



ORIGINAL ARTICLE

Norwegian paediatric habilitation centres judge their own competence on cerebral visual impairment as limited

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Abstract

Aim: Cerebral visual impairment (CVI), a frequently occurring functional impairment in children with neurodevelopmental disorders, leads to communicative, social and academic challenges. In Norway, children with neurodevelopmental disorders are assessed at paediatric habilitation centres. Our aims were to explore how CVI is identified, how paediatric habilitation centres assess their CVI competence and the reported prevalence of CVI among children with cerebral palsy.

Methods: An electronic questionnaire was sent to all 19 Norwegian paediatric habilitation centre leaders in January 2022. The results were analysed quantitatively and qualitatively. The prevalence of CVI among children with cerebral palsy was estimated using register-based data.

Results: The questionnaire was answered by 17. Only three judged their habilitation centre as having sufficient competence on CVI. None of the centres used screening questionnaires systematically, and 11 reported that CVI assessment was not good enough. Awareness that a child may have CVI typically occurred during examinations for other diagnoses. The prevalence of CVI among children with cerebral palsy was only 8%, while CVI status was unknown in 33%.

Conclusion: Better knowledge and assessment of CVI at Norwegian paediatric habilitation centres are needed. CVI appears to be often overlooked in children with neurodevelopmental disorders.

KEYWORDS

assessment, cerebral palsy, cerebral visual impairment, cortical visual impairment, screening

1 | INTRODUCTION

Cerebral visual impairment (CVI) is a functional visual impairment resulting from lesions or malfunctioning of the brain and not attributed to damage in the anterior visual pathways or the eye.¹ It is the primary cause of visual impairment in economically developed

countries^{2,3} and CVI-related problems are rather common in the general population. In a study from mainstream schools in the UK, an estimated one of 30 children had CVI-related problems.⁴ In addition, CVI seldom occurs in isolation. In fact, 85% of children with CVI have at least one additional motor or cognitive impairment.^{2,5} CVI occurs frequently in children with neurodevelopmental disorders such as

Abbreviations: CVI, cerebral visual impairment; NorCP, Norwegian Quality and Surveillance Registry for Cerebral Palsy; Statped, National Service for Special Needs Education.

cerebral palsy (40%–50%), autism spectrum disorders (20%–50%), and Down syndrome (38%).^{6–8} A population-based study in Sweden found that 11 per 10000 children (0–19 years old) had visual impairments, and of these 30% had CVI, indicating a prevalence of 25 per 100000.⁹ While the actual prevalence of CVI in Norway is unknown, a recent study found that 234 (37%) of 628 Norwegian children with visual impairments had CVI.⁵

There is a great variation in CVI manifestations. Children with CVI may appear to have an almost normal visual function, including normal visual acuity, visual field and contrast sensitivity. Despite this, they still struggle with the functional use of their vision and have impaired visual skills.^{1–3} Examples of impaired visual skills are difficulties with recognising objects, shapes, faces and facial expressions, space and direction orientation, visually guided bodily movements, and distinguishing between the background and foreground in visually cluttered scenes.^{10,11} CVI may cause major challenges for a child in everyday life, including academically, socially, in communicating, and, in activities of daily living.

There is no national or international consensus on how to screen for, investigate and diagnose CVI.¹² In general, a combination of the patient's history and a questionnaire are recommended for screening. If CVI is suspected, a multidisciplinary assessment should follow.¹³ A systematic review described the 10 most commonly used assessment methods (Table 1).¹⁴ In Norway, a multidisciplinary assessment includes collaboration between a paediatric habilitation centre, an ophthalmological department, and the National Service for Special Needs Education (Statped).

