



OPEN
Collaboration for
Cognitive Accessibility

**Virginie Cobigo, Danika Lévesque,
Yves Lachapelle and Muriel Mignerat**

January 28, 2024

Towards a Functional Definition of Cognitive Disability

White Paper

Open Collaboration for Cognitive Accessibility

Open brings persons with a range of cognitive abilities together with researchers and accessibility specialists, combining their knowledge and experience to test, improve and assure cognitive accessibility.

Table of contents

Authors	2
Summary	3
Introduction	4
Method	7
Findings	8
Discussion	15
Conclusion	18
References	18
Appendix A	22

Authors



Virginie Cobigo

Virginie is the founder and Executive Director of Open. She is committed to promoting the social inclusion of people with cognitive disabilities and enhancing the cognitive accessibility of our environment. As a professor at the University of Ottawa, she leads research that supports evidence-based practice in sectors that support people with cognitive disabilities.



Danika Lévesque

Danika is a PhD student in Clinical Psychology at the University of Ottawa. Her doctoral thesis focuses on the offer of clinical services in French for adults with neurodevelopmental disorders (ID/ASD) who present challenging behaviours. Her research interests also include program evaluation, cognitive accessibility and inclusive research.



Yves Lachapelle

Yves Lachapelle, PhD, FAAIDD, is a full professor in the Département de psychoéducation at the Université du Québec à Trois-Rivières. He holds a bachelor's degree in psychology, a master's degree in education and a PhD in educational psychology. He specializes in research on the integration and social inclusion of people with intellectual disabilities, and is particularly interested in the areas of self-determination and social participation of these individuals, notably through the use of technologies to support self-determination.



Muriel Mignerat

Muriel Mignerat is an Associate Professor at the Telfer School of Management, University of Ottawa. Her current research focuses on the use of information technology by adults with cognitive disabilities, including ADHD. She serves on the Board of Directors at Open, at the Lotus Centre for special music education and has served on the board at SFOA (Société Franco Ontarienne de l'Autisme).

Summary

Introduction

The absence of a clear definition of cognitive disability can have an impact on prevalence rates and developing policies and programs. This study aims to analyze and discuss definitions used in the scientific literature to describe individuals who may experience cognitive disability.

Method

We conducted two scoping reviews of peer-reviewed studies. In each, we analyzed definitions of cognitive disabilities, limitations and impairments.

Findings

Few papers defined cognitive disability, and existing definitions are inconsistent and do not meet criteria for properly defining a clinical entity.

Conclusion

This review allows us to propose a definition that will help increase consistency in how we define cognitive disability.

Key points

- ➡ There is a lack of consistency in using the terms cognitive impairment, limitation, and disability in research, which can be detrimental to those who experience cognitive disability as it leads to inequities in how programs and policies apply to them.
- ➡ We propose a definition that increases consistency in how we define cognitive disability and hopefully resulting into equity in how interventions, programs and policies apply to individuals who may be referred to with this label.
- ➡ This definition will also lead to a better understanding of cognitive disabilities.

Introduction

Social inclusion

The social inclusion of individuals who experience challenges in their cognitive functioning partially relies on supports and accommodations provided to alleviate obstacles (Cobigo & al., 2016).

For example, work integration is facilitated when their needs for flexible hours, alternative communication modes, control for external stimuli, and assistive technology are recognized and addressed (Yalon-Chamovitz et al., 2016; Sauer et al., 2010).

However, **access to accommodations and supports are dictated and guided by clinical and legal definitions of disability** that determine eligibility criteria for programs and services (Iezzoni & Freedman, 2008). Definitions resolve ambiguity by explaining the meaning of words (Department of Justice, 2020).

Terminology

According to the WHO (2002), **impairment** refers to problems in body functions or structures. **Limitations** refer to difficulties in executing activities. Finally, **disability** reflects a complex phenomenon that precludes individuals to function at their best potential and participate meaningfully in society because of environmental barriers.

Cognitive impairment

Term that should be used to refer to structural deficits or losses in the brain functions or structures.

Cognitive limitation

Term that should refer to difficulties in executing cognitive activities, or in how the brain processes information.

Cognitive disability

This should be the preferred term when referring to one's functioning and participation in society and to emphasize the social construction of the phenomenon.

Conceptualization of disability

As we conceptualize disability as an experience of discrimination and unfair treatment, the term disability is preferred in most circumstances to demonstrate an understanding of the entity as a complex social phenomenon (Berghs et al., 2019).

Additionally, the Convention on the Rights of Persons with Disabilities (Guide, 2014) states that “disability is an evolving concept and that it results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others”.

Cognitive disability, impairment and limitation used as umbrella terms

Cognitive disability, impairment and limitation are umbrella terms used in legislative frameworks, as well as in the scientific and gray literature.



For example, in the **Accessible Canada Act (2019)**, disability means “any impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment - or a functional limitation - whether permanent, temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a person’s full and equal participation in society”.



Conversely, the **United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2013)** states that the term “persons with disabilities includes, but is not limited to, those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (p. 4).

We note the juxtaposition of the adjectives mental, intellectual, and cognitive in the former example, while mental and intellectual impairments are explicitly listed in the latter, but the adjective cognitive is omitted.

The **significant lack of consensus on definitions of cognitive impairments affects cognitive impairment descriptors and categorizations** (Lande & Wanless, 2015). Rehabilitation professionals remain largely unaware of this discrepancy, which calls for education to decrease the risks of miscommunication (Lande & Wanless, 2015).

Definitions Change Over Time

The terminology used to refer to conditions associated with cognitive disability has changed over time to reflect better clinical understanding and changes in social norms.



For example, the **term “mental retardation” has been discarded** and replaced by “intellectual disability” because of its pejorative meaning and an intention to better reflect the impact of intellectual and adaptive limitations on one’s functioning (Schalock et al., 2007).

A critical analysis of current definitions of the terms cognitive impairment, limitation and disability appears essential to determine whether they reflect changes in related terminology.

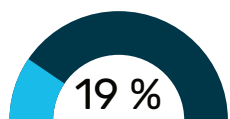
Social Model of Disability

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) calls for policies and laws to be informed by definitions that reflect the social model of disability. Disability does not equate to deficits in individual's body functions, rather it is the result of external barriers and discrimination. The explicit reference to barriers, external to the subject, as constituting factors of disability represents an important step away from notions that equated disability with functional limitations.

Difficulties in Establishing Prevalence Rates



Bouchet (2019) estimates that at least 10% of the French workforce report have moderate to severe cognitive limitations.



A systematic review of studies in community dwelling older adults reveals prevalence rates of cognitive impairments ranging from 5.1% to 41%, with a median of 19.0% (Pais et al., 2020).

The lack of consensus on a definition makes prevalence rates difficult to estimate and leads to concerns about the predictive validity of statistical models (Robertson & al., 2019).

Further characterizing the group labelled as having a cognitive disability is also instrumental to design representative samples (Bonardi & Lauer, 2011).

Increase in prevalence rates of many of the conditions associated with cognitive disability (e.g. Autism, ADHD, dementia) have been reported and add to the difficulties establishing overall prevalence rates (Ouellette-Kuntz & al., 2014; Visser & al., 2010).

Aim of this paper

This paper is built on the assumption that it is critical to revisit our use of the terms cognitive impairment, limitation and disability to inform research, clinical practices, interventions and policy development.

Lack of consistency in using these terms is detrimental to those who experience cognitive disability as it leads to inequities in how programs and policies apply to them. The lack of clarity on the boundaries of these terms also diminishes advocacy efforts since it is unclear whose voices should be heard and the scope of reported inequities.

