



JÖNKÖPING UNIVERSITY

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The participatory profiles of children and adolescents with cerebral palsy: with and without mental health issues

A narrative scoping review

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ABSTRACT

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Among children and adolescents with cerebral palsy, their participatory profiles differ from their typically functioning peers. However, there is no known research comparing the participatory profiles between children and adolescents with cerebral palsy and those individuals with additional mental health issues. Therefore, the aim of this narrative scoping review is to investigate the participatory profiles between children and adolescents with cerebral palsy with and without mental health issues. The findings were categorized based on the subdomains of participation and activities from the International Classification of Functioning, Disability and Health, version for Children and Youth (ICF-CY) as a framework. Results revealed there to be 23 studies on the participation of children or adolescents with cerebral palsy and 11 studies on children or adolescents with cerebral palsy and additional mental health issues. In both groups of children with and without mental health issues, the most common subdomains were community, social and civic life and interpersonal interactions and relationships. A greater proportion of studies found the subdomain of community, social and civic life on children and adolescents with cerebral palsy but without known mental health issues to be more common than those with additional mental health issues. The most common subdomain among children and adolescents with cerebral palsy and additional mental health issues was interpersonal interactions and relationships. Communication was also revealed to differ in findings between the groups. Although adolescents and children with cerebral palsy communicated less among peers, it was found that those with additional mental health issues have more communication problems. Despite the number of studies found, not enough research has been done to assess whether it is the lack of participation that causes a change in mental health or it is mental health issues that leads to limitations in participation. This indicates that future research should focus more on the role of mental health on children and adolescents with cerebral palsy and their participation profiles.

Keywords: participation, engagement, cerebral palsy, children and adolescents, mental health issues

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List of abbreviations

CP	Cerebral palsy
ICF-CY	International Classification of Functioning Child and Youth
WHO	World Health Organization
GMFCS	Gross Motor Function Classification Score
RMP	Recurrent Musculoskeletal Pain
CAPE	Children's Assessment of Participation and Enjoyment
CBCL	Child Behavior Checklist
TDS	Total Difficulties Score
SDQ	Strengths and Difficulties Questionnaire

1 Introduction

Children with disabilities are at a substantially higher risk for a violation of their human rights (Donohue, Bornman & Granlund, 2014). According to the Conventions on the rights of the child, children have the right and necessity to participate in society (Convention on the Rights of the Child, 1989). However, this is often not actualized by individuals who have a disability. In alignment with the social model of disability, children or adolescents who have a disability are defined as having a physical or mental deviation which in touch with societal barriers hinder their participation (UNICEF, 2013) More specifically, children and adolescents with disabilities have often been reported to participate less in school and leisure activities (World Health Organization, 2011). This is particularly noteworthy considering participation in school and leisure activities are vital for the acquisition of skills such as cognitive and social skills (Askari, Anaby, Bergthorson, Majnemer, Elsabbagh & Zwaigenbaum, 2015).

In other words, participation is crucial for one's well-being and development. However, due to the nature of disabilities, individuals may not participate across several life domains such as in leisure activities, domestic life and school to the extent to which their typically functioning peers. Differing factors, ranging from personal and environmental factors, impact the magnitude of barriers that limit their participation. This parallels the social model of disability which is emphasized within the International Classification of Functioning, Disability and Health version for Children and Youth (ICF-CY) framework (WHO, 2007). The ICF-CY describes the functioning of a child or youth by taking into account the various domains such as body structure and functioning, health condition, personal factors, environmental factors, participation and activities (WHO, 2007). This framework emphasizes how participation is a crucial component for functioning. However, since the focus of this research is to analyze the participatory profiles, the domains participation and activities from the ICF-CY will be the main source of reference. It will include all of the sub-domain categories from participation and activities such as the following: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas and community, social and civic life (WHO, 2007).

Another aspect which is associated with functioning is mental health or condition. Mental health issues can lead to social isolation, lower self-esteem and poorer overall functioning. Mental health problems such as anxiety and depression are not uncommon among adolescents (Sweeney & Pine, 2004). This may indicate that children and adolescents with both cerebral palsy and mental health issues may have different participatory profiles in relation to their peers, leisure activities or at school compared to children who only have cerebral palsy. In other words, additional or modified interventions may need to be considered for this particular group of children with cerebral palsy and mental health issues.

2 Background

The theoretical framework will be the ICF-CY (WHO, 2007) and the family of participation-related constructs (Imms et al. 2016). The key concepts within this paper will focus on participation, mental health and children and adolescents with cerebral palsy.

2.1 ICF-CY framework

The term ‘functioning in everyday life’ stems from the ICF-CY model that references the complex processes which occur in the child’s daily functioning (WHO, 2007). For example, ‘functioning in everyday life’ includes the dynamic interaction between a child’s health condition, body function and structure, activities, participation, including environmental and personal factors is illustrated in Figure 1.

The health condition can include a specific diagnosis such as Autism spectrum disorder or cerebral palsy. The body function domain consists of the physiological functions of the body as well as the psychological aspects. Body structure includes the anatomical system such as limbs and organs. The activity is the task or action in which an individual is part of, which is highly connected to the participation domain. The participation domain is described as ‘involvement in a life situation’. The final two domains include environmental factors and personal factors. Environmental factors are comprised of the physical, attitudinal and social aspects and the personal factors include the specific background information relevant to the particular individual (Riva & Antonietti, 2010) such as age, gender and personal preferences. The terminology adopted stems from the systems theory which emphasizes how all parts and areas of a child’s life mutually interact and thereby shape the functioning and developmental outcome. Moreover, the ICF-CY demonstrates the ways it can help contribute to increasing participation and the quality of life of children and youth in need of special support (Simeonsson, 2009). The subdomain categories of the participation and activities domain are described as the following:

Learning and applying knowledge subdomain includes learning through senses such as observing and listening. The other aspect is basic learning which is obtaining information, acquiring skills, copying or learning through play. This allows one to apply the knowledge by focusing attention and solving problems or making decisions.

General tasks and demands subdomain involves doing tasks, daily routines and controlling and managing behavior or psychological demands. More specifically, it emphasizes the ability to complete tasks independently or in groups. In addition, this domain evaluates the ability to cope with stress, responsibilities and one’s own behavior.

The third subdomain category is communication. This underlines the ability to communicate with others such as expressing oneself through body language or vocalization and understanding others.

Moreover, it can be through different mediums such as symbols, electronic communication devices or written letters. It is also the ability to maintain a conversation.

The subdomain mobility domain is the ability to move, sustain or change oneself into a new position. This can be through walking or crawling. It can also be through handling objects with the use of legs, hands or arms. In addition, this domain includes transportation such as being transported through wheelchair, bicycling car or riding an animal.

The self-care subdomain is the ability to care for oneself. More specifically, it is caring for one's health and body such as washing, using toilet, dressing and eating appropriately. It can also include taking the medicine one requires and avoiding harmful substances such as excess alcohol, unsafe sex and dangerous drugs. Domestic life is the act of doing everyday tasks and domestic routines. It includes obtaining life necessities such as having a place to live, services and goods. It also evaluates the ability to help or prepare daily meals or household tasks. Moreover, caring for household valuables or objects such as cars, devices or pets. It can also include assisting others like those in the family who are sick.

The seventh subdomain category is interpersonal interactions and relationships. This includes the ability to have a socially appropriate interaction with others by responding to social cues and demonstrating consideration and esteem. It not only includes information relationships such as friends, neighbors and family but also formal relationships such as professionals.

The major life areas subdomain is engaging in work, education or play. In the education aspect, it is how the individual participates, progresses and completes school or other educational programs. In relation to work, it is how the individual is able to obtain or maintain a job or the lack thereof. This domain also reflects one's economic life such as how persons deals with money and one's economic resources. The final aspect is play which is the ability to engage in solitary or social play.

The last subdomain is the community, social and civic life. This is an individuals' engagement in organized social life such as playing with others in the playground, recreation or leisure activities.

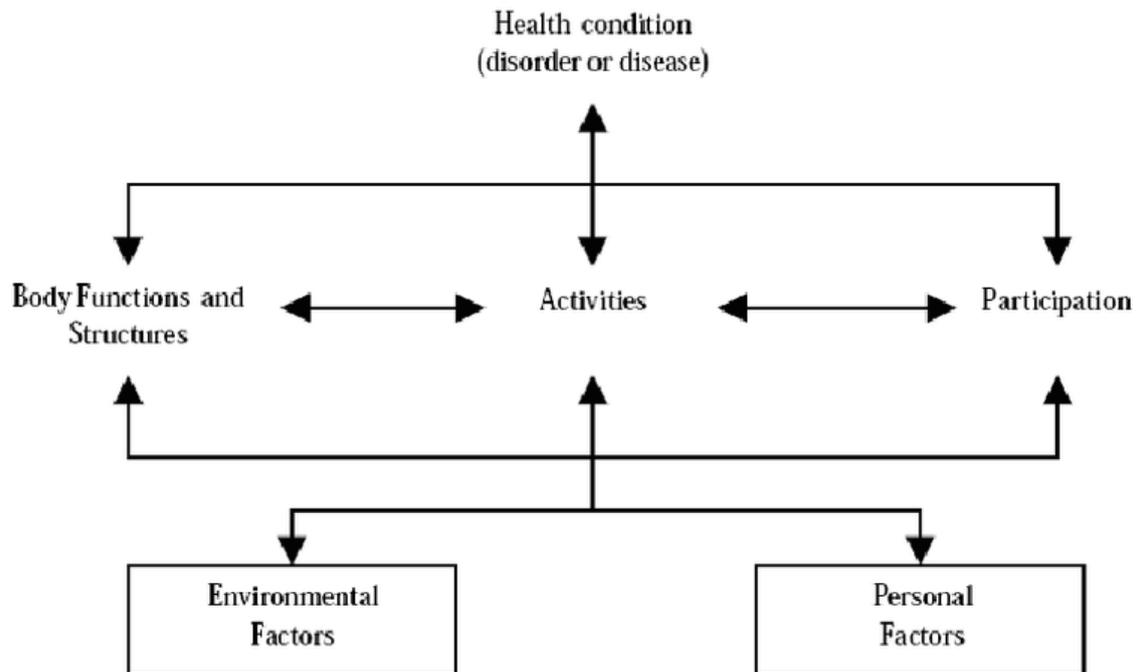


Figure 1. The framework of the International Classification of Functioning, Disability – Child and Youth version (ICF-CY; WHO, 2007).

2.2 Family of participation-related constructs

The family of participation-related constructs is another framework which underlines the more inherent features related to participation. It describes the connections between inherent personal factors which are not only influenced by previous participation but also impact future participation (Imms et al. 2016). Participation has been described as having two main components which are involvement and attendance. Involvement includes the intangible aspects such as engagement, social connection, motivation, level of affect and motivation. This component is essential but can only happen if the individual is attending to the event at hand. Attendance is the amount of times or frequency one is present at activity or task (Imms et al. 2016). The other part of the family of participation constructs highlights the intrinsic factors such as sense of self, activity competence and preferences. The sense of self aspect includes personal factors such as optimism, self-esteem, autonomy and self-determination. The activity competence aspect is characterized by capacity, capability and performance. Capacity is described as maximum ability an individual can attain. The capability aspect are the everyday skills an individual can use within their environment. Performance reflects the abilities or skills an individual is utilizing in their daily environment.

