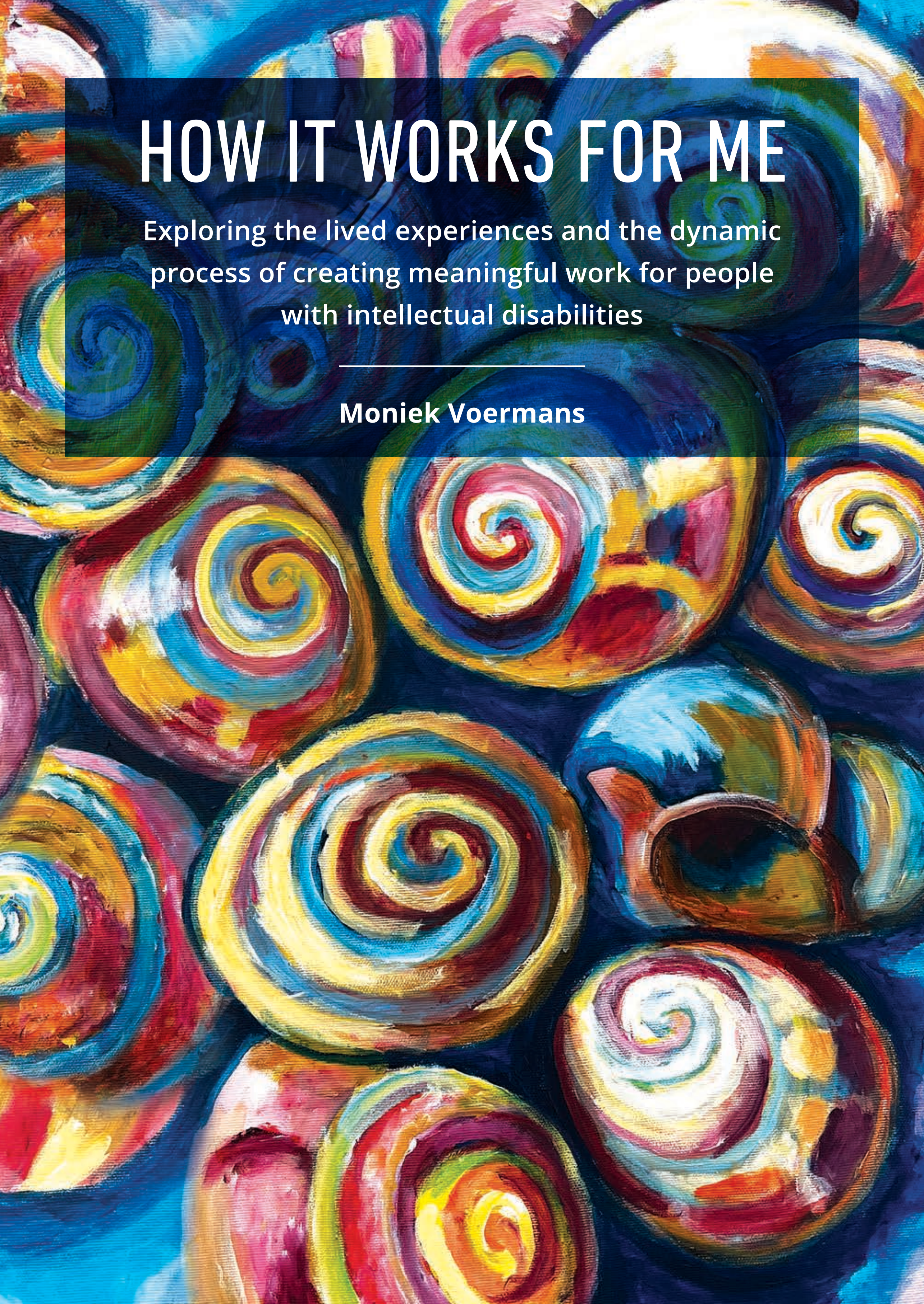
HOW IT WORKS FOR ME

Exploring the lived experiences and the dynamic process of creating meaningful work for people with intellectual disabilities

Moniek Voermans



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You shouldn’t ask ‘What can he do?’

You should ask things like ‘How far is he willing to go?’

