

Supporting continued work under the UNCRPD – views of employees living with mild cognitive impairment or early onset dementia

Article

Published Version

Creative Commons: Attribution 4.0 (CC-BY)

Open access

Karjalainen, K., Issakainen, M., Ylhäinen, M., Marashi, S., Nedlund, A.-C., Boger, J., Astell, A. ORCID: <https://orcid.org/0000-0002-6822-9472>, Mäki-Petäjä-Leinonen, A. and Nygård, L. (2022) Supporting continued work under the UNCRPD – views of employees living with mild cognitive impairment or early onset dementia. *International journal of Discrimination and the Law*. ISSN 1358-2291 doi: <https://doi.org/10.1177/13582291221115266> Available at <https://centaur.reading.ac.uk/107862/>

It is advisable to refer to the publisher's version if you intend to cite from the work. See [Guidance on citing](#).

To link to this article DOI: <http://dx.doi.org/10.1177/13582291221115266>

Publisher: Sage

All outputs in CentAUR are protected by Intellectual Property Rights law, including copyright law. Copyright and IPR is retained by the creators or other copyright holders. Terms and conditions for use of this material are defined in

the [End User Agreement](#).

www.reading.ac.uk/centaur

CentAUR

Central Archive at the University of Reading

Reading's research outputs online

Supporting continued work under the UNCRPD – views of employees living with mild cognitive impairment or early onset dementia

International Journal of
Discrimination and the Law
2022, Vol. 0(0) 1–15
© The Author(s) 2022



Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/13582291221115266
journals.sagepub.com/home/ijdl



Katja Karjalainen¹ , Mervi Issakainen² , Marjo Ylhäinen¹ ,
Sheida Marashi³, Ann-Charlotte Nedlund⁴ , Jennifer Boger^{3,5} ,
Arlene Astell^{6,7,8} , Anna Mäki-Petäjä-Leinonen¹ and
Louise Nygård⁹

Abstract

This article reports the results of a socio-legal investigation into how continued work among people living with progressive cognitive impairments such as mild cognitive impairment (MCI) or early onset dementia (EOD) can be supported. This study that makes use of empirical data collected in Finland, Sweden and Canada seeks to give voice to people living with MCI or EOD and set their experiential knowledge in dialogue with equality rights related tools provided by the UN Convention on the Rights of the Persons with Disabilities (UNCRPD). The results illustrate that there are effective tools available that remove barriers to participation and support continued work of employees living

¹Law School, University of Eastern Finland, Joensuu, Finland

²Department of Social Sciences, University of Eastern Finland, Kuopio, Finland

³Department of System Design Engineering, University of Waterloo, Waterloo, ON, Canada

⁴Department of Health, Medicine and Caring Sciences (HMC), Division of Society and Health, Linköping University, Linköping, Sweden

⁵Research Institute for Aging, Waterloo, ON, Canada

⁶KITE Research Institute, University Health Network, Toronto, ON, Canada

⁷Departments of Occupational Science and Occupational Therapy and Psychiatry, University of Toronto, Toronto, ON, Canada

⁸School of Psychology and Clinical Language Sciences, University of Reading, Reading, UK

⁹Department of Neurobiology, Care Sciences and Society (NVS), Division of Occupational Therapy, Karolinska Institute, Stockholm, Sweden

Corresponding author:

Katja Karjalainen, Department of Law, University of Eastern Finland, Yliopistonkatu 2, Joensuu 80101, Finland.

Email: katja.karjalainen@uef.fi

with cognitive impairments at least for some time while impairments are mild. Ideally, flexibility and solidarity in the workplace automatically eliminates the effects of individual impairment. However, cognitive impairments are often such that along with general accessibility measures individual accommodations are needed. Supporting continued work expands the freedom to continue meaningful work in the preferred manner and offers people the means to gain a livelihood and participate in society as a member of the work community on equal basis with others.

Keywords

UNCRPD, reasonable accommodation, continued work, workplace, sociolegal study, dementia, accessibility

Introduction

This study is a socio-legal investigation conducted in Finland, Sweden and Canada into how continued work among people living with progressive cognitive impairments such as mild cognitive impairment (MCI) or early-onset dementia (EOD) can be supported. We seek to give voice to people living with MCI or EOD and set their experiential knowledge in dialogue with the human rights framework, in particular equality rights tools, provided by the UN Convention on the Rights of Persons with Disabilities (UNCRPD). We shed light on (1) what kind of workplace is accessible for a person living with cognitive impairment and (2) what kinds of individual accommodations can be made to enable them to continue working. In doing so, we combine our previous research on the legal framework ([Karjalainen and Ylhäinen 2021a](#), [2021b](#)) and experience-based knowledge regarding how to support continued work among people living with MCI or EOD.

In accordance with the functional and flexible approach to determining disability laid down in the Article 1(2) of the UNCRPD, we ignore the question of whether a person has a diagnosis. Rather we focus on long term de facto impairments and insufficiencies that affect employees' ability to fulfill the work tasks required under their existing work contracts. We draw from six cases which offer encouraging examples of situations in which people have continued to work in the context of employment relationships (as opposed to any form of self-employment) despite long-term cognitive impairment. Our focus is on the actions of the parties to the employment relationship – the employee and employer. The role of the public sector and, for example, occupational health specialists are excluded from the scope of the article.

