



ELSEVIER

Disponible en ligne sur [www.sciencedirect.com](http://www.sciencedirect.com)

ScienceDirect

et également disponible sur [www.em-consulte.com](http://www.em-consulte.com)



Research Paper

# Citizenship of persons with intellectual disabilities within the frame of inclusive research: A scoping review of studies to inform future research<sup>☆</sup>

*Citoyenneté des personnes ayant une déficience intellectuelle dans le cadre des recherches sur l'inclusion : bilan critique des recherches pour éclairer les recherches futures*

Anna Chalachanová<sup>\*,1</sup>, Inger Marie Lid, Anita Gjermestad

VID Specialized University, Vaagsgata 40, 4306 Sandnes, Norway

## INFO ARTICLE

*Historique de l'article :*  
Reçu le 9 octobre 2019  
Accepté le 2 septembre 2020  
Disponible sur Internet le xxx

*Keywords :*  
Inclusive research  
Intellectual disability  
Citizenship  
Dimensions of citizenship

## ABSTRACT

This scoping review aims to explore the citizenship of people with intellectual disabilities and its expression in inclusive research. The deductive lens used is the general principles embedded in Article 3 of the UN's Convention on the Rights of Persons with Disabilities. The review was conducted using the framework proposed by Arksey and O'Malley. Seven databases were searched for peer-reviewed journal articles dating from 2005 to 2019. Our key findings are: the term *citizenship* is seldom mentioned or explicitly discussed in the articles; the articles highlight a broad range of dimensions closely related to the exercise of citizenship. Citizenship in the articles is connected to participation, autonomy, decision-making, self-direction and inclusion in society. Articles also uncover violations of the rights and barriers to participation in the society; more attention needs to be paid to conceptualization and exploration of the citizenship of people with intellectual disabilities.

<sup>☆</sup> We confirm that the article is not submitted or considered for submission elsewhere.

\* Corresponding author.

Adresse e-mail : [anna.chalachanova@vid.no](mailto:anna.chalachanova@vid.no) (A. Chalachanová).

<sup>1</sup> The article is a part of the PhD study of the first author.

<https://doi.org/10.1016/j.alter.2020.09.001>

1875-0672/© 2020 The Authors. Published by Elsevier Masson SAS on behalf of Association ALTER. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Pour citer cet article : Chalachanová, A., et al. Citizenship of persons with intellectual disabilities within the frame of inclusive research: A scoping review of studies to inform future research. *ALTER, European Journal of Disability Research* (2020), <https://doi.org/10.1016/j.alter.2020.09.001>

*Implications for further research.* – The citizenship of people with intellectual disabilities needs to get more attention regarding both the understanding of the concept of citizenship and its exercise, so that people with intellectual disabilities get a real chance to become equal partners in society and research.

© 2020 Les Auteurs. Publié par Elsevier Masson SAS au nom de Association ALTER. Cet article est publié en Open Access sous licence CC BY (<http://creativecommons.org/licenses/by/4.0/>).

## R É S U M É

### Mots clés :

Recherche inclusive  
Déficience intellectuelle  
Citoyenneté  
Dimensions de la citoyenneté

Ce bilan critique explore la question de la citoyenneté des personnes ayant une déficience intellectuelle ainsi que son expression dans les recherches sur l'inclusion. Le point de vue déductif adopté est celui des principes généraux énoncés dans l'article 3 de la CDPH. Le bilan utilise le cadre d'analyse proposé par Arksey et O'Malley. Sept bases de données ont été explorées pour trouver des articles de revues expertisés par des pairs datant de 2005 à 2019. Nos principales conclusions sont les suivantes : le terme citoyenneté est rarement mentionné ou rarement discuté explicitement dans les articles ; les articles mettent en évidence un grand nombre de dimensions diverses étroitement liées à l'exercice de la citoyenneté. Dans les articles, la citoyenneté est liée à la participation, à l'autonomie, à la prise de décision, à l'autodétermination et à l'intégration dans la société, mais les articles révèlent également des violations des droits et des obstacles à la participation à la société; une plus grande attention doit être accordée à la conceptualisation et à l'exploration de la citoyenneté des personnes ayant une déficience intellectuelle.

*Implications pour des recherches ultérieures.* – La recherche doit mettre plus l'accent sur la compréhension du concept de citoyenneté ainsi qu'à son exercice afin que les personnes ayant une déficience intellectuelle aient une chance réelle de devenir des partenaires égaux dans la société et dans la recherche.

© 2020 Les Auteurs. Publié par Elsevier Masson SAS au nom de Association ALTER. Cet article est publié en Open Access sous licence CC BY (<http://creativecommons.org/licenses/by/4.0/>).

## 1. Introduction

Inclusive research is an umbrella term uniting emancipatory and participatory approaches in research (Nind, 2014; Walmsley & Johnson, 2003). While participatory approaches in inclusive research are based on involving people with intellectual disabilities and their lived knowledge in different ways, emancipatory approaches focus more on the control those engaged in the research can have and stress the empowerment as one of the core values of research (Nind, 2014; Walmsley & Johnson, 2003). The emancipatory and deliberating values of inclusive research, together with the thought of equality and power balance, are central ideas for this research. Core values within the discourse of inclusive research build on citizenship, inclusion, participation, and recognition of people with intellectual disabilities as equal partners in research (Nind, 2014; Walmsley & Johnson, 2003). Following framework proposed by Arksey and O'Malley (2005) and Levac, Colquhoun, and O'Brien (2010), this review will explore dimensions of the citizenship of people with intellectual disabilities as they unfold in inclusive research projects. In the case of this study, the term inclusive research is used to cover the broad variety of participatory and emancipatory approaches within the field of research together with people with intellectual disabilities.

An increased interest in the concept of citizenship and disability in general has emerged during recent years (Halvorsen et al., 2018; Sépulchre, 2017; Stainton, 2017). The idea of citizenship is that it is never fully realized, and it always needs to be reconstructed and negotiated (Hansen, 2015). Citizenship is within CRPD rooted in relational understanding of disability (Skarstad, 2018) and build on the assumption of common human vulnerability, diversity, and interdependency (Lid, 2017a; Mackenzie, 2019). Relational perspective supports the idea of disability as a natural part of human diversity, human beings as naturally interdependent, human rights exercised through supportive structures, and understanding of human rights as equal for all regardless of abilities (Lid, 2017a; Mackenzie, 2019; Skarstad, 2018). In such relational perspective, citizenship is a multi-layered phenomenon which implies several dimensions, such as political, social, cultural and intimate. Dimensions of citizenship as they are applied in this study are deducted from the general principles in article 3 of CRPD and reflect the rights and citizenship connected to different areas of everyday life and research.