The overarching aim of this literature review is to **inform a definition of cognitive disability**.

Objectives of this paper

01

Explore how the terms cognitive impairment, limitation and disability are used in the scientific literature.

02

Explore the evolution of the term cognitive disability in the scientific literature

03

Critically appraise the definitions of cognitive impairment, limitation and disability cited in recently published studies across disciplines

Findings will help enhance research quality and improve equity in how programs and policies apply to persons with cognitive disability.

Method

This study was carried out in two different phases.

Phase 1

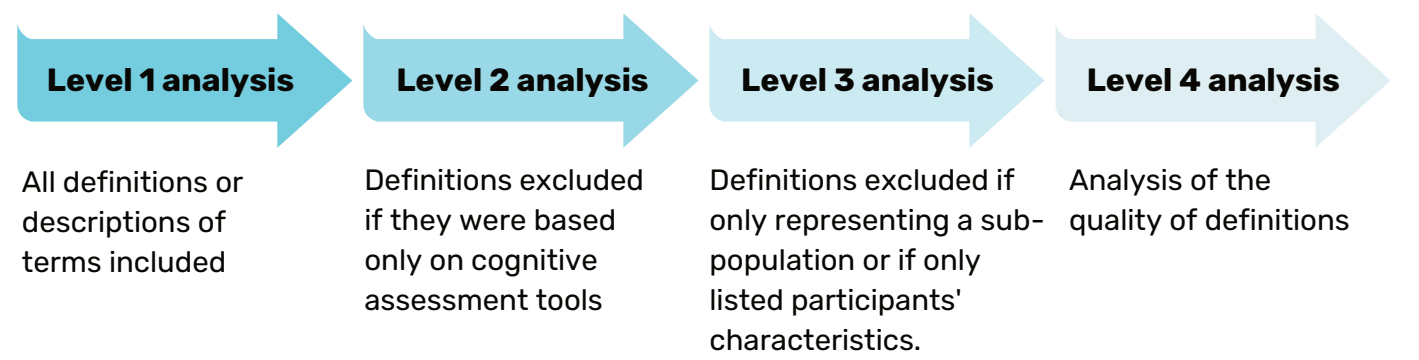
Phase 1 was an exploratory phase and it aimed to explore how the terms cognitive impairment, limitation and disability are used in the scientific literature. We included empirical, peer-reviewed research studies published between September 2020 to March 2021.

Phase 2

Phase 2 focused on the term cognitive disability to determine if an evolution could be observed in the use of this term to reflect current understanding of the disability experience. We included empirical, peer-reviewed research studies published between June 2022 to June 2023.

Both phases were completed using scoping reviews. Scoping reviews provide an overview of a broad topic and allow more flexibility than a traditional systematic review or meta-analysis (Peterson et al., 2017). We used Covidence, a web-based platform, to streamline the process of conducting a comprehensive literature review.

Each scoping review employed a 4-step analysis process.



Please refer to **Appendix A** for a detailed description of the method.

Findings

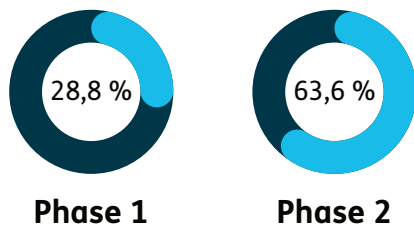
In Phase 1, 750 studies were included in the review, with only 3 providing promising definitions of cognitive impairment, limitation or disability (i.e., reaching level 4 of analysis). In Phase 2, we reviewed 31 studies but only 1 provided a promising definition of cognitive disability. Findings below are only reported for studies that were included in Level 2 analysis for both phases (Phase 1, n=473; Phase 2, n=12). First authors' geographic locations and disciplines are reported in the table below.

Continents		Disciplines
Phase 1: Exploring the terms cognitive impairment, limitation and disability	40% from Asia (n=189)	66% from Health and medicine (n = 313) 30% from Science and Technology (n = 140) 5% from Social Sciences (n = 24) 1% from Other (n = 6)
	30% from Europe (n = 142) 25% from North America (n = 119) 3% from Australia (n = 15) 1% from South America (n=5) 1% from Africa (n=3)	
Phase 2: Exploring cognitive disability definitions		
Phase 2: Exploring cognitive disability definitions	36% from Europe (n = 4)	46% from Health and Medicine (n = 5) 27% from Science and Technology (n = 3) 27% from Social Sciences (n = 3)
	36% from Australia (n = 4) 28% from North America (n = 3)	

Table 3. Authors' geographic locations and disciplines for Phase 1 and Phase 2.

Participants' Characteristics

Participants' characteristics fell into two categories: (1) diagnosis(es) or (2) cognitive limitations or impairments.



For **Phase 1**, 28.8% of selected studies (n = 136) described participants according to a list of different diagnoses, compared to 63.6% of selected studies (n = 7) for **Phase 2**.

See Figure 5 below for the list of diagnoses mentioned at least once in selected studies.

Conditions whose core features are cognitive

Neurodevelopmental disorders

- Intellectual Disability
- Developmental Language Disorder
- Autism Spectrum Disorders
- Attention-Deficit/Hyperactivity Disorder
- Specific Learning Disorder
- Dyslexia
- Foetal alcohol syndrome disorder
- Down Syndrome
- Prader-Willi Syndrome
- Ohdo Syndrome

Neurocognitive disorders

- Dementia
- Alzheimer's Disease
- Vascular cognitive impairment (VCI)
- Lewy Bodies
- Traumatic Brain Injury
- Stroke
- Parkinson's Disease
- Frailty Syndrome
- Multiple Sclerosis
- Cerebral Palsy
- Brain Atrophy
- Alcoholism
- Chemotherapy-induced cognitive impairment (CICI)
- Acquired cognitive disability (traumas during childbirth, meningitis in early childhood or other)

Conditions whose core features are not cognitive

Mental health conditions

- Schizophrenia
- Psychosis and delirium
- Bipolar Disorder
- Major Depressive Disorder

Medical conditions

- Chronic Pulmonary Disease
- Coronary Artery Disease

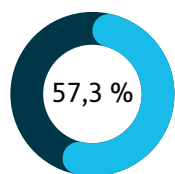
Etiology unknown or unspecified

- Amnesic mild cognitive impairment (aMC)
- Mild cognitive impairment (MCI)
- Subjective cognitive impairment (SCI)
- Subjective and objective cognitive decline

Normal aging

Figure 5. Summary of diagnoses associated with cognitive disability, limitation and impairment and mentioned in reviewed articles after Level 1 analysis for Phases 1 and 2.

Participants' Characteristics Based on Diagnoses



Phase 1

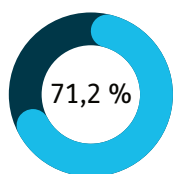


Phase 2

For **Phase 1**, 57.3% (n = 193) of those studies used psychological tests to determine whether participants had limitations in different cognitive domains. The Montreal Cognitive Assessment—MoCA (Nasreddine & al., 2005), the Mini-Mental State Exam—MMSE (Folstein & al., 2010) and the Cognitive Abilities Screening Instrument (CASI) (Teng & al., 1994) are the tests most widely used.

No study for **Phase 2** used psychological tests results to assess if participants had a cognitive disability.

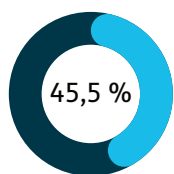
Participants' Characteristics Based on Cognitive Limitations or Impairments



Phase 1

For **Phase 1**, 71.2 % of selected studies (n=337) used a description based on difficulties presented in different domains of cognitive functioning.