This model also notes the external factors that impact participation (Imms et al. 2016). Since individuals experience the environment based on their own perspective, it implies that there can be multiple contexts within one environment depending on the individual. Therefore, contexts are also incorporated

within this model to describe participation and how an individual and their context mutually impact each other. This relates to the final aspect of the model which states engagement as being the connection between the internal state and external contexts. The internal states are described as the cognitive, emotional and behavioral components of an individual.

2.3 The concept of participation

Participation is understood to be a multi-dimensional construct which highlights not only the physical presence of participation but also active engagement (Granlund, 2017). Physical presence in participation is the most observable in that it can be determined through frequency of attendance. In contrast, engagement includes internal states such attention allocation and the ability to focus on a task or situation (Imms, Granlund, Wilson, Steenbergen, Rosenbaum & Gordon, 2016). This definition of participation emphasizes the necessary mental capabilities in order to fully participate.

Another definition of participation stems from the World Health Organization's (2001) ICF-CY which defines participation as 'involvement in life situations'. **This** means an individual is autonomous to an extent and capable of exerting some control over one's life (Perenboom & Chorus, 2003). Others have defined it as 'frequently occurring routines or activities that are complex, including sequences of actions suitable in societal contexts, involve engagement and are directed towards meaningful goals' (Adolfsson, Malmqvist, Pless & Granlund, 2011).

As noted in the definitions, participation in life situations includes engagement in activities, underlying the close relationship between activity and participation. Activities are what the individual is participating in. However, an activity can be done at an individual level, and does not necessary require others involvement. In contrast, participation by societal standards is perceived as a performance and typically includes social inclusion (Coster, Law, Bedell, Khetani, Cousins & Teplicky, 2012).

Likewise, inclusion is also closely related to participation, but is defined as subjective experience consisting of a sense of belonging and engagement (Granlund, 2017). This also emphasizes the social and psychological aspects of inclusion both of which are vital since they enhance the development of life skills (Engel-Yeger, & Hamed-Daher, 2013).

2.4 Mental health

One out of four people will develop mental health issues within their lifetime (WHO, 2017). Mental health is defined as the condition in which an individual can cope with the normal amount of stress and is characterized as a state of well-being. Other studies have defined mental health as the absence of psychological issues such as anxiety, stress or depression (Westerhof & Keyes, 2010). The state of healthy mental well-being is at risk when there is a clinically significant deviation from the normal range of functioning. This is described in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

(DSM-V) in which mental disorder is attributed to being disabling and associated with an increase in emotional pain and suffering (Stein, Phillips, Bolton, Fulford, Salder & Kendler, 2010). However, a formal diagnosis of a disorder is not necessary to evaluate a decline in one's mental health. Mental health issues can consist of negative emotions and thoughts such as having low self-esteem, anxiety and depression (World Health Organization, 2017).

Although mental health is described as an individualized phenomenon, adopting the ICF-CY approach can be beneficial as environmental and contextual factors can be considered in relation to an individual's functioning and participation. This is due to the fact mental health can be very dependent on one's social or physical environment.

2.5 Cerebral palsy

Cerebral palsy consists of various forms of movement disorders categorized by type such as spastic bilateral and unilateral, atactic and dyskinetic. (Bjorgaas, Elgen, Boe & Hysing, 2013). These forms of cerebral palsy are known for causing limitations in activities due to the motor disorders in movements and postures. In addition, it is often associated with disturbances in communication and cognition (Rosenbaum, Paneth, Leviton, Goldstein & Bax, 2007). Since there are different forms of cerebral palsy, the functioning can also vary depending on the difficulty of performing a task. These variations can be measured by the Gross Motor Function Classification System (GMFCS) which reveal the level of independence and functioning on an ordinal scale ranging from level I to level V. Those within level I and II are considered as having more mild movement limitations, level III is moderate and levels IV and V reflect more severe difficulties in physical/mobility functioning (Chagas, Defilipo, Lemos, Mancini, Frônio & Carvalho, 2008).

It has been estimated that the prevalence of cerebral palsy is approximately 2 per 1000 births (Oskoui, Coutinho, Dykeman, Jetté & Pringsheim, 2013). Other studies have found the trend to be up to 3 per 1000 births (Winter, Autry, Boyle & Yeargin-Allsopp, 2002). These groups of children and adolescents with developmental disorders such as cerebral palsy have been associated with a greater risk of negative behavioral and emotional symptoms than typically functioning individuals (Downs et al. 2017). The prevalence of behavioral or emotional problems among children with cerebral palsy has been estimated to be between 20 to 80 percent (McDermott, Coker, Mani, Krishnaswami, Nagle, Barnett-Queen & Wuori, 1995).

3 Aim and research questions

The aim of this narrative scoping review is to investigate the participatory profiles of children and adolescents with cerebral palsy and with and without mental health issues. Secondary aims will explore the potential impacts on participation and related factors in order to consider the risks that mental health issues in addition to cerebral palsy may have for participation. The findings from the secondary aims are labeled secondary findings. Secondary findings are the results which are not directly related to the aim of this study, but are related to the main findings and may have a significant meaning as well.

3.1 Research questions

What are the participatory profiles of children and adolescents with cerebral palsy with and without mental health issues?

What are the secondary findings in relation to the ICF-CY?

4 Methods

A scoping review is the method used for this research on children and adolescent with cerebral palsy, mental health issues and their participatory profiles. This method was chosen due to there being limited or no prior research done on the differences of the participatory profiles between children and adolescents with cerebral palsy with and without mental health issues. Therefore, a scoping review allows this broader topic to be addressed and for there to be an analysis on the possible gaps in the literature (Arksey and O'Malley 2005).

4.1 Search strategy

The process of searching for articles through different databases began on March 2018. Databases included were Psycinfo, Medline, PsycArticles, AMED, Eric and PubMed. These databases were chosen to ensure a broad range of topics across psychology, psychiatry, social work, health and education. The key words related to the aim of the study were used in the search process.

The following search terms were used but defined differently to conform to the differing database requirements: Child* OR adolescen* AND participa* AND cerebral palsy, Children OR adolescents AND (mental health or mental illness or psychiatric illness or anxiety or depression) AND participation AND cerebral palsy, (children or adolescents) AND participa* AND (Emotional problems or emotional issues) AND cerebral palsy. The following Mesh Terms were used in the Pubmed database: "Child" OR Adolescent AND cerebral palsy AND social participation. In the Medline database the search terms Child* OR adolescent* AND cerebral palsy AND social participation OR social engagement OR social activities.

Four article were obtained through the snowball effect which included hand searching of articles through the references of articles already included.

4.2 Inclusion and exclusion criteria

The participant, interest, comparison and outcome (PICO) framework was used in order to pinpoint the exact components necessary for the aim of this review (see Table 1). The participants included with the first group were children or adolescents diagnosed with cerebral palsy within the age range 5-19 years of age. The second group of participants were children or adolescents diagnosed with cerebral palsy and having mental health issues or diagnosed with mental illness. The topic of interest included mental health, mental health issues or problems, emotional issues or problems, behavioral issues or problems, psychiatric illness or disorder and anxiety or depression. Autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) are not included within this research review because the mentioned diagnosis can include an additional diagnosis of anxiety or depression which can then lead to an increase risk of confounding

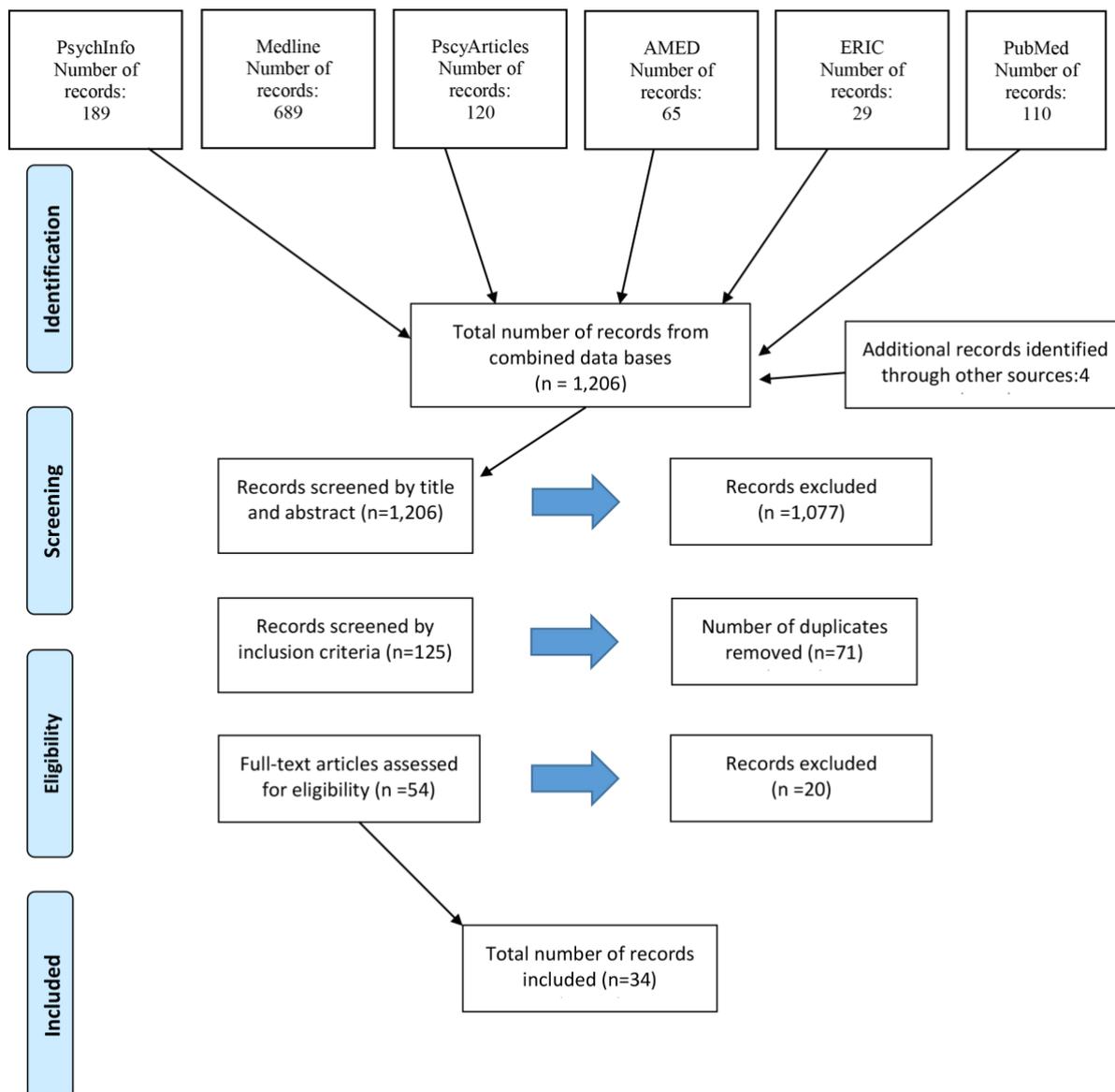
factors or biases. The optional comparison group are children or adolescents who are typically functioning without any diagnosis such as mental disorder or cerebral palsy. The two main groups which are to be investigated in this research are those with cerebral palsy and with and without mental health issues. However, most of the articles included typically functioning children or adolescents within their comparison groups therefore their profiles were also included within the inclusion criteria. In addition, this group matched the main participants in regard to their age range. The outcome criteria included measures of engagement, involvement, participation, (performance of) activities of daily living, health related quality of life, motivation, task performance and physical activities. Information on the publication type can also be observed in Table 1 below. Articles which were published between 2008-2018 were only included in order to have the most recent information concerning the topic.

