the project included goals related to eating and pain (cf. The Goal attainment scale – see Chapter 2). The team's training approaches in these areas was informed by knowledge and skills from neurorehabilitation of people with acquired brain injury. An important distinction

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[e] CP clinic for young adults at Rigshospitalet, Copenhagen

to brain injury rehabilitation is, that it is seldomly possible to reverse functional decline. Therefore, the focus is not on isolated movement training but on meaningful everyday activities. Examples of areas of intervention were:

- *Dysphagia and eating difficulties*. Interventions included compensatory techniques such as optimal seating positions, texture modification, and assistive devices. These interventions required adaptation to the adult's bodily and cognitive abilities, as standard dysphagia recommendations (for acquired brain injury) are often not applicable to CP. A key component has been education and dialogue with caregivers, as dysphagia is often neglected.
- *Management of pain and spasticity* using Botulinum Toxin injections. The CP team used a neuro-pedagogical approach in administering Botulinum Toxin and has taken advantage of the therapeutic window that emerges when spasticity is treated, aiming to achieve a specific functioning goal in daily life (for example, walking without pain or drinking from a bottle using the spastic hand). The training has thus been directly linked to functional tasks in everyday life. Follow-up has included assessment of treatment effect and adjustment of dosage after 4–6 weeks. Besides this, a central element has been psychoeducation on spasticity, in particular helping individuals recognise when spasticity is triggered and understanding how it can be reduced. A detailed description of the project's Botulinum Toxin treatment and example of teaching material on spasticity can be found in Appendix 2 (separate document).

Case 24. Karl: Overlooked clinical evaluation needs

Karl is young man with significant spasticity in both legs. As a child, treatment with a baclofen pump was considered, but not initiated. Now as an adult, the need for a baclofen pump has not been reevaluated. Karl can no longer use his legs and experiences daily severe pain, substantially limiting his everyday life and affecting his mood.

During his patient pathway, the CP-team argues for the potential benefit of a pump and Karl is referred for a baclofen pump test. He responds very positive and is scheduled for the procedure. The outlook improves Karls's well-being, and he is very grateful for being acknowledged as the person he now is, and not the child he once was.

Case 25. Henriette: CP is more than physical challenges
Henriette has a higher education and works part-time. Throughout childhood and adolescence, the possibility of cognitive difficulties was never mentioned. She remembers being told that she was "lucky" because she "only" had a mild form of CP. Henriette is experiencing increasing physical discomfort, including significant bodily pain and headaches. She also experiences fatigue, difficulty remembering appointments, and irritability. During a webinar hosted by CP Denmark, she heard a psychologist discuss cognitive difficulties. She recognised the symptoms, prompting her curiosity about her own experience of these challenges.

At the initial appointment, the CP team explained how common cognitive difficulties are among adults with CP and acknowledges her experiences. Throughout her pathway, the CP team consistently returned to psychoeducation on how cognitive difficulties manifest, and how such difficulties influence other aspects of daily life. With this understanding and acceptance, it became meaningful for Henriette to work with strategies and adjust approaches for everyday life.

Case 26. Ulrik: Constipation
Ulrik is middle-aged wheelchair user, uses communication aids, and is cared for around the clock. For several years, Ulrik has experienced frequent constipation and nausea due to scoliosis having caused an anatomical shift in his gastrointestinal tract. When Ulrik develops constipation, a cascade of other symptoms is triggered severely affecting his well-being. Because Ulrik has limited ability to describe his symptoms, it is crucial that his carers have knowledge of and can interpret his signs of discomfort.

The CP team focused on strengthening the carers knowledge and competencies regarding gastrointestinal function. They were guided in daily systematic monitoring of Ulrik's bowel function, including Ulrik's general well-being. The aim was to establish a shared, objective basis for evaluating bowel function and adjusting interventions, including medication. In addition to this, a collaboration was established with the municipal home nursing service to support follow-up on Ulrik's gastrointestinal function.

Recommendations

Recommendation 1: Increase support during life stage transitions

Additional attention, support, and coordination is needed during life stage transitions (e.g., transition from adolescence to adulthood, entering the labour market, becoming a parent, during ageing).

Interdisciplinary evaluations, including neuropsychological assessment of cognitive functions, should be used more consistently to ensure appropriate expectations and reduce the risk of stress reactions.