The habilitation centres are part of the specialised health care services, offering multidisciplinary assessments and follow-up to children with congenital or early acquired neurological conditions and neurodevelopmental disorders. There are 21 paediatric habilitation centres in Norway, and professionals working at these centres include paediatricians, physiotherapists, occupational therapists, neuropsychologists, and special educators.¹⁵ Statped serves many of the same children, but in contrast to the habilitation centres, it is part of the educational services. The organisational separation between the two services hampers effective collaboration because a habilitation centre cannot directly refer a child suspected of having CVI to Statped for further diagnostic work-up or intervention. Similarly, Statped cannot refer a child in need of a neuropaediatric assessment directly to a habilitation centre.

In May 2021, a nationwide CVI network was established based on concerns gained through clinical experience, that CVI was underdiagnosed and that many children with CVI are not getting appropriate help. The network includes neuropaediatricians, ophthalmologists, neuropsychologists, orthoptists, occupational therapists, physiotherapists, vision educators, and other professionals representing the habilitation centres, Statped, and the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP), as well as representatives of two user organisations, the Norwegian Cerebral Palsy Association and the Norwegian Association of the Blind and Partially Sighted. The aim of the network is to increase the knowledge of CVI, improve CVI assessments and ensure that children with CVI receive

Key Notes

- Concern has been raised that cerebral visual impairment (CVI) is underdiagnosed in Norwegian children with neurodevelopmental disorders.
- Norwegian paediatric habilitation centres judged their CVI competence as limited, and that many children with this impairment may not get appropriate interventions.
- There is a need for improved awareness of CVI among professionals working in Norwegian paediatric habilitation centres and for validated screening and assessment tools.

TABLE 1 The 10 most commonly used assessments used to investigate and diagnose CVI in children, according to a systematic review of 45 publications in 2021^a.

Categories of assessment	Occurrence ^a (%)
1 Medical history	94
2 Vision assessment/Ophthalmologic examination	94
3 Ocular movements and posture assessment	72
4 Neuroimaging	63
5 Visual behaviour and direct observation	41
6 Structured history-taking	37
7 Intelligence/cognitive/IQ assessment	35
8 Clinical electrophysiology	33
9 Visual perception tests	26
10 Neurodevelopmental tests	17

^aPercentage of publications included in the survey where the assessment was used.

appropriate interventions. As a first step, it was decided to explore how children with CVI are followed up in the habilitation centres.

The aims of the present study was therefore to gain knowledge on how the paediatric habilitation centres identified children at risk for CVI, how children at risk were further assessed, how the centres assessed their own CVI competence, and the reported prevalence of CVI among children with cerebral palsy.

2 | PARTICIPANTS AND METHODS

The CVI network developed a questionnaire addressing (1) how CVI screening and assessment are performed at the habilitation centres, (2) which professionals are responsible for the assessment, (3) how the centres judge their own CVI competence and (4) how the organisation of services affect the collaboration between habilitation centres and Statped (see Table 2). A questionnaire developed

TABLE 2 Questionnaire sent to Norwegian paediatric habilitation centres regarding their assessment practices and knowledge concerning CVI.

Question number	Question and response options
Q1	How does the suspicion that a child may have CVI arise? <i>Response options: Questionnaire used for all children assessed; Questionnaire used for children with a diagnosis increasing likelihood of CVI; Questionnaire as supplement if CVI is suspected; Little use of questionnaires covering CVI; CVI usually not assessed; Other; Don't know; Free-text option</i>
Q2	What type of assessments are included in a CVI assessment at your paediatric habilitation centre? <i>Response options (multiple responses possible): Ophthalmological assessment; Visual perception tests; Questionnaires; Observation of visual behaviour; Neuroimaging; Cognitive assessment; Other; Don't know; Free-text option</i>
Q3	Is a professional group expected to have a particular focus on CVI? <i>Response options: No, everyone has equal responsibility; Yes (please specify); Don't know; Free-text option</i>
Q4	Is there a vision team at your paediatric habilitation centre? <i>Response options: Yes; No; Don't know; Free-text option</i>
Q5	Do you believe that you discover all children with CVI? <i>Response options: Yes, all; Yes, most; No; Don't know; Free-text option</i>
Q6	Is there a specific diagnostic code (from ICD-10) that is use for CVI at your paediatric habilitation centre? <i>Response options: Yes (please specify); No; Don't know; Free-text option</i>
To which extent do you agree to the following claims: <i>Scale from "completely disagree" (1) to completely agree (5), plus free-text option</i>	
Q7	The assessment of CVI in children followed at our paediatric habilitation centre is good enough
Q8	It would be preferable if the paediatric habilitation centres could refer directly to Statped for assessment of CVI
Q9	Children with CVI followed up by our paediatric habilitation centre receive the interventions they need
Q10	Our paediatric habilitation centre has sufficient knowledge of CVI