Earlier research has documented the challenges faced in managing work and the tendency of early retirement when a person develops dementia while still employed (e.g. [Evans, 2019](#); [Issakainen et al., 2021](#); [Ritchie et al., 2018](#)). Several studies address the lack of support and understanding of reasonable accommodations that narrow down opportunities available for people living with dementia or mild cognitive impairment (e.g. [Chaplin and Davidson, 2016](#); [Evans, 2019](#); [McCulloch, et al., 2016](#); [Ritchie et al., 2020](#); [Silvaggi et al., 2020](#)). However, as supporting the continued work of employees living

with cognitive impairments may contribute to safeguarding their overall health outcomes and wellbeing, reduce stigma, promote participation and social inclusion (Egdell et al., 2018; Silvaggi et al., 2020) it is important to increase knowledge about tools that enable continued work (Egdell et al., 2021).

Importantly, the article also emphasizes a perspective of general accessibility and universal design that have as a scope structure of society. Structural support by general accessibility is of the utmost importance to the most vulnerable individuals – those who cannot or do not want to invoke accommodation rights, perhaps because they are in atypical employment that lacks the relative security of a stable employment relationship (Karjalainen and Ylhäinen, 2021a: 947, similarly in relation to legal capacity Ward, 2020: 14). Finally, the article contributes to widening understanding on the personal scope of the UNCRPD, which is often assessed in relation to people whose disabilities are not caused by unstable long-term illnesses, but are permanent, often innate, cognitive or physical impairments. For example, Donnelly has raised the same problem in relation to supported decision-making and Article 12 of the Convention (Donnelly, 2019).

The article is structured as follows. First, we describe the materials and methods on which this article is based. This part consists of explaining the legal framework provided by the UNCRPD and makes a reference to the national legal systems of Finland, Sweden and Canada. It also sheds light on how empirical data were collected and how these were analysed for the purposes of this study. Second, we report our results, which classify supportive tools as being either ‘general accessibility’ measures or ‘individual accommodation’. Third, we summarize and discuss our results.

Materials and methods

This study adopts a socio-legal approach (see e.g. Webley, 2020). It makes use of legal research into the UNCRPD and individual labour law as well as empirical data consisting of six cases which can be regarded as illustrative examples in relation to the topic at hand. Both the legal research and the empirical data form part of a larger multidisciplinary research project conducted in Finland, Sweden and Canada to explore what happens when people develop MCI or EOD while still working, how this interacts with legislation, and how it is experienced and managed by those concerned.

The legal framework provided by the UNCRPD

Working in the context of an employment relationship represents a significant way in which to participate in society. Article 27 of the UNCRPD provides that States must ensure that the right to work entails “the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities”. Article 27 is to be interpreted in accordance with the overall goal of the UNCRPD, which is to secure the social inclusion of all individuals despite their personal characteristics and faculties (Karjalainen and Ylhäinen, 2021a: 949-950). Persons with disabilities should be able to enjoy their human rights on

an equal basis with others as hindrances and obstacles to participation have been removed (Article 3).

The UNCRPD is a significant move away from a formal model of equality towards a substantive model of equality (CRPD/C/GC/6, para. 10). This means, *inter alia*, that in the context of the UNCRPD the prohibition of discrimination should be seen as only one of the means available to achieve the Convention's objectives (see e.g. [Quinn, 2009: 92](#)). Achieving substantive equality requires reinforcement of individual agency "by taking into account the systemic and structural constraints of that agency" ([Shephard, 2010: 136; Wolff and de-Shalit, 2007](#)). One can refer to combined capabilities, which means internal capabilities plus suitable political and social conditions in which to choose the relevant functioning ([Nussbaum, 2020: 2441](#)). To illustrate this, one can argue that, in terms of the scope of this article, this means (1) that the working environment is accessible in a way that it automatically supports the continued work of persons who have, for example, symptoms of MCI; or (2) their continued work is reasonably supported by individual measures to give them sufficient prospects of being able to gain a living by working if they choose.

Under the human rights framework provided by the UNCRPD, an employee's continued work can be supported at both collective (work environment) and individual (accommodations) levels, using equality rights related tools such as accessibility, non-discrimination and reasonable accommodation. The right to reasonable accommodation (see e.g. Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation [2000] OJ L 303/16 and case C-335/11 HK Danmark ECLI:EU:C:2013:222) serves as an illustration of the significance of supporting continued work (work capabilities). From the perspective of the goal of social inclusion. Supporting employees' continued work through the provision of individual accommodations leads in turn to further capabilities being realized as working facilitates, *inter alia*, gaining a livelihood and having significant relationships with others ([Nussbaum, 2006; Nussbaum, 2011; Wolff and de-Shalit, 2007](#)). Significantly, the provision of such support contributes to achievement of the goal of minimum justice ([Tjon Soie Len, 2017: 31-37](#)). Fairness entailing redistribution to address socioeconomic disadvantages and participation to reaffirm the social nature of people as members of social groups are important elements of this endeavour (CRPD/C/GC/6, paras. 23-24).