For example, Chung & Kim (2020) define cognitive impairment as a condition in which “a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life” (p. 1).



Phase 2

For **Phase 2**, 45.5% of selected studies (n=5) used a description based on difficulties presented in different domains of cognitive functioning.

For example, Alshenaifi et al. (2022) highlighted that "Cognitive disabilities include difficulties related to cognitive functions such as learning, communication, comprehension, attention, and memory" (p. 596).

Definitions' Characteristics

Phase 1 – Definitions of cognitive impairment, cognitive limitation and cognitive disability

Level 3 analysis

We removed 69 papers that only provided examples of conditions associated to cognitive impairment, limitation or disability or examples of cognitive functions. For example, we removed the following definitions at this step:



“Common areas of difficulty for people with cognitive disabilities include problems with perception and information processing, memory, problem solving and attention.” (García-Catalá & al., 2020, p. 880)



“Mothers with cognitive limitations include those with such diagnoses as mild intellectual disabilities (IDs), autism and attention deficit hyperactivity disorder (ADHD).” (Adolfsson & al., 2021, p. 79)

Level 4 analysis

We appraised the quality of remaining definitions of cognitive impairment, limitation or disability using the criteria below (Luckasson & Reeve, 2001).

- 1 Does this definition indicate the boundaries of the term, that is, who or what is inside the boundaries and who or what is outside the boundaries?
- 2 Does this definition indicate the class of things to which it belongs?
- 3 Does this definition differentiate the term from other members of the class?
- 4 Does this definition allow some generalizations about characteristics of the individual or group named by the term?

We removed 19 definitions that did not meet all criteria, leaving us with three remaining definitions (see table 4). For example, we removed the following definitions :



“Cognitive impairment was characterized by reduced visuospatial ability, verbal fluency, and attention” (Ciolac & al., 2021, p. 3)



“Cognitive impairment is an intermediate state between normal aging and dementia. It signifies the transitional zone between normal cognitive function and clinically probable Alzheimer’s disease (AD)” (Chireh & D’Arcy, 2020, p. 2)

Study	First authors' discipline	First authors' country	Location of definition	Definitions of cognitive disability, cognitive impairment, or cognitive limitation
Janney et al., 2021	Medicine	United States	Introduction	“According to the CDC, “cognitive impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life”. Those with mental illness may experience cognitive impairments due to medications, symptoms, substance abuse or the disorder itself.” (p.1)
Synovec, 2020	Medical Respite Care	United States	Introduction	“Cognitive impairment, or cognitive dysfunction, has been defined as “functioning below expected normative levels or loss of ability in any area of cognitive functioning” (Evans, 2010). Cognitive impairment may occur as the result of a variety of diagnoses, such as traumatic or acquired brain injury, mental health disorders, long-term substance or alcohol use, trauma, neurological disorders, and chronic conditions, and can affect individuals across the life span.” (p. 332)
Cobigo et al., 2020	Psychology	Canada	Introduction	“In using the term “cognitive disability” (CD), we refer to limitations that a person might have in their intellectual or cognitive functioning. CD includes cognitive and adaptive limitations with onset in childhood (e.g., Down Syndrome). It may also result from brain injuries or a disease acquired later in life, such as dementia. Cognitive disabilities exist in all age groups, but become more prevalent in later life with nearly one quarter of adults 65 years-old and older living with a cognitive disability. People who have CD may experience challenges in their daily living and barriers to social inclusion due to limitations in their abilities to process and recall information, or communicate with others.” (p.1)

Table 4. Definitions left after Level 4 Analysis for Phase 1.

We appraised the quality of the 3 remaining definitions based on the second part of Luckasson & Reeve’s (2001) criteria listed below.

- 5 Does this definition use words that are no more complicated than the term itself?
- 6 Does the definition define what something is, not what it is not?
- 7 Is this definition consistent with a desired theoretical framework?
- 8 Does this definition contribute positively to the portrayal of people included in the term?

The analysis of the 3 remaining definitions revealed that only the definitions proposed by [Janney & al. \(2021\)](#) and [Cobigo & al. \(2020\)](#) meet the following criterion: **“Does this definition use words that are no more complicated than the term itself?”**

However, none of the definitions respect this criterion: **“Does the definition define what something is, not what it is not?”**. Furthermore, none of the three definitions specified a theoretical framework, so we were not able to determine if they met the following criterion: **“Is this definition consistent with a desired theoretical framework?”**

Finally, only [Cobigo & al.’s \(2020\)](#) definition respected this criterion: **“Does this definition contribute positively to the portrayal of people included in the term?”** since they acknowledge that social barriers have an impact on the person’s functioning.

In summary, none of the definitions identified in the literature review met all the criteria proposed by Luckasson & Reeve to help name and define a clinical entity.

Phase 2—Definitions of cognitive disability

Level 3 analysis

We removed 7 papers that only provided examples of conditions associated to cognitive disability or examples of cognitive functions. For example, we removed the following definition:



“Children with cognitive disabilities (CD), including intellectual disabilities (IDs), and cognitive impairment [...]” ([Albani et al., 2022, p. 1784](#)).

Level 4 analysis

For the remaining 4 definitions, we appraised their quality using the criteria listed on [page 11](#) ([Luckasson & Reeve, 2001](#)), leaving only 1 study with a definition that attempted to define the term in a clear and generalizable way (See table 5 next page).

We appraised the quality of the remaining definition based on the second part of [Luckasson & Reeve’s \(2001\)](#) criteria listed on [page 12](#).

Study	First authors' discipline	First authors' country	Location of definition	Definitions of cognitive disability
Woodlock & Harris, 2022	Social Sciences	Australia	Introduction	“Definitions of cognitive disabilities include a wide range of conditions that do not necessarily include intellectual functioning. Issues with speech, memory, communication and attention can all be defined as cognitive impairments, with these conditions being permanent, short-term or intermittent. These impairments can be caused by acquired brain injuries, dementia and stroke (Australian Commission on Safety and Quality in Health Care 2020). Mental health conditions, such as schizophrenia and depression, can also be classified as cognitive impairments (Mental Health Coordinating Council 2015)” (p.3)

Table 5. Definition left after Level 4 Analysis for Phase 2.

The analysis of the remaining definition revealed that it met the following criterion: **“Does this definition use words that are no more complicated than the term itself?”** but not this criterion **“Does the definition define what something is, not what it is not?”**.

Furthermore, this definition did not specify a theoretical framework, so we were not able to determine if they met the following criterion: **“Is this definition consistent with a desired theoretical framework?”**

Finally, it did not respect this criterion: **“Does this definition contribute positively to the portrayal of people included in the term?”** since they used pejorative terms, such as issues, and did not acknowledge the role of the environment in this definition.

In summary, none of the definitions identified in the second phase of this literature review met all the criteria proposed by Luckasson & Reeve to help name and define a clinical entity.

Discussion

Lack of Clarity and Coherence in Definitions

Findings confirm that the terms cognitive impairment, limitation and disability are commonly used in research, across disciplines, and across the globe. However, authors rarely define these terms and when they do, it is with great inconsistency. This lack of clarity and coherence in definitions is a major threat to scientific rigour, validity and generalizability. It also may limit in fundamental ways access to services for individuals.

The number of conditions found to be associated with cognitive impairment, limitation or disability prevent the use of definitions based on etiology. This list is too long and the conditions too varied for etiological definitions to be used consistently and comprehensively. Indeed, our review of more than 400 studies led to an incomplete list of diagnoses, with the notable absence of some learning disabilities, or cognitive challenges related to human immunodeficiency virus (HIV) infection, post-traumatic stress disorder (PTSD), anxiety disorders or Covid-19. From our review, no existing definition can be recommended.