It is important to openly discuss ageing and prognosis (see barrier 1)

Recommendation 2: Disseminate the clinical pyramid-shaped model

It is recommended that the pyramid-shaped model[30] (**Figure 6**), developed specifically for the clinical evaluation, treatment, and rehabilitation of people with CP, be disseminated more widely. The model provides the interdisciplinary team with a structured, professional foundation. It acknowledges that adults may have reduced awareness of their own symptoms. The model's extended focus on evaluation contribute to prevent overlooked needs.

Of note, cognition is not included in the current model although assessment of cognition is an important part of the interdisciplinary assessment in the current project. Relational work is also not included in the current model although symptoms can often only be uncovered once a trusting relationship has been established. Hence, the model could be improved by adding Cognition and Relational work to the base of the model.

Recommendation 3: Apply knowledge and competencies from acquired brain injury neurorehabilitation

The competencies required to support adults with CP largely overlap with those required to support adults with acquired brain injury. Areas that need to be adapted specifically for adults with CP include:

- **Psychoeducation** should be a consistent component of specialised support provision for adults with CP. Relevant topics may include understanding CP as a brain injury, ageing, spasticity, energy management and fatigue, nutrition, and sensory processing.
- **Training should focus on everyday activities and functioning** in daily life rather than on isolated movements. In contrast to certain rehabilitation principles after acquired brain injury, it is only seldomly possible to reverse functional decline and regain lost functional ability in CP.

3.6 Overview of barriers, tested initiatives, and derived recommendations

Factors related to narratives and beliefs		
Identified in the project	**Tested in the project**	**Recommendations**
Barrier 1: Stereotypical knowledge and understanding of CP		**Recommendation 1: Disseminate knowledge that CP is a spectrum of consequences following early brain injury** to reduce stigma, misunderstandings, and unrealistic expectations, and improve societal and municipal understanding during transitions. **Recommendation 2: Adopt a bio-psycho-social (ICF) framework in clinical practice** to support realistic expectations and reduce guilt/shame; and to support individuals in recognising and managing symptoms proactively; and to enhance health literacy
Persistent simplified views of CP (either “severely disabled” or “only motor disorder”). Cognitive challenges often misunderstood or overlooked.	Communication of CP as a spectrum of consequences of early brain injury to people with CP, relatives, personal care assistants, residential staff, and professionals.	
Barrier 2: Societal expectations during life stage transitions		
Parents of young adults with CP perceived as “over-involved.” Adults expected to maintain earlier function despite age-related decline. These expectations discourage seeking help.	Communication of CP as a lifelong brain injury helped adjust expectations at network meetings with schools, municipalities, and services around transitions.	
Barrier 3: Focus on “normalisation”		
Internalised belief among adults with CP that functional deterioration reflects insufficient training. Strong desire to appear “normal”; shame and guilt hinder help-seeking. Childhood services focus on normal development rather than lifelong consequences.	Brain injury framing and ICF-based communication created relief and reframe self-blame. ICF perspective integrated in in the interdisciplinary clinical status report (Appendix 4). Use of brain scans helps individuals understand the cause of functional decline. Shift from “normalisation” to realistic functional ability.	

Barrier 4: Variations in health literacy		
Limited understanding among adults with CP and their relatives of cognitive function, fatigue, spasticity, pain, dysphagia, and their impact. Adults may underreport challenges or misattribute symptoms to ageing or personal failure.	Strengthened health literacy through education on CP manifestations, functional consequences, and ICF concepts. Practical learning experiences supporting better symptom recognition and help-seeking.	**Recommendation 3: Establish safe and supportive spaces for dialogue about concerns** Health professionals should openly acknowledge barriers and explore underlying concerns. Prioritize relational work
Barrier 5: System stress ("Clinical evaluation anxiety" and "Municipality anxiety")		
Fear of diagnostic consequences such as surgery, fear of losing existing support scheme, and negative past experiences with hospitals and municipalities.	Outpatient, long-term pathways created a safe, low-pressure environment. Team acknowledged anxiety and explored reasons behind apparent refusal. Prioritized relational work.	
Health and social policy related facors		
Identified in the project	**Tested in the project**	**Recommendations**
Barrier 1: Lack of health policy strategies for adults with CP		
There are no national initiatives for adults with CP. Existing policies focus exclusively on children (CPOP, outdated paediatric guidelines). Missing elements include: HTA; inclusion of CP in the neurological specialty plan; health & collaboration agreements; care pathway descriptions; and adult-specific clinical guidelines.	The CP team engaged directly with policymakers: presenting the project to a Member of Parliament in 2023; proposing an HTA to Ministry in 2024; initiating collaboration with CP Denmark and the Elsass Foundation to pursue a joint health policy strategy.	**Recommendation 1: Place challenges faced by adults with CP on the health policy agenda** Strengthen alliances among CP Denmark, the Elsass Foundation, Hammel Neurorehabilitation centre, and professional societies to push for national strategies, guidelines, and structural anchoring within existing brain injury frameworks.