Understood in a constructive way, citizenship theories can guide positive and new paths for action and research (Duffy, 2017, p. 26). The citizenship of people with disabilities is a crucial goal within social policies and health and welfare services. It is connected to such fundamental rights as the right to vote, choose where one wants to live, choose with whom one likes to spend leisure time, get the opportunity to influence how the services are provided, and to get the right help with, for instance, decision-making. Citizenship, simply put, is about whether and how we can take part in shaping our local communities (Duffy 2006, 2017; Stainton, 2017).

However, research elaborating the significance of citizenship for people with intellectual disabilities is scarce (Sépulchre, 2017). This lack of attention toward significant dimensions of the citizenship of people with intellectual disabilities compared to the rest of society may be interpreted as marginalization and oppression of people in vulnerable situations who are not always able to claim their rights on their own. People with intellectual disabilities remain living in oppression, poverty, and exclusion, without society supporting their full citizenship (Bach, 2017).

The current review includes articles that were defined as inclusive studies in line with the principles suggested by Walmsley and Johnson (2003). The principles highlight how research should take into consideration the contribution of participants with intellectual disabilities. The scoping review included only articles that were defined as inclusive according to the original literature such as Walmsley and Johnson (2003) or Nind (2014). The authors did not evaluate how and in what details the principles were followed.

Approved in 2006, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006) emphasizes the rights of people with disabilities as equal citizens and provides a standard for evaluating these rights (McCausland, McCallion, Brennan, & McCarron, 2018). In such way, the CRPD serves as a promising catalyst for contextualizing and constructing the citizenship of people with intellectual disabilities, while at the same time raising the discussion about operationalization of citizenship. The CRPD also have a potential in strengthening the awareness of people with disabilities as equal citizens. In this review, the eight general principles in Article 3 of the CRPD were a central pivot for exploration and mapping of citizenship: (a) respect for inherent dignity and individual autonomy, (b) non-discrimination, (c) full and effective participation and inclusion in society, (d) respect for differences and acceptance of persons with disability as part of human diversity, (e) equality of opportunities, (f) accessibility, (g) equality between men and women, and (h) respect for the evolving capacities of children with disabilities (UN, 2006, p. 5).

The CRPD, especially the general principles in Article 3, serve as a deductive tool for operationalization of the dimensions of citizenship and function as an adequate lens for interpretation of citizenship related to people with intellectual disabilities in the journal articles selected for the scoping review. Against this background, this scoping review aims to take stock of the research and examine dimensions of the citizenship of people with intellectual disabilities as they unfold in inclusive research.

Researchers' position: the authors have worked together with people with intellectual disabilities in different settings, both as care workers and as researchers. All three authors have carried out studies within the field of inclusive research. Two of the authors have bachelor's degrees in social education, a

specific Scandinavian degree with a stress on the quality of life and services for people with intellectual disabilities, similar to the British disability nurse.

## 2. Methods

The framework proposed by [Arksey and O'Malley \(2005\)](#) and enhanced by [Levac et al. \(2010\)](#) has been used to structure this review. The scoping review follows the structure suggested by [Arksey and O'Malley \(2005\)](#). We adapted the step of consultation as proposed by [Levac et al. \(2010\)](#). Finally, we present and discuss our results with a purpose to inform future research.

### 2.1. Identifying the research question

What dimensions of citizenship based on the general principles in article 3, CRPD, unfold in inclusive research studies?

### 2.2. Identifying eligible studies

Eligible papers were identified through a thorough and broad iterative search in seven different databases: Scopus, Ebsco (Academic Search Elite, Cinahl, Eric, Socindex) and Pubmed. Google Scholar was used to identify additional sources and grey literature. Hand-searched articles were added in the later stages of the work. We looked for the articles published from 2005 to 2019. Adaptation of the CRPD by the UN in 2006 and increasing number of published inclusive studies that coincides with the same period influenced our decision in this regard. The preparatory search (pre-search) included the terms *inclusive research* and *intellectual disability* and *citizenship* with synonyms. The results of this search varied from two to four articles, depending on the database. We observed that many articles in the search results emphasized citizenship implicitly, and, therefore, the citizenship category was excluded as a search category. The process of searching for citizenship was changed to a more inductive search by looking for keywords often used when describing different dimensions of citizenship connected to participation, inclusion, autonomy, empowerment, community living, self-direction, political participation, voting and all the aspects embedded in the general principles in Article 3 of the CRPD. In what follows, we adapted the term intellectual disability to describe all the terms in the first searched category. In the latter searched category inclusive research is the most used umbrella term. The search terms in this study were as follows: “learning disabilities” or “intellectual disabilities” or “developmental disabilities” or “intellectual impairment” or “mental retardation” or “intellectual developmental disorder” AND “inclusive research” or “participatory research” or “participatory research methods” or “emancipatory research” or “participatory action research”.

### 2.3. Study selection

The CRPD and its general principles in Article 3 served as a lens when searching for traces and dimensions of citizenship in the articles. Article 3 was deconstructed into a practical tool for the reading and analysis of the abstracts and full texts. It served as a guideline when reading abstracts and keywords. Every principle in Article 3 was broken down to a specific description of what to look for in abstracts and keywords. As an example, paragraph six (f) reads ([UN, 2006](#), p. 6).

#### 2.3.1. Accessibility

We rewrote and adapted the general description of accessibility to a more specific version to make it easier to look for and identify suitable studies. In this case, we searched for the articles highlighting accessibility in any form. For example, articles that implicitly or explicitly explored accessibility in various forms, both physical and material, but also social, emotional, and spiritual, including access to services, participation in society and community participation.