Table 1 Participation, Interest, Comparators, Outcomes Framework and additional inclusion Criteria

Inclusion Criteria	Exclusion Criteria
Population	
Children and adolescents with cerebral palsy aged 5-19 years	Infants 0-5, young adults 19-29, middle age, old age
Children and adolescents with cerebral palsy and mental health diagnosis or issues	
Interest	
Mental health, mental health issues, mental disorders, psychiatric illnesses or disorders anxiety or depression, emotional issues or problems, behavioral issues or problems	comorbidities such as attention deficit hyperactivity disorder or autism spectrum disorder (ASD)
Comparators	
Typically developing children and adolescents aged 5-19	Diagnosis of mental illness or physical disability
Outcomes	
Measurement of engagement/occupational engagement, involvement, participation (performance of) activities of daily living, occupational performance, health-related quality of life, motivation, task performance, physical activity	As the outcome variables may contain proxy variables of interests, exclusion criteria were minimal to prevent excluding relevant articles
Design	
Quantitative Qualitative Empirical studies Mixed	Systematic literature review

4.3 Selection process

A detailed overview of the search process and article selection can be observed in the flow chart below (*Flowchart 1*).



4.4 Title and abstract

The articles were then screened through title and abstract contents based off of the criteria delineated in Table 2 inclusion and exclusion criteria. The articles excluded included articles which were comments on other articles, study protocols, participants exceeded the age limit of 19 or were below the age of 5. A total of 1,022 articles were omitted based off of the criteria.

4.5 Duplicate articles

Next, duplicate articles were omitted ($n=71$). Duplicate articles consisted of articles which were found in other databases during the search and selection process.

4.6 Full-text scanning for eligibility

The remainder articles ($n=54$) were then assessed through full text readings for eligibility based also on the inclusion criteria (Table 1) and the quality assessment protocol (Table 2). The quality assessment protocol can be observed in *Appendix A*. When the articles were deemed to be low quality (See section 4.7) or not did adhere to the inclusion criteria, they were excluded ($n= 19$) leaving a total of 35 articles in the study. A total of 34 articles were finally included in this research.

4.7 Quality assessment

In order to assess the quality of the articles, an assessment protocol was created. The final quality assessment tool labeled Table 2 can be observed in *Appendix A*. The Quality assessment for this study was derived from the CASP (Center for Evidence Based Management, 2018) and the critical appraisal of a cross-sectional study (Critical Appraisal Checklist for Cross-Sectional study, 2014). Since articles consisting of different methodology types such as qualitative, quantitative or both were included in this study, different questions from these checklists were adopted into the final quality assessment for this scoping review. Among the checklists, the CASP qualitative checklist and CASP cohort study checklist were incorporated for a total of 14 questions (see Table 2 in appendix). When an article scored 50 percent or lower (e.g 7 items rated 'No'), it was deemed low quality. The medium quality articles were those which scored 55-75 percent and the high quality articles were articles scoring between 80-100 percent. All of the low quality articles were omitted ($n=2$) due to the lack of confidence in interpretation of findings due to potential bias. The remainder articles were deemed to be of medium or high quality ($n=34$).

4.8 Ethical considerations

Due to the content of this study involving children, ethical principles from the Helsinki Declaration were upheld. The Helsinki declaration states the major principles of beneficence, respect for persons and justice as vital for any scientific research (Zion, Gillam & Loff, 2000). Therefore, all of the studies ($n=34$) which were included in this review had to have been approved by an Ethics committee.

In accordance with the Helsinki Declaration, all of the information extracted from the articles included were reported with transparency, honesty and integrity which can be observed with the robust inclusion/exclusion criteria (see Table 1) and a quality rating scale (see Table 2) in order to avoid biases in interpretation. Limitations of the selection of articles can be observed in the discussion section 6.4.

4.9 Data extraction and themes

Information on study design and main outcomes were extracted into a template. Studies of the participation profiles of children with CP were mapped against significant findings. Themes related to mental health were then identified based on the main findings within the articles. A narrative synthesis was then undertaken to

report the findings. Categorization of problems and participatory profiles of children with CP with and without mental health problems were considered with respect to the domains of function on the International Classification of Functioning, Disability and Health (WHO, 2007). This framework was chosen in order to assess the participatory profiles in a broader and definable way.

5 Results

A total of 1,206 articles were obtained through the six databases and four through the snowball effect as illustrated in the *Flowchart 1*. After the removal of duplicates, screening titles and abstracts, 54 articles were accessed and full manuscripts assessed for eligibility. Then the exclusion and inclusion criteria were used on the remaining articles which led to a final total of 34 articles. An overview of the selected articles can be observed in the appendix (Appendix B and C). After following the exclusion and inclusion criteria in the selection of articles, a total of 34 articles were obtained. The results are categorized based on the two research groups: Children and adolescents with cerebral palsy and the other group children and adolescents with both cerebral palsy and mental health issues. Both of the group's results are placed within the ICF-CY framework and the subdomain categories. This allows their participatory profiles to be outlined based on the ICF-CY themes.

5.1 Study designs

The selected articles were all published between 2008-2018. The majority of the studies were quantitative studies ($n=28$). The other articles consisted of mixed methods ($n=5$) and one qualitative study ($n=1$). The specific measurements of studies can be observed in the extraction protocol in the appendix (Appendix B and C). 13 of the articles were rated as medium quality and the remainder 21 as high quality.

Studies were conducted in Australia ($n=6$), Canada ($n=4$), Netherlands ($n=4$), Norway ($n=4$), Spain ($n=2$), Brazil ($n=2$), Sweden ($n=1$), Israel ($n=1$), South Africa ($n=1$), Denmark ($n=1$), Ireland ($n=1$), Norway and Sweden ($n=1$), USA ($n=1$) and United Kingdom ($n=1$). Four of the articles were part of a SPARCLE group which conducted their research in either 8 or 6 different European countries. Two of the SPARCLE studies conducted their research in Northern England, Northern Sweden, West Sweden, East Denmark, Northern Ireland, South East France, Central Italy, Southwest Ireland and Southwest France (11, 23). The other two SPARCLE studies extracted their data from the following countries: southeast France, Southwest France, west Sweden, southwest Ireland, Northern Ireland, Denmark and North England (14).

5.2 The participatory profiles of children and adolescents with cerebral palsy

Out of 34 selected articles, a total of 23 articles focused on children and adolescents with cerebral palsy and participation but without known mental health issues. A visual overview of results from can be observed in *Table 3* below.

Table 3. The participation profiles of children and adolescents without (known) mental health issues

Participation and activities subdomain categories	Number of articles	References
Community, social and civic life	N=15	1,2,6,7,8,9,10,12,17,18,28,31,32,33,34
Interpersonal interactions and relationships	N=4	2,29,31,33
Major life areas	N=4	27,29,32,33
Mobility	N=3	3,14,29
Domestic life	N=2	5,19
Communication	N=1	22
Self-care	N=1	19
General tasks and demands	N=0	
Learning and applying knowledge	N=0	

The primary findings related to the participatory profiles of children and adolescents with cerebral palsy are delineated on Table 3. The main subdomain categories present with the articles for this group were the following: community, social and civic life ($n=15$), interpersonal interactions and relationships ($n=5$), major life areas ($n=4$), mobility ($n=3$), domestic life ($n=2$), communication ($n=1$) and self-care ($n=1$).

5.2.1 Community, social and civic life

The majority of articles (1,2,6,7,8,9,10,12,17,18,28,31,32,33,34) based on children or adolescents with cerebral palsy and their participation, focused on the aspects related to community, civic and social life. Participation diversity and intensity in recreational or skill-based activities have been noted to decrease or be low among this group (2, 7, 10, 31, 32, 33, 35). One study found recreational activities (playing with toys or doing sports), while commonly reported among adolescents with cerebral palsy, were less diverse than peers without cerebral palsy (8). Other studies revealed that adolescents with cerebral palsy participated the most in informal social activities (6,8). More specifically, females had higher scores in diversity and intensity in social activities than males (6).

Another study by Imms and colleagues (32) found the intensity, frequency and diversity of social activities increases over time. Likewise, increased participation in social activities was also found to be associated with better social, communication and daily living skills (8). In comparison to typically functioning adolescents, adolescents with cerebral palsy had lower intensity scores within the domain of social

participation (1) Children and adolescents with cerebral palsy tended to stay at home rather than going out (6,33) Similar articles stated that children with CP participated more in sedentary behavior and did less physical activity than typically functioning children (17,18). A further study noted that more boys than girls with CP engaged in physical activities (18). Adolescent boys were also found to have lower intensity scores and less diversity of participation in skill-based activities (8).

In the physical activity aspect, an increase in age was also demonstrated to be associated with a decrease in physical activity in daily life (9,18,28,17). One study mentions that over half of their participants with CP participated in physical activities in their leisure time (9).

5.2.2 Interpersonal interactions and relationships

Four studies described the interpersonal interactions, relationships (2,29,31,33). The intensity of participation in social activities was reported to be related to the psychological well-being and quality of life (31). Children with cerebral palsy tended to participate with family close to home, rather than with friends in the broader community, except when they were participating in activities within the formal domain or skill-based activities (33). This parallels another study's finding in which parents reported that their children to have the highest participation in the relationship domain (29). In comparison, a further study revealed that adolescents with cerebral palsy actually emphasize the importance of organized sports in order to make friends (2).

5.2.3 Major life areas

Four studies included major life areas (27,29,32,33). Parents of children with cerebral palsy have reported the lowest level of participation in school (29). For children who transitioned to secondary school, their diversity and intensity in participation in recreational activities decreased (32)

In regard to physical activities, only six out of the 33 children in one study's sample participated in sports more than once a week. Four of the children were in segregated physical programs for children with disabilities and the remainder two were part of a community football club along with typically developing peers (27).

However, another study showed more children with cerebral palsy to participate in organized sports and cultural activities compared to typically developing peers (33). The same study found there to be no difference in the amount of television watching or reading. Children with cerebral palsy tended to participate more in arts and crafts and playing video games than their typically developing peers (33).

5.2.4 Mobility

Three articles found a significant relationship between children and adolescents with cerebral palsy and mobility (3,14,29). The children and adolescents with greater mobility impairments participate less in school contexts such as classroom, transportation or playground activities than typically functioning individuals (3). Likewise, parents of children with cerebral palsy have reported their children to have the lowest level of

participation in mobility (29). Improved mobility was associated with better physical environment such as in having a home with walking aids or having ramps at school (14).

5.2.5 Domestic life

Two articles included domestic life (1,19). Typically developing and adolescents with cerebral palsy had similar scores on performance and assistance in family-care tasks (19) In contrast to this finding, another study found that all adolescents with CP and especially adolescents with motor impairment helped less often with chores at home than adolescents in the general population (1)

Bimanual performance and unimanual capacity of the dominant upper limb are significantly associated with Activities related to Daily Living (ADL) motor skills (5).

5.2.6 Communication

One study reported results pertaining to communication among adolescents and children with cerebral palsy (1). Adolescents with cerebral palsy tended to communicate less often but also spend less time with their friends compared to their typically functioning peers (1).

5.2.7 Self-care

Findings of one study showed participation in tasks of adolescents with cerebral palsy to be less than their peers (19).