Barrier 2: Lack of clarity and insufficient gradation in rules and legislation		
Many adults struggle to understand income support rules (flexible employment, disability pension, student grants) and access relevant services. Legislation is broad, inconsistently interpreted, and influenced by financial constraints at system and family level. Terminology across sectors is inconsistent, leaving people with CP with services that are poorly tailored. Numerous examples arise across education, employment, daily living support, physiotherapy, and transitions - See examples in the text. These issues also apply to other adults with different types of disabilities.	The social worker in the project coordinated complex pathways, assisted with navigation, applications, documentation, and translation of clinical information into language accessible to municipalities. Interdisciplinary status reports were used to clarify needs and support trust-based dialogue (Appendix 4). The team participated in municipal network meetings to align understanding and ensure coherent pathways.	**Recommendation 2: Adapt the administration of rules to the needs of individual - not the reverse** Aim for trust-based dialogue between adults with CP and municipal caseworkers. Introduce coordinating caseworker function (linked to existing brain injury coordinators). Improve child-adult transitions with youth mentors. Strengthen translation tools such as interdisciplinary status reports to ensure needs are clearly understood in the municipality.
Economic factors		
Identified in the project	**Tested in the project**	**Recommendations**
Barrier 1: Lack of economic incentives for establishing specialised services		
Specialised services for adults with CP lack financial justification because no overview exists of needs, costs, or societal benefits.	To explore cost-benefit analyses, the CP team collaborated with a municipality, which reported lack of overview of services provided to adults with CP. CP team found, that the regional EHR system lacks documentation of relevant clinical procedure codes for health-economic analyses. The team proposed to the Ministry of Interior Affairs and	**Recommendation 1: Establish an overview of the needs, costs, and benefits of specialised services for adults with CP.** Eg an HTA or similar

	Health that a Health Technology Assessment (HTA) be developed for this area.	
Barrier 2: Costs associated with health care services		
Individuals face financial barriers to essential treatments (such as TAI for chronic constipation). Many must personally pay for necessary items (sheets, weighted blankets, cushions). Co-payments for transport and treatment limit participation. Specialised dental care requires municipal approval and user fees, which prevents access.	The team, especially the project's social worker supported adults in navigating funding and financing options, identifying rights, and assisting with correct applications.	**Recommendation 2: Guide on economic support options within the system** through a coordinating caseworker.
Organisational factors		
Identified in the project	**Tested in the project**	**Recommendations**
Barrier 1: Silo mentality and lack of information sharing		
Hospital departments, general practice, and municipal services operate within separate routines (parallel silos) with limited flexibility within and across sector - see examples in the text. These issues also apply to other adults with different types of disabilities. Adults with CP typically do not qualify for brain injury coordinators or rehabilitation plans (key bridge-builders in brain injury care). The 2024 Health care reform's intention to strengthen coherence via cross-sectoral, standardised, and individually tailored initiatives could address silo problems in the future. However, main focus is on large chronic disease groups and older adults, while adults with CP form a small target group. Key lesson:	The project acted as a bridge-builder across and within sectors: comprehensive medical histories, interdisciplinary assessments, functional status reports (Appendix 4) shared with municipalities. Coordinated network meetings, and cross-sector collaboration. Provided structured clinical pathways and holistic, coordinated assessments guided. Description of outpatient function and interdisciplinary team in Appendix 3. **Figures 5 and 6** in comprehensive report illustrate the projects bridge-building	**Recommendation 1: Establish bridge-building functions:** coordinating municipal caseworker e.g., brain injury coordinators; interdisciplinary municipal support teams; strengthened healthcare competencies in residential facilities; youth mentors for transitions from child to adult; specialised regional hospital-based neurorehabilitation services. **Recommendation 2: Integrate CP services into the existing and future healthcare system for brain injury**