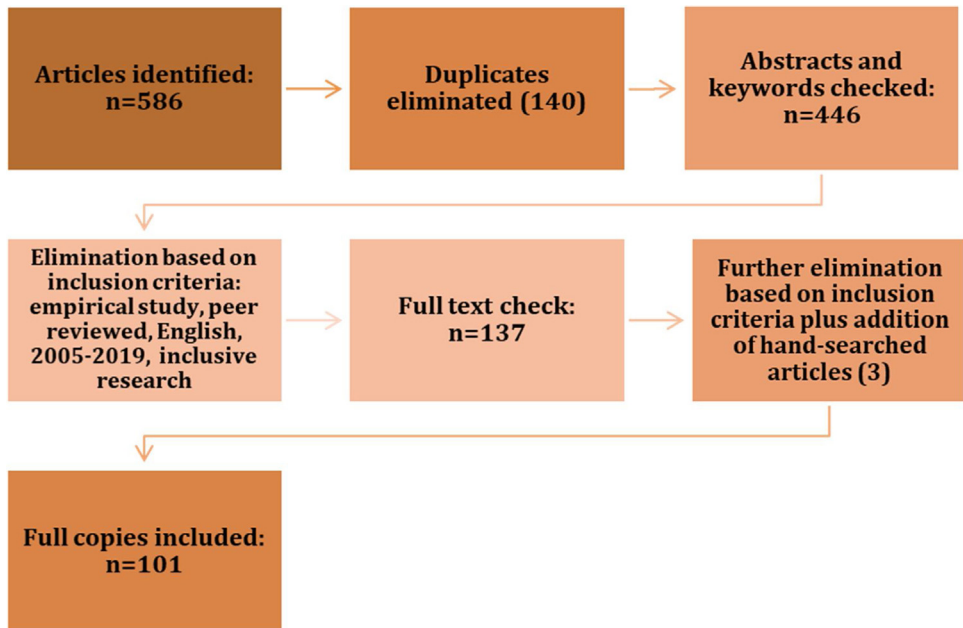


Fig. 1. Flow diagram of the selection process.

#### 2.4. Charting the data

Studies were included if they were peer-reviewed, empirical or based on empirical studies, based on inclusive, participatory, community-based participatory research or emancipatory research together with people with intellectual/learning/developmental disabilities where the voices of the co-researchers with intellectual disabilities were represented. Only articles written in English were included. We decided to include a wide range of articles within the field of inclusive research because we thought it was important to gain a comprehensive picture of the inclusive research area. Moreover, we wanted to make space for all the different approaches and voices and gain a comprehensive picture of the dimensions of citizenship and how they are embedded in the field of inclusive research. Only articles representing the voices of participants with intellectual disability were included. Fig. 1 shows a flow diagram of the search and selection of the articles. We did the search together, with support from a trained librarian.

#### 2.5. Collating, summarizing and reporting the results

Five hundred and eighty-six articles were identified from the search of the databases. After manually removing duplicates, we read 446 abstracts and keyword lists. Three hundred and nine of these did not meet the inclusion criteria.

For the reading of 137 full-text articles, we made an Excel spreadsheet table with several categories. After reading through the full text articles, additional 36 articles were excluded, reducing the number of remaining articles to 101. The spreadsheet table structured the systematic work with all the full copies. Categories in the spreadsheet table consisted of following categories: Author and year, country, title, research method, context/area explored, participants, categories according to the general principles in article 3 of CRPD, inclusion (Yes/No), comments.

The first author read all the full-text articles, while the second and the third authors each read half of the articles. All authors used the spreadsheet structure when reading the articles. After reading through the articles, the group met for discussion. Study after study was presented on a big-screen

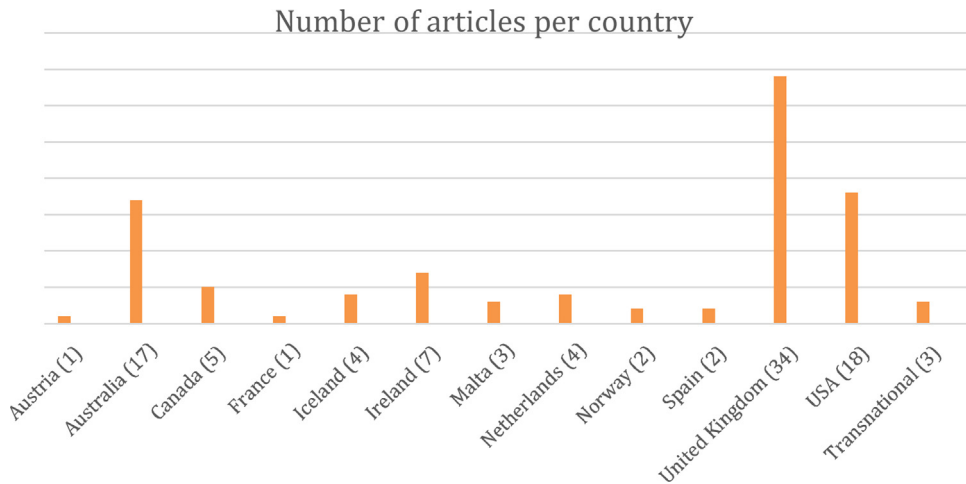


Fig. 2. Nationality and numbers of articles per country.

TV and discussed. Articles that we questioned after the first round of reading were highlighted and re-examined in the second round of reading and discussion. If the authors still disagreed, the articles in question were thoroughly read for a third time and discussed at greater length. The interrater reliability between authors was approximately 80%. The Excel spreadsheet was used for the analysis/extraction, calculation, and charting of the different categories as illustrated in the graphs of this study. Categories reflecting different parts of Article 3 of CRPD were further explored against the content of Article 3 and charted according to different dimensions of citizenship as presented in this scoping review.

### 3. Results

#### 3.1. General characteristics of the articles

##### 3.1.1. Nationality

The 101 articles included in the study originated from 12 countries. Three studies are transnational (see below for details). The number of studies from the UK and Australia reflects the longer inclusive research tradition in these countries. They were followed by the USA and their focus on community-based participatory research. Fifty-eight articles were published in Europe, twenty-three in North America and seventeen in Australia. The included articles represent the studies from countries that signed and implemented CRPD at different times. This may have had influence on the conducted studies. However, the scoping review did not evaluate included articles against adaptation of CRPD in respective countries. Overview of the nationality, number of articles per country below in Fig. 2.

##### 3.1.2. Publications by year

Results show how the publication of inclusive research articles involving people with intellectual disabilities has varied over the last thirteen years. Fig. 3 reflects the number of inclusive studies published per year from 2005 to 2019.