Damian (pseudonym)

Table of contents

Chapter 1 Gerenal Introduction 9

Chapter 2 The value of competitive employment: In-depth accounts of people with intellectual disabilities 35

Chapter 3 Long-term social restrictions and lack of work activities during the Covid-19 pandemic: Impact on the daily lives of people with intellectual disabilities 61

Chapter 4 Informal network members’ perspectives and experiences on work for people with intellectual disabilities: A thematic synthesis 87

Chapter 5 The ‘perceived customer perspective’ of employers hiring workers with additional support needs: An exploration via two cases 125

Chapter 6 Employer perceptions of customer attitudes and their impact on the employment of workers with additional support needs 149

Chapter 7 General Discussion 175

Appendices Scientific summary 208
Wetenschappelijke samenvatting 219
Public summary 230
Publiekssamenvatting 232
Easy to read summary 234
Makkelijk lezen samenvatting 236
Dankwoord (Acknowledgements) 238
Curriculum Vitae 242
Publications 243

Chapter 1

General Introduction

In addition to the fact that the social inclusion of people with intellectual disabilities has increased in recent decades, the role of work more broadly within the lives of people both with and without intellectual disabilities has also undergone transformation. Given the importance of work to achieving social participation, there has been a greater focus upon promoting labour market participation for people with intellectual disabilities. This has been driven by the UN Convention on the Rights of People with Disabilities recognising the right of people with disabilities to have equal access to work as other people (United Nations [UN], 2006). However, the actual participation of people with intellectual disabilities in meaningful work has hitherto lagged behind (e.g., Van Echtelt et al., 2019). In light of this, this thesis aims to contribute towards extant knowledge about meaningful work for people with intellectual disabilities within the context of social inclusion. Moreover, this thesis aims to explore both the necessary conditions for facilitating meaningful work for people with intellectual disabilities and the factors that hinder it, in an attempt to increase their work opportunities.

Definition of Meaningful Work

This thesis is about work. Within this thesis the word ‘work’ is preferred to other common terms, such as ‘labour’ or ‘employment’, for the express reason that ‘work’ is broader in scope and, as such, more recognisable and meaningful to a larger group of people. The noun ‘work’ refers to both the activity and the results of the particular activity. In this respect, it differs from the noun ‘labour’ by virtue of the fact that ‘labour’ refers exclusively to the activity itself and is primarily associated with physical and manual work activities (Arendt, 1958). Cholbi (2023) describes work as activities that create goods, experiences, and states of mind that other people both have reason to value and can enjoy in their own way.

Today, the term ‘decent work’ is commonly used by international policy-setting organisations, including the UN and the International Labour Organisation (ILO). A person with decent work is someone who has a productive job with a fair salary in an environment characterised by equal opportunities for men and women, physical and social safety, opportunities for personal development and social integration, freedom to express concerns and participation within decision making (ILO, 2024). However, despite the focus within the concept of 'decent work' on fairness, equality and good working conditions, there remains scarce discussion over the meaning of work for workers (Blustein et al., 2023). Furthermore, both the economic value of work and arguments over what constitutes a fair salary dominate within the concept. This thesis deliberately sets out to move beyond the binary distinction between paid and unpaid work. One reason for this is that for many people with intellectual disabilities paid work may not be desirable or feasible, whilst unpaid work can still be experienced as meaningful and valuable (Bos & Elshout, 2023; Dearing, 2021). Therefore, this thesis adopts the concept of *meaningful work*, which is defined as work that is experienced by the individual as both personally meaningful and dignified (Rosso et al., 2010).

Definition of Intellectual Disabilities

Intellectual disability is defined by the American Association on Intellectual and Developmental Disabilities (American Association on Intellectual and Developmental Disabilities [AAIIDD], 2010) as "characterised by significant limitations in intellectual functioning and in adaptive behaviour, as expressed in conceptual, social and practical adaptive skills". Approximately one percent of the global population has an intellectual disability of some kind (Maulik et al., 2011). The number of people with an intellectual disability in the Netherlands is estimated to be 142,000, of which approximately 74,000 of whom are diagnosed with a mild intellectual disability (VGN, 2024). There is a tremendous degree of variety with respect to both the abilities and limitations experienced by people with intellectual disabilities (Vigna et al., 2023). Given that this thesis focuses upon meaningful work for people with intellectual disabilities, the term 'intellectual disabilities' is used consistently throughout the introduction. It is important to stress, however, that the last two studies within this thesis, which examine the perspective of employers, focused upon a broader group of people with disabilities. This decision was taken in order to prevent stereotypical images amongst employers, insofar as employers often employ workers with various types of disabilities without having any particular knowledge about their specific diagnoses. Moreover, researching a broader group also helps our aforementioned aim to improve the labour market position of people with different types of disabilities.