CP initiatives should be embedded within existing structures, e.g., brain injury care	functions across sectors and departments.	Access to brain injury coordinators; rehabilitation plans; follow-up by a physiotherapist and/or occupational therapist who is part of an interdisciplinary team; Specialised regional, hospital-based neurorehabilitation services **Recommendation 3: Establish specialised regional, hospital-based neurorehabilitation services**: A cross-regional knowledge centre; Regional centres in all four Danish regions. Formalise referrals to regional centres; Use outpatient pathways rather than inpatient; focus on life-stage transitions
Barrier 2: Challenges in meeting system requirements and carrying information between professionals		
Digital Post alone is insufficient; letters may be missed. Adults struggle with attending appointments, completing diaries, filling forms, or tolerating inpatient admissions. Inpatient admissions often cause overstimulation, poor sleep, and difficulty transferring skills to everyday life. Outpatient care pathways also represent a cost-effective and efficient approach. Adults are expected to carry clinical information themselves despite dysarthria,	Tailored communication strategies and tools; support to attend appointments and accompanied adults to appointments; encouraged bringing companions; home visits when clinic attendance was overwhelming. Barriers documented when adults cannot meet municipal requirements. Outpatient pathways are the preferred model after inpatient	**Recommendation 4: Support appointment management and communication:** Use multi-channel communication to ensure attendance (text message, email, contact relatives); Support communication with healthcare professionals by: allocating additional time for consultations; encourage companions; provide simple tools for structure and

cognitive-communication difficulties, limited insight, or assistants lacking CP-specific knowledge. Result in misunderstandings, missed appointments, and fragmented care.	pathways showed limited benefit. Outpatient pathways also more cost-effective. See results from a break even analysis in appendix 5.	overview; Provide structured information-sharing between professionals; Prioritise outpatient, long-term pathways rather than inpatient stays
Factors related to needs		
Identified in the project	**Tested in the project**	**Recommendations**
Barrier 1: Life stage transitions and limited recognition of changing needs		
Life transitions (adolescence → adulthood, entering education/employment, family changes, ageing) create significant vulnerability. Adults with CP are expected to identify and articulate needs independently, despite early ageing and declining reserve capacity. Many misinterpret functional decline as insufficient training. Needs at age 18 (end of follow-up in CPOP) are often social/activity-related, not strictly medical.	Life stage transitions were a core clinical focus. Parents and personal assistants were included as key resources. Ageing and prognosis were systematically addressed using psychoeducation.	**Recommendation 1: Increase support during life stage transitions.** Use interdisciplinary evaluations, especially cognitive assessments, to set realistic expectations and minimise stress reactions. Provide open dialogue on ageing and prognosis to prepare adults, families, and support networks.
Barrier 2: Reduced or altered perception of bodily signals		
Adults with CP often have lifelong difficulty sensing, interpreting, or communicating bodily signals (pain, fatigue, sensory overload). Symptoms present atypically, complicating identification of health issues. Pain and fatigue often go unrecognised; sensory challenges complicate interpretation; personal assistants frequently act as interpreters.	The pyramid-shaped clinical model guided evaluation. All bodily changes were taken seriously; self-reports were supplemented with observations from relatives and assistants. Objective exams (blood tests, X-ray) helped reveal underlying conditions. Questionnaires were used to compare perceived vs observed function. Significant time was dedicated to building trust and relational understanding.	**Recommendation 2: Disseminate the pyramid-shaped model** - to support holistic inter-disciplinary assessments and to acknowledge that individuals may have altered perception. - to ensure structured reasoning and prioritisation of clinical evaluation before treatment and rehabilitation.