Even though this article focuses on continued work only from the perspective of the equality rights related tools provided by the UNCRPD, one must pay attention to the fact that national employment regulations play a significant role in relation to how the continued work of a particular individual is supported in different jurisdictions. In the Nordic countries, international, European and domestic equality rights supplement, in practice, the employer's traditional contractual obligation to support an employee's continued work. The employers have different kinds of obligations stemming from the labour law legislation that pinpoint the importance of maintaining work ability of the employees. For example, Chapter 2, section 1 of the Finnish Employments Contract Act (55/2001) and section 8 of the Finnish Occupational Safety and Health Act (738/2002) oblige employers to evaluate, support and maintain employees' work ability ([Karjalainen and Ylhäinen, 2021a: 955-958](#)). In addition, under section 12 of the Occupational Safety

and Health Act employers have a general obligation to ensure the accessibility of the work environment. The Swedish legal system addresses questions of work ability in similar vein (See e.g. [Lunning and Tojter, 2016](#): 488-489).

By way of comparison, under Canadian common law employees have the right to non-discrimination and to reasonable accommodation under the human rights framework (e.g. section 15 of the Canadian Charter of Rights and Freedoms, which concerns equality rights). However, employers are not subject to the kinds of contractual obligations relating to supporting continued work that exist in the Nordic countries. For example, the Ontario Employment Standard Act (Employment Standards Act 2000, S.O. 2000, c. 41) Part XV stipulating on termination of employment consists only of rules covering the formal procedure of termination of employment. It does not set forth any provisions regarding material conditions under which an employment can be terminated. In this sense, the human rights framework seems to have more importance in the Canadian legal context.

It is important that in Canada the absence of the need to meet contractual obligations related to work ability, rehabilitation and replacement of work tasks before ending employment relationships makes it significantly easier to dismiss employees than is the case under legal systems that impose contractual obligations aimed at protecting the weaker party to the contract (cf. e.g. [Lunning and Tojter, 2016](#); [MacNeill, 2003](#)). When there are no obligations based on the contract an employer can dismiss, inter alia, an employee with a disability that affects his or her work ability if the dismissal is not based on discriminatory grounds. It is up to the dismissed employee to prove that there is a reason to believe that dismissal is based on discriminatory grounds. In Nordic countries, the employer must show that it has sufficiently investigated the possibilities to continue the employment, and if such possibilities exist, whether the employer has tried to realize them. These obligations are based on the contract and standards in labour law legislation regulating it and must be fulfilled before an employment relationship is terminated.

Finally, it is important to note that it is up to individual employees as to whether to give information on their state of health and when. There are two obvious reasons for this. First, as illustrated by the cases below in practice a person themselves is the one who decides whether to disclose information on their state of health. Second, in many legal systems privacy rights restrict employers from gaining and using information concerning an employee's state of health. To give an example under section 5(1) of the Finnish Act on the Protection of Privacy in Working Life (759/2004) an employer has the right to process information concerning an employee's state of health only if there is a justified reason to do so and the information has been collected from the employee either personally or otherwise with the employee's written consent. Therefore, there is an inherent requirement of reciprocity that impacts on possibilities to support the continued work of an employee living with MCI or EOD (see e.g. [Karjalainen and Ylhäinen, 2021b](#): 562; similarly in relation to U.S, [Gates and Akabas, 2011](#): 382-383).

Empirical data and analysis

The empirical data used in this study include interviews with six people living with MCI/EOD: three from Finland, one from Sweden and two from Canada. The interviews were

conducted pre-COVID in 2019–2020 (i.e. the data do not reflect the impacts of COVID-19 on ways of working). The analysis was started by seeking preliminary insights from the Finnish data, including three cases that met the selection criteria: persons that had continued working despite long-term cognitive impairment and who worked in the context of an employment relationship, i.e. an employee not self-employed. Particular attention was paid to what contributed to creating an accessible work environment for individuals and supported their continued work. Also, to what kinds of accommodations/modifications, and when and how these had been made in each case. These insights were shared with the researchers in Sweden and Canada, following which they selected illustrative cases from their data and provided information on the work environment and accommodations/modifications that supported continued work in these cases. Then, the first authors (Issakainen and Karjalainen) developed a coding framework with main categories and sub-categories (Kvale, 1996) reflecting different socio-relational aspects (i.e. solidarity that realizes itself as cooperation and as a respectful and a caring atmosphere in the work community) and work-related aspects (in relation to work tasks, working hours, work environment, and various tools and strategies) that supported continued work in different cases. To bind individual views and experiences and the legal framework together (Kvale, 1996: 201), the first authors engaged in an ongoing discussion throughout the analysis and writing process. Amendments and revisions were made based on the other authors' comments and reflections.