5.3 Factors influencing participation and activities for children and adolescents with cerebral palsy

Secondary findings related to the influences on participation were the following: structures related to movement ($n=16$), personal factors ($n=10$), support and relationships ($n=5$), attitudes ($n=4$), services, systems and policies ($n=4$), sensory functions and pain ($n=3$), natural environment and human-made changes to the environment ($n=3$) and mental functions ($n=2$). A visual illustrated can be observed in Table 4.

Table 4. Factors influencing participation and activities for children and adolescents with cerebral palsy

Factors influencing participation	Number of articles	References
Structures related to movement	N=16	1,2,3,5,7,8,9,10,12,14,18,27,28,29,33,34
Personal factors	N=10	2,6,7,8,10,12,31,32,33,34
Support and relationships	N=6	8,14,22,27,29,34
Services, Systems and policies	N=4	3,8,14,19
Attitudes	N=4	14,15,16,37

Sensory functions and pain	N=3	2,3,14
Natural environment and human-made changes to the environment	N=3	8,14,33
Mental functions	N=2	8,14

5.3.1 Structure related to movement

Sixteen out of the 23 articles found significant findings associated with body structures related to movement (1,2,3,5,7,8,9,10,12,14,18,27,28,29,33,34). The GMFCS was the tool used in all studies in order to measure the body function and impairments of children or adolescents with cerebral palsy. Adolescents with cerebral palsy and parents have described the physical impairments has a barrier to their participation (2, 27). In addition, children with unilateral cerebral palsy were found to be below recommended physical activities (18) The more severe the bodily impairment was according to the GMFCS levels, the less or the lower intensity of participation children or adolescents with cerebral palsy had (5, 7, 8,14, 9,34,3,28,29,33,1). Children and adolescents with GMFCS level III had significantly lower rates of participating in regular physical activity in leisure time than children and adolescents with level I (9). The same study found that higher gross motor functioning was a significant predictor of a greater diversity and intensity of recreational activities. (8) GMFCS level I had higher school participation scores than those with levels II and III. Children and adolescents with level I GFMCS also had the greatest variation in the types of activities (9) Adolescents with less severe motor impairments also tended to participate as their peers (1) Similarly, significant differences were revealed between Level III and Level I in their participation scores. That is, those within level III had lower participation scores. (3) Another article also found that there were differences between the GMFCS levels, but even the adolescents with little impairments were disadvantaged (1). Gross motor function was negatively related to preferences to perform skill-based activities (10). Children with more severe motor impairments were more likely to prefer skill-based activities (12). Notably, both GMFCS level and intellectual impairment significantly predicted differences in the diversity of participation in all domains and in the types of activities- except social activities (7)

5.3.2 Personal factors

There were ten different articles which mentioned personal factors such as preferences and enjoyment (2,6,7,8,10).

5.3.2.1 Preferences

The social activities are the most preferred activity for children and adolescents with cerebral palsy (32,10,12). Children with cerebral palsy demonstrated high preference for recreational activities such as board games and crafts (12,10). However, the preference for these recreational activities was reported decreases over time or during adolescence (10,32) One study noted that preferences for all activity types decreases over time with the exception of social activities (32). Another study found that personal factors did not impact the intensity or diversity of social activities (8).

Preferences for particularly activity types remained consistent from childhood to adolescence (10). However, those children who were are more likely to have a negative reaction to failure were less likely to prefer social activities (12) Most females preferred going to someone's house. Activities most preferred by both groups were hanging out with friends, talking on the phone (12). Two articles highlighted how older children or adolescents were not participating or provided the opportunities to participate in the activities they prefer (34,2). However, younger children demonstrated to engage more in activities which they prefer compared to older children (12). In one study, 58% of children with cerebral palsy were participating in self-improvement activities (reading, doing homework or writing letters) which they do not prefer (34).

5.3.2.2 Enjoyment

High levels of enjoyment among a broad range of activities including formal and informal activities were reported among children or adolescents with cerebral palsy (6,7,33). Badia and colleagues (31) notes how an increase in participation within recreational activities contributed a better psychological well-being. The level of enjoyment among youths with CP was also higher on self-improvement activities compared to typically functioning youths (6). The same study found that girls had higher levels of enjoyment than boys in informal social activities and self-improvement skills also typically developed group too (6). In contrast, another study measured lower enjoyment levels or a decline in enjoyment for self-improvement activities in comparison to other activities (7,10). In a study which measured the impact of transitioning to secondary school on children with cerebral palsy, enjoyment levels were reduced for the group of children who did not transition to a new school (32)

5.3.3 Support and relationships

There were five articles that related to support and relationships (8,14,22,27,29,34). In one study, which measured parent's perception of barriers and facilitators in their child's participation, the majority of parents were more likely to state that social environment such as not being accepted by peers or other parents as a barrier (27) Parenting stress was also demonstrated to impact the social participation in community groups (29). The relationship between a very low income and GMFCS level was significant. Children at a higher GMFCS level such as IV/V (more severe restrictions to movement) and in families with low income (<15,000) participated 17.2% fewer social activities than they prefer (34). Parenting organization (the method in which the parent modifies their child's environment) was associated with a larger social network. Indirect methods of parenting were more effective when predicting the social outcomes of typically developing children than children with cerebral palsy (22). Family independence (the extent to which each member of the family has the opportunity to experience a certain degree of independence) was positively associated with intensity of recreational activities, while family expressiveness (extent to which each member of the family has the opportunity to express their own opinions) was associated with participation in social activities. Family inclination toward different activities (both recreational and intellectual) was related to the intensity of engagement in active-physical activities and self-improvement activities (8) Social support at home was the strongest independent predictor of participation in responsibilities (14)

5.3.4 Attitudes

Three articles mentioned personal attitudes of others as a significant finding in relation to children with cerebral palsy (2,3,14). Parents have described that the attitudes from their children's school peers as one of the greatest barriers to participation of their children with CP (3). Similarly, attitudes of teachers and therapists were the strongest predictor of participation in school life (14). Adolescents with cerebral palsy have often felt excluded from participation and put into a role of a spectator because professionals and teachers often make assumptions of their needs and abilities (2). In addition, attitudes of classmates were the strongest predictor of participation in relationships. Both transport and attitudes of family and friends independently predicted participation in recreation (14).

5.3.5 Sensory functions and pain

Four articles included sensory functions and pain (14,15,16,37). One article found that children and adolescent in more pain participated much less in was in personal care, home life and health hygiene (14) In addition, children with recurrent musculoskeletal pain (RMP) were older and had greater motor impairment than children without RMP (16)

Walking, running and immobilization were all reported by children with RMP to be the most common pain intensifiers (16). For the children with RMP, their most common type of pain relievers was rest (37), massage or change in position (15).

5.3.6 Natural human-made changes to environment

Three articles mentioned natural environment as significant to their findings (8,14,33). Children tended to participate more with family that were physically closer to their homes instead of friends that were further away in their town (33) Physical environment at home (modified kitchen, adapted toilet or communication aids) as significantly related to higher participation in mealtimes, personal care and home life (14). However, one article found there to be no significant associated between total number of barriers in the physical environment and participation in leisure activities (8)

5.3.7 Mental functions

In reference to the ICF-CY subdomain mental functions, the articles focused on self-perception and motivation of children or adolescents with cerebral palsy (8,14). Aspects of self-perception that were associated with participation were job competence and athletic competence for active-physical activities and perception of a positive physical appearance was associated with more participation in skill-based activities (8). Different aspects of mastery motivation were associated with more involvement in all activities domains, except for skill-based activities. (14) Negative reaction to failure as reported by parents and by adolescents was also shown to be positively associated with intensity of participation in recreational activities as was a higher impact of difficult behavior in the adolescent. (8)

5.4 Participatory profiles of children and adolescents with cerebral palsy and mental health issues

Among the studies addressing the issue of mental health among children and adolescents with cerebral palsy, the most common subdomains were the following: interpersonal interactions and relationships ($n=6$), community, social and civic life, communication, mobility, general tasks and demands, major life areas, domestic life, self-care and learning and applying knowledge. These results can be observed in Table 5 below.

Table 5. The participation profiles of children and adolescents with cerebral palsy and mental health issues.

Participation and activities subdomain categories	Number of articles	References
Interpersonal interactions and relationships	N=6	13,20,21,23,24,30
Community, social and civic life	N=3	11,13,23,
Communication	N=2	21,26
Mobility	N=1	4
General tasks and demands	N=1	13
Major life areas	N=0	
Domestic life	N=0	
Self-care	N=0	
Learning and applying knowledge	N=0	

5.4.1 Interpersonal interactions and relationships

Five studies found significant findings in relation to interpersonal interactions and relationships (20,21,23,24,30). Children with RMP were reported to have higher level of peer problems and higher total difficulties scores than children without RMP (24). When combining the borderline and abnormal scores, the most frequent difficulties were peer problems (23,30). There were significant differences between females and males with cerebral palsy in regard to social difficulties. Males in this study tended to have more social difficulties than females (24). Another study found that girls had higher level of peer problems. (20). The level of social functioning was lower in children with more externalizing behavior problems and older children had decrease in social functioning (21). Mothers of children with cerebral palsy tended to rate their children with CP has having more peer problems than the children themselves (20)

5.4.2 Community, social and civic life

Five studies found significant findings in relation to interpersonal interactions and relationships (20,21,23,24,30). Children with RMP were reported to have higher level of peer problems and higher total difficulties scores than children without RMP (24). When combining the borderline and abnormal scores, the most frequent difficulties were peer problems (23,30). There were significant differences between females and males with cerebral palsy in regard to social difficulties. Males in this study tended to have more social difficulties than females (24). Another study found that girls had higher level of peer problems. (20). The level of social functioning was lower in children with more externalizing behavior problems and older children had decrease in social functioning (21). Mothers of children with cerebral palsy tended to rate their children with CP has having more peer problems than the children themselves (20)

5.4.3 Communication

Two studies included findings relevant to communication (21,26). One study found that increased risk for psychiatric disorder was only found for children with communication problems (26). Within another study, measuring communication problems among children with cerebral palsy, seventy-four percent of them had restrictions in communication (21) Differences in communication difficulties were found across all GMFCS levels. Communication were significantly lower in children categorized as GMFCS LEVEL III, IV, or V than in children categorized level I or II (21) The same study found that children with more externalizing problems had a lower levels of communication (21).

5.4.4 Mobility

One study had mobility within their findings (4). This study revealed that mobility had an influence on children and adolescents emotional and behavior problems. That is, those who had more difficulty with physical mobility impacted their Total Difficulties Score (TDS). The TDS is a scale that measures their total issues in relation to their emotional and behavior problems (4).

5.4.5 General tasks and demands

One article had findings related to general tasks and demands (13). Similar to the previous section, there was little information in this subdomain. The results in this article found that children with cerebral palsy, recurrent musculoskeletal pain (RMP) and mental health problems to be associated with a reduction in completing daily activities (13).

5.5 Factors influencing participation of children and adolescents with cerebral palsy and mental health issues

Mental functions ($n=9$), neuromusculoskeletal and movement-related functions ($n=7$), support and relationships ($n=5$), natural environment and human-made changes to environment ($n=1$), speech functions ($n=1$), and services, systems and policies ($n=1$) were among the factors found to influence participation among children or adolescents with cerebral palsy and mental health problems. The number of articles in each domain can be observed in Table 6.

Table 6 Factors influencing participation and activities for children with cerebral palsy and mental health problems.