Work and its meaning for people

The meaning of work from a historical perspective

The intrinsic meaning of work for people, besides earning a living, has been the subject of philosophical inquiry for centuries (Cholbi, 2023). As early as antiquity, Plato already stressed the essential role of work within both personal and social life, whilst Aristotle viewed work as both a vehicle through which to realise human potential and a source of personal vitality. In the 18th century, Immanuel Kant linked the meaning of work to the capacity of autonomous decision making (Roessler, 2012), whilst in the 19th century, Karl Marx argued that work enables humans to be both rational and playful beings, insofar as it fosters creativity, social connection, and personal development (Cholbi, 2023; Stanford Encyclopedia of Philosophy, 2020). A century later, John Rawls asserted that a lack of meaningful work can lead to a loss of self-respect, and, therefore, that a stable society must ensure access to meaningful work for all its members (Rawls, 1996).

Despite the meaning that has historically been attributed to work within philosophy, people have long held a different perspective upon work. For example, during the industrial economy in the 19th and first half of the 20th century people had a mostly instrumental valuation of, and perspective upon, work, which framed it primarily in terms of income and job security (Van der Klink, 2016; Wilthagen & Stolp, 2021). At that juncture, a large amount of people within Western Europe had physically demanding jobs within the agriculture or industrial sectors, where they often spend their lives working (Van der Klink et al., 2016). Work was generally experienced as a necessary evil which was only done to earn income and often involved health risks (Achterhuis, 1984). Based upon this assumption, in the first several decades of the 20th century many countries implemented regulations that protected people from the negative effects of work, such as the introduction of the minimum wage and social security. These measures were predicated upon the notion of ‘distributive justice’ and sought to achieve justice through the distribution of income and wealth (Cholbi, 2023). The transition from the industrial- to the post-industrial economy in the latter half of the 20th century helped to profoundly change the meanings that people attributed to work. For example, in countries with stronger welfare systems the perspective upon work changed to a more intrinsic valuation of work (Van der Klink et al., 2016; Wilthagen & Stolp, 2021). After the transition to the post-industrial economy, in Western countries such as the Netherlands the nature of work changed towards less physically demanding jobs, with a large proportion of workers employed within the service sector, such as healthcare, education and ICT (Eurofound, 2012).

Contemporary meaning of work at an individual and social level

At the individual level, over the last several decades work has increasingly been recognised as a life-domain that, alongside earning a living, contributes towards people’s quality of life and broader health (Jahoda, 1981; Roeters et al., 2021; Van der Klink et al., 2016; Wilthagen & Stolp, 2021). Today, people who have access to meaningful work experience work as a life-domain that helps them realise their ambitions, values and life purpose (Boccalandro, 2021; Roe & Ester, 1999), alongside contributing towards their personal identity, self-esteem and social contacts (Jahoda, 1981). Abma et al. (2016) studied what aspects of work were valued amongst a large study population, and ultimately identified seven factors that makes people's work meaningful: 1) use of knowledge and skills; 2) development of knowledge and skills; 3) involvement in important decisions; 4) building and maintaining meaningful contacts at work; 5) setting own goals; 6) having a good income; and 7) contributing towards something valuable. Overall, they found that the extent to which individuals were able to realise the aspects of work that they personally valued were associated with positive work outcomes, such as work performance and sickness absence (Abma et al., 2016). Whilst contemporary studies show that access to meaningful work positively impacts upon people's happiness and health, the lack of access to meaningful work appears to have negative effects. Recent research stressed that doing work that is either not experienced as meaningful or experienced as useless negatively impacts upon people's well-being (Soffia et al., 2022). Moreover, the complete and long-term lack of access to work is found to be strongly associated with reduced physical and mental health amongst people (Marrone & Swarbrick, 2020). A meta-analytic investigation of 237 cross-sectional and 37 longitudinal studies by Paul & Moser (2009) demonstrated that unemployed people reported more distress and poorer psychological health than employed people, whilst 34% of unemployed people experienced psychological problems compared to only 16% of employed people. This meta-analysis strongly confirmed the correlation between unemployment and distress. In addition to a lack of income and social security, the negative effects of unemployment upon mental health can also be explained by the loss of additional elements of work, including structure, activity, social contacts and status (Jahoda, 1981; Creed & Bartum, 2006), and an inability to achieve one's personal values and life goals (Paul & Moser, 2009).