The interviewees (two men and four women) were between 48 and 62 years of age. In Finland and Sweden, each person was followed over the course of 1 year during which the interviewees narrated their work-related experiences and current life situation. In addition, in relation to the Swedish interviewee, interviews were also carried out with related persons (her family and former work manager) to supplement the information. In Canada a two-part design was used. In the first part, semi-structured interviews explored the experience of people with MCI/EODs in the workplace and the challenges they experienced. In the second, part participatory workshops were organized to specifically examine their use of technology. Most of the data were collected in person, excluding three phone interviews conducted with one Canadian and two Finnish participants. In all, the data consist of 20 interviews (nine in Finland, seven in Sweden and four in Canada), which were audio-recorded and transcribed verbatim. Ethical approvals for the studies in the three countries were obtained from the local ethics review boards. The names of the interviewees discussed in this article have been replaced by pseudonyms.

Four interviewees were or had been white collar workers and two blue collar workers. Five had worked in the same organization for several years or even decades. At the time of their participation, Finns Sanna, Leena and Harri worked full-time, Joe from Canada was a seasonal worker, Maria from Sweden had just retired after 4 years of work following diagnosis, while Jane from Canada was employed but on long-term sick leave.

It is important to acknowledge that as the interviews focussed on subjective experiences of persons with MCI/EOD, the legal basis under which the continued work has been supported cannot be identified. The national employment context described in the previous section means that not all modifications to work or the working environment that contribute to supporting continued work are made under the human rights framework and

using equality rights tools it provides. However, this gap in knowledge does not compromise our aim. As stated in the introduction, the intent of this article is to shed light on: (1) what kind of workplace is accessible and (2) what kinds of individual accommodations enable continued work.

Results: Measures supporting continued work

The following section combines measures that support continued work described by people living with MCI/EOD and the human rights framework as comprising either collective (accessibility) or individual measures (the right to reasonable accommodation). The legal concepts of accessibility and reasonable accommodation overlap and interact both in theory and practice. The former is a general and collective right that focuses on an environment that ought to be equally accessible to all. The latter is an individual right that is needed if, in a particular case, general accessibility rights are not sufficient to remove environmental barriers or have not yet been realized to a sufficient extent. Formal equality is a precondition for these measures (see e.g. [Lawson, 2017: 365-367](#); CRPD/C/GC/6 para 42).

As our interviewees' views show, supporting continued work requires multidimensional reciprocity, interaction and trust within the work community: “[i]nclusion into the workplace is not just a function of reducing the extent to which individual characteristics and symptoms interfere with workplace policies and practices, but also a function of organizational responsiveness to these individuals as expressed through the attitudes and behaviours of management, supervisors and coworkers” ([Gates and Akabas, 2011: 375](#)). Hence, an inclusive and supportive approach of the employers and coworkers is important (similarly [Egdell et al., 2021](#)).

Towards an accessible work environment

The legal concept of disability as expressed in the preamble of the UNCRPD is organic and context-bound in nature: “an evolving concept, something that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”. The core element of disability lies in the dynamics between impairment and environment and, hence, takes into consideration individual circumstances. This means that the legal concept of disability acknowledges accessibility as a changing experience (see e.g. [Borsson et al., 2011](#)).

As laid down in the legal practice related to UNCRPD and working life, impairment must, in its interaction with obstacles presented by the environment, cause limitations that influence the possibility to attend fully to work or professional life. The case of Z. heard by the European Court of Justice (ECJ) well illustrates this interaction between impairment and the environment. In this case the Court stated that the medical condition of a woman who did not have a uterus certainly constituted a limitation resulting from physical, mental or psychological impairment, and that it was of a long-term nature. However, it was not in itself a condition that made it impossible to carry out her work or

constituted a hindrance to the exercise of her professional activity, meaning that her condition did not form a disability in the context of working life (ECJ 18 March 2014, Z, C-363/12, ECLI:EU:C:2014:159, paras. 79, 81).

As environmental barriers are at the core of disability, they must be mitigated as far as possible. Hence, Article 9 of the UNCRPD addresses accessibility. It is both a precondition for and a means of achieving de facto equality for all persons with disabilities (CRPD/C/GC/6 para 40). It requires States Parties to take appropriate measures to ensure access to persons with disabilities, on an equal basis with others, to, inter alia, the physical environment and to information and communications technologies and systems. Persons with disabilities must be able to participate fully in all aspects of life on an equal basis with others (Article 3). In an accessible work environment employees should have equal opportunities to work regardless of their individual characteristics, such as disability.

Based on our empirical data, the maintenance of an accessible working place in principle involves only the setting of general guidelines and structures for working but leaves space for individual freedom. Inter alia, flexible working hours for all employees, remote working possibilities or different kinds of technology (e.g. written working guidelines and communication tools) may remove barriers to work. For example, Harri was of the view that it might be good for him to work from home occasionally and that his work tasks would allow it. However, remote working was not an option at his workplace at the time. At Leena's workplace employees were able to modify their work schedules in collaboration with each other. This supported Leena in managing the organization of her own work.