Factors influencing participation	Articles	References
Mental functions	N=9	4,11,13,15,20,21,23,24,25,26,30
Neuromusculoskeletal/movement-related functions	N=7	13,15,21,24,25,26,30
Support and relationships	N=5	11,13,15,23,25
Sensory functions and pain	N=5	4,11,13,20,23
Natural environment and human-made changes to environment	N=1	23
Speech functions	N=1	24
Services, systems and policies	N=1	30

5.5.1 Mental functions

All of the studies within the group of children or adolescents with cerebral palsy and mental health issues were related to the subdomain mental functions (4,11,13,15,20,21,23,24,25,26,30). Compared to normative data, children or adolescents with cerebral palsy were significantly more likely to have mental health issues (24,30,25,11,21). Some studies stated there to be a high risk or actual presence of mental health problems at clinical level (23,26,25). The studies which provided the percentages of children or adolescents with mental health issues within their samples ranged from 13 percent to over 50 percent (11,30,23,15,20,26). Boys but not girls obtained a lower total difficulties score. However, both genders reported higher level of emotional problems, but the difference reached statistical significance only for boys (20). In regard to age, younger adolescents with cerebral palsy had higher scores on emotional symptoms, conduct problems, hyperactivity and total difficulties subscales than the older adolescents. Although behavioral difficulties somewhat diminished in the older age group, significant differences were still present when comparing scores in older adolescents (15 years and up) with cerebral palsy and those in the normative sample. This is particularly true for emotional symptoms, prosocial behaviors and peer problems (30). Girls demonstrated less externalizing problems than boys (25).

5.5.2 Neuromusculoskeletal and movement related functions

Seven studies found significant results on neuromusculoskeletal and movement related functions (13,15,21,24,25,26,30). Children and adolescents motor ability was significantly related to behavior problems. More specifically, children at GMFCS I and III showed significantly less problems than children at GMFCS V (25). Poorer gross motor function was also revealed to increase the risk of a higher of total

difficulties score (23). However, in another study Life-H total satisfaction scores revealed no significant difference between GMFCS levels (13)

One study using the child behavior checklist (CBCL) found that scores were the lowest among children with higher GMFCS levels (15). Higher scores would imply there to be possible psychopathology. Compared to typically developing children, the children with even the best motor ability scores still scored higher on the CBCL (15). The type of cerebral palsy, that is either bilateral or unilateral, was also not found to reveal any significant associations with CBCL scores in the GMFCS levels (15).

However, the type of cerebral palsy, that is either bilateral or unilateral, did not reveal any significant association with CBCL scores in the GMFCS levels (15). Compared to typically developing children, the children with even the best motor ability still scored higher on the CBCL (15). Children at GMFCS IV showed more externalizing behavior problems than children in GMFCS I (25). Unlike externalizing behavior problems, internalizing behavior problems were not associated with GMFCS (25). One study could not diagnosis children with cerebral palsy with any distinct psychological disorder because of the severity of their physical condition (GMFCS level V) and having an intellectual disability (26). In addition, they found that functional level measured by GMFCS and the type of CP, did not impact the risk for psychiatric disorders in children with cerebral palsy (26)

Better motor performance was related to more prosocial behavior. Adolescents with spastic quadriplegia had a significantly lower score on the prosocial subscale. Associations of lower magnitude were also found between lower motor impairment and more peer problems (30). Children on higher GMFCS levels had more limitations in social functioning than those on lower GMFCS levels (21). Moreover, children categorized as level IV or IV had significantly lower scores in social functioning than children categorized on lower levels (21). Another study revealed there to be no significant differences between GMFCS levels and social difficulties (24).

5.5.3 Support and relationships

In the subdomain of support and relationships, five studies were found (11,13,15,23,25). The more situational stress vs support parents experienced, the more behavior problems they reported for their children across the 3-year study period (25) Parenting stress during their child 's childhood was significantly related to adolescent participation in mobility, hygiene and relationships (11). Parenting stress during adolescence also impacted health hygiene and relationships (11). In addition, children and adolescents with parents that had more mental health problems experienced less satisfaction with the accomplishment of daily activities (13)

Children with cerebral palsy and internalizing problems was strongly associated with more situational stress than support for the parents. These particular factors were based on job satisfaction, health status and income. (25)

Children living with a single parent showed increased odds for a positive CBCL screening compared to children living with two parents. There was no significant association between positive psychopathology screening and parental education level (15) Children of parents with an academic education had significantly higher odds for psychological evaluation (15). Moreover, having at least one disabled or chronically ill sibling significantly increased the risk of having a high total difficulty score of the child and so did being an only child compared to those children with CP who had well, able bodied siblings (23).

5.5.4 Sensory functions and pain

Five studies had significant findings in relation to sensory functions and pain (4,11,13,20,23). In one of the articles, 59 percent of parents reported that their child with CP are currently experiencing pain (4). Another article mentioned that within their sample population of children with cerebral palsy, 67 have recurrent musculoskeletal pain (20) Pain intensity along with intellectual disability and mobility accounted for 23 percent variance in the Total difficulty score (4) Children with severe pain were significantly more likely to have a high total difficulty score than children without (23).

As for children without mental health problems, pain in childhood of children with cerebral palsy and mental health problems also predicted a significant restriction in adolescent participation in all domains except mealtimes (11). RMP and increasing level of child mental health problems were associated with reduction in accomplishment of both daily activities and social roles and with satisfaction with the accomplishment of social roles (13) Other functional disabilities such as hearing impairments in addition to cerebral palsy also increased the likelihood of obtaining a higher score within the Total Difficulties Score test (23).

5.5.5 Natural environment

One study mentioned natural environment in their study (23). Those living in a small town had a significantly more likely to have a higher Total Difficulties Score (TDS) compared to those living in a big city or suburbs (23)

5.5.6 Speech functions

One study found speech functions to be related to mental health and peer relationships (24). Non-verbal compared to verbal participations were found to have higher social difficulties. Higher percentage of parents of nonverbal participants with CP reported their children's friendships to be impaired by their emotional and behavioral difficulties (24).

5.5.7 Services, systems and policies

Only one article within this group mentioned the utilization of special services (30). The adolescents with cerebral palsy who displayed more hyperactive symptoms were more likely to participate in professional health care services such as psychological help or rehabilitation. Those with other behavioral difficulties, 23.7% have received psychological services, 28.8% have special education classes and 64.4% rehabilitation aid (30)

6 Discussion

The purpose of this research was to explore the participatory profiles of children and adolescents with cerebral palsy and with or without mental health issues. The participation profiles were outlined through the participation and activities subdomain categories of the ICF-CY.

There were a range of studies identified through the search strategy, 23 involving children or adolescents with cerebral palsy and 11 including children or adolescents with cerebral palsy and mental health issues. There were no studies found which compared those with cerebral palsy and with or without mental health issues. These papers predominately reported on participation in countries from western cultures.

As the results reveal, there was less information found on children with cerebral palsy and mental health issues and their participatory profiles than for children without these additional problems. In both groups of children with and without mental health issues, the two most common subdomains were community, social and civic life and other subdomain interpersonal interactions and relationships. The most common subdomain for children with cerebral palsy without known mental illness was the community, social and civic life. The most common findings for the other group of children with cerebral palsy and mental health issues was interpersonal interactions and relationships. However, both groups were similar in that their participation in leisure, recreational or community activities were lower or restricted in comparison to their typically developing peers. The other categories which were discussed among both groups were communication and mobility. Although not as much information was provided within these categories, it still revealed that reduced mobility and communication to have an aggravating influence on participation and even mental health. Interestingly enough, none of the studies from both groups had any findings which could be categorized within the participation and activities subdomain group: learning and applying knowledge.

Secondary findings revealed that the most common subdomain categories present among children and adolescents with cerebral palsy were structures related to movement, personal factors and support and relationships. The most common findings among the children and adolescents with cerebral palsy with additional mental health issues were related to the subdomain category of mental functions, movement related functions, support and relationships and sensory functions and pain.

6.1 Social participation and relationships

In relation to the subdomain community, social and civic life, studies revealing the specific intensity and diversity of participation in different informal and formal activities were only identified in studies with children with cerebral palsy and without mental health issues. The studies focusing on children with both cerebral palsy and mental health issues did not include specific measurement of intensity or diversity of participation in any specific community or recreational activities. This demonstrates a lack of research that

delves into the role of mental health into children and adolescents with cerebral palsy's activity intensity and diversity.

The subdomain community, social and civic life with studies on children or adolescents with cerebral palsy and mental health issues were limited to just three. These studies focused more on the restriction of their participation in their social lives in relation to community life or recreation. That is, compared to those without mental health issues, children and adolescents with cerebral palsy participated less in social activities. In contrast, those without known mental health issues and cerebral palsy participated more in informal social activities over time. However, they were still reported to undertake more sedentary behavior and do less physical activity compared to their typically functioning peers.

In addition, adolescents with cerebral palsy enjoy social activities the most and have also revealed that they would like to be more active in organized activities in order to make friends. The results have shown their high preference and enjoyment for social activities (6,7,33). This parallels findings which state that children with disabilities enjoy the same activities as those who do not have any disability (Heah, Case, McGuire & Law, 2007). However, they still tended to stay at home with family rather than outside with friends compared to their typically functioning peers (6,33).

With regard to children and adolescent with cerebral palsy and mental health issues, information on their social participation differed. Unlike the group with only cerebral palsy, there was a lack of information on their activity preferences but issues in social life were noted. Social problems among peers were the most reported difficulties among children and adolescents with mental health issues. In considering the broader literature, children with cerebral palsy with RMP have been reported to have higher levels of peer problems and higher total psychosocial difficulties scores on the Strengths and Difficulties questionnaire (SDQ) (20). Thus there is a potential aggravating factor in which pain may further compound opportunities to develop friendships and participate in social activities. Also under the domain of body functions, it is reported that those children and adolescents with higher GMFCS levels (more severe movement restrictions) have also more social problems (21). Whereas those with better motor skills and performance demonstrate more prosocial behavior.

This demonstrates that children and adolescents with cerebral palsy do not lack social skills, but other factors may be intervening to influence social participation. This has also been found in other literature that those with cerebral palsy tend to have more social difficulties (Bottcher, 2010). However, parents of children with cerebral palsy have stated that it is the attitude of their peers which is the biggest barrier to their child's social participation (3). Another external factor resides within the environmental domain which found that adolescents with cerebral palsy who are in special schools participate more in social activity as oppose to mainstream schools (8). This could indicate that those within special education schools are within an environment that is more adjusted and has developed a better understanding of cerebral palsy as opposed to those within mainstream schools. They may also have peers who have similar or the same diagnosis and

therefore their attitude towards disability is not marked by stereotypes and misconceptions. This reflects the dynamics of body functions and environmental factors which influence participation as illustrated in the ICF-CY.

Both groups of young people indicate there to be issues for participation in social activities within the broader community or with peer groups. Among the group with only cerebral palsy, they have the highest preference for social activities but do not participate as much as their peers. In contrast, the children and adolescents with cerebral palsy and mental health issues there is reported information in regard to their preferences, but findings reveal there to be difficulties in their peer relationships (23,30). In addition, among the group with only cerebral palsy there is an increase in participation in social activities but among those with mental health issues, such as externalizing disorders, their social functioning decreases (21). This indicates how those with additional mental health issues are not participating as much in social relations. However, it is important to note that the lack of participation among peers may not be a sign of mental health issue but may be a risk factor for developing it. For example, other literature on mental health have shown the link between reduced mental well-being and social isolation (Kawachi & Berkman, 2001).