Barrier 3: Frustration when perceived needs do not align with professional evaluation		- to ensure systematic evaluation and rehabilitation Consider incorporating assessment of cognition into the model. Consider incorporating relational work into the model as symptoms are best identified within a trusting, respectful relationship; and to address fear-driven resistance. **Recommendation 3: Apply knowledge and competencies from acquired brain injury neurorehabilitation** Integrate consistent psychoeducation on CP as a brain injury, fatigue, spasticity, cognition, and nutrition. Focus on meaningful everyday activities rather than isolated motor training.
Individuals may seek interventions that do not match clinical priorities (for example requesting strong analgesics vs. evidence of underlying surgical need). Requests may stem from fear of diagnostic consequences or misunderstandings about symptom origins.	The pyramid model helped maintain focus on necessary clinical evaluation (history, exam, imaging) before proceeding to rehabilitation. Thorough evaluation created relief once adults understood the causes of symptoms. The model helped CP team manage frustration experienced by CP people	
Barrier 4: Distorted focus and overlooked needs		
Common needs (related to cognitive difficulties, fatigue, bowel/bladder challenges, dysphagia, nutritional problems, spasticity, osteoporosis, comorbidities) are frequently overlooked. GMFCS is used inappropriately as a proxy for overall functioning despite not capturing cognition, activity, participation, or environmental factors. Many adults never discuss everyday functional ability with professionals.	Interdisciplinary evaluations (PT/OT tests, neuropsychology, home visits) clarified needs. Education and psychoeducation (group and individual) covered fatigue, cognition, spasticity, dysphagia, pain, and daily functioning Teaching slide example on spasticity in Appendix 2. Targeted training emphasised meaningful daily activities rather than isolated exercises. Tailored interventions included dysphagia techniques, Botulinum Toxin treatment (Appendix 2), and caregiver education. Overview of outpatient clinic and interdisciplinary team in Appendix 3.	

4. Perspectives

The experiences and recommendations presented in Chapters 2 and 3 underline a critical need for a shift in how the Danish healthcare and social systems perceive and support adults with CP. By moving away from a narrow biomedical focus on physical "normalisation" and toward a comprehensive bio-psycho-social perspective on functioning[1]. By understanding CP as a spectrum of lifelong consequences following early brain injury, including the complex and changing patterns of functioning, the actual needs of adults with CP may be more efficiently addressed.

4.1 Integration with International Guidelines

To our knowledge, only two national clinical guidelines for adults with CP currently exist. Below, the experiences and recommendations made by the CP team, are compared with the evidence and recommendations summarised in the 2019 NICE Evidence Reviews Collection of clinical guidelines for adults with CP[5-20] (hereafter referred to as NICE), and the 2024 Norwegian Diagnosing and Follow-up of People with CP[4] (hereafter referred to as NorCP).

Factors related to narratives and beliefs

In line with NorCP and NICE, the CP team recommends understanding CP as a spectrum of consequences following early brain injury and recommend disseminating this understanding not only to individuals with CP and their relatives, but also to healthcare professionals and society in general. This is an intended part of our ongoing clinical development within the next five years (see Chapter 5). In this context, we also intend to scientifically explore the narrative identity and belonging of individuals with CP.

Some of the experiences of the current projects that led to this recommendation are different from the evidence presented in NICE.

The team experienced, that because individuals have lived with CP their whole lives, symptoms like chronic pain or extreme fatigue may be perceived as irreversible. This fatalistic understanding may lead adults to "habituate" to the pain rather than seeking help. The project provides specific examples of how gaps in health literacy can create barriers: for instance, the misconception that "cognitive challenges" are synonymous with "low intelligence," which prevents people from seeking necessary neuropsychological evaluations. By contrast, NICE emphasises acceptance of changes associated with CP such as accelerated ageing,[14] and both NICE and NorCP frame knowledge gaps primarily as an issue for health professionals rather than for adults with CP.

The CP team recommend that clinical practice adopts the bio-psycho-social approach defined in International Classification of Functioning, Disability and Health (ICF).[1] In alignment with NorCP, which is likewise grounded in ICF's biopsychosocial approach, the ICF has informed the approach to adults with CP throughout the project. One example is the interdisciplinary clinical status report (Appendix 4 - separate document), which is a key document for communication with other professional in the social- and healthcare system, and for patient-centred goal setting.

NICE does not explicitly refer to the ICF framework. However, some of the experiences of the current projects that led to the recommendations are echoed in the evidence presented in NICE. This includes the observed tension between the desire to be perceived as normal and the reality of living with CP, which was a significant barrier to seeking and using social- and healthcare services. Adults often viewed CP solely as a motor function disorder, and technical aids as a personal defeat or a threat to their identity. This observation aligns with NICE,[14] which identifies the use of walking aids or acceptance of support as a threat to independence or a marker of being "different".