Note: Other comments (e.g., about resources, wait lists, referrals, collaboration between hospital departments and so forth).

specifically for this study was required since we were unable to identify any relevant validated questionnaires capturing these areas.

The development of the questionnaire started during the summer of 2021, followed by discussions at a network meeting in August. Further refinement occurred within the author group during the fall, including testing the feasibility of an electronic version.

The final questionnaire included 10 items: six questions with pre-defined answer options (see Table 2), and four statements (claims) using a Likert scale ranging from one (completely disagree) to five (completely agree), with the unlabelled numerals 2, 3, and 4 spaced evenly between 1 and 5. All 10 items also had options for free text comments.

The questionnaire was sent electronically to the leaders of all 21 Norwegian paediatric habilitation centres in January 2022. As there are two managers who are responsible for two centres each, 19 leaders received the questionnaire. The request was to either answer themselves or delegate to an employee who could best answer on behalf of the habilitation centre.

The Norwegian Centre for Research Data assessed that the survey was not subject to ethical approval (#663381/2021) as the respondents had the option of remaining anonymous. For this reason, we did not ask whether it was the leader or another employee who answered the questionnaire.

Data were analysed both quantitatively and qualitatively, and following a pragmatic approach treated as equally informative.¹⁶ Given the small number of respondents, the quantitative analyses

comprised descriptive distributions of frequencies and percentages and no statistical analyses. For the qualitative analyses of the 10 free-text options, responses were coded (R1 to R17) and collected in one document. The content was then categorised thematically, after careful reading of the content several times. The themes identified were competence, inter-sectoral collaboration and intervention.

In addition, we also extracted information from the NorCP, where the habilitation centres register data on children with cerebral palsy. The NorCP comprises over 93% of children with cerebral palsy in Norway, born from the year 2002 onwards.¹⁷ Since 1 January 2022 a question regarding CVI (yes/no/unknown) was added.

3 | RESULTS

In all, we received responses from 17 of the 19 habilitation centres, covering 94% of Norway's population.¹⁸

The first question pertained to the detection of CVI (Table 2). No habilitation centre reported that they routinely screen all patients for CVI, while only one centre reported that they used a screening instrument to screen for CVI in diagnostic groups known to have an increased risk of CVI.

The second question was about assessment practices when a child was suspected of having CVI. It was possible to indicate several assessment methods. Five habilitation centres reported that they used four different assessment methods, five used three, four used

two and one used one. One habilitation centre responded that they referred to Statped and one centre responded that they did not know which method was used. Of the 15 habilitation centres reporting that they did assess, 12 reported that their assessment included observation of visual behaviour. For two-thirds of those reporting that they observed visual behaviour, observations were also performed at home, school or in kindergarten. Three centres reported that they used questionnaires for assessment when they suspected a child had CVI, although they did not indicate which assessment questionnaire they used. One of the three aforementioned centres indicated that, in addition to the assessment questionnaire, they also used questions proposed in a Norwegian textbook. Cognitive testing was considered part of the CVI assessment by 13 habilitation centres, while only four reported that they used a test of visual perception, specifically. All four included the Beery-Buktenika Developmental Test of Visual-Motor Integration¹⁹ in their test battery. Four habilitation centres reported that CVI assessment also included referrals to both ophthalmological examination and neuroimaging and three habilitation centres reported referring to either ophthalmological examination (one centre) or neuroimaging (two centres).