In addition to the individual meaning work affords, today work is also regarded as a vitally important means through which to achieve social participation (Wilthagen & Stolp, 2021). Work is perceived by Kalleberg (2009) as a core social activity in which the identity of the individual is central and simultaneously connects individuals to each other and situates people within the broader social system. In this respect, work is also deemed to be valuable for society as a whole, insofar as the sustainable employability of citizens within the contemporary labour market contributes towards people's broader wellbeing, which is increasingly important in light of the social and economic realities of an aging society (Roeters et al., 2021; Van der Klink et al., 2016). Given the largely positive and broad individual and social valuations of the meaningful nature of work for people, policies are increasingly shifting towards a more contributive notion of justice. In contrast to distributive justice, which aims to achieve justice via the distribution of income and wealth, contributive justice seeks to both endorse everyone's right to participate in meaningful work and protect people from unemployment (Cholbi, 2023).

Work for people with intellectual disabilities

Social inclusion through work for people with intellectual disabilities

Participation within meaningful work is also a goal that is pursued for people with intellectual disabilities, insofar as it is deemed to contribute towards their social inclusion and broader well-being (Beyer et al., 2010; Dean et al., 2018; Lysaght et al., 2009; Robertson, 2019; Taylor et al., 2022). However, the participation of people with intellectual disabilities within meaningful work is intertwined with the broader issue of social inclusion. Therefore, the social participation of people with intellectual disabilities via work must be situated within a broader perspective.

Prior to the 19th century, many people with intellectual disabilities lived and worked amongst others in society, and their disability was not specifically labelled as an intellectual disability. Due to the medicalisation of society from the end of the 19th century onwards, ever-more people have been labelled as 'deviant', such as people with intellectual disabilities. Special facilities were set up for these people, including residential institutions, special education, and sheltered workshops (Beltman, 2002). Since the 1970s, there has been a significant transformation with respect to both the lives and social position of people with intellectual disabilities, and their rights to full citizenship have been increasingly recognised (Verdonschot et al., 2009, Meininger, 2013). The deinstitutionalisation movement emerged within many Western countries, which, in turn, led to a significant amount of people with intellectual disabilities moving to live within community-based settings rather than living within large institutions outside the community (Hall, 2010; Mansell & Beadle-Brown, 2010). This movement aimed to promote social inclusion and improve the quality of life of people with intellectual disabilities by giving them access to common facilities and economic, cultural, and social activities, such as work.

Work is considered to be a significant component of community participation for people with intellectual disabilities (Simplican et al., 2015). Similar to the situation with living arrangements, work for people with intellectual disabilities historically took place primarily within segregated settings (Wehman et al., 2007). For example, between 1950 and 1980, people with intellectual disabilities within Western countries, such as the Netherlands and the United States, primarily worked within sheltered employment facilities (Dague, 2012; Meininger, 2013). In the Netherlands, the Social Service Employment Act (SSEA; *Wet Sociale Werkvoorziening* in Dutch) was introduced in 1969, which created employment within institutions for people with disabilities or mental illness in order to enable them to work regularly under adapted conditions. The majority of SSEA workers were employed within subsidised sheltered workshops where they were paid a minimum wage and performed basic tasks like assembling semi-finished products, repairing consumer goods and maintaining forests and parks (Van Eijkel et al., 2024). Both prior to and throughout the 1970s people with intellectual disabilities had no access to community-based work, especially not to paid work. Beginning in the 1980s, within Western countries, such as the Netherlands and the United States, supported employment became increasingly prevalent. Supported employment allowed people with intellectual disabilities to participate within community-based work through the provision of necessary support (Dague, 2012; Meininger, 2013). Ever since then, an increasing number of people with intellectual disabilities have been supported to participate within community-based paid work; however, there remains a large number of people with intellectual disabilities participating within work in either segregated or semi-segregated settings (Dague, 2012; Meininger, 2013).

Settings of work for people with intellectual disabilities

The opportunities for people with intellectual disabilities to engage in meaningful work vary across different work environments. These environments can be broadly defined as sheltered versus integrated environments (Metzel et al., 2007). Sheltered work can be described as work activities that take place within a facility in which most people have disabilities and work-related support and supervision are continuously available (Metzel et al., 2007). Sheltered work is subsidised by the state and can be implemented in different forms and environments, including sheltered workshops, day centres and vocational rehabilitation centres, either within non-profit organisations or for-profit organisations (Malo & Rodriguez, 2022; Metzel et al., 2007; Migliore et al., 2007). Integrated work can be defined as work activities "in a community setting in the general labour market where the proportion of workers with disabilities does not exceed the natural proportion in the community" (Migliore et al., 2007, p. 7). Integrated work can also be implemented in different forms, such as regular jobs within organisations without support, supported employment placements within organisations and self-employment (Metzel et al., 2007; Visier, 1998). There is considerable variation both within and between countries in the way that sheltered and integrated work environments are implemented and designed, including wage rates and how wages are paid, such as via actual salaries or income transfers (Malo & Rodriguez, 2022).