The NICE guideline however identifies the drive for normalisation as a barrier related to adults with CP, whereas the current project identified it as a general barrier related to the knowledge and understanding of CP among both adults

with CP and their relatives, health- and social care professionals and society in general. An insight of the project is also that many adults believe it is due to their own lack of effort, when function inevitably declines earlier than among their peers.
The central concept in the ICF is "functioning", defined as the dynamic interaction between body functions and structures, activities, and participation. Functioning also captures the positive aspects of the interaction between the person with a health condition and their environmental and personal contextual factors. It is used by health care professionals to shift the focus from the individual's "deficits" to the individual's "functioning" and what enables individuals to lead meaningful lives. Despite the theoretical concept of "functioning" being defined in ICF, and despite it being used by health care professionals (for example in the current project and in NorCP), its interpretation in clinical and social contexts and how these interpretations inform holistic and person-centred rehabilitation, remains to be explored for CP. We intend to explore this in the future.

The CP team recommends, that healthcare professionals should actively create safe spaces for open dialogue about concerns and experiences, by prioritising relational work. Both NICE[17] and NorCP promote user involvement and shared decision-making which are relational components, but neither specifically advocate for "safe spaces" or relational work, nor do they provide other explicit recommendations aimed at mitigating the underlying barrier of system stress. Both guidelines, however, describe that adults with CP often mistrust the systems designed to support them. Both NorCP and NICE[14] reflect a belief among adults with CP that they have been "abandoned" by the healthcare system after age 18, as the system prioritises paediatric care. The experiences of the CP team expand on this through the concepts of "Medical examination anxiety" (*udredningsangst*) and "Municipality Anxiety" (*Kommuneangst*) i.e., the fear that undergoing assessments or seeking new help might lead to a reduction in current support or benefits.

Both NorCP and NICE also note that the health care professionals lack specific knowledge about adults with CP. NICE mentions a “lack of faith” in doctors who only see physical issues while ignoring psychological needs. The current project echoes this, stating that professionals may have a stereotypical understanding of CP, often confusing it with general developmental delay or multi-handicap.

Health- and social policy and Economic factors

Based on the project, it is recommended, that challenges for adults with CP are placed on the Danish health policy agenda. The vision is to develop, among others, a Danish national clinical guidelines for adults with CP, similar to NICE and NorCP, both of which exemplify the product of health policy initiatives for adults with CP in England and Norway. The long-term vision is that the public healthcare system assumes responsibility for providing a dedicated service for adults with CP, as proposed in the section on Organisation.
A Health Technology Assessment (HTA) played a key role at the time in placing brain injury on the political agenda.[40] Therefore, a possible starting point for a health policy process in CP could be the conduct of a HTA or similar assessment, as recommended in Chapter 3.3.
NICE includes health economic analyses which are core components of an HTA. They provide cost descriptions for some specific interventions (Botulinum toxin[20]) and developed some economic models,[17] for example, an “ideal” organisation of specialist services would represent good use of resources if it could reduce unplanned emergency visits or shorten hospital stays to a certain degree. As such the NICE guidelines may inspire needed future health economic analyses. However, as experienced in the project, there is a need for uniform documentation of regional and municipal procedure codes, as these may prerequisites for detailed health economic assessments.

The CP team recommends adapting the administration of rules and legislation to the individual needs of adults with CP. This addresses the underlying barrier of

unclear interpretation and inconsistent application of rules and legislation and hence inequality in the provision of services. Although Denmark in principle has free and equal access to services, the CP team noted a high degree of variation across Danish municipalities regarding which services are granted, and how specific policies (or the implementation hereof) lack graduation and flexibility.
Neither NICE nor NorCP explicitly provide examples of inequality and how to mitigate inequality; however, both guidelines emphasize equality for people with CP, for example as the overall aim of NorCP, and by highlighting that NICE recommendations reinforce the rights of people with disabilities.[14]

The CP team recommends that adults with CP receive guidance on the social system's financial support options through a coordinating caseworker, such as brain injury coordinators. Some of the experiences that led to this recommendation are also reflected in barriers summarised in NICE,[14] for example transport costs and physical access. Specific for the Danish healthcare setting, the CP team noted that many adults struggle to receive funding for "quality of life"-treatments, such as Transanal Irrigation or specialised dentistry, which are often not covered or require co-payments.
Overall, the examples of adults with CP struggling with rules, regulation and financing, presented in Chapter sections 3.2 and 3.3, can be used by Danish patient interest organisations to highlight the need for policy changes for adults with CP and more broadly for people with disability in Denmark.