##### 3.1.3. Inclusive research approaches, methods, authorship, and participants

Methodologically, there was a variety of inclusive approaches employed in the articles included. Most often used terminology included umbrella terminology, such as, *participatory action research*, *collaborative research*, and *dialogue-based methodology*. American studies tended to use the term *community-based participatory research* (CBPR). Based on this, all the articles can be defined as inclusive research studies. Other additional/specific methods applied in the studies were methods such as

## Number of selected publications per year

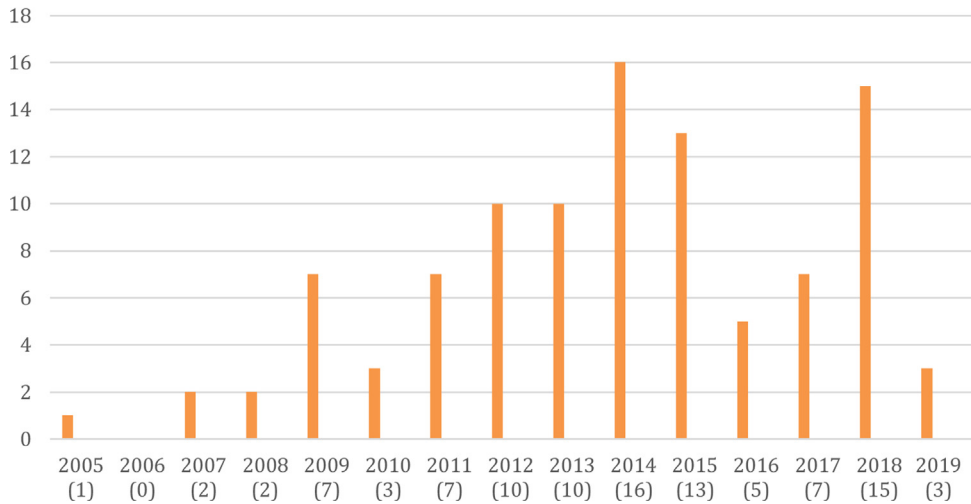


Fig. 3. Number of selected publications per year.

focus groups, photovoice, interview, seminar, forum theatre, narrative interview, questionnaires, and dialogue conference. One article was defined as an emancipatory study (Stevenson, 2010), and one study was fully inclusive throughout the whole research project (Walmsley & Team, 2014). This fully inclusive study was initiated, designed, carried out and published by people with intellectual disabilities. Ten articles reported from the same research project from different perspectives or with a focus on different parts of the selected project (Brake, Schleien, Miller, & Walton, 2012; Morgan, Cuskelly, & Moni, 2014; Morgan, Moni, & Cuskelly, 2013, 2015; Nicolaidis et al., 2015; Oschwald et al., 2014; Schleien, Brake, Miller, & Walton, 2013; Tilly, 2013; Tilly, Money, & Group, 2015; Walton, Schleien, Brake, Trovato, & Oakes, 2012).

All but seven articles were fully written by researchers. Those seven were co-written with or on behalf of co-researchers (Deguara, Jelassi, Micallef, & Callus, 2012; Flood, Bennett, Melsome, & Northway, 2013; Hopkins, 2009; Hreinsdóttir & Stefánsdóttir, 2010; Money & Tilly, 2012; Stefánsdóttir & Hreinsdóttir, 2013; White & Morgan, 2012).

The content of the articles varies thematically. Twenty-six articles highlight different aspects of inclusive research, research process, and decision-making in research, collaboration, building inclusive research networks, building capacities, and discussions on the needs for training of research skills. These articles focused on the participation of people with intellectual disabilities in the studies, in what way co-researchers had a say in the research, and in what way co-researchers influenced the research topics or content of the studies, how they built their research cooperation, or the barriers that hindered the research. Participants in the studies were people with intellectual disabilities both as co-researchers and as informants, relatives of the people with intellectual disabilities, researchers, university employees, and service providers. Only two articles included people with profound intellectual disabilities or people with high support needs (Rojas & Sanahuja, 2012; Williams, Ponting, & Ford, 2009).

### 3.1.4. Topics explored

Topics explored in the articles were rooted in everyday life and based on the needs or possibilities for full participation and accessibility in society in areas such as work, health, transition to adulthood, higher education, school, art, parenthood, sexuality or sexual identity, accessibility to, for example, historical sights, dental services, health services and activities supporting social inclusion, but also aging and well-being. We first sorted the articles in to dimensions based on thematic approaches

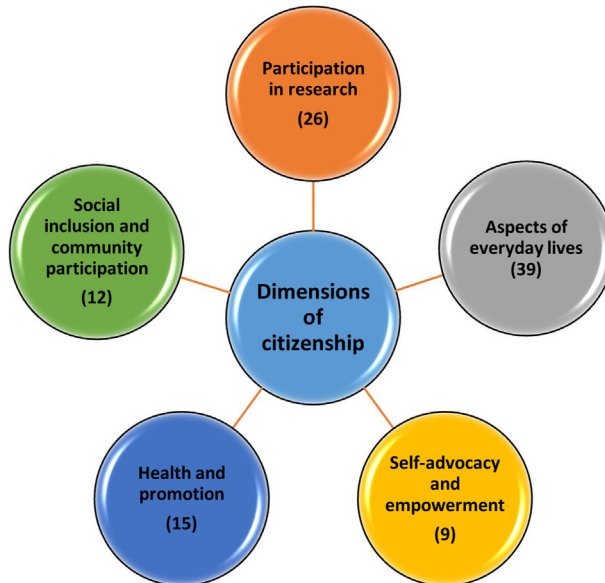


Fig. 4. Dimensions of citizenship.

and then collated them in to the smaller groups/subcategories based on topics explored for a more detailed overview in numbers. Seven articles explored development of a measuring tool or a training program that could ease accessibility or enhance quality of services provided to people with intellectual disabilities. Thirty articles (six articles in each subcategory) explored the following topics: (a) sexual identity or sexuality and sterilization, (b) relationships and friendship, (c) transition to adulthood, work or moving, (d) social inclusion and participation in society, (e) support. Ten articles (five articles in each subcategory) explored (a) health promotion or barriers to health promotion and (b) education and inclusive education. Four articles explored self-advocacy and building capacity. Nine articles (3 articles per subcategory) explored (a) oral healthcare/dental health, (b) life story, and (c) everyday life. Two articles highlighted empowerment and the other two abuse. The remaining ten articles explored an array of topics: poverty, intellectual accessibility, employment, mobile technology, development of a political voice, power, safety, well-being, aging, literacy, and parenthood. The variety of topics explored is wide and provides valuable information about the process of research (doing research together), methodological approaches and relevance of the research topics for the everyday life of people (citizens) with intellectual disabilities and their peers.