According to the family of participation related constructs, preference and the intrinsic factors both influence present and future participation (Imms, C. et al. 2016). However, in many of the results pertaining to preference and actual participation, children or adolescents with cerebral palsy are not participating in their desired activity. In addition, intrinsic personal factors described in the construct as optimism, self-determination and self-esteem as influencers in participation were not explicitly found to be related to a child or adolescent's participation. It was found within the group with only cerebral palsy that they reported high enjoyment levels within social activities, just as much as their typically functioning peers. However, they still do not participate as much in social activities. This implies that their intrinsic features such as enjoyment does not impact as strongly their involvement when engaging in social activities but there are limitations in frequency.

This review reflects the discrepancies between those with mental health issues and those without in relation to their social participatory profiles. In addition, it reveals there to be no or less information on the exact intensity and diversity of activities among children and adolescents with both cerebral palsy and mental health issues.

6.2 The role of communication

The subdomain area within the participation and activity domain that was also common among both groups was communication.

Even though communication problems are a typical symptoms of cerebral palsy (Rosenbaum, Paneth, Leviton, Goldstein, Bax, Damiano & Jacobsson, 2007), this was not highlighted as much among the group with cerebral palsy and no known mental health issues. Within this group, it was noted that they

communicated less among friends compared to their typically functioning peers (1). However, explicit communication issues were not emphasized. Among the group of adolescents and children with both cerebral palsy and mental health issues, communication issues were revealed to be significantly related to their participation (26). Of importance is evidence to suggest that communication issues are also related and or contribute to mental health (21,26); individuals with cerebral palsy and communication problems were more likely to have mental health problems. This questions whether the other group without known mental health issues but who communicate less with their peers may have communication problems as well. Notably, those who were non-verbal compared to verbal participants had more social difficulties and more likely to have emotional issues that impair their peer relationships (24). In which case, this would place this group at a risk for mental health issues along with the other group.

This may be one of the reasons to why a decrease in mental health develops among children and adolescents with cerebral palsy. Communication is vital for social participation, which as described in the previous section, is an aspect of their lives which is not full-filled to the extent to which they prefer. It is known in the literature, that social isolation and stress can trigger a decline in one's mental health (Cacioppo & Hawkey, 2009). Therefore, their limitations in communication may further compound risks for poor mental health in this group.

Of course, in the studies with children with only cerebral palsy, it is not known if some may have been included who do have additional mental health issues -as these questions may not have been included in recruitment or reported in the findings.

6.3 Mobility and mental health

Both of the groups revealed mobility to have a significant impact on either their mental health or participation. Naturally, the children and adolescents who had more mobility impairments could not participate as much as their typically functioning peers. Similarly, participation in mobility is low among those with cerebral palsy, with the more severe GMFCS level the less they participated. This relates to their body functions, in which it is their GMFCS and environmental barriers which influences their participation. Even though the mental health of the group without known mental health issues were not assessed, there could be a relationship between the lack of mobility and mental health problems. Within the group of adolescents and children with cerebral palsy and mental health issues, mobility has shown to be related to their emotional and behavioral problem scores (4). This parallels findings in other literature stating that the worse the mobility was for the child (in terms of GMFCS levels) the lower the scores were on mental health (Liptak et al. 2001).

The lack of mobility among children and adolescents may account for increasing mental health issues since physical activity is highly correlated with improved mental health (Kim, Park, Allegrante, Marks, Ok, Ok cho & Ewing Garber, 2012).

This poses as an issue as it was uncovered within the secondary findings that children with unilateral cerebral palsy are not meeting the recommended amount of physical activity (18). Moreover, those deemed to be on the higher GMFCS levels were less likely to engage in physical activities in their leisure time (9). From the perspective of the family of participation related constructs, their capacity will be limited the more severe the motor impairment (reflected by higher GMFCS levels). This in turn makes them not as able perform such physical activities. In addition, those with cerebral palsy and with more severe impairments, may be less able to cope with stress or sadness by engaging in physical or recreational activities. As mentioned previously, their social participation was reported to be less than they would prefer which then also implies that their social coping resources are not accessible either. The lack of available coping mechanisms such as engagement in physical activity or social support, this may be one of the reasons to why those with cerebral palsy have a higher prevalence rate of mental health issues.

On the other hand, external resources such as assistive devices in conjunction with their current body functions may enhance their participation or performance within an activity. In this way, physical activity could be reached but requires external support in addition to the concerning individual's intrinsic features such as self-determination. However, this would be dependent on environment factors as well.

Environmental factors such as family life also impacts the extent to which children and adolescents engages in physical activities. Family independence, which is the degree to which each family member has the freedom to make choices, was positively associated with the intensity of recreational activities. In other words, the lack of mobility between both those with and without mental health issues poses as a risk for not only their participation but their general mental health.

6.4 Discussion of methodology and limitations

The purpose of this narrative scoping review was to gather all of the information from the literature pertaining to the topic of mental health, children and adolescents with cerebral palsy and participatory profiles. This scoping review followed the steps from Arksey and O'Mallery's methodological framework for scoping reviews. The steps were as follows: creating a research question or questions, finding relevant research information, article or study selection, mapping out the data and finally summarizing and analyzing the results. This method of conducting a scoping review allows there to be a clear procedure and for future researchers to repeat the study or elaborate on the findings. In addition, the clear search terms descriptions, inclusion and exclusion criteria and quality assessment provided for others to readily observe enhances the transparency and supports the ethical standards.

6.4.1 Scoping review weaknesses

Although there are some strengths within scoping reviews, there are also weaknesses. Scoping reviews are a relatively new methodology and studies have found that numerous scoping reviews lack a uniform definition and purpose (Allen, Peckham & Goodwin, 2008). Therefore, one's interpretation of a scoping

review may differ between individuals and that could potentially lead to a different analysis despite initially having a similar research question. Another weakness within this scoping review is that there was only one author reviewing the articles, mapping the results and conducting the analysis. This increases the risk for potential bias such as the author's preunderstanding of mental health, participation and subjective interpretation of ICF-CY framework and the family of participation construct theory.

In addition, the author was the sole assessor for quality assessment of included articles. It also poses as a risk since unknown errors could have been overlooked. Ideally, there should be multiple peer reviewers to review and analyze the quality of articles in order to increase the reliability.

6.4.2 Framework limitations

One of the primary limitations of this research is the categorization of the results by using the ICF-CY framework. Even though it provides a clear and structured approach of collecting data from the selected studies, it forces factors to be placed within specific categories of the ICF-CY. The factors or the domains within the ICF-CY are all mutually influencing each other and are not to be perceived as independent from another as what it may appear within the results section. In addition, the categorization led to some factors that were highly related to another domain such as communication and social interaction with lack of separation. In addition, body functions in relation to the GFMCS were often related to the mobility and mental functions domain.

Another limitation is that the ICF-CY has separate domains for mental condition and mental function domain which resides in the body functions. The one domain is health condition which can consist of the mental or physical health disorder. This is then said to influence the other domains such as participation, body functions or environment. The body function domain includes a mental function subdomain category which includes psychosocial functions, temperament, behavioral style and cognitive functions (World Health Organization, 2007). However, on the ICF-CY framework, mental disorders are not within this subdomain category but within the health condition domain. This review on the other hand, placed mental health issues within the mental functions subdomain since a number of the participants in the studies were not formally diagnosed with a mental disorder but had higher scores on emotional or behavioral issues.

6.4.3 Selected articles and subject groups

In regard to the selected articles, four of the articles were part of a SPARCLE group in which their data collections were taken from the same or similar population. This could suggest that some participants were the same as in their previous studies. This may impact on the weight of evidence regarding participation profiles, frequency and enjoyment, in which study participants may have been reported in more than one study. There also may have been errors in capturing an accurate participation profile between groups, considering that most of the articles which only focused on the participation aspects of those with cerebral palsy, did not assess the mental health status of their participants. Therefore, they were not placed within

the other comparison group that consisted of children and adolescents with cerebral palsy and mental health issues. Thus the results of the group of adolescents or children with cerebral palsy but without known mental health issues, may not actually be a genuine reflection of their participation profiles without mental health problems.

The studies may not have included information on their mental health status because current theoretical frameworks may not emphasize the role of mental health issues or mental illness on participation.

6.5 Future research

Even though results indicated that children and adolescents with cerebral palsy tend to stay at home more (6,33) and not be as socially active within the broader community compared to their typically functioning friends, it may be not an accurate portrayal of their participation in social or leisure activities. For example, it was revealed that they participate more in video games (8). This may not mean that they were engaging solely in solitary activities, but interacting with others virtually (online). Virtual social interaction is not an aspect captured on social functioning or the CAPE measurement which was used in several of the articles measures. This is a crucial aspect to take into consideration since computer or video games and online media interaction are among the most common activities in which children and adolescents participate in (Paulus, Ohmann, Von Gontard & Popow, 2018). In addition, one study found that typically functioning adolescents favorite feature of online gaming was the social aspect (Griffiths, Davies & Chappell, 2003).

Therefore, online interaction should perhaps be considered as a form of social interaction. This form of interaction may not be the same as personal face-face interaction but may be one way in which social interaction can reached those who currently do not have easy accessibility to the broader community such as those with disabilities.

The results from the search also revealed that the selected studies did not include the learning and applying knowledge aspect of participation. More information within this area would allow one to evaluate how those with cerebral palsy participate in learning in their everyday lives and to what extent are they learning as much as their typically functioning peers. One way of analyzing the applying knowledge and learning domains could be through the framework of the family of participation-related constructs since it highlights the capacity for performance and participation.

Another area which needs to be more addressed is the assessment of mental health on participation. As mentioned in the previous section and as revealed within the results, the specific personal factors such as enjoyment levels or preferences were not assessed among those with mental health issues and cerebral palsy. Moreover, those with mental health issues were not assessed on the intensity or diversity of activities, making this comparison with the no known mental health issues not entirely possible.

The other potential area for future research should explore interventions which would allow those with cerebral palsy and who cannot participate or cope through physical activity, to be able to do so. In addition, it would be valuable to analyze current interventions and determine if those interventions need to be modified for those with cerebral palsy and mental health issues.

7 Conclusion

The purpose of this narrative scoping review was to compare the participatory profiles of children and adolescents with cerebral palsy with or without mental health issues. There were no studies found comparing the two groups in relation to their participation profiles, but studies were found on each group. There were more studies revealing the participation profiles among children or adolescents with cerebral palsy than those defining children with additional mental health issues.

However, there were some studies that revealed children and adolescents with cerebral palsy and mental health issues to have different participation profiles in relation to the subdomain categories of the ICF-CY compared to those without known mental health issues. It appears that within the domain of interpersonal relations and interactions that social participation with peers decreases over time and more peer problems were noted among those with cerebral palsy and additional mental health issues. In addition, mobility and communication were among the common aspects that were discussed in both comparison groups. The extent of mobility was demonstrated to be dependent on GFMCS levels among both groups, and to be related to mental health issues. Communication was also revealed to differ in findings between the groups. Although adolescents and children with cerebral palsy communicated less among peers, it was found that those with additional mental health issues have more communication problems.

The findings of this scoping review reflects the dynamics and relationship between participation and mental health among those with cerebral palsy. However, that is not to suggest that this phenomenon is exclusive to those with cerebral palsy, but they may have more factors that hinder their participation which may further exacerbate risks to mental health and vice versa. Therefore, it is imperative to be aware of the mutually influencing interaction between participation and mental health. However, not enough research has been done to evaluate whether it is the lack of participation that triggers a change in mental health or it is mental health issues that causes limitations in participation.

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9 Appendices

9.1 Appendix A

The quality assessment tool (Table 2) is observed below.