Organisational factors

Based on the experience, that adults with CP often fall between "silos" within the Danish health and social care system, the long-term vision is the public healthcare system assuming responsibility for providing dedicated services for adults with CP. Dedicated services may be organised through regional services in all four administrative districts, in addition to a central knowledge centre for adults with the most complex needs. By placing the responsibility in a setting with specialised knowledge of CP, continuity of care is expected to be optimised. This aligns with NICE recommendations, which suggest that an identified primary point of contact (a department or service in primary or secondary care) should be responsible for maintaining continuity of care.[17] Placing the responsibility in a setting with specialised knowledge of CP would also address the identified challenges in general practice, which are also identified as barriers to healthcare in NICE and NorCP e.g., the lack of specialist CP expertise among GPs, and that standard appointment lengths are often too short for adults with CP.[14,17]

In addition to the dedicated services, it is recommended to establish further bridging functions and better integration of CP services in the existing healthcare system. The recommendation is to build on existing brain injury rehabilitation structures, as they are already well established, and the competencies required to support adults with acquired brain injury largely overlap with those needed to meet the needs of adults with CP.

The leverage on existing policies and structures is similar to NICE recommendations, which use existing policies for people with learning disabilities[17] to recommend that adults with CP who have learning disabilities are offered annual health checks.

NorCP, similar to the experience in the current project, note that adult services in Norway are often fragmented and vary by region and highlight the need for more coordinated service delivery. The recommendations in NorCP reflect, that CP services in Norway are already organised around a CP specific follow-up programme. NorCP primarily focuses on bridging gaps between paediatric and adult health services. By contrast, we recommend addressing life-phase transitions across the entire adult life span through systemic, specialised follow-up. The specific actions recommended for the transition from child to adult within the Norwegian system (for example meetings related to goals and the need for further follow-up) may serve as inspiration for the overall future clinical setup in Denmark.

We propose a needs-based follow-up system that partially aligns with NICE, which recommends that adults with complex needs receive an annual health check; however, "complex needs" is not defined in the NICE guideline.[17] Several projects within our future research plan will contribute to the development of a structured understanding and measurement of "needs" thereby supporting the establishment of a needs-based follow-up system: We will explore how life transitions are experienced by adults with CP and identify the types of support required to ensure coherent and safe transitions across services and life stages. In addition, we envision a co-created digital long-term follow-up tool for adults with CP which integrates patient-reported outcomes with a digital information guide designed to support adults with CP, their relatives, and clinicians.

Finally, the CP team recommends that adults with CP are provided with support for managing appointments and meetings within the healthcare system, for example tools that enhance structure and overview in the dialogue with health care professionals. Neither NICE nor NorCP specifically mention the need for tools that adults with CP can use to manage appointments. However, both advocate for the use of augmentative and alternative communication systems for adults with communication difficulties, which may support participation in appointments.[4,8]

Factors related to needs

In line with NorCP and NICE,[4,14] the CP team recommends attention to life transitions, including ageing. However, some of the experiences of the current project that led to this recommendation are different from the evidence presented in NICE. The team experienced that many adults attribute ageing-related decline in functioning to incorrect use of aids or lack of training. Here the clinical experience shows that this may prevent adults from seeking help for secondary conditions. By contrast, NICE reports that adults accept functional decline as age-related, and do not identify this as a barrier as such.[14]

Both NorCP and NICE emphasize the importance of informing adults with CP about their increased risk of health problems[4,6,14] in order to support timely help-seeking. As previously described (Chapter 3.4), Danish social- and healthcare services are insufficiently adapted to the needs of people with CP, meaning that even when adults seek help, appropriate assessment and follow-up are often not available. Hence, dedicated services for adults with CP are recommended.

The CP team recommends the wider adoption of the pyramid-shaped clinical model developed in this project[30] (**Figure 6**). The model, based on the ICF framework and a multidisciplinary approach, prioritises holistic assessments (the base of the pyramid). The model supports professional judgment when individuals express frustration, and may prevent the pitfall where symptoms, such as challenging behaviour, are dismissed as "just part of CP" rather than being recognized as treatable conditions like hip luxation (see for example case Poul).