The overall work community and all its members are crucial when it comes to the accessibility of the workplace. The work community removes environmental barriers via social support (see [Waddington et al., 2017: 85](#)). This support may be expressed in terms of colleagues' flexibility in organizing work tasks and shifts, and in terms of their solidarity when it comes to looking out for and respecting each other. Some interviewees noted the importance of their colleagues' subtle and patient responses to challenges they experienced at work. Maria was comfortable with being open with her diagnosis and trusted the judgement of her workmates, confident that they would let the boss know when she was no longer able to perform as required, which eventually happened after some years. Sanna conveyed the meaning of an open work culture in which admitting one's mistakes or omissions is possible without disclosing information regarding one's state of health. The supervisor's readiness to listen to an employee's views and experiences and respond in a natural and sensitive way to challenging situations is also important. For example, Sanna described how a supervisor who expresses an interest in how employees are doing contributes to an atmosphere that also facilitates the disclosure of difficulties experienced at work and creates space for negotiating support that enable the continuation of working. All in all, solidarity expressed in the work community supports a sense of belonging and help that manifests itself as "cooperation between differentially resourceful but equal individuals" ([Nadler, 2020: 172](#)).

It is important to note that flexibility related to general accessibility means that accessibility rights have an individual dimension, which comes to the fore especially in relation to use of technology in the workplace. Information technologies, for instance in

the form of reminders and calendars, may support an individual in managing their work tasks in important ways. For example, Sanna said that a chat system they used at work enabled her to ask colleagues for help and advice when needed. However, information technology may also become an additional burden to a person with cognitive impairment due to the need to keep pace with developments and keep one's skills up to date.

An accessible workplace leaves space for individual freedom and allows a person with disabilities to use his or her own strategies to manage work. Utilizing different tools and techniques, delegating tasks, carrying out preparatory work and asking for help are examples of these kinds of strategies. The strategies Jane employed included taking notes and creating to-do lists in a daybook, delegating some of her tasks to assistants at work, assigning specific places on her desk to put certain bills and reminders, and using colour-coding strategies for her notes and tools to help manage memory-related problems. Maria's strategy was to use named photos of people in her phone, and to arrive early to make sure she could choose the same desk most days. As Maria's case illustrates, there is a subtle line between these individual strategies and the employer's obligation to ensure the accessibility of the workplace and employees' right to reasonable accommodation. It is worth noting that individual strategies may have also been used because the employee considered them to be the only available option, for example in a situation in which the employer was not aware of cognitive impairment. For example, to compensate for memory-related challenges, Joe – who had not disclosed his cognitive challenges at work – started writing things down and asking for help from his co-workers. Sometimes a person indeed chose not to disclose information about their health or challenges they were experiencing due to the desire to find a way to manage their work by themselves or avoid stigma (see also e.g. [MacDonald-Wilson et al., 2011](#)).

Supporting continued work in a particular case

The UNCRPD provides a right to reasonable accommodation. It is an individual measure that contributes to supporting work capabilities, among other things. The right to reasonable accommodation being made in the workplace lies at the very core of Article 27.1. States Parties are to promote the right to work, inter alia, by ensuring that reasonable accommodation is made for persons with disabilities in the workplace (para i). Refusal to make a reasonable accommodation is discrimination. However, the right to have one's continued work supported by accommodation measures is not unlimited. The fulfilment of the right requires dialogue and in the context of work relations interpretation and balancing of conflicting rights ([Karjalainen and Ylhäinen, 2021b](#): 558).

The duty of reasonable accommodation is an ex nunc duty. It must be provided if it does not impose an undue burden on the other party, from the moment that a person with a disability requires access to non-accessible situations or environments (CRPD/C/GC/6, para. 24). The mode of accommodation depends on the social circumstances of a particular case. Among other things, the financial costs, the possibility of obtaining public support, the size of party who has the duty to accommodate and the length of the relationship between parties are mentioned as factors that must be evaluated in terms of reasonable accommodation (CRPD/C/GC/6, paras. 26-27). According to the Committee

on the Rights of Persons with Disabilities, accommodations include, for example, making existing facilities and information accessible to the individual with a disability, modifying equipment, reorganizing activities, rescheduling work and enabling access to support personnel (CRPD/C/GC/6, para 23).

The empirical data show that employees identified that their job descriptions were often changed to better fit their life situations, which may be considered as the application of individual measures that contribute to supporting continued work and thus as accommodation in the meaning of the UNCRPD. Maria, for example, was relieved of her leadership role and assigned to other work tasks in the same organization where she had been employed for a long time. These work tasks were flexible and chosen to utilize her skills (the carrying out of administrative tasks in the absence of time pressure). Specifically, she was selected to supervise a new employee and in turn had someone supervising all her work, with no individual responsibility. In a similar vein, Harri and Sanna struggled with stress related to management tasks and wanted to be transferred to a position involving less responsibility. In Harri's case, the change involved transferring some tasks to other employees by hiring new ones. Whilst undergoing memory investigations, Sanna considered whether to continue in or leave her management position. Receiving the diagnosis of early onset dementia helped make up her mind to seek a reduction in her responsibilities. Changing work tasks and obtaining support may, however, be a double-edged sword: the reduction in responsibility may come as a relief but may also lead the person to question their contribution to the organization that employs them. This highlights the need to consider how to accommodate work in a way that also maintains job satisfaction and identity as a contributing member of the organization.