The third and fourth questions pertained to professionals involved in identifying CVI and whether the habilitation centre had a vision team. Neuropsychologists and special educators were indicated as the professionals responsible for identifying or suspecting CVI in six centres, while at seven centres the paediatrician was responsible (Table 3). None of the centres had dedicated vision teams. One habilitation centre had employed a teacher for the visually impaired, who was responsible for CVI screening and assessment. One centre indicated that an ophthalmologist was involved in the assessment but clarified in the free-text response that they were employed outside of the habilitation centre and patients were referred there.

Three centres considered it likely that they identified CVI in the majority of children with this impairment, while the remaining 14 answered no or do not know. In the free-text comments, it was indicated that the detection of CVI most often occurred by coincidence,

often in connection with the assessment of other diagnoses such as cerebral palsy. None of the centres used an ICD-10 code for CVI, although one centre indicated that from time to time the ICD-10 codes H53.9 (Visual disturbance, unspecified) or H47.6 (Disorders of visual cortex) were used.

Only one centre considered that their CVI assessment was good enough. However, in the free-text option, this was followed up with the comment "we have good experience with the assessment done at Statped." Four centres indicated that children with CVI received the interventions they needed and that the centre's knowledge on CVI was sufficient (Table 4).

From the qualitative analyses of the free-text responses, the theme competence emerged. Respondents expressed that CVI is an area where there were major shortcomings on how to screen and that there is a need for more standardised assessment procedures. Furthermore, it was reported that although many professionals have some knowledge, competence and experience of working with CVI, the centres lacked the specialised competence on the condition.

Sixteen of the 17 centres agreed that the referral process to Statped could be improved. This is reflected in the second theme, inter-sectoral collaboration, that emerged from the qualitative analysis. The lack of a possibility for direct referral between the health care system and Statped was described as cumbersome, representing a detour and an obstacle. Three respondents mentioned challenges in the collaboration with their respective ophthalmological departments, including long wait times, inadequate CVI competence and lack of systematic cooperation.

The third theme identified in the qualitative analysis was that of interventions. The habilitation centres identified Statped and vision educators in the municipalities as responsible for interventions. One respondent expressed that it was unclear how the centre should gain information about interventions, while another related lack of knowledge about interventions to the assessment practices in the habilitation centre and challenges with inter-sectoral collaboration.

TABLE 3 Professionals (type and number of different professionals) expected to have a special focus on CVI in Norwegian paediatric habilitation centres ($n = 17$).

	Number of professionals involved					Total
	1	2	3	4	Unspecified	
Paediatrician	1	2	1	3		7
Special Educator	1 ^a		1	4		6
Psychologist	1	2	1	2		6
Occupational Therapist		2		3		5
Physiotherapist				3		3
Nurse				2		2
Ophthalmologist				1		1
Unspecified				4	2	6
Number of habilitation centres ^b	3	3	1	8	2	17

^aTeacher for visually impaired.

^bThe table shows that at three habilitation centres (last row/first column) only one type of professional is expected to have a special focus on CVI, while at eight centres (last row, fourth column) four clinicians [with different competences (expertise)] are expected to have such focus.

	Disagree ^a	Neutral	Agree
Claims from questionnaire	N	N	N
Q7: The assessment of CVI in children followed at our paediatric habilitation centre is good enough	11	5	1
Q9 ^b : Children with CVI followed up by our paediatric habilitation centre receive the interventions they need	7	6	4
Q10: Our paediatric habilitation centre has sufficient knowledge of CVI	6	8	3
Q8: It would be preferable if the paediatric habilitation centres could refer directly to Statped for assessment of CVI	1	0	16

^aThe response options were given on a Likert scale ranging from 1 (completely disagree) to 5 (completely agree). The responses were reduced to three categories, whereby scores 1–2 were interpreted to indicate disagreement, a score of 3 to indicate a neutral response, and scores 4 and 5 to indicate agreement with the claim.