The model ensures that basic health problems are acknowledged, systematically assessed and addressed. The CP team noted several commonly overlooked common health problems in the project. Some of these are also highlighted in NICE and NorCP as insufficiently recognised and are accompanied by recommendations: assessment methods for pain,[13] respiration (to address dysphagia),[10,12] osteoporosis,[6] malnutrition,[5] and periodic monitoring of function and related health domains (cognition, motor function, bone health, malnutrition)[4]. Constipation is only addressed in the guidelines as an area that needs intervention in connection with being an aggravating factor in spasticity.[18,20]

In alignment with the multidisciplinary management embedded throughout NorCP,[4] and the NICE recommendations for managing spasticity and dystonia,[19,20] and deterioration in functional abilities,[17] the pyramid-shaped clinical model incorporates service delivery through a specialised multidisciplinary team, helping to ensure that care extends beyond motor function alone.

This leads to a final recommendation: dedicated services should draw on knowledge and competencies from neurorehabilitation following acquired brain injury, as the skills required to assess and address the needs of adults with CP largely overlap with those needed in brain injury rehabilitation. The CP team specifies psychoeducation as integral part, including psychoeducation in pain and accelerated aging, which are also recommended areas for education in NICE.[13,14] By contrast, NorCP does not mention formalised psychoeducation or education, however, it does contain a general recommendation that health professionals should strengthen patients' knowledge, insight, and coping skills.

4.2 Future directions for research

Most of the current evidence for CP is based on paediatric populations,[2] including the majority of evidence summarized in NorCP.[4] By contrast, the NICE guidelines is based on adult CP population, however, the methodological quality of the underlying evidence was generally rated as very low to low.[5-20] Also specified in the NICE guidelines, research-based knowledge is lacking in many areas, and therefore recommendations were often based on the committee's expertise and experience, rather than empirical research.

In the future, we aim to generate research-based knowledge on clinical interventions, healthcare organisation, and policy changes that address currently unmet healthcare needs among adults with CP. Research should be guided by the bio-psycho-social perspective on functioning as it is defined in the ICF framework.[1] The data collected in the current project and presented in Chapter 2 enables exploratory, hypothesis-generating analyses.

The challenges and overlooked needs among adults with CP described in Chapter 3 also applies to other adults with different types of disabilities. Hence, research in the area has the potential to inform and advance practice across a broader range of disability groups.

5. Proposed future clinical set-up

An outline of a potential organisational structure for future dedicated rehabilitation services for adults with CP is presented in Table 8. The presented outline is derived from the experiences and recommendations in Chapters 2 and 3. Hammel Neurorehabilitation Centre intends to play a leading role in the development and implementation of the dedicated services.

Table 8. Overview of proposed specialised, hospital-based neurorehabilitation services for people with CP in Western Denmark.

Component	Location	Main responsibilities	Notes
Cross-Regional Knowledge Centre for CP	Hammel Neurorehabilitation Centre	• Advisory support to regional centres, GPs*, and others • Disseminate general CP knowledge through existing knowledge-sharing structures[41,42] • Advocate for policy changes, led jointly by CP Denmark (patient perspective), the Elsass Foundation (financial capacity), and Hammel Neurorehabilitation Centre (clinical expertise)** • Receive patients by referral from regional CP centres • Interdisciplinary expert assessments of complex cases, and initiation of complex rehabilitation pathways	* The specific advisory needs of GPs to be identified ** The vision: publicly funded, national integration of CP services into existing and future brain injury services.
Regional CP Centres	Neuroenhed Nord Brønderslev, Hammel Neurorehabilitation Centre, Grindsted, Svendborg	• Receive patients by referral of all 18-year-olds from paediatric services[†] at completion of CPOP; receive adults by referral from GPs, neurology departments based on needs[††] • Create overview and coordinate care for adults with CP within each region, based on their knowledge of regional structures and municipal service options[†††]. • Interdisciplinary management of less complex pathways • Continuation of complex pathways initiated at Hammel • Interdisciplinary status reports with clear recommendations for follow-up at GPs (referrals, treatment) and in the municipality	[†]Collaboration with paediatric services to be clarified (how to “flag" complex cases, so they do not get lost in the system; how to establish clear contact points for young adults completing CPOP) [††]Needs to be defined, including needs in individuals who do not perceive or articulate them. [†††]Users affiliation to be defined (eg based on PRO-data, pre-approved admission [“åben indlæggelse”])

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