One typical individual modification/accommodation the empirical data shed light on is changes to working hours. These changes may be hoped for or accepted by the individual him or herself, but they may have the downside of decreasing income. In Leena's case, night shifts and overtime work were removed to support the maintenance of a daily rhythm. Even though she adjusted to this change, it had a significant impact on her monthly income. Jane's work was also accommodated by reducing work hours after the organization she worked in disallowed remote working. This happened after her direct supervisor retired. The change in accommodation left Jane stressed and frustrated, because she did seek to continue remote working and discussed this with her new supervisor but was turned down.

As Jane noted, remote working may be an important way to support continued work. Remote work alleviated some of her symptoms and enabled her to continue working full-time. Maria also worked 1 day a week from home and as mentioned above, Harri took the view that working from home time to time would be a good solution for him, albeit he did not request this modification. Considering individual needs in terms of the work environment in general seems indeed to be a key element in the provision of accommodation. For example, Leena emphasized that it was best for her to continue working in a familiar place with familiar people instead of transferring to another that otherwise might better support the maintenance of a daily rhythm.

Communication between employee and employer (and other relevant stakeholders such as health care professionals) plays an important role when planning accommodation or providing support based on individual needs. Maria was very open regarding her health condition which allowed her employer to accommodate her work in multiple ways. Besides other measures, Maria had a weekly one-to-one meeting with her supervisor whom she knew well. The aim was to receive feedback on her performance and plan for the next week, and she carefully prepared topics for the meetings. In Sanna's situation, her supervisor and health care professionals encouraged her to contact them whenever she felt there was a need.

It may be that necessary accommodation cannot be evaluated if an employee does not reveal his or her health condition to an employer. This may be the case, for example, when an employee works in an atypical work relationship. Joe discussed the changes in his physical abilities with his employer, but he did not mention his challenges with memory and remembering tasks. As Joe's employer was unaware of his dementia, the employer only provided accommodation to support Joe with his physical challenges. A lack of communication between an employer and employee in relation to accommodation may be burdensome for the employee. The lack of communication between Joe and his employer resulted in him feeling continually overwhelmed and stressed, leaving him worried as to whether he would not be rehired for the job in the next season.

Discussion

In this socio-legal investigation, we explored experiential knowledge of the measures that can be used to support continued work among employees living with progressive-cognitive impairments such as MCI or EOD and set these measures in dialogue with the human rights framework and equality rights related tools provided by the UNCRPD. We classified potential measures as being either general accessibility measures or individual accommodations. Identifying the measures as general or individual pinpoints employers' obligation to promote equality by providing possibilities to work as their primary obligation and perceives individual accommodations as final measures.

As addressed in other studies, early retirement from work is not always necessary despite the challenges caused by progressive cognitive impairment (e.g. [Chaplin and Davidson, 2016](#); [Evans, 2019](#); [McCulloch et al., 2016](#); [Ritchie et al., 2018](#)). Previous research has however, reported that for example inconsistency of initial symptoms and subsequent delays in getting diagnosis, stigma associated with dementia, and ineffectiveness of adjustments may hinder continued work ([Ritchie et al., 2015](#); [Thomson et al., 2018](#)). There may also be a lack of knowledge of the feasible tools supporting continued work and of the requirements of relevant law and human rights standards ([Stavert et al., 2018](#)).

Ideally, the workplace automatically eliminates the effects of individual impairment to the extent that they are prevented from constituting a disability through flexibly taking into consideration individual characteristics and faculties and automatically supporting them. Our results suggest that accessible workplaces can be created by means of general guidelines and structures for working that also leave space for individual freedom (e.g.

flexible working hours for all employees and an opportunity to use one's own strategies to manage work). Furthermore, cooperation as well as respectful and a caring atmosphere in the work community contributes to inclusive working environment, including, for example, supervisor's and co-workers' subtle responses to challenges at work as well as supervisor's readiness to listen to an employee's views and experiences (also e.g. [Ritchie et al., 2020](#)). Thus, at the core of ensuring the social inclusion of all individuals despite disparities in their personal faculties is increasing general accessibility; in working life this means developing accessible workplaces. It supports the continued work of all employees, including those who do not meet the legal definition of disability or those who are unwilling to disclose their disability. General accessibility effectively eliminates possible problems related to lack of reciprocity and risk of stigmatization.

However, cognitive impairments are often such that along with general accessibility measures individual accommodations are also needed. The individual measures identified in this study include, among others, modifying work tasks, offering flexible working hours, remote working as well as providing individual guidance and opportunities to discuss work with one's supervisor (similarly e.g. [Egdell et al., 2018](#)). The question of what accommodations can be made depends on the individual employee's work tasks. For example, not all work can be done remotely or can be pace adjusted. Furthermore, adjustments should be reviewed regularly ([Thomson et al., 2018](#)) and support provided in a way that keeps visible how an individual contributes to the workplace through continuing to work ([Ikeuchi et al., 2020](#)).