The method of scoring was as follows:

TOTAL SCORE : __/14 TOTAL percentage : __%

Responses were rated as Yes Present, No, Not present (Unclear items were not included in percentage of quality).

Note: 50% or below = Low Quality 55-75% =Moderate Quality 80%-100% = High quality

Protocol 1. Table 2. Quality Assessment Modified CASP (Critical Appraisal Checklist for Cross-Sectional Study)

Appraisal Questions	Yes	Unclear	No
1. Did the study address a clearly focused question/issue?			
2. Was relevant literary background information reviewed?			
3. Is the research method (study design) appropriate for answering the research question?			
4. Is the method of the selection of subjects clearly described?			
5. Was the sample of subjects representative with regard to the population to which the findings referred?			
6. Was the sample size justified?			
7. Was a satisfactory response rate achieved?			
8. Was the statistical significance assessed?			
9. Could the confounding factors be accounted for?			
10. Were the ethics of the study described?			
11. Were the limitations described?			
12. Are the measurements (Questionnaires) likely to be valid and reliable?			
13. Could the way the sample was obtained introduce selection bias?			
14. Were the findings valuable for future research?			

9.2 Appendix B

Extraction protocol. Overview of selected studies on children and adolescents with cerebral palsy and their participation profiles.

ID	Article & Authors	Country	Aim	Methods	Main findings	Quality Rating
2	Developing programmes to promote participation in Sport among adolescents with disabilities: perceptions expressed by a group of south African adolescents with cerebral palsy Bantjes, J., Swartz, L., Conchar, L., Derman, W.,	South Africa	To gain insight into the perspectives of adolescents with CP and how to improve sports programmes	Semi-structured interviews	Adolescents with CP in SA would like to have more opportunities to be involved in physical activities	Medium
3	Moderating effect of the environment in the relationship between mobility and school participation in children and adolescents with cerebral palsy	Brazil	To analyze the moderating impact of the environment and the relationship between mobility and school participation of children and youths with CP	Gross Motor Classification System, School function assessment and the Craig Hospital inventory of Environmental factors	Mobility was a strong predictor of participation while environmental factors had a weak predicative effect.	Medium

	Furtado, S., Sampaio, R., Renata, K., Vaz, D., Mancini,.					
5	Relationships between activities of daily living, upper limb function, and visual perception in children and adolescents with unilateral cerebral palsy James, S., Ziviani, J., Ware, R., Boyd, R.,	Australia	To investigate the relationships between pain intensity, pain anxiety and behavioral and emotional problems in children with CP	Gross motor function classification system, the wong-baker faces pain rating scale, 30-item non-communicating children's pain checklist-revised, Fear of pain questionnaire-parent reported, Strength and difficulties Q, Total difficulties Score, 47-item revised child anxiety and depression scale – parent report	59 percent of parents reported that their child is currently experiencing pain. Pain intensity and mobility account for 23% variance in the Total Difficulties Score.	Medium
6	Differences in Patterns of participation between youths with cerebral palsy and typically developing peers Engel-Yeger, B., Jarus, T., Anaby, D., Law, M.,	Israel	To examine the participation in activity of children with cerebral palsy in comparison to those children who are typically developing	Participants (22 diagnosed with CP and 30 TDP) completed the CAPE (Children's Assessment of Participation and Enjoyment)	Typically developing peers participated in a wider range of activities compared to those with CP. Similar levels of enjoyment were found in both groups. Youths with CP participated more in activities alone or at home.	Medium
7	Patterns and predictors of participation in leisure activities outside of school	Spain	To investigate the patterns of participation in leisure activities outside of school in Spain among children and adolescents with CP.	A cross-sectional design. CAPE and GMFCS. Children and adolescents with CP participated.	Children and adolescents with CP have low intensity and diversity in regard to participation but have high levels of enjoyment.	High

	in children and adolescents with cerebral palsy Longo, E., Badia, M., Orgaz, Begoña, O.,					
8	Determinants of participation in leisure activities among adolescents with cerebral palsy Shikako-Thomas et al.	Canada	To estimate the influence of characteristics from adolescents with CP and environmental factors as determinants of participation in leisure activities.	Cross-sectional design. GMFM-66 was the criterion used. Questionnaires: Self-perception profile for adolescents, Dimensions of Mastery Questionnaire, Strengths and difficulties questionnaire, The family environment scale, European child environment questionnaire, Preferences for activities of children.	Participation in leisure activities appears to be associated with adolescent characteristics and attitudes, family environment, socioeconomic status and other contextual factors such as type of school.	High
9	Physical activity in a total population of children and adolescents with cerebral palsy Lauruschkus, K., Westborn, L., Hallström, I., Wagner, P., Nordmark, E.,	Sweden	To describe children with cerebral palsy participation in physical activities.	Observational study with cross-sectional design. Gross motor function classification system expanded and revised. Manual ability classification, Anthropometry.	87 percent of the total group were actively participating in PE. Differences in GMFCS-ER levels with the lowest frequency of participation in level V. Younger children participated more than older children.	High
10	Stability of leisure participation from school-	Canada	To describe any changes in participation in regard to leisure	Cross-sectional.	Intensity and density of engagement in most leisure activity types declines significantly from	Medium

	age to adolescence in individuals with cerebral palsy Majnemer, A., Shikako-Thomas, K., Schmitz, N., Shevell, M., Lach, L.,		activities and preferences of children and adolescents with CP.	38 children (24 males) participated in the CAPE and preferences for activities of children. Gross motor function measure-66.	school age to adolescence and enjoyment of leisure activities also decreases with increasing age. Adolescents with CP also have a constant desire to do a wider range of activities but their actual engagement decreases	
12	Leisure activity preferences for 6- to 12-year old children with cerebral palsy Majnemer et al.	Canada	To describe the leisure activity preferences of children with cerebral palsy and their relationship to participation	55 school aged children (36 males 19 females) with CP. GMFCS. Complete the Preferences for activities of children	Social and recreational activities are the most preferred and self-improvement activities are least preferred. Younger age, motivation and higher IQ's were related to interest in active-physical activities. Negative reaction to failure predicated less preference for social activities	Medium
14	Association between participation in life situations of children with cerebral palsy and their physical social, and attitudinal environment: A cross-sectional study multicenter European study Colver, et al.	6 European countries	To analyze how children with cerebral and their participation varied with their environment	Home visits to children, Assessment of life habits and European Child Environment Questionnaires.	Increased participation was related to better availability of environmental items. In regard to daily activities in home life, increased Participation was related to better physical Environment. Participation in social roles was related to attitudes of classmates and social support at home.	High

16	<p>Characteristics of recurrent musculoskeletal pain in children with cerebral palsy aged 8 to 18 years</p> <p>Ramstad, K., Jahnsen, R., Skjeldal O., Diseth, T.,</p>	Norway	To examine the prevalence, severity, impact and predictors of recurrent musculoskeletal pain in children and adolescents with cerebral palsy	<p>Cross-sectional study.</p> <p>Two groups: one hospital based and one population based.</p> <p>153 (81 males and 72 females)</p> <p>Assessed by clinical examination, interview and questionnaires.</p> <p>GMFCS levels too.</p> <p>Assessment of pain through stepwise.</p> <p>Face Pain scale –revised</p> <p>Child Health Questionnaire.</p>	62% of the population with CP experienced recurrent musculoskeletal pain, and age was the significant predictor. Most of them reported the severity of pain to be moderate. Pain severity was not influenced by gross motor function. Parents reported that the pain to be more severe and with higher impact on sleep than children did.	High
17	<p>Comparison of patterns of physical activity and sedentary behavior between children with cerebral palsy and children with typical development.</p> <p>Ryan, J., Forde, C., Hussey, J., Gormley, H.,</p>	Ireland	To describe the vigorous, moderate and light physical activity and sedentary behavior in preadolescent children with and without cerebral palsy.	<p>Cross-sectional with 2 groups. 33 children with CP. 33 aged matched peers who are typically developing.</p> <p>Physical activity was measured using the RT3 accelerometer over 7 days.</p>	Children with cerebral palsy in comparison to children without CP, spent more time in sedentary behavior and accumulated less total activity, moderate activity, vigorous activity and sustained bouts of moderate to vigorous activity.	High
18	<p>Habitual physical activity of independently ambulant children and adolescents</p>	Australia	To evaluate the physical activity and asses the proportion of children with CP who are	<p>Cross-sectional,</p> <p>1 group.</p>	The majority of ambulant children and adolescents with unilateral CP do not meet physical activity recommendations.	High

	with cerebral palsy: are they doing enough? Mitchell, L., Ziviani, J., Boyd, R.,		adhering to the recommended 60 minutes to moderate-to-vigorous physical activity(daily in independently ambulant children and adolescents with CP	GMFCS levels and physical activity measurement.		
19	Household task participation of children and adolescents with cerebral palsy, down syndrome, and typical development do Amaral, F., M., de França Drummond, A., Coster, W., Mancini, M.,	Brazil	The aim was to compare the participation patterns of adolescents and children with cerebral palsy, DS and TD in household tasks related to routines of self-care and family care	Cross-sectional study. Three groups: typically developing, cerebral palsy and down syndrome. GMFCS. MACS. CHORES questionnaire. (administered twice to the same group within a period of seven to 14 days) Kaufman brief intelligence test. Interview with parents.	There were differences and similarities in patterns of performance, assistance, and independence n household tasks by adolescents and children with cerebral palsy (CP), Down Syndrome (DS) and typically developing peers. Differences among DS and CP did not differ on performance of household tasks or on assistance provided by their caregivers.	High
22	Parenting and social functioning of children with and without cerebral palsy	USA	To investigate the relationship between parenting aspects and the social functioning of children with and without cerebral palsy	41 children with CP and 60 Typically developing ages 6-12. Questionnaire: Parenting dimensions inventory, social network inventory for children, Friendship quality	There are group differences in the associations between a child's cognitive ability, parenting dimensions and child social functioning in families of children with and without CP. Statistically significant differences between the groups were found for parental organization.	Medium