### 3.2. Dimensions of citizenship in the included articles

Only one article brings up and mentions the term *citizenship* (García Iriarte, O'Brien, McConkey, Wolfe, & O'Doherty, 2014). Others touch upon citizenship more indirectly by mentioning characteristics associated with citizenship, such as social inclusion, participation, council election, and accessibility. None of the articles uses any form of citizenship theories or frames citizenship in any other way.

Although almost none of the included articles define citizenship per se, by applying Article 3 of CRPD as a deductive lens, it is unquestionable that the citizenship of people with intellectual disabilities and its exercise are reflected in the studies implicitly (Fig. 4). All the included articles build, in one way or another, on the rights of people with intellectual disabilities to take an active role in their everyday lives or in research. The dimensions reflect important areas of everyday life where people with intellectual disabilities should get the opportunity to claim or practice their rights by, for instance,



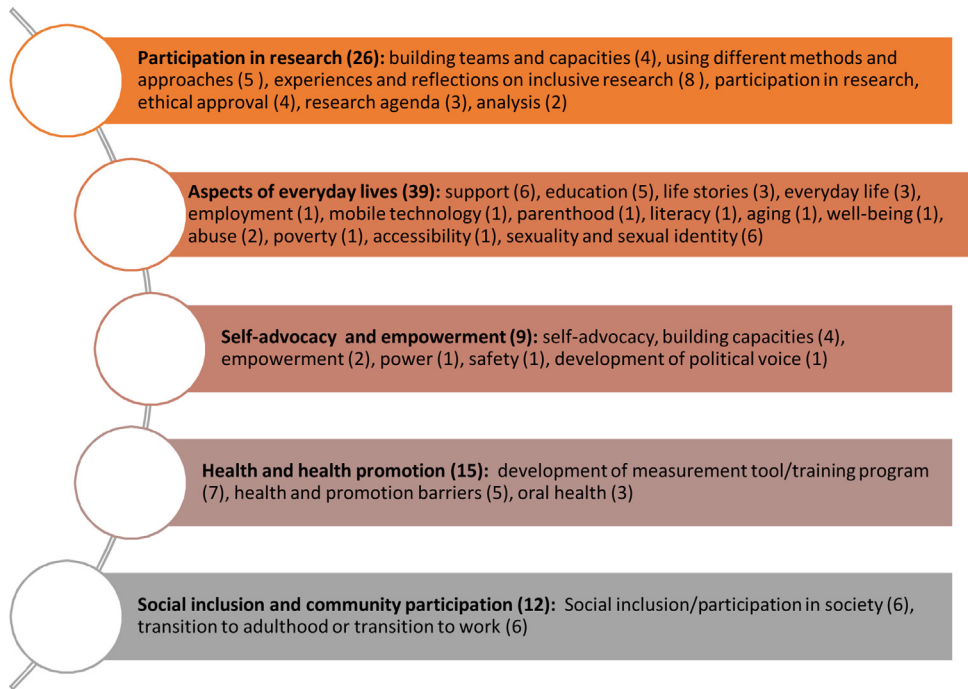


Fig. 5. Subcategories of different dimensions of citizenship.

facilitating exercise of rights as described in CRPD. Whether it is as partners in research (dimension 1), in everyday life (dimension 2), self-advocacy and empowerment (dimension 3), in the area of health promotion (dimension 4), or inclusion and participation in society (dimension 5).

The implicit meanings of citizenship in the articles are built on the assumptions of appreciation, acknowledgment, participation, and social inclusion and are connected to the social policy in general, and the importance of the voices of people with intellectual disabilities becoming a part of public discussions/voice, often justified by CRPD. The studies highlight how the inclusive research supports autonomy, empowerment, participation, and inclusion in society. By addressing issues that are of importance for people with intellectual disabilities, inclusive research might be essential for increased participation and inclusion of people with intellectual disabilities in research and in public life.

In Fig. 5, we suggest a more detailed picture of the dimensions. Some of the subcategories overlap and many articles could be placed in several dimensions. For instance, the first dimension is 'Participation in research.' Even though the focus in the article is research-related, many of the reflections in the articles are built on specific projects, such as about self-advocacy or support. The categories are hence informative.

#### 4. Consultation

The overall findings in this review regarding dimensions of citizenship for people with an intellectual disability in inclusive research studies indicate several significant results and information for future research.

Studies included in this review uncover that inviting people with intellectual disabilities to take an active part in research reveals both good examples of the exercise of the rights but also shows violation of the rights, hence barriers to citizenship. Information about barriers to citizenship gives research community and professional practice crucial knowledge about obstacles people with intellectual disabilities face daily.

We will now attend to the findings of the study. The first finding is that although citizenship is not explicitly mentioned or discussed in the included articles, nor was it in Sépulchres' (2017) review, different dimensions of citizenship are an implicit aspect in the included studies. The included studies reflect a variety of good practice examples concerning citizenship connected to research and everyday life. Articles stress the importance of accessible societies, supportive structures in the form of high-quality services, and supportive relationships with staff and family. The subcategories in Fig. 5 represent many examples of the importance of supporting structures and facilitating factors that ease, for instance, access to community life, the transition to adulthood, supportive relationships, accessible measurement tools, sexual health, etc. Besides, they name the challenges connected to these areas of everyday life. The included articles give examples of the importance of supportive relationships that ease exercise of the rights and participation in community. In that way, the relational perspective of citizenship enhances the exercise of citizenship that is based on the principles of equal rights for all, and not conditioned by ability (Lid, 2017b; Mackenzie, 2019; Skarstad, 2018).

By exploring different topics of everyday life, the studies uncover what works well and what the obstacles are. The articles thus have a potential in creating awareness about what citizenship might look like in these contexts. In what follows, the scoping review presents obstacles for citizenship as identified against article 3, CRPD.