In their definition of community participation, Simplican et al. (2015) add a third element to the differentiation between sheltered and integrated work environments: *segregated*, *semi-segregated* and *integrated* settings. They conceptualise activities within *segregated settings* as involving only people with intellectual disabilities and paid staff and/or family members within sheltered facilities, such as sheltered workshops. Activities within *semi-segregated settings* are conceptualised as those activities that involve people with intellectual disabilities and paid staff and/or family members only, but which take place within community settings, such as a segregated group of workers in a factory, or activities that take place within segregated settings, but which include community members, such as work activities that are led by volunteering community members. Finally, *integrated settings* are conceptualised as those activities that take place within regular settings in the community, and thus involve community members.

Sheltered or integrated?

Despite the movement towards integrated work, a large amount of people with intellectual disabilities continue to work within segregated or semi-segregated settings (Dague, 2012; Meininger, 2013). Both the difference between sheltered or segregated and integrated work settings and its impact upon people with intellectual disabilities has received considerable scholarly attention in recent decades.

The majority of the research underscores the positive effects of diverse types of integrated work upon a range of outcome measures, including mental and physical health (Robertson et al., 2019), economic wellbeing, quality of life, self-determination, personal independence, reduced support needs (Taylor et al., 2022), social inclusion and empowerment (Kober & Eggleton, 2005). In addition to the strong evidence-base for the positive effects of the shift towards more integrated work settings for people with intellectual disabilities, there are also studies that specifically report positive effects related to the participation of people with intellectual disabilities within integrated work settings in comparison to segregated work settings. Specifically, higher rates of job satisfaction were found amongst people with intellectual disabilities within integrated settings compared to segregated settings (Akkerman et al., 2016; Kocman & Weber, 2016), in addition to better quality of life scores (Beyer et al., 2010; Randall et al., 2023). However, not all scientific studies endorse these findings, and, in fact, some indicate that people with intellectual disabilities experience similar amounts of job satisfaction (Akkerman et al., 2014) or quality of life (Blick et al., 2016) within integrated and segregated settings. Although several studies suggest that unemployed people with intellectual disabilities might experience disadvantages in terms of both their physical and mental health and participation within society (Banks et al., 2010; McGlinchey et al., 2013; Robertson et al., 2019; Taylor et al, 2020), research that specifically captures the impact of unemployment upon the lives of people with intellectual disabilities is scarce.

Integrated work may be beneficial to both people with intellectual disabilities themselves and the organisations that employ them. Lindsay et al. (2018) studied the benefits of hiring people with disabilities, such as intellectual disabilities, from the perspective of employers. They found that employers experienced benefits related to improvements in profitability, competitive advantage, inclusive work culture, and ability awareness within their workforce. For regular employees working within organisations, being involved in inclusive hiring practices provides them with opportunities to both contribute towards social justice and find social purpose within their working lives (Boccalandro, 2021), which, in turn, can increase employees' job satisfaction (Blake et al., 2019), performance (Hedblom et al., 2022), happiness (Curry et al., 2018) and health (e.g., Whillans et al., 2016). Consequently, within an inclusive company both employees with intellectual disabilities and their co-workers without disabilities who support them may experience making a valuable contribution towards society, which also positively effects their well-being.

However, making people with intellectual disabilities feel included within integrated work settings is a complex and dynamic process in which various factors interact across different levels, such as individual characteristics (e.g., skills), the nature of the job, conditions and characteristics of the work environment and the availability of support and accommodations (Vornholt et al., 2018). The impairments that many people with intellectual disabilities face can lead to a number of challenges within integrated work situations, including more time being needed to learn new tasks, limited memory capacity, slow motor performance, concentration problems, communication problems, reluctance to change roles and routines or struggles with stress and anxiety (Lysaght et al., 2009; Vigna et al., 2023).