^bThe original order of the claims is found in Table 2.

Thus, the theme intervention was linked to the other two themes, competence and inter-sectoral collaboration.

In 2022, the new registration form of the NorCP, which included a question about CVI, was completed for 158 children. Of these, the reporting paediatrician indicated that CVI was present in 12 (7.6%) children, not present in 94 (59.5%) and unknown in 52 (32.9%) children.

4 | DISCUSSION

We found that of 17 habilitation centres, 14 judged their own CVI competence to be insufficient. Furthermore, none of the habilitation centres reported satisfaction with their level of knowledge or assessment and identification of children with CVI. These quantitative findings were mirrored in the qualitative theme competence, where the respondents indicated that they had less focus on CVI and knowledge about the condition than desired. Furthermore, these findings were supported by the results from the NorCP, indicating that only 8% of children with cerebral palsy had CVI, and in 33% the CVI status was unknown. It is, therefore, a great risk that CVI is currently not identified in children who would benefit from professional help, a viewpoint also expressed by the centres as the majority expressed that they probably do not detect all children with CVI.

However, as the questionnaire was not an objective measurement of the employees' competence, there might have been expertise at the habilitation centres that our study did not identify. Interdisciplinary assessment, involving three or more different professionals, was present at nine of the 17 habilitation centres. Such multidisciplinary assessment approaches are in line with international recommendations.^{11–14} Meanwhile, our findings highlight a need for professional competence development, including a common understanding of CVI, what the impairment encompasses, screening procedures, which diagnosis groups are susceptible to CVI impairment, targeted interventions, and expanded educational curriculums.

TABLE 4 Responses by paediatric habilitation centres ($N=17$) to four claims addressing assessment, intervention, competence and referral practices related to CVI (and corresponding to questions 7–10 in Table 2).

Regarding the assessment methods used, three of four habilitation centres relied on cognitive testing (76%) and over two-thirds of the services used observation (70%). These figures are significantly higher than internationally reported (cognitive tests 35% and observation 41%).¹⁴ This might indicate that although approximately the same number of professionals are involved in the assessment of CVI in Norway as in other countries, the types of professionals involved differ from that of other countries. Specifically, it might be that psychologists and special educators are more often involved in the assessment of CVI in Norway.

CVI is an impairment that may be detected at an early age, and targeted measures can improve function significantly.^{20,21} It is of great concern that none of the habilitation centres routinely screen for CVI. One likely reason is that none of the internationally available screening tools, such as TeachCVI,²² Flemish CVI Questionnaire²³ or CVI Inventory,²⁴ have yet been translated into Norwegian. However, this will hopefully be amended in the not-too-distant future as there is ongoing work in Statped²⁵ to translate the first instrument into Norwegian (the first and third instruments are already available in Swedish).²⁶ Furthermore, a validation of these questionnaires is necessary for the Norwegian population. When they become widely available for the habilitation centres, we expect an increase in the number of children diagnosed with CVI, an improvement in targeted measures to improve function, as well as an improvement in the quality of life of children with CVI. However, screening for CVI will only be the first step, as screening might also lead to false-positive responses. A thorough and multidisciplinary assessment, taking into consideration the complexity of the neurodevelopmental condition of the child, is therefore called for when children are identified as having a risk of CVI through a screening instrument.^{11,12}

Despite the high incidence and serious outcomes of CVI, little research has been performed.^{21,27} Additionally, CVI is not specified in the International Statistical Classification of Diseases and Related Health Problems,²⁸ which may lead to limitations in the recognition of the impairment by health personnel and authorities.²⁹ The same applies to the lack of national CVI guidelines.¹⁵ Without clear

guidelines, it is the responsibility of each habilitation centre to determine whether and how CVI is assessed.