Importance of a Functional Definition

We argue that a functional definition would avoid inequities in how programs and legislative frameworks are implemented and would significantly increase scientific rigour. A functional definition is one that would define the concept based on functions impacted by the entity labelled with the term.



According to the DSM-5 ([American Psychiatric Association, 2013](#)), cognitive functions are divided in 6 domains:

- | | |
|-------------------------|-----------------------------|
| 1) complex attention; | 4) language; |
| 2) executive functions; | 5) perceptual-motor skills; |
| 3) learning and memory; | 6) social cognitions. |

Defining cognitive disability using domains of cognitive functioning that may be impacted helps set boundaries and reflects the heterogeneity of the population labelled with the term. We note, however, the circular definitions of cognitive, intellectual and mental.



For example, the APA Dictionary of Psychology defines intellectual functions as mental functions ([APA, 2022a](#)), and mental processes as types of cognitions ([APA, 2022b](#)). A critical analysis of these terms is required to determine whether they can be used interchangeably.

We propose the following definition to inform policy development and scientific rigour.

Cognitive disability is a situation of disadvantage experienced by individuals with cognitive abilities that differ from what is considered typical, in one or more of the following domains: (1) attention, (2) executive functions, (3) learning and memory, (4) language, (5) perceptual motor skills or (6) social cognitions. People with cognitive disability constitute a heterogeneous group with a range of co-existing cognitive strengths and limitations that often evolve over time and can be persistent, episodic or temporary.

Does the proposed definition meet Luckasson & Reeve's (2001) criteria ?

- 1 No. Comparable to all reviewed definitions, we acknowledge that the proposed definition **fails to indicate what is outside of the boundaries**. This limitation stems from the absence of a clear definition regarding what constitutes typical cognitive functioning.
- 2 Yes. The definition identifies individuals with cognitive abilities **that differ from what is considered typical**. Once again, we acknowledge here that it remains unclear how typical cognitive functioning can be described.
- 3 Yes. The definition **differentiates cognitive disability from typical cognitive abilities** by specifying the domains in which differences may occur.
- 4 Yes. The definition **allows for generalizations about the characteristics** of individuals with cognitive disabilities, highlighting the range of strengths and limitations they may have.
- 5 Yes. The language used in the definition is **clear, concise and does not introduce unnecessary complexity**.
- 6 Yes. The definition focuses on **describing what cognitive disability** is rather than what it is not.
- 7 Yes. The definition aligns with the **conceptualization of disability** as a social phenomenon influenced by interactions between individuals with cognitive disabilities and environmental barriers.
- 8 Yes. This definition **avoids negative stereotypes or stigmatization** by highlighting cognitive disability as a situation of disadvantage experienced by individuals, rather than framing it as deficits and by highlighting its heterogeneous nature.

We highlight here tensions between a **need to identify who can be accurately labelled with the term**, and the reality of neurodiversity. On one end, clinicians and policy makers need to determine what is not considered as typical to determine eligibility to resources and programs, and researchers seek precision in their sample description. On the other end, **neurodiversity refers to different ways of perceiving, processing and retrieving information that are distributed normally in the population** (Armstrong, 2011). These tensions reveal the need to pursue the conversation this paper aims to spark and provide definitions that would lead to an equitable determination of resources and programs.

It remains unclear which societal norms might be used to determine what is typical cognitive functioning, and the extent to which a deviance from these norms constitutes a limitation. In the absence of such benchmarks, developing and relying on psychometric measures to classify individuals as experiencing cognitive disability is flawed.

Furthermore, there are many contexts where an inclusive approach that does not dichotomize the us and the they is legitimate and preferable, and arguably better than the absence of definition. **Emphasizing the difference to norms in definitions of disability is an ableist approach, and refrains from conceptualizing disability as an experience of disadvantage and inequity** (Riddle, 2020).

Research Limitations

Although we used a comprehensive list of search terms and multiple databases, it is possible that relevant articles were not included because they did not appear in our initial search or because we restricted our search to publications between September 2020 and March 2021 (phase 1) and June 2022 and June 2023 (phase 2). It is likely that we have missed promising definitions, but our review reveals that no authoritative and consensual definition exists. Additionally, only published articles available in English were included in this scoping review.

Future studies should also determine how to translate cognitive disability in terms that are culturally acceptable (Gjersing & al., 2010). For example, in French, the Processus de production du handicap (Fougeyrollas & al., 2019) is an influential framework for understanding disability, but it is unclear how the proposed definition would translate into this framework. However, a simple translation of terms may lead to resistance in adopting the proposed definition because of the pejorative connotation of some words in different languages and cultures.

Conclusion

This review proposes a definition that will help increase consistency in how we define cognitive disability, which in turn can result in equity in how interventions, programs and policies apply to individuals who may be referred to with this label. However, existing definitions, including the one we propose, were developed without directly consulting those who may be labelled with this term. Without the direct input of individuals with cognitive disability, it is impossible to appraise quality as it refers to the following criterion (Luckasson & Reeve, 2001): “Does this definition contribute positively to the portrayal of people included in the term?” **Amplifying the voices of persons with cognitive disability through inclusive research methods is essential to provide crucial insights in how we refer to them and apply this label in research and decision-making that affect their life** (Ghaderi et al., 2023; Walmsley & al., 2018).

References

Accessible Canada Act S.C. 2019, c. 10 (Canada). <https://laws.justice.gc.ca/eng/acts/A-0.6/FullText.html#h-1153395>

Adolfsson, P., Janeslätt, G., Lindstedt, H., & Jöreskog, K. (2021). Mothers with cognitive limitations who have children in placement benefit from intervention. *Child and Family Social Work*, 26(1), 79–88. Scopus. <https://doi.org/10.1111/cfs.12791>

Albani, E., Petsios, K., Saridi, M., Fradelos, E. C., Tzenalis, A., & Toska, A. (2022). Pain Assessment in Children with Cognitive Disabilities: Critical Review and Clinical Implications. *International Journal of Caring Sciences*, 15(3), 1784-1791.

Alshenaifi, R., Nguyen, N. P., & Feng, J. H. (2022, November). Mining and Understanding Arabic Tweets Related to Cognitive Disabilities. In 2022 IEEE/WIC/ACM International Joint Conference on Web Intelligence and Intelligent Agent Technology (WI-IAT) (pp. 596-603). IEEE. DOI: [10.1109/WI-IAT55865.2022.00094](https://doi.org/10.1109/WI-IAT55865.2022.00094)

American Psychiatric Association [APA]. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>

American Psychological Association. (2022a). Intellectual function. *APA Dictionary of Psychology*. Retrieved July 6, 2022, from <https://dictionary.apa.org/intellectual-function>

American Psychological Association. (2022b). Higher mental process. *APA Dictionary of Psychology*. Retrieved July 6, 2022, from <https://dictionary.apa.org/higher-mental-process>

Armstrong, T. (2011). *The Power of Neurodiversity: Unleashing the Advantages of Your Differently Wired Brain* (published in Hardcover as *Neurodiversity*). Da Capo Lifelong Books.

Barry, C. A., Britten, N., Barber, N., Bradley, C., & Stevenson, F. (1999). Using reflexivity to optimize teamwork in qualitative research. *Qualitative health research*, 9(1), 26-44.