Ongoing challenges in realising work for people with intellectual disabilities

Policies to promote work participation

In 2006, the right to full and effective community participation for people with disabilities were recognised in the Convention on the Rights of Persons with Disabilities (UN, 2006). The convention was adopted by a large number of Western countries, including subsequently by the Netherlands in 2016. The recognition of the right to full citizenship and participation within meaningful work boosted the implementation of policies aimed at helping people with disabilities, such as intellectual disabilities, participate in work, within several Western countries. However, there are notable differences between countries in terms of how these policies are pursued. Specifically, Shima (2008) distinguishes between three types of models within EU countries: I) a mainstreaming disability model with measures within all policy domains that aim at the inclusion of people with disabilities within integrated work; II) a separate and special policies model with measures that seek to create special and separate work opportunities for people with disabilities; and III) a mixed model in which the two previous approaches are combined. Countries that historically attached significant value upon the availability of sheltered employment, such as Belgium, Italy and Spain, implemented either the second or third models, whereas countries that explicitly aimed to increase supported employment, such as the Netherlands, UK and United States, implemented the first model (Malo & Rodriguez, 2022; Shima et al., 2008).

In line with the strategy aimed at the integrated work participation of people with disabilities in the Netherlands, the SSEA was replaced by the Participation Act (PA, *Participatiewet* in Dutch) in 2015. The PA assigned municipalities the responsibility of supporting citizens and employers in order to ensure that as many people as possible could participate within meaningful work (van Deth et al., 2016). In this respect, it served as an instrument through which to create more contributive justice within society rather than distributive justice, that is, a society in which everyone who is willing can make a contribution through work to society and can perform a valued social role (Wilthagen & Stolp, 2021). As part of its aim to enhance employment rates for people with disabilities, such as intellectual disabilities, the PA introduced a range of tools, such as providing wage-cost subsidies to employers who hire people with disabilities. In addition, a Social Agreement was implemented, which involved a job agreement (*banenafspraak* in Dutch) between trade unions, employers' organisations, and the government to create 125,000 additional jobs for people with work-limiting disabilities before 2026. This strategy is less coercive than the quota strategies seen in other countries, such as Belgium and Germany, where employers are required to employ a certain percentage of people with disabilities and are fined if they do not comply. However, these quota strategies have not led to higher inclusion rates within those countries that implemented them and, in fact, in some instances have been found to actually encourage stigma and discrimination (Vornholt et al., 2018). The Dutch public employment services (*UWV* in Dutch) assesses the labour participation rate of people, and in the event that people are assessed as having low work capacity, they will then be included within the so-called 'target group register', which means that they have the capacity to work, but require support and accommodations in the workplace (Van Echtelt, 2019). Furthermore, the PA closed access for new employees to sheltered workshops. The rationale for this, in addition to enhancing integrated work, was that employing people with disabilities within regular organisations through wage subsidies would be less expensive than employing them within sheltered workshops. At the introduction of the PA, there were years of waiting lists for sheltered workshops, as the flow to regular jobs was minimal (especially as a result of the Great Recession between 2008 and 2014). From then on, municipalities received a lump sum, an unconditional grant as an incentive to place people with disabilities, such as intellectual disabilities, within regular jobs in a cost-effective manner, alongside the provision of wage-cost subsidies to employers to compensate for employees' reduced productivity. Within the PA, municipalities may only offer sheltered work to employees with intensive support needs, such as when an individual needs continuous supervision and intensive support that cannot reasonably be provided by an employer (Van Eijkel et al., 2024). However, a number of years after its introduction, the actual effects of the PA are considered to be meagre. This is because only a small group of workers with intellectual disabilities have been able to find and maintain integrated work (Van Echtelt et al., 2019), which indicates that an inclusion deficit persists.

Inclusion deficit in work for people with intellectual disabilities

The 'inclusion deficit' refers to the fact that many people with intellectual disabilities who would like to participate within integrated work are left standing on the sidelines of the labour market, despite the implementation of policies like the PA, even within The Netherlands, a country with the highest level of labour market shortages in the EU. International research consistently underscores that people with intellectual disabilities participate much less frequently within integrated work than people without intellectual disabilities, including within countries that actively pursue participation in integrated work within their policies. In the United States, for example, Hennessey and Goreczny (2022) found that although 53% of people with intellectual disabilities would like to participate within integrated work, only a small number (8.6%) actually do compared to 78% of the general population (Winsor et al., 2019). The UK displays comparable numbers with only 5.1% of the adult population with intellectual disabilities participating within integrated work (NHS Digital, 2021). Furthermore, the outcomes of a UK project that was designed to lead young adults with intellectual disabilities into integrated work reported that only 23% of the project participants actually found employment within integrated work (Vigna et al., 2023).

Low participation rates of people with intellectual disabilities within integrated work have also been reported in the Netherlands. Recent measurements show that only 13% of people with intellectual disabilities are in integrated work, compared to 43% of people with physical disabilities and 86% of people within the general population (Zonneveld et al., 2022). With respect to the broad population of people with disabilities, it was noted that within the Netherlands the gap between the participation rates of people both with and without disabilities was larger than in comparable EU-countries. Specifically, whilst in the Netherlands 80% of the regular population participated within integrated work in 2015, which is higher than in other European countries, at the same time only 43% of people with disabilities within the Netherlands participated in integrated work, which is lower than the average 47% in Europe (Prins & Van Vuuren, 2015).