The second finding regarding the citizenship of people with intellectual disabilities in the included articles is that the participants are expressing a violation of fundamental human rights in all aspects of their life. The studies included in the review, except for the studies focusing on research co-operation only, reveal that people with intellectual disabilities are not respected for their inherent human dignity and their individual autonomy is threatened. In addition, the participants with intellectual disabilities are experiencing discrimination and struggle with participation and inclusion in society often due to the absence of or neglect of supportive structures in the societies. Opportunities for people with intellectual disabilities are less promising and not equal compared to others and depend on support from outside, for example from families or service providers.

The findings in the included studies also reveal that people with intellectual disabilities are struggling with exercising their citizenship, claiming their rights or are even not recognized as citizens in all aspects of their everyday life. The included studies reveal that people with intellectual disabilities lack access to adequate health services and support, access to education and employment (St. John, Hladik, Romaniak, & Ausderau, 2018; Tilly, 2013; Timmons, Hall, Bose, Wolfe, & Winsor, 2011). In everyday life, people with intellectual disabilities experience neglect, abuse, poverty, marginalization, and lack of accessibility (Money & Tilly, 2012; Witsø & Hauger, 2018). The dimension of citizenship such as self-determination in everyday life or access to common goods are often taken for granted by others, but these shortcomings become very visible as an obstacle in the lives of people with intellectual disabilities. These citizens experience vulnerability to the point of being excluded from being recognized as equal citizens. Vulnerability regarding citizenship is central as persons who have been seen as dependent, such as persons with disabilities, have been excluded from political and social participation (Nussbaum, 2006, p. 33). Taxonomy of vulnerability entails both sources of vulnerability – that is, inherent, situational, and pathogenic for example cognitive impairment – and states of vulnerability, which are dispositional and occurrent (Mackenzie, Rogers, & Dodds, 2014, p. 1). In the context of citizenship for persons with intellectual disabilities, the sources of vulnerability relate to, for example, intellectual impairment leading to a need for individual services to support participation, and the states are occurrent in everyday situations such as access to education and exercise of rights.

The included studies reflect how the practice of citizenship is closely related to being interdependent on others (family, friends, staff, and community). Many people with intellectual disabilities require lifelong care and support from others. This need often implicates power relations where people with intellectual disabilities experience being disempowered, with decisions about their life often being decided by others. Thus, it is necessary to focus on the relational aspects of citizenship and to rethink the understanding of the subject. An understanding of individuals as independent of others excludes individuals who are identified as less independent (Kittay, 1999, p. 17). Family, friends, staff, and community are among the important structures to support citizenship for persons with intellectual disabilities. The term *citizenship*, therefore, is most properly understood as *relational* (Mackenzie, 2019).

Finally, yet also important, the studies are questioning inclusive research itself. Studies exploring research cooperation stress the importance of people with intellectual disabilities taking part in research but also how participation in inclusive research brings deliberation into the co-researchers' lives and supports, for instance, their empowerment, self-direction, and participation in community (Beighton et al., 2019; Ryan et al., 2015; Stack & McDonald, 2018; White & Morgan, 2012).

#### 4.1. *The role of inclusive research in relation to the conceptualization of citizenship*

Research question in the scoping review targets towards taking the scope of (implicit) citizenship as it is expressed in inclusive research. In general, all the articles mention how co-researchers' voices were included in the research and how important it was for people with intellectual disabilities to take part in research as equal partners. In this sense, we assume that the studies facilitate the exercise of the rights actively by acknowledging experience-based and lived knowledge of participants with intellectual disabilities as equally important as the knowledge of scholars. The situated knowledge represented by the co-researchers are thus valued as equally important as the scientific knowledge (Harding, 1992). However, there might be an imbalance in power between the researchers and co-researchers (Strnadová & Walmsley, 2018). Some of the articles describe in detail how the studies met criteria set by Walmsley and Johnson (2003) or what the obstacles were if they did not. Most often, researchers initiated the studies. All the articles emphasize the importance of including people with intellectual disabilities in research, especially when the research concerns different aspects of their lives or communities. Authors of the studies discuss the importance of co-researchers taking part in the studies and accommodation of the criteria to meet the needs of co-researchers and for co-researchers to become equal partners in research. The arguments in the articles are often built on the principles of inclusion and participation in society, deliberation, and empowerment. The articles discuss further, the importance of inclusion of people with intellectual disabilities in research that sheds light on different aspects of their lives and the research that contributes to the improvement of their living conditions, as well as how it increases accessibility in society with respect for their inherent dignity, with the right support and professional help. Even if the studies do not discuss citizenship per se, we can argue that inclusive research serves as a means of acknowledgment of co-researchers with intellectual disabilities as equal partners but also supports a notion of citizenship built on the values of respect for inherent dignity, accessibility, participation, and inclusion. As we only included papers where the voices of the people with intellectual disabilities were included, mostly welcoming research practices are presented, how to get research collaboration work rather than why or how the process was difficult. The scoping review did not explore whether and how the research process is transformed by the new practice of inviting people with intellectual disabilities to take an active part and control in research.

Inclusive research with its principles becomes a useful tool and supportive structure for the exercise of the rights of citizenship as proposed by Lid (2017b) but also as a context for exploration of the concept of citizenship. By paying close attention to accommodation of the research process for the real influence – not just a token participation of people with intellectual disabilities in research – researchers take an active part in supporting the exercise of citizenship of co-researchers who, despite ratification and implementation of acts safeguarding their rights, live in poverty or on the margins of society (Bach, 2017). Inclusive research, in this context, might also serve as a means for the conceptualization of and accommodation for exercise of citizenship. In addition, inclusive research can serve as an empowering tool that goes beyond the project and research topic itself (Strnadová & Walmsley, 2018). Set up against the general principles in Article 3 of CRPD, inclusive research itself supports the citizenship of people with intellectual disabilities, by rising awareness on the rights of the people with disabilities, and by stressing the importance of participation of people with intellectual disabilities in every area of their lives, research included. For instance, these articles meet several key principles in article 3, CRPD, such as respect for inherent dignity, empowerment, full and active participation in every area of society, respect for differences, and equality of opportunity. It does not mean that inclusive research answers the question of citizenship of people with intellectual disabilities, but it can become one of the tools for conceptualization and exploration of citizenship of people with intellectual disabilities.