References

- Berghs, M., Atkin, K., Hatton, C., & Thomas, C. (2019). Do disabled people need a stronger social model: a social model of human rights?. *Disability & Society*, 34(7-8), 1034-1039. <https://doi.org/10.1080/09687599.2019.1619239>
- Bouchet, C. (2019). Handicaps et inégalités professionnelles en France : des disparités qui se creusent au fil des parcours de vie (No. 84). LIEPP Working paper. <https://celiabouchet.hypotheses.org/files/2021/09/2019-Bouchet-compresse.pdf>
- Bonardi, A., & Lauer, E. (2011). Developing an operational definition of intellectual disability for the purpose of National health surveillance. <https://shriver.umassmed.edu/wp-content/uploads/2020/07/Developing-an-Operational-Definition-of-Intellectual-Disability-for-the-Purpose-of-National-Health-Surveillance-PDF.pdf>
- Chireh, B. & C. D'Arcy. (2020). A comparison of the prevalence of and modifiable risk factors for cognitive impairment among community-dwelling Canadian seniors over two decades, 1991–2009. *PLoS One*, 15(12). *Nursing & Allied Health Premium*. <https://doi.org/10.1371/journal.pone.0242911>
- Chung, W., & Kim, R. (2020). Which occupation is highly associated with cognitive impairment? A gender-specific longitudinal study of paid and unpaid occupations in South Korea. *International journal of environmental research and public health*, 17(21), 7749. <https://doi.org/10.3390/ijerph17217749>
- Ciolac, D., Crivorucica, I., Zota, E., Gorincioi, N., Efremova, D., Manea, D., ... & Groppa, S. A. (2021). Extensive cerebellar involvement and cognitive impairment in COVID-19-associated acute necrotizing encephalopathy. *Therapeutic Advances in Neurological Disorders*, 14, 1756286420985175. <https://doi.org/10.1177/1756286420985175>
- Cobigo, V., Czechowski, K., Chalghoumi, H., Gauthier-Beaupre, A., Assal, H., Jutai, J., ... & Bah, F. (2020). Protecting the privacy of technology users who have cognitive disabilities: Identifying areas for improvement and targets for change. *Journal of Rehabilitation and Assistive Technologies Engineering*, 7, <https://doi.org/10.1177/2055668320950195>
- Cobigo, V., Brown, R., Lachapelle, Y., Lysaght, R., Martin, L., Ouellette-Kuntz, H., ... & Fulford, C. (2016). Social inclusion: A proposed framework to inform policy and service outcomes evaluation. *Inclusion*, 4(4), 226-238. <https://doi.org/10.1352/2326-6988-4.4.226>
- Department of Justice (2020, June 1st). Logistics Definitions. Government of Canada. <https://www.justice.gc.ca/eng/rp-pr/csj-sjc/legis-redact/logistics/p1p5.html>
- Folstein, M. F., Folstein, S. E., & Fanjiang, G. (2010). Mini-mental state examination: MMSE-2. Lutz, FL: Psychological Assessment Resources.
- Fougeyrollas, P., Boucher, N., Edwards, G., Grenier, Y., & Noreau, L. (2019). The Disability Creation Process Model: A Comprehensive Explanation of Disabling Situations as a Guide to Developing Policy and Service Programs. *Scandinavian Journal of Disability Research*, 21(1), 25–37. <http://doi.org/10.16993/sjdr.62>

García-Catalá, M. T., Rodríguez-Sánchez, M. C., & Martín-Barroso, E. (2020). Survey of indoor location technologies and wayfinding systems for users with cognitive disabilities in emergencies. *Behaviour & Information Technology*, 1-25. <https://doi.org/10.1080/0144929X.2020.1849404>

Ghaderi, G., Milley, P., Lysaght, R., & Cobigo, V. (2023). Including people with intellectual and other cognitive disabilities in research and evaluation teams: A scoping review of the empirical knowledge base. *Journal of Intellectual Disabilities*, 17446295231189912. <https://doi.org/10.1177/17446295231189912>

Gjersing, L., Caplehorn, J. R., & Clausen, T. (2010). Cross-cultural adaptation of research instruments: language, setting, time and statistical considerations. *BMC medical research methodology*, 10(1), 1-10. <https://doi.org/10.1186/1471-2288-10-13>

Guide, T. (2014). The convention on the rights of persons with disabilities. New York and Geneva. United Nations of Human Rights. https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

Iezzoni, L. I., & Freedman, V. A. (2008). Turning the disability tide: the importance of definitions. *JAMA*, 299(3), 332–334. <https://doi.org/10.1001/jama.299.3.332>

Janney, C. A., Tobe, E., Matteson, S., & Long, B. (2021). Social service provider's perceptions of financial education for adults with mental illness and/or cognitive impairments. *Journal of Consumer Affairs*. <https://doi.org/10.1111/joca.12352>

Lande, E. S., & Wanlass, R. L. (2015). Rehabilitation professionals still do not communicate effectively about cognition. *Archives of Physical Medicine and Rehabilitation*, 96(1), 158-162. <https://doi.org/10.1016/j.apmr.2014.08.020>

Luckasson, R., & Reeve, A. (2001). Naming, defining, and classifying in mental retardation. *Mental retardation*, 39(1), 47-52. [https://doi.org/10.1352/0047-6765\(2001\)039<0047:NDACIM>2.0.CO;2](https://doi.org/10.1352/0047-6765(2001)039<0047:NDACIM>2.0.CO;2)

Nasreddine, Z. S., Phillips, N. A., Bedirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, J. L., & Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, 53(4), 695–699. <https://doi.org/10.1111/j.1532-5415.2005.53221.x>

Ouellette-Kuntz, H., Coe, H., Lam, M., Breitenbach, M. M., Hennessey, P. E., Jackman, P. D., ... & Chung, A. M. (2014). The changing prevalence of autism in three regions of Canada. *Journal of autism and developmental disorders*, 44(1), 120-136. <https://doi.org/10.1007/s10803-013-1856-1>

Pais, R., Ruano, L., P Carvalho, O., & Barros, H. (2020). Global cognitive impairment prevalence and incidence in community dwelling older adults—a systematic review. *Geriatrics*, 5(4), 84. <https://doi.org/10.3390/geriatrics5040084>

Peterson, J., Pearce, P. F., Ferguson, L. A., & Langford, C. A. (2017). Understanding scoping reviews: Definition, purpose, and process. *Journal of the American Association of Nurse Practitioners*, 29(1), 12-16. <https://doi.org/10.1002/2327-6924.12380>

Robertson, K., Larson, E. B., Crane, P. K., Cholerton, B., Craft, S., McCormick, W. C., ... & Trittschuh, E. H. (2019). Using varying diagnostic criteria to examine mild cognitive impairment prevalence and predict dementia incidence in a community-based sample. *Journal of Alzheimer's Disease*, 68(4), 1439-1451. <https://doi.org/10.3233/JAD-180746>

Sauer, A. L., Parks, A., & Heyn, P. C. (2010). Assistive technology effects on the employment outcomes for people with cognitive disabilities: a systematic review. *Disability and Rehabilitation: Assistive Technology*, 5(6), 377-391. <https://doi.org/10.3109/17483101003746360>

Schalock, R. L., Luckasson, R. A., & Shogren, K. A. (2007). The renaming of mental retardation: Understanding the change to the term intellectual disability. *Intellectual and developmental disabilities*, 45(2), 116-124. [https://doi.org/10.1352/1934-9556\(2007\)45\[116:TROMRU\]2.0.CO;2](https://doi.org/10.1352/1934-9556(2007)45[116:TROMRU]2.0.CO;2)

Synovec, C. E. (2020). Evaluating Cognitive Impairment and Its Relation to Function in a Population of Individuals Who Are Homeless. *Occupational Therapy In Mental Health*, 36(4), 330-352. Nursing & Allied Health Premium. <https://doi.org/10.1080/0164212X.2020.1838400>