The empirical data used in the present study included six example cases – all these cases were such that measures had been adapted to support continued work. While this is a small number of cases, these six cases, drawn from Finland, Sweden and Canada, offer valuable information on how international human rights can be promoted in practice and continued work among persons with cognitive impairments supported. The results of our study illuminate how a person living with cognitive impairment can both be given the support they need and positioned as an active and competent agent ([Nadler, 2020](#); [Nedlund and Taghizadeh, 2016](#)). The results can also be seen to apply to vulnerabilities other than MCI/EOD. For example, people living with mild traumatic brain injuries (TBI) benefit from similar measures to those living with MCI/EOD ([Fraser, 2011](#)).

In principle, human rights frameworks can effectively support continued work of people with MCI/EOD. This legal framework plays a significant role by expressing the measures to promote participation in working life as right of the person, which elevates the measures above the pure willingness of the employer. At the same time, it is important to note the significance of solidarity and trust in the workplace that has a positive effect on individuals' rights at the workplace. The focus of this article on the experiential knowledge of the people living with EOD/MCI limits the possibilities to evaluate instrumental impact of the legislation to the workplace practices. As the study does not address to questions, such as, (1) what was the legal basis under which the continued work was supported in cases under scrutiny? or (2) how have human rights norms been implemented to national laws? More research is needed to know whether legal systems offer adequate means to invoke equality rights related tools and to what extent the fulfilment of human rights lies on the "benevolence" of employers. References to national

legislations of the countries in which the study was conducted implies that there are significant differences in this respect.

To conclude, there are effective tools available that remove barriers to participation and may support continued work by employees living with MCI or EOD at least for some time while impairments are mild. Importantly, supporting continued work expands the freedom to continue meaningful work in the preferred manner and offers people the means to gain a livelihood and participate in society as a member of the work community on equal basis with others.

Acknowledgements

We would like to thank the people who took time to participate in studies conducted in Finland, Sweden, and Canada. Our thanks also go to professor Juha Rinne for his help in recruiting Finnish participants, Charlotta Ryd for collecting data in Sweden, as well as Parminder Flora, Karan Shastri and Erica Dove for collecting data in Canada. Furthermore, we would like to thank Canadian legal scholars and professionals (Kathleen Cunningham, Krista James, Ravi Malthotra, Sebastián Jodoin, Kerri Joffe) who offered their precious help in explaining Canadian legal framework in the field of labour law and non-discrimination law. All mistakes are of course our own.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was supported by the Academy of Finland (318848); Swedish Council for Health, Working Life and Welfare, FORTE r1b1rd(2017-02303); Canadian Institute for Health Research (MYB155683) under the framework of the JPI MYBL; as well as the Academy of Finland (314749), Canadian HIV Trials Network, (63, Ontario shores research chair in Dementia Well-being and Schlegel Research Chair in Technology for Independent Living.

ORCID iDs

Katja Karjalainen  <https://orcid.org/0000-0001-7794-5000>
Mervi Issakainen  <https://orcid.org/0000-0001-7471-2148>
Marjo Ylhäinen  <https://orcid.org/0000-0001-9766-9138>
Ann-Charlotte Nedlund  <https://orcid.org/0000-0003-0204-4536>
Jennifer Boger  <https://orcid.org/0000-0001-6150-151X>
Arlene Astell  <https://orcid.org/0000-0002-6822-9472>

References

Brorsson A, Öhman A, Lundberg S, et al. (2011) Accessibility in public space as perceived by people with Alzheimer's disease. *Dementia* 10(4): 587–602.