#### 4.2. What dimensions of citizenship are not highlighted in the review?

None of the articles highlighted political citizenship and participation in elections. Additionally, articles were limited when it came to exploration of the civic duties of people with intellectual disabilities, regarding both work and participation in the local community in general.

### 5. Conclusions and future research

This scoping review has explored dimensions of citizenship of people with intellectual disabilities as it unfolds in inclusive research projects. The findings picture citizenship as a relational phenomenon (Lid, 2017a, 2017b; Mackenzie, 2019), depending on supporting structures from legal frame to individual support. Furthermore, the findings highlight human interdependency and the vulnerability of people with intellectual disabilities. Assuming vulnerability and interdependence as natural parts of being human (Kittay, 1999; Lid, 2017a, 2017b; Mackenzie, 2019), the findings show that the cognitive ableism our societies are built around (Bach, 2017; Stainton, 2017) devalue people with intellectual disabilities and prevent them from being equal members of societies. Inclusive research is built around values of appreciation and different but equal contribution of all participants when co-producing knowledge together with people with intellectual disabilities which might be a helpful reference when building down the cognitive barriers in society at large.

We have to pay attention and acknowledge the contribution of participants with intellectual disabilities in more distinctive ways, both regarding the research process itself but also how the participation in inclusive research influences other areas of life, such as relationships with staff, self-direction, and empowerment. All the included studies indicate in some way or the other that experiences with inclusive research are beneficial for co-researchers in different ways.

The articles implicitly highlight a broad range of dimensions of citizenship mostly connected to participation, autonomy, accessibility, decision-making, self-direction, and inclusion in society, but one finds references to violation of rights, powerlessness, discrimination and barriers to participation and inclusion in the society.

The findings in this scoping review can be concluded along two lines. The first one concerns dimensions of citizenship and included studies focusing on inclusive research. In all, 26 articles discuss the matters of inclusive research, which might serve as support for the notion of citizenship of people with intellectual disabilities as essential partners when researching matters of importance for the everyday lives of people with intellectual disabilities themselves. In the future, there is a need to pay closer attention to whether and how inclusive research supports the exercise of citizenship of co-researchers with intellectual disabilities or whether and how it creates an area for the exercise of citizenship. When inclusive research builds on the values of equality and exploration of the topics of relevance for and supporting the wishes of persons with intellectual disabilities, one might assume that inclusive research may play a crucial role for further exploration of citizenship of people with intellectual disabilities. It might also seem that inclusive research serves as a means of discovering barriers to the exercise of citizenship and the violation of the rights embedded in CRPD. However, it might not necessarily be the only way. More research anchored in theories of citizenship will highlight citizenship of people with intellectual disabilities in various ways. Other means of research may serve the same goal.

The second line is connected to the oppressive practices and barriers for citizenship as they are reflected in the articles. The scoping review shows that even though the CRPD has been a part of many legislatures for years, the rights of the persons with intellectual disabilities are still a target for oppression. More attention needs to be paid to the exploration of different dimensions of citizenship and the inclusion of people with intellectual disabilities so that all societies can develop supporting structures with respect and acceptance for human diversity. Inclusive research approaches might yield solid results when exploring oppressive practices as well.

Limitations of the literature review: most of the included articles involve people with intellectual disabilities who can speak for themselves and participate in dialogues in inclusive research projects. Nevertheless, people with intellectual disabilities do not represent a homogeneous group, but

rather are characterized by a diversity and variety of cognitive, communicative and social abilities and functions.

### Disclosure of interest

The authors declare that they have no competing interest.

### Acknowledgment

Thank you to the research group Citizenship for the consultation work on the article and all the constructive feedback.

### Références

- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32.
- Bach, M. (2017). Inclusive citizenship: Refusing the construction of “cognitive foreigners” in neo-liberal times. *Research and Practice in Intellectual and Developmental Disabilities*, 4(1), 4–25.
- Beighton, C., Victor, C., Carey, I. M., Hosking, F., DeWilde, S., Cook, D. G., et al. (2019). 'I'm sure we made it a better study. . .': Experiences of adults with intellectual disabilities and parent carers of patient and public involvement in a health research study. *Journal of Intellectual Disabilities*, 23(1), 78–96.
- Brake, L. R., Schleien, S. J., Miller, K. D., & Walton, G. (2012). Photovoice: A tour through the camera lens of self-advocates. *Social Advocacy and Systems Change Journal*, 3(1), 44–53.
- (2006). *CRPD, UN Convention on the rights of persons with disabilities*.
- Deguara, M., Jelassi, O., Micallef, B., & Callus, A. M. (2012). How we like to live when we have the chance. *British Journal of Learning Disabilities*, 40(2), 123–127.
- Duffy, S. (2017). The value of citizenship. *Research and Practice in Intellectual and Developmental Disabilities*, 4(1), 26–34.
- Flood, S., Bennett, D., Melsome, M., & Northway, R. (2013). Becoming a researcher. *British Journal of Learning Disabilities*, 41(4), 288–295.
- García Iriarte, E., O'Brien, P., McConkey, R., Wolfe, M., & O'Doherty, S. (2014). Identifying the key concerns of Irish persons with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(6), 564–575.
- Halvorsen, R., Hvinden, B., Beadle-Brown, J., Biggeri, M., Tøssebro, J., & Waldschmidt, A. (2018). *Understanding the lived experiences of persons with disabilities in nine countries: Active citizenship and disability in Europe Volume 2*. London: Routledge.
- Hansen, T. B. (2015). Citizenship as horizon. *Citizenship Studies*, 19(2), 229–232.
- Harding, S. (1992). Rethinking standpoint epistemology: What is “strong objectivity?”. *The Centennial Review*, 36(3), 437–470.
- Hopkins, R. (2009). Making research live!. *British Journal of Learning Disabilities*, 37(4), 330–331.
- Hreinsdóttir, E. E., & Stefánsdóttir, G. (2010). Collaborative life history: Different experiences of spending time in an institution in Iceland. *British Journal of Learning Disabilities*, 38(2), 103–109.
- Kittay, E. F. (1999). *Love's labor: Essays on women, dependency, and equality*. New York, NY: Routledge.
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation science*, 5(1), 69.
- Lid, I. M. (2017a). Martha C. Nussbaums politiske teori om rettferdighet som bidrag til et teoretisk grunnlag for likeverd og medborgerskap. *Fontene Forskning*, 10(1), 16–28.
- Lid, I. M. (2017b). Forestillinger om medborgerskap i lys av kjønn og funksjonsevne. *Tidsskrift for kjønnsforskning*, 41(03), 187–202.
- Mackenzie, C. (2019). *Feminist innovation in philosophy: Relational autonomy and social justice*. Paper presented at the Women's Studies International Forum.
- Mackenzie, C., Rogers, W., & Dodds, S. (2014). *Vulnerability: New essays in ethics and feminist philosophy*. Oxford University Press.
- McCausland, D., McCaillion, P., Brennan, D., & McCarron, M. (2018). The exercise of human rights and citizenship by older adults with an intellectual disability in Ireland. *Journal of Intellectual Disability Research*, 62(10), 875–887.
- Money, F., & Tilly, M. E. (2012). Having friends—they help you when you are stuck from money, friends and making ends meet research group. *British Journal of Learning Disabilities*, 40(2), 128–133.
- Morgan, M. F., Cuskelly, M., & Moni, K. B. (2014). Unanticipated ethical issues in a participatory research project with individuals with intellectual disability. *Disability & Society*, 29(8), 1305–1318.
- Morgan, M. F., Moni, K. B., & Cuskelly, M. (2013). Literacy strategies used by adults with intellectual disability in negotiating their everyday community environments. *Australian Journal of Adult Learning*, 53(3), 411.
- Morgan, M. F., Moni, K. B., & Cuskelly, M. (2015). The development of research skills in young adults with intellectual disability in participatory research. *International Journal of Disability, Development and Education*, 62(4), 438–457.
- Nicolaidis, C., Raymaker, D., Katz, M., Oswald, M., Goe, R., Leotti, S., et al. (2015). Community-based participatory research to adapt health measures for use by people with developmental disabilities. *Progress in community health partnerships: research, education, and action*, 9(2), 157–170.
- Nind. (2014). *What is inclusive research?* London Bloomsbury Academic.
- Nussbaum, M. C. (2006). Frontiers of justice: Disability, nationality, species membership. In *Tanner lectures on human values (Cambridge, Mass)*.
- Oswald, M., Leotti, S., Raymaker, D., Katz, M., Goe, R., Harviston, M., et al. (2014). Development of an audio-computer assisted self-interview to investigate violence and health in the lives of adults with developmental disabilities. *Disability and Health Journal*, 7(3), 292–301.