Riddle, C. A. (2020). Why we do not need a 'stronger' social model of disability. *Disability & Society*, 35(9), 1509-1513. <https://doi.org/10.1080/09687599.2020.1809349>

Teng, E. L., Hasegawa, K., Homma, A., Imai, Y., Larson, E., Graves, A., ... & White, L. R. (1994). The Cognitive Abilities Screening Instrument (CASI): a practical test for cross-cultural epidemiological studies of dementia. *International psychogeriatrics*, 6(1), 45-58. [doi:10.1017/S1041610294001602](https://doi.org/10.1017/S1041610294001602)

United Nations (2013). Convention on the Rights of Persons with Disabilities. USA: United Nations. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

Visser, S. N., Bitsko, R. H., Danielson, M. L., Perou, R., & Blumberg, S. J. (2010). Increasing prevalence of parent-reported attention-deficit/hyperactivity disorder among children—United States, 2003 and 2007. *Morbidity and mortality weekly report*, 59(44), 1439-1443. <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5944a3.htm>

Walmsley, J., Strnadova, I., & Johnson, K. (2018). The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 751-759. <https://doi.org/10.1111/jar.12431>

World Health Organization [WHO]. (2002). Towards a common language for functioning, disability, and health: ICF. The international classification of functioning, disability and health. https://cdn.who.int/media/docs/default-source/classification/icf/icfbeginnersguide.pdf?sfvrsn=eead63d3_4&download=true

Yalon-Chamovitz, S., Shach, R., Avidan-Ziv, O., & Tenne Rinde, M. (2016). The call for cognitive ramps. *Work*, 53(2), 455-456. <https://doi.org/10.3233/WOR-152244>

Appendix A

Phase 1: Exploring the terms cognitive impairment, limitation and disability

Search Strategy

Two researchers conducted a database search using a variety of subject headings and keywords that were combined using “OR” relations (see Table 1). Consistent with scoping review guidelines, we included empirical, peer-reviewed research studies published between September 2020 to March 2021.

Databases	Search Terms
MEDLINE	((cognitive disabilit*[Title]) OR (cognitive impairment*[Title])) OR (cognitive limitation*[Title])
CINAHL	TI "cognitive disabilit*" OR TI "cognitive impairment*" OR TI "cognitive limitation"
PsycINFO	title("cognitive disabilit*") OR title("cognitive impairment*") OR title("cognitive limitation*")
Web of Science Core Collection	“cognitive disabilit*” OR “cognitive impairment*” OR “cognitive limitation*” (Title)
Scopus	TITLE ("cognitive disabilit*" OR "cognitive impairment*" OR "cognitive limitation*") AND PUBYEAR > 2019 AND PUBYEAR < 2022 AND PUBYEAR > 2019 AND PUBYEAR < 2022
AARP Ageline	TI “cognitive disabilit*” OR TI “cognitive impairment*” OR TI “cognitive limitation*”
IEEE Xplore Digital Library	("Publication Title":“cognitive disabilit*”) OR ("Publication Title":“cognitive impairment*”) OR ("Publication Title":“cognitive limitation*”) OR ("Publication Title":“cognitive limitation*”) OR ("Publication Title":“cognitive limitation*”) OR ("Publication Title":“cognitive limitation*”)
Nursing and Allied Health Source	title("cognitive disabilit*") OR title("cognitive impairment*") OR title("cognitive limitation*")
CBCA Complete	title("cognitive disabilit*") OR title("cognitive impairment*") OR title("cognitive limitation*")
Business Source Complete	TI “cognitive disabilit*” OR TI “cognitive impairment*” OR TI “cognitive limitation*”

Table 1. Specific search terms/keywords per database.

After removing duplicates, we screened relevant papers based on titles and abstract reviews. We excluded all studies on animals, studies that referred to cognitive disability as an exclusion criterion and articles that could not be accessed through the institutional library.

Figure 1 provides an overview of this process.

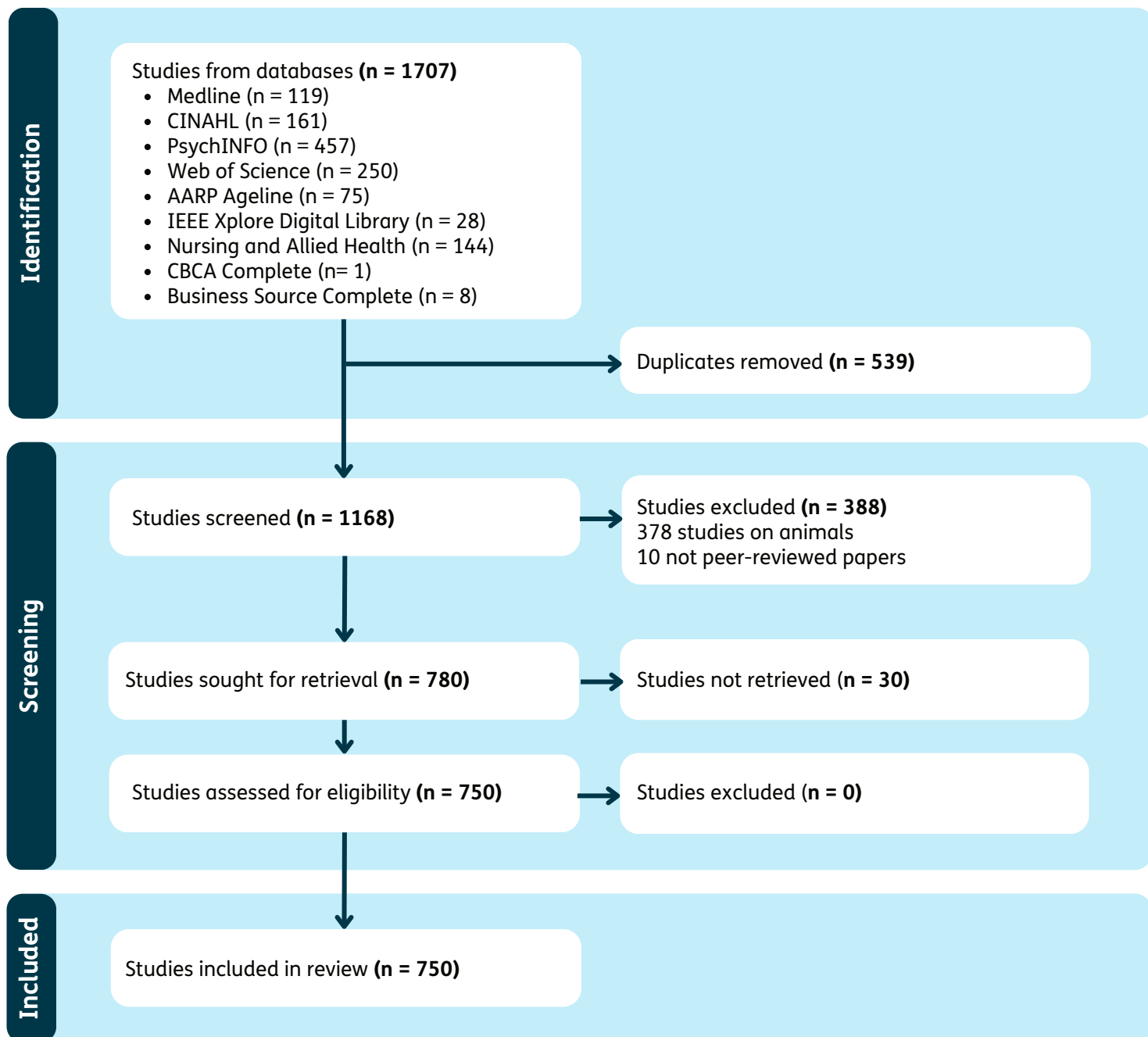


Figure 1. Flow diagram of Phase 1 search strategy.