	Cunningham, S., Warschausky, S., Dixon Thomas, P.,			questionnaire, personality inventory for children-second edition.	Higher scores were found within the group with cerebral palsy. In CP group, vocabulary was significantly correlated with social adjustment.	
27	Stages of change in physical activity behavior in children and adolescents with cerebral palsy Verschuren, O., Wiart, L., Ketelaar, M.,	.Netherlands	To pinpoint the facilitators and barriers which are commonly experienced by families of children with Cerebral palsy	Interviews with 33 ambulatory adolescents and children with CP and their parents. Followed up by questionnaires: Activity-Related parenting questionnaire	Seven major themes that outlined the barriers and facilitators were identified from the transcript: body, functions, child-related personal factors, parental factors, opportunities for sport and physical activity; practical feasibility; social environment; and facility/program factors.	Medium
28	Ambulatory activity of children with cerebral palsy:which characteristics are important? Van Wely, L., Becher, J., Balemans, A., Dallmeijer, A.,	Netherlands	To evaluate the ambulatory activity of children with cerebral palsy ,aged 7 to 13 years and to pinpoint related characteristics	Cross-sectional study. 62 with spastic cerebral palsy (39 males, 23 females) GMFCS. Activity measured through StepWatch activity per day.	Parents reported that their children had the greatest participation in relationship domain which was higher than the other domains such as mobility, personal care and school domains. Decrease participation with an increase of severity of impairment. Gross motor function related to five of the six domains with the exception of communication. Parenting stress impacted the child's participation in relation to community activity where children with parents who are more stressed had statistically	Medium

					significantly lower levels of participation in community groups.	
29	To what extent do children with cerebral palsy participate in everyday life situations? Parkes, J., McCullough, N., Madden, A.,	United Kingdom	To describe children with cerebral palsy participation in everyday life situation and to explore the relationship between participation of child and parent characteristics.	Cross sectional study. Surveys conducted in families' homes. Life habits questionnaire, the frequency of participation questionnaire. SPARCLE	Parents reported that their children had the greatest participation in relationship domain which was higher than the other domains such as mobility, personal care and school domains. Decrease participation with an increase of severity of impairment.	Medium
31	The influence of participation in leisure activities on quality of life in Spanish children and adolescents with cerebral palsy Badia, M., Longo, E., Orgaz, M., Gómez-Vela, M.,	Spain	To verify that there is a relationship between the participation in leisure activities and the quality of life in children and adolescents with cerebral palsy	Total of 206 children and adolescents with Cerebral palsy. 115 boys, 91 girls. GMFCS. Questionnaires: Children's Assessment of participation and Enjoyment and QOL using the KIDSCREEN parent's version.	Children and adolescents with CP engaged in an average of 20.6 activities and mainly in informal activities. Diversity was lowest in activities in active-physical, self-improvement, skill-based and formal activities. High levels of enjoyment for all types of activity were reported. Children and Adolescents with CP showed low QOL for most domains	High
32	Participation trajectories: impact of school transitions on children and	Australia	To explain the course of participation and the impact of school transition on children with cerebral palsy.	Longitudinal study that evaluates the activities outside of school of children with CP.	Higher proportion of children classified in GMFCS II. Participation diversity and intensity decreased over time for recreational, active-physical,	High

	adolescents with cerebral palsy Imms, C., Adair, B.,			The children assessment of participation and enjoyment, and the preferences of activities of children.	intensity, and self-improvement. Preferences for each activity type also decreased over time.	
33	Diversity of participation in children with cerebral palsy Imms, C., Reilly, S., Carlin, J., Dodd, K.,	Australia	The purpose was to explore children with cerebral palsy participation in activities outside of school and to compare it to a normative sample	114 children (65 males, 49 females) Population based survey: CAPE questionnaire. GMFCS.	Participation levels were lower in formal than informal activities, with diversity being lowest in active-physical and skill-based activities. Intensity of participation was low. Children tended to participate with family close to home rather than friends in community. High levels of enjoyment for all activities.	High
34	Leisure participation-preference congruence of children with cerebral palsy: a Children's Assessment of Participation and Enjoyment international network description study Imms, C. et al.	Australia	To evaluate the relation of participation and preferences, regional differences in participation, and determinants on whether children with CP actually engage in their preferred activities.	236 (148 males and 88 females) GMFCS. Questionnaire: CAPE, PAC.	Around 50% of children with CP said they are not doing active physical, skill-based and social activities they prefer doing. 25% reported that they are not doing the self-improvement activities in which they prefer. 58% were doing self-improvement activities they do not prefer. Children at GMFCS levels IV-V had poorer participation preference congruence than children at GMFCS level I	High

9.3 Appendix C

Extraction protocol. Overview of selected studies on children and adolescents with cerebral palsy and additional mental health issues

ID	Article & Authors	Country	Aim	Methods	Main findings	Quality
4	Pain, pain anxiety and emotional and behavioural problems in children with cerebral palsy Yamaguchi, R., Nichol森, P., Hines, M.,	Australia	To investigate the relationships between pain intensity, pain anxiety and behavioral and emotional problems in children with CP	Gross motor function classification system (GMFCS), the Wong-Baker faces pain rating scale, 30-item non-communicating children's pain checklist-revised, Fear of pain questionnaire-parent reported, Strength and difficulties Q, Total difficulties Score, 47-item revised child anxiety and depression scale – parent report	59 percent of parents reported that their child is currently experiencing pain. Pain intensity and mobility account for 23% variance in the TDS	Medium
11	Predictors of participation of adolescents with cerebral palsy: A European multi-center longitudinal study Dang et al.	8 European countries	The aim was to examine how adolescents with cerebral palsy and their participation is related to childhood factors such as pain, psychological	SPARCLE group. Random sampling from 8 European regions. Longitudinal study, through interview and questionnaires. Life Habits Q. Total difficulties Score from parent-reported strengths and difficulties questionnaire. Total stress score of	Participation in childhood was the main predictor of adolescent participation. Three factors in childhood (pain, psychological problems and parenting stress) predicted limited participation in adolescence with the exception of meal times	High

			problems and parenting stress	parenting stress index form. (GMFCS)		
13	Parent-reported participation in children with cerebral palsy: the contribution of recurrent musculoskeletal pain and child mental health problems Ramstad, K., Jahnsen, R., Skjelda, O., Diseth, T.,	Norway	To examine the contribution of recurrent musculoskeletal pain and mental health to aspects of participation in children with CP.	Cross-sectional design, one population based and one hospital based. Clinical examination, interview, parental questionnaire. GMFCS. Assessment of life habits, Strengths and difficulties Questionnaire, General health Questionnaire	Recurrent musculoskeletal pain was related to reduced accomplishment of daily activities., social roles. Increasing levels of child mental health problems was associated with reduced accomplishment of daily activities, social roles and with reduced parental satisfaction with the accomplishment of social roles	Medium
15	Screening of psychopathology in a national cohort of 8- to 15-year-old	Denmark	To examine the prevalence of psychopathology in Danish children with	Cross-sectional study. Questionnaire, about child's treatment and family characteristics and 446 the CBCL.	Psychopathology was present among 46.% of children with cerebral palsy compared to 15.1% in general population. Cognitive disability was associated with increased rate of psychopathology.	High

	children with cerebral palsy Rackauskaite, G., Bilenberg, N., Bech, B., Uldall, P., Østergaard, J.,		CP and analyze this association with the cognitive ability and families social characteristics		Children with CP and with only a single parent showed increased odds for a positive odds for a positive CBCL screening compared to children living with two parents.	
20	Self-reported mental health in youth with cerebral palsy and association to recurrent musculoskeletal pain Ramstad, K., Loge, J., Jahnsen, R., Diseth, T.,	Norway, Sweden	To investigate the conduct, emotional, hyperactivity and peer problems and prosocial behavior in youth with cerebral palsy and compared it to normative data and mothers reports.	Cross-sectional. Participants from defined geographic area and one tertiary hospital. Structured interview on pain, clinical assessment and a questionnaire on mental health filled out by the youth and mothers.	Those with CP had similar levels of peer problems, less conduct problems and less hyperactivity problems and more prosocial behavior. Boys had lower Total Difficulties Scores than girls. Girls had more prosocial behavior. Boys reported less hyperactivity problems. Children with RMP had higher level of peer problems and total difficulties score than those who don't have RMP. Girls had higher level of peer problems with RMP than boys.	High
21	Social functioning and communication in children with cerebral palsy: association with disease characteristics and personal and	Netherlands	The aim is to describe the trajectory of social functioning and communication in children with CP.	Longitudinal study 110 children with CP (70 males 40 females) GMFCS Vineland Adaptive behavior scales measured social functioning and communication.	The percentage of children with behavior problems was higher in the CP group. Children with more externalizing problems had a lower level of communication. Levels of communication were lower in children whose parents experienced higher levels of relational stress.	High

	environmental factors. Voorman, J., Dallmeijer, A., Van Eck, M., Schuengel, C.,			CBCL questionnaire about externalizing and internalizing problems.	Increasing behavior problems or increasing parent stress over the years might be associated with a decrease in the level of social functioning or communication. Increase in externalizing problems was significantly related to a decrease in social functioning	
23	Psychological problems in children with cerebral palsy: a cross-sectional European study Parkes et al.	8 European countries	To explain the psychological symptoms among 8-12 year-old children with CP and explore the predictors of these symptoms and the impact of it on the child and family.	Cross-sectional study. 818 children with CP using the strengths and difficulties questionnaire and the Total difficulties score.	A quarter of children had TDS implying that there is significant emotional and behavioral symptoms. The most common problems were in the domain of peer problems then hyperactivity, emotion. Problems with conduct were less common and about half the rate of peer problems. Children with pain and who had no siblings or had disabled siblings or attending special education schools or living in small town also had higher TDS.	High
25	Course of behavior problems of children with cerebral palsy: the role of parental stress and support Sipal et al.	Netherlands	To test if parental stress and support, beside the severity of CP of the child, play a major role in the course of behavior problems	Participants aged, 9,11 and 13 were assessed and analyzed after 1,2 and 3 years. Situational and relationship sources of support and stress of primary caregiver were rated with a questionnaire, CBCL, behavior problems with the child behavior	Behavior problems of children with CP started significantly higher than in the general population, but diminished over the 3 year- old. Older children showed less problems overall and girls have less externalizing problems than boys.	High

				checklist. Physicians rated motor ability using the GMFCS.		
26	<p>Psychiatric disorders among children with cerebral palsy at school starting age</p> <p>Bjorgass, H., Hysing, M, Elgen, I.,</p>	Norway	<p>To estimate the rate of psychiatric illnesses in children with cerebral palsy and effect of comorbid conditions.</p>	<p>Cohort of children with cerebral palsy. Three western counties of Norway.</p> <p>ICD-criteria classification.</p> <p>GMFCS and MACS.</p> <p>Mental health assessed through Kiddie-SADS interview.</p>	<p>56 children with GMFCS level I-IV, 32 met the criteria for a child psychiatric disorder according to Kiddie-SADS. Behavioral disorders were most frequent and found in 29/32 children including 28 fulfilling criteria for ADHD/ADD. Mental health symptoms defined as meeting 75% of criteria for a distinct child psychiatric disorders were found in more than half the children.</p> <p>Increased risk for psychiatric disorder who was only found for children with communication problems.</p>	High
30	<p>Behavioral difficulties in Adolescents with cerebral palsy</p> <p>Brossard-Racine et al.</p>	Canada	<p>To describe the frequency and nature of behavioral difficulties in adolescents with cerebral palsy and to explore the related factors</p>	<p>Parents of the children completed the strengths and difficulties questionnaire. Gross motor function measure also used</p>	<p>Presence of problematic behaviors as measured by the total difficulties score was observed in 36.9% of the sample and included 18.9% of the adolescents who scored in the clinically deviant range and 18.1 in the borderline range. Among that group,</p> <p>The most common issues were peer problems, emotional symptoms, conduct problems, hyperactivity and lack of prosocial behavior.</p> <p>Higher prosocial behavior score was consistently related to a better motor performance. Lower motor impairment related to more peer problems.</p>	High

24	Mental health, health related quality of life and recurrent musculoskeletal pain in children with cerebral palsy 8-18 years old Ramstad, K., Jahnsen, R., Skjeldal, O.,	Norway	To elaborate on the current knowledge on mental health among children with CP.	Cross-sectional design with two groups – One population-based and one hospital based. There is a clinical evaluation, structured interview, and standardized questionnaire to children and parents. 83 children both self-report and maternal proxy-report was obtained.	Compared to typically developing youth, children reported a corresponding level of mental health problems in contrast to mothers that proxy-reported more mental health problems. Self-reported scores on SDQ peer problem scale was significantly higher among children with RMP. Self-reported RMP and female gender associated with mental problems. increased motor impairment was associated with reduced HRQL. Mothers proxy-reported that more own mental problems were associated with both more child mental problems and reduced HRQL	Medium
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