- Rojas, S., & Sanahuja, J. M. (2012). The image as a relate: Video as a resource for listening to and giving voice to persons with learning disabilities. *British Journal of Learning Disabilities*, 40(1), 31–36.
- Ryan, S. M., Yuan, S. J., Karambelas, A. M., Lampugnale, L. E., Parrott, B. J., Sagar, C. E., et al. (2015). "We are researchers": Students with and without intellectual disabilities research the university experience in a participatory action research course. *The Canadian Journal of Action Research*, 16(2), 70–82.
- Schleien, S. J., Brake, L., Miller, K. D., & Walton, G. (2013). Using Photovoice to listen to adults with intellectual disabilities on being part of the community. *Annals of Leisure Research*, 16(3), 212–229.
- Sépulchre, M. (2017). Research about citizenship and disability: A scoping review. *Disability and Rehabilitation*, 39(10), 949–956.
- Skarstad, K. (2018). Human rights through the lens of disability. *Netherlands Quarterly of Human Rights*, 36(1), 24–42.
- St. John, B. M., Hladik, E., Romaniak, H. C., & Ausderau, K. K. (2018). *Understanding health disparities for individuals with intellectual disability using photovoice*. pp. 371–381.
- Stack, E. E., & McDonald, K. (2018). We are "both in charge, the academics and self-advocates": Empowerment in community-based participatory research. *Journal of Policy and Practice in Intellectual Disabilities*, 15(1), 80–89.
- Stainton, T. (2017). Moving towards full citizenship and inclusion for people with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities*, 4(1), 1–3.
- Stefánsdóttir, G. V., & Hreinsdóttir, E. E. (2013). Sterilization, intellectual disability, and some ethical and methodological challenges: It shouldn't be a secret. *Ethics and Social Welfare*, 7(3), 302–308.
- Stevenson, M. (2010). Flexible and responsive research: Developing rights-based emancipatory disability research methodology in collaboration with young adults with Down syndrome. *Australian Social Work*, 63(1), 35–50.
- Strnadová, I., & Walmsley, J. (2018). Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *Journal of Applied Research in Intellectual Disabilities*, 31(1), 132–141.
- Tilly, L. (2013). 'I ain't been bothered to go': Managing health problems in people with a learning disability who live without support. *Diversity & Equality in Health & Care*, 10(4).
- Tilly, L., Money, F., & Group, M. E. M. R. (2015). Being researchers for the first time: Reflections on the development of an inclusive research group. *British Journal of Learning Disabilities*, 43(2), 121–127.
- Timmons, J. C., Hall, A. C., Bose, J., Wolfe, A., & Winsor, J. (2011). Choosing employment: Factors that impact employment decisions for individuals with intellectual disability. *Intellectual and developmental disabilities*, 49(4), 285–299.
- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities. Past, present and futures*. London and Philadelphia: Jessica Kingsley Publishers.
- Walmsley, J., & Team, C. E. P. F. H. P. (2014). Telling the history of self-advocacy: A challenge for inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 34–43.
- Walton, G., Schleien, S. J., Brake, L. R., Trovato, C., & Oakes, T. (2012). Photovoice: A collaborative methodology giving voice to underserved populations seeking community inclusion. *Therapeutic Recreation Journal*, 46(3), 168.
- White, E. L., & Morgan, M. F. (2012). Yes! I am a researcher. The research story of a young adult with Down syndrome. *British Journal of Learning Disabilities*, 40(2), 101–108.
- Williams, V., Ponting, L., & Ford, K. (2009). 'I do like the subtle touch': Interactions between people with learning difficulties and their personal assistants. *Disability & Society*, 24(7), 815–828.
- Witsø, A. E., & Hauger, B. (2018). 'It's our everyday life'—The perspectives of persons with intellectual disabilities in Norway. *Journal of Intellectual Disabilities* [1744629518774174].