Data Extraction and Analysis

Figure 2 provides an overview of the approach used for data extraction and analysis.

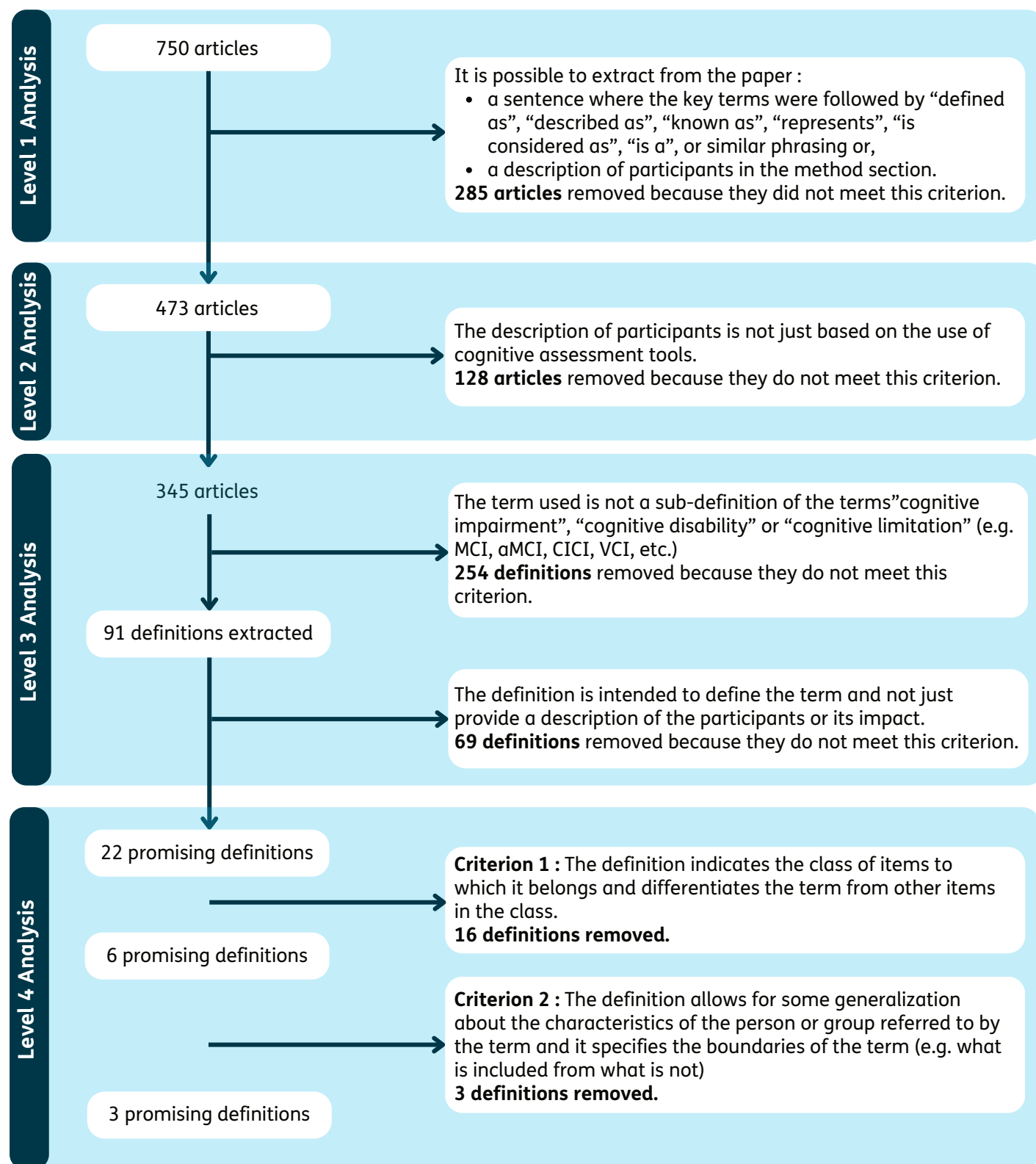


Figure 2. Flow diagram of Phase 1 Levels 1, 2, 3 and 4 of analysis

Level 1 Analysis: Extracting Definitions

We performed a search using the search tool of the PDF reader application of the terms “cognitive impairment*”, “cognitive limitation*” or “cognitive disability*”. We only kept papers in which we could extract a sentence where these terms were followed by “defined as”, “described as”, “known as”, “represents”, “is considered as”, “is a”, or similar phrasing.

Level 2 Analysis: Data Extraction

We extracted the following data from selected articles: (1) authors’ characteristics (first authors’ disciplines and country), (2) study characteristics (methods, participants, description of cognitive impairment, limitation or disability status), (3) terms used to refer to cognitive impairment, limitation or disability and related definitions. We also noted where the terms in which section of the article the definition was found. At this stage, we excluded studies that only referred to a score on a cognitive functioning assessment tool to determine a status of cognitive impairment, limitation or disability, as these scores do not inform the development of a definition.

Level 3 Analysis: Removing Studies Without a Definition

We removed studies that only offered definitions of related terms, such as mild cognitive impairment, chemotherapy-induced cognitive impairment, or vascular cognitive impairment. We removed studies that used cognitive impairment, limitation or disability as an inclusion criterion, without defining these terms. Articles and definitions were reviewed by 2 independent reviewers who resolved disagreements by consensus and when consulting a senior author.

Level 4 Analysis: Selecting and Appraising the Quality of Definitions

At this stage, we extracted and analyzed definitions of cognitive impairment, limitation or disability, following the procedure described below, with the intention to appraise their quality. We adapted a list of criteria proposed by Luckasson & Reeve (2001) to help name and define a clinical entity (see Table 2 for the list of criteria). They were previously used to name, define and classify the term “mental retardation” (Luckasson & Reeve, 2001). Authors highlighted that Questions 1 to 6 can help define a class of members with a disability. Additionally, they mentioned that Question 7 may be unique to each discipline, and that this creates tensions around a desired theoretical framework. Question 8 questions whether the definition is respectful to those who would be labelled using the term.

At Level 4, we first applied 4 criteria chosen because they rely on an objective analysis of the definition. One reviewer independently appraised definitions using these criteria. The remaining 4 criteria from Luckasson & Reeve's (2001) list were applied to remaining definitions. Across the different levels of analysis, we used an audit process to promote reflexivity and dialogue among team members, as required for reliable data analysis and interpretation (Barry et al., 1999). The audit process involved two research assistants and a senior researcher. Regular meetings were held to discuss the different inclusion criteria for each step, as well as to discuss which papers and definitions to keep/remove when conflicts arise. This process was repeated until a consensus was reached.

Phase 2: Exploring definitions of cognitive disability

Search Strategy

Phase 2 replicates Phase 1 search strategy but only using the following keywords: ("cognitive disability"). We included empirical, peer-reviewed research studies published between June 2022 to June 2023. See Figure 3.