- Chaplin R and Davidson I (2016) What are the experiences of people with dementia in employment? *Dementia* 15(2): 147–161.
- Donnelly M (2019) Deciding in dementia: the possibilities and limits of supported decision-making. *International Journal of Law and Psychiatry* 66(1): 101466.
- Evans D (2019) An exploration of the impact of younger-onset dementia on employment. *Dementia* 18(1): 262–281.
- Fraser RT (2011) Employment interventions for persons with mild cognitive disorders. In: Schultz IZ and Rogers ES (eds) *Work Accommodation and Retention*. Berlin, Germany: Springer, 263–276.
- Egdell V, Stavert J and McGregor R (2018) The legal implications of dementia in the workplace: establishing a cross-disciplinary research agenda. *Ageing & Society* 38(11): 2181–2196.
- Egdell V, Cook M, Stavert J, et al. (2021) Dementia in the workplace: are employers supporting employees living with dementia? *Aging & Mental Health* 25(1): 134–141.
- Gates LB and Akabas SH (2011) Inclusion of people with mental health disabilities into the workplace: accommodation as a social process. In: Schultz IZ and Rogers ES (eds) *Work Accommodation and Retention*. Berlin, Germany: Springer, 375–391.
- Ikeuchi S, Omote S, Tanaka K, et al. (2020) Work-related experiences of people living with young-onset dementia in Japan. *Health and Social Care in the Community* 30(2): 548–557.
- Issakainen M, Mäki-Petäjä-Leinonen A, Heimonen S, et al. (2021) *Experiences of Influencing One's Own Life When Living with Working-Age Dementia*. Cambridge, UK: Cambridge University Press: Ageing & Society. DOI: [10.1017/S0144686X21001525](https://doi.org/10.1017/S0144686X21001525).
- Karjalainen K and Ylhäinen M (2021b) On the obligation to make reasonable accommodation for an employee with a disability. *European Journal on Labour Law* 12(4): 547–563.
- Karjalainen K and Ylhäinen M (2021a) Vammaisten oikeuksien yleissopimus ja sosiaalinen osallisuus – oikeus työhön. *Lakimies* 2021(6): 946–962.
- Kvale S (1996) *InterViews. An Introduction to Qualitative Research Interviewing*. Thousand Oaks, CA: Sage Publications.
- Lawson A (2017) Reasonable accommodation in the convention on the rights of persons with disabilities and non-discrimination in employment: rising to the challenges? In: O'Mahony C and Quinn G (eds) *Disability Law and Policy: An Analysis of the UN Convention*. Dublin, UK: Clarus Press, 359–374.
- Lunning L and Toijer G (2016) *Anställningsskydd: En Lagkommentar, Elfte Upplagan*. Alphen aan den Rijn, The Netherlands: Wolters Kluwer.
- MacDonald-Wilson KL, Russinova Z, Rogers ES, et al. (2011) Disclosure of mental health disabilities in the workplace. In: Schultz IZ and Rogers ES (eds) *Work Accommodation and Retention*. Berlin, Germany: Springer, 191–217.
- MacNeill KD (2003) *The Duty to Accommodate in Employment*. Aurora, Canada: Canada Law Book.
- McCulloch S, Robertson D and Kirkpatrick P (2016) Sustaining people with dementia or mild cognitive impairment in employment: a systematic review of qualitative evidence. *British Journal of Occupational Therapy* 79(11): 682–692.
- Nadler A (2020) *Social Psychology of Helping Relations. Solidarity and Hierarchy*. Hoboken, NJ: Wiley-Blackwell.

- Nedlund A and Taghizadeh LA (2016) To protect and to support: how citizenship and self-determination is legally constructed and managed in practice for people living with dementia in Sweden. *Dementia. The International Journal of Social Research and Practice* 15(3): 343–357.
- Nussbaum MC (2006) *Frontiers of Justice*. Cambridge, MA: The Belknap Press.
- Nussbaum MC (2011) *Creating Capabilities. The Human Development Approach*. Cambridge, MA: The Belknap Press.
- Nussbaum MC (2020) Harassment and capabilities: discrimination and liability. In: Wetzel v Glen St. Andrews Living Community, LLC. *The University of Chicago Law Review* 87(special issue): 2437–2452.
- Quinn G (2009) A short guide to the United Nations convention on the rights of persons with disabilities. In: *European Yearbook of Disability Law*. Cambridge, UK: Intersentia, Vol. 1, 89–114.
- Ritchie L, Banks P, Danson M, et al. (2015) Dementia in the workplace: a review. *Journal of Public Mental Health* 14(1): 24–34.
- Ritchie L, Tolson D and Danson M (2018) Dementia in the workplace case study research: understanding the experiences of individuals, colleagues and managers. *Ageing & Society* 38(10): 2146–2175.
- Ritchie L, Egdell V, Danson M, et al. (2020) Dementia, work and employability: using the capability approach to understand the employability potential for people living with dementia. *Work, Employment and Society*. Online ahead of Print. DOI: [10.1177/0950017020961929](https://doi.org/10.1177/0950017020961929).
- Shepherd C (2010) *Inclusive Equality. The Relational Dimensions of Systemic Discrimination in Canada*. Montreal, Canada: McGill-Queens University Press.
- Silvaggi F, Leonardi M, Tiraboschi P, et al. (2020) Keeping people with dementia or mild cognitive impairment in employment: a literature review on its determinants. *International Journal of Environmental Research and Public Health* 17(3): 842.
- Stavert J, Ritchie L, Danson M, et al. (2018) *Employer Responses to Dementia in the Workplace. A Report to the Carnegie Trust for the Universities of Scotland*. Stanford, CA: The Carnegie Trust.
- Thomson L, Stanyon M, Denning T, et al. (2018) Managing employees with dementia: a systematic review. *Occupational Medicine* 69: 89–98.
- Tjon Soie Len LKL (2017) *Minimum Contract Justice. A Capabilities Perspective on Sweatshops and Consumer Contracts*. London, UK: Bloomsbury.
- Waddington L, Priestley M and Yalcin B (2017) Equality of opportunity in employment? Disability rights and active labour market policies. In: Blanck P and Flynn E (eds) *Routledge Handbook of Disability*. London, UK: Routledge, 72–87.
- Ward A (2020) Incapacity law: visions for the future drawn from the unfinished story of a new subject with a long history. *International Journal of Mental Health and Capacity Law* 26(2020): 13–34.
- Webley L (2020) The why and how to of conducting a socio-legal empirical research project. In: Creutzfeldt N, Mason M and McConnachie K (eds) *Routledge Handbook of Socio-Legal Theory and Methods*. London, UK: Routledge, 58–69.
- Wolff J and de-Shalit A (2007) *Disadvantage*. Oxford, UK: Oxford University Press.