This inclusion deficit is far from desirable given the positive effects of meaningful work upon the health and well-being of people with intellectual disabilities (e.g., Robertson et al., 2019; Taylor et al., 2022). In light of this, the inclusion deficit may create a higher demand for health care, alongside resulting in a waste of talent and human capital (Wilthagen & Stolp, 2021), particularly within the rapidly changing contemporary labour market.

A changing labour market

A different type of society and labour market is currently emerging. Western society is facing the end of an industrial age in which material growth was central and natural and human resources were abundant. Society is increasingly coming to realise that the industrial society and labour market profoundly damaged both natural and human resources, and that society must therefore make complex decisions regarding the qualitative or selective growth of the circular economy, which places greater emphasis upon self-sufficiency (Putters, 2023). Currently, there is a major shortage in the labour market of teachers, employees within childcare, healthcare, ICT, technology, and so forth. This shortage will probably continue for the next 20 years, at least in the Netherlands (Olsthoorn & Roeters, 2023) and stands in marked contrast to the lagging work participation rates of people with intellectual disabilities. Both the changing labour market and its shortages, in addition to the inclusion deficit, necessitates being approached from the perspective of broad prosperity and requires actively tapping into unused labour potential, including people with intellectual disabilities (Olsthoorn & Roeters, 2023). However, despite the persistent labour market shortages, employers are still making little use of this untapped labour source. Notwithstanding the explanation that companies' lack of staff leads to work stress, which, in turn, prevents them from offering jobs to people with intellectual disabilities (Putman & Van Echtelt, 2022), other factors are related to the lagging participation rates within organisations.

Lagging participation within public and commercial organisations

Both public and commercial organisations can be considered the gatekeepers of the inclusive labour market and therefore have a crucial role to play, insofar as they determine whether or not job opportunities are offered to people with intellectual disabilities (Bredgaard & Salado-Rasmussen, 2020). Scholars have begun to identify the organisational factors that are associated with the inclusive hiring behaviour of organisations, such as the size of the company, fear of high costs and perceptions of the work performance of workers with intellectual disabilities (Borghouts-van de Pas & Freese, 2020; Bredgaard & Salado-Rasmussen, 2019; Dean et al., 2022; Nagtegaal et al., 2022). Ellenkamp et al. (2016) conducted a systematic review in order to capture work-environment-related factors associated with both the hiring and retention of people with intellectual disabilities. They found that employers who either had experience in hiring workers with intellectual disabilities or knew people with intellectual disabilities within their personal environment appeared to exhibit more favourable attitudes towards inclusive hiring than employers who lacked such experience. In addition, the assignment of fitting tasks and having feasible expectations were also found to contribute towards the performance of workers with intellectual disabilities. Finally, they indicated that the support of job coaches and workplace-culture-related aspects, such as management style, structure, social support, and the level of attention paid to diversity within the workplace were important conditions for the sustainable employment of workers with intellectual disabilities. In addition to factors within organisations and the work environment, scholars have also paid increased interest to how the perspective of customers relates to the inclusive hiring behaviour of employers (Essa, 2023). Customers are pivotal stakeholders in an organisation's success and survival (Chen et al., 2012). Within a service organisation, for example, customer contact often begins with employees and these interactions can strongly influence both the behaviour of customers and their perceptions of the organisation (Essa, 2023). Therefore, organisations can fear the negative reactions of their customers to their inclusive hiring practices (Dwertmann et al., 2023), especially within customer-facing industries (Houtenville & Kalargyrou, 2015). However, this fear does not necessarily correspond to the actual positive attitudes that many customers have towards inclusive employment practices (Dwertmann et al., 2023; Kuo & Kalargyrou, 2013; Siperstein et al, 2006). Therefore, the way in which employers' perceptions of their customers' perspectives may influence their hiring behaviour requires further attention within academic research. Given that customers can be considered as citizens who use the services of an organisation, research into customers' perspectives of organisations can provide expedient knowledge into how the employer perspective interacts with a broader societal perspective on inclusive employment. Other societal phenomena that potentially hinder the realisation of meaningful work for people with intellectual disabilities also warrant further attention will be discussed below.