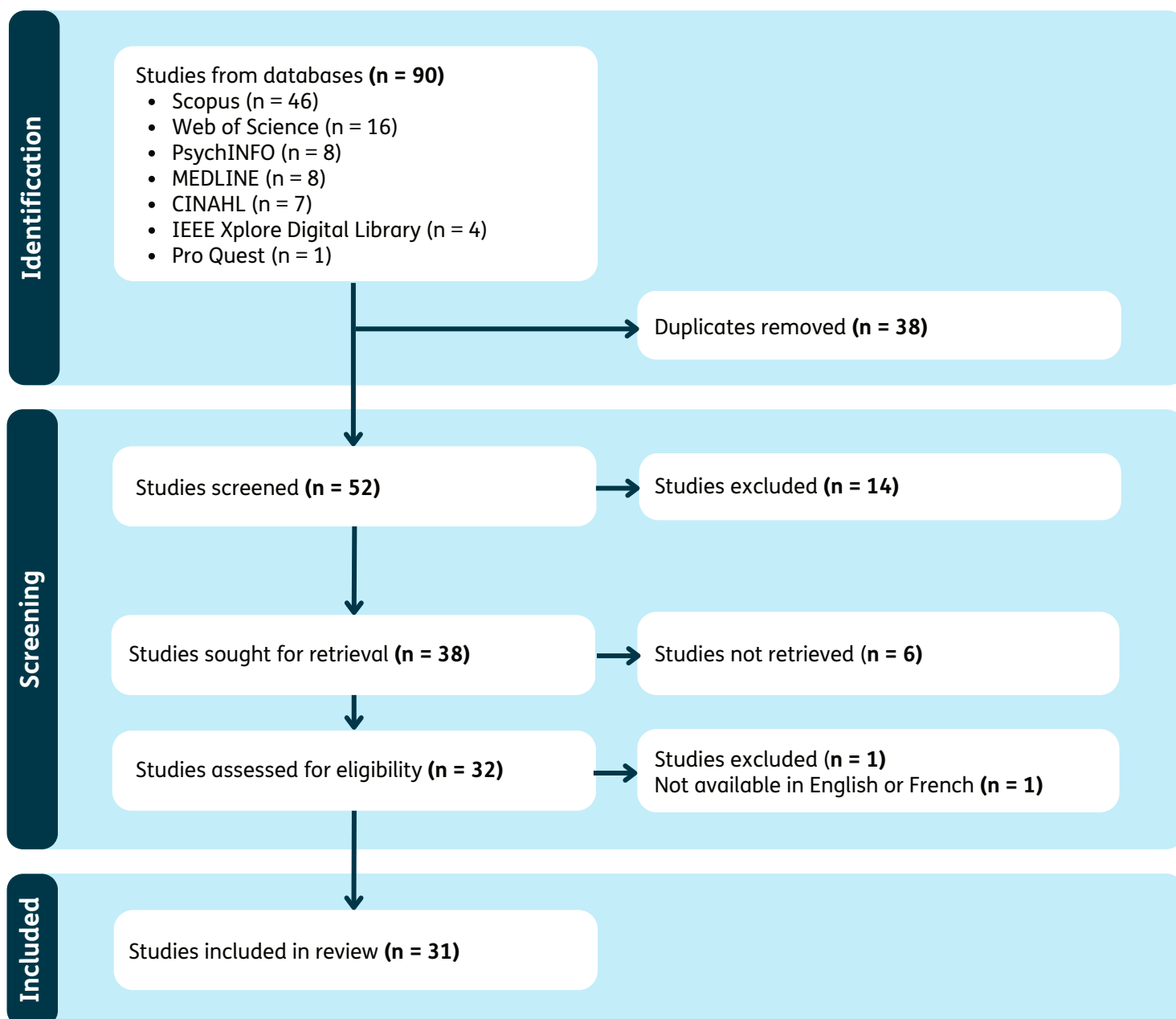


Figure 3. Flow diagram of Phase 2 search strategy.

Data Extraction and Analysis

We followed the same procedure as described in Phase 1 (see Figure 4) but including only information and definitions on cognitive disabilities.

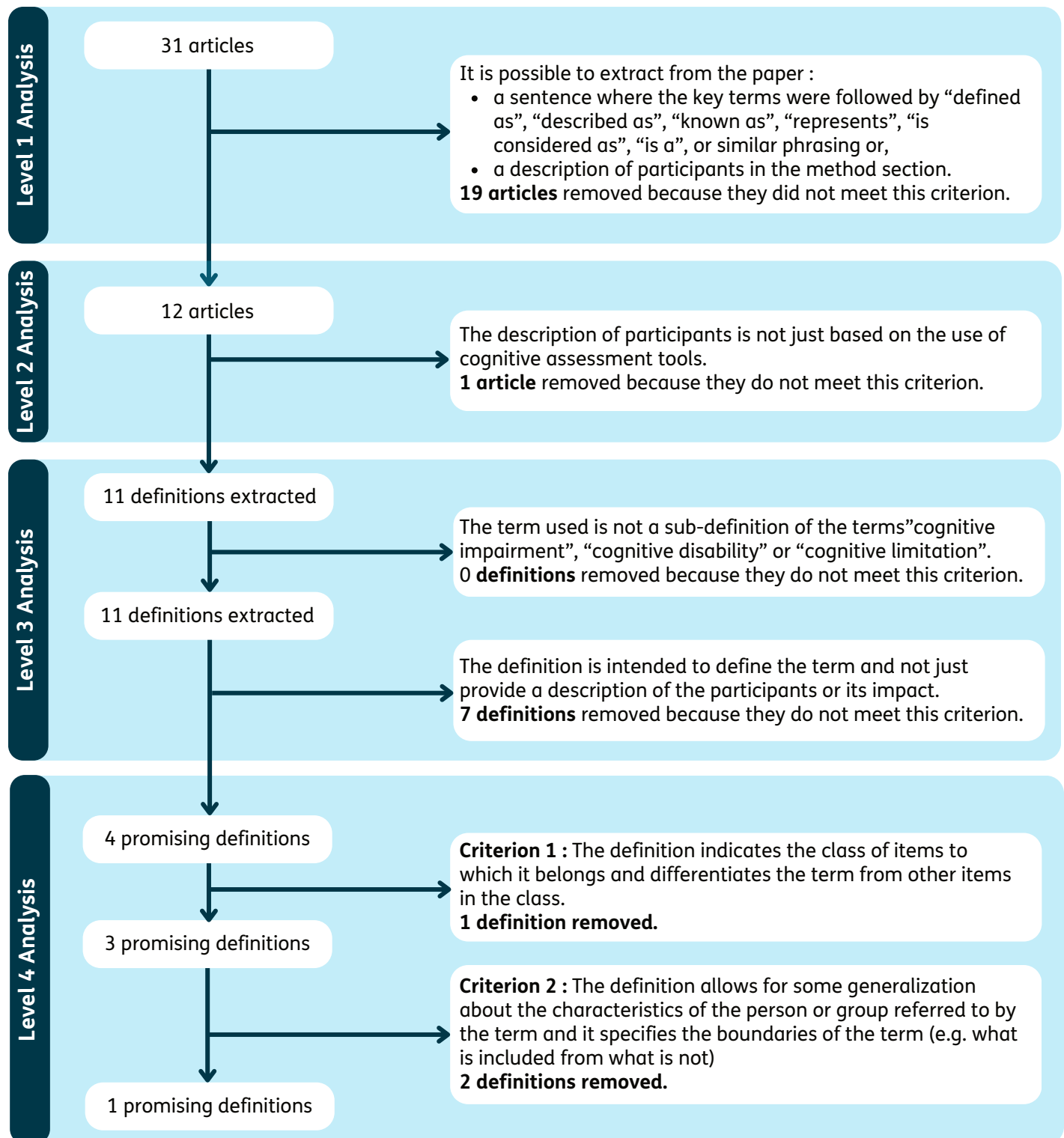


Figure 4. Flow diagram of Phase 2 Level 1, 2, 3 and 4 of analysis