The results of the questionnaire show a wide gap in the ability and quality of CVI screening and assessment among the habilitation centres, as shown by the heterogeneity of the different types of professionals responsible for CVI assessment, as well as the number of assessment methods used. Five of 17 centres used four different assessment methods requiring variable expertise, while the remaining used one to three methods. Furthermore, only four habilitation centres reported that they agreed with the claim that children with CVI receive the interventions they need, a finding mirrored in free-text comments where lacking knowledge of instigated interventions was reported. Our findings, therefore, give reason to worry, as they may indicate that many children with CVI go unidentified and are not receiving appropriate habilitation and targeted interventions. The development of national guidelines would reduce the great variation between the centres that we have uncovered in this study. However, the need for guidelines is not unique to Norway. In an ongoing European project, efforts are being made to define an internationally accepted consensus on the definition, diagnosis, assessment and classification of CVI.^{11,12}

The reported prevalence of CVI among children with cerebral palsy varies between 16% and 70% in different studies. This variation was due to different sources of clinical information, for example, direct observation versus telephone questionnaires, the definition of visual impairment, which tests were used for assessing visual disorders, as well as the visual parameters taken during a clinical assessment.³⁰ Our data from the NorCP, could suggest a much lower prevalence (8%) among Norwegian children with cerebral palsy. However, taken together with the high percentage of children with missing information, the more likely explanation is that CVI is underdiagnosed, consistent with the main results of the questionnaire. Together, this speaks to the importance of increasing the focus on CVI in the paediatric habilitation centres so that children with this impairment are identified, assessed and receive proper interventions.

4.1 | Limitations and strength

A strength of our study is that it included nearly all habilitation centres nationwide, serving more than 90% of the paediatric population in Norway. A limitation was that the questionnaire was self-developed and not validated. However, the questionnaire was developed by an interdisciplinary national CVI network. Another potential limitation is that the questionnaire was addressed to the leader of each habilitation centre. Since the leaders do not necessarily have the most knowledge about CVI, we suggested that they forward the questionnaire to employees in the habilitation team with the best competence to answer. However, we do not know to what extent the leaders delegated the questionnaire, or to whom. Therefore, there may potentially be an underreporting of CVI competence, although we do assume that the leaders would have discussed the questionnaire with employees, if necessary.

Finally, we might have asked the same questions regarding another impairment, for comparison. However, our knowledge of the competence of professionals working in habilitation centres makes it unlikely that our results reflect a generally low competence or low self-estimated competence in these centres. Rather, we suspect that CVI may be underdiagnosed and that the competence on this impairment is low, a finding that may be reflected in the low prevalence of CVI among children with cerebral palsy registered in the NorCP, and the high proportion of children with missing information regarding CVI.

In the interpretation of methods included in the screening of CVI, it must also be taken into account that it was assumed that an adequate ophthalmological examination of the child had been carried out, which is often included in the standardised assessment of children with neurological diagnoses. Therefore, the risk of underdiagnosis of CVI may be somewhat less than what appears in this study. However, it is uncertain to what extent ophthalmologists are aware of CVI when examining the vision of children with underlying neurodevelopmental disorders, and it would be of interest to send out a similar questionnaire to this group of professionals.

5 | CONCLUSION

Our study indicates that there is inadequate focus on CVI in paediatric habilitation centres in Norway. None of the centres had a dedicated vision team, a structured assessment procedure, or a systematic use of screening tools for CVI. If CVI was detected, it was most often in connection with examinations of other conditions. The probability of CVI remaining undetected was assessed as high by 14 of the 17 respondents. This was echoed in the findings from NorCP, where the presence of CVI was unknown in 33% of children with cerebral palsy.

There is a need for the development of reliable, targeted screening tools for the detection of children at risk of CVI in Norway, in order to properly assess them and initiate targeted interventions. To further this, the CVI network intends to organise meetings and workshops with professionals working in the habilitation centres, ophthalmological departments, Statped and the user organisations to improve knowledge and develop guidelines both for screening, assessment and interventions for children at risk of or diagnosed with CVI.

CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

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