Further social frictions to the inclusion of people with intellectual disabilities within work

Achieving the full social participation of people with intellectual disabilities requires adjustments and reformations across all layers of society. This necessitates, amongst other things, acceptance and support of citizens in their roles as colleagues, friends, or neighbours. It also requires the adaptation of generic services, such as public transport (Mansell & Beadle-Brown, 2010) and other social environments, such as workplaces (Ellenkamp et al., 2016). Policies and legislation were implemented to guide these necessary social reformations, such as the Dutch movement towards a participatory society from the previous decade onwards. This movement expected citizens to take responsibility for their own social environments (Putters, 2023), and was endorsed by both the Dutch ratification of the UN Convention for the rights of people with disabilities (UN, 2006) and the implementation of the PA (2015). However, the participation movement has not necessarily brought about the intended and required reformations within society. One reason for this is that the movement was accompanied by cuts in essential services, which, in turn, resulted in both citizens feeling abandoned and an increase in individualisation. These cuts gave the impression that the participatory movement might be driven by austerity goals (Putters, 2023).

In addition, despite the increased number of people with intellectual disabilities both living and working in society in recent decades, actual social inclusion often lags far behind the levels experienced by people without intellectual disabilities (Myers et al., 1998). People with intellectual disabilities either living or working within the community generally experience limited meaningful relationships with other people, such as friends and romantic partners (Giesbers, 2020), and little sense of belonging to society (Cobigo et al, 2012; Hall, 2010; Verdonschot et al., 2009). Parents and other close family members continue to play a crucial role in their social lives, whilst parents are considered by people with intellectual disabilities to be their principal source of emotional support (Giesbers et al., 2020). Moreover, parents and other close family members also typically play a crucial role in terms of both finding and retaining meaningful work for people with intellectual disabilities (Donelly et al., 2010). People with intellectual disabilities regularly experience significant social barriers to feeling included within society, such as stigma, discrimination, and rejection (Hall, 2005; 2010; Pelleboer-Gunnink et al., 2019). Researchers are paying increased attention to how stigma functions as a barrier to finding and retaining work for people with intellectual disabilities (Bonaccio et al., 2020; Vornholt et al., 2018). The mechanisms of stigma are complex, however (Rassett et al., 2022), and more knowledge is needed to better understand how the stigmatising attitudes of different stakeholders involved within the employment process, such as employers and their customers, can hinder the work participation of people with intellectual disabilities (Vornholt et al., 2018).

In parallel with stigmatisation, other societal changes may also complicate the full participation of people with intellectual disabilities. First, society in general has become *more complex*, due to individualisation, technological innovation and increased mobility, which has made participation within this complex society more difficult for some people as a result (Machielse, 2023; Wottiez et al., 2014). Moreover, participation within the labour market has also become more complex and demanding, as far as work requirements have increased and there is a stronger emphasis upon productivity and efficiency (Vornholt et al., 2018; Wottiez et al., 2014). The present model of society can best be characterised as meritocratic (Young, 1958), which is also reflected within the labour market. Within a meritocratic society, optimal developmental opportunities are offered to individuals and, ultimately, it is competition that determines which individuals perform best. In this form of coexistence, blame is placed upon individuals themselves if they are not able to seize upon certain opportunities that are presented to them (Swierstra & Tonkens, 2011). Although a meritocracy may create equal opportunities, it also produces unequal outcomes, especially for people with intellectual disabilities (Kolen, 2017). Further, the modern state has evolved into a *moralising and normative* state in which the government sets -implicit- standards for what constitutes good and normal behaviour, such as healthy living and self-reliance (Ankersmit & Klinkers, 2008). These standards are neither always self-evident nor achievable for people with intellectual disabilities (Kolen, 2017). Citizens tend to be less attentive to people who are different from those within their own networks and deviant behaviour is becoming less and less acceptable within society (Bos, 2016; Kamphuis, 2023; Machielse, 2023), which stands in contrast to the participation movement within society (Wottiez et al., 2014).

A contextual approach to work inclusion for people with intellectual disabilities

Realising inclusion within meaningful work for people with intellectual disabilities is a complex issue in which individual, social, organisational and community factors all potentially play a role. The most optimal way to realise work participation for people with intellectual disabilities can be seen as personal and dependent upon individual and social factors for a given person within a given situation (Hall, 2010). In order to better understand the research topic within the context of the increased complexity of society, exploring and organising information at the individual, social, organisational and community levels may prove expedient (Beltman, 2006). It is for this reason that a contextual approach was utilised within this thesis.

Within the contemporary intellectual disability literature, social inclusion is often conceptualised at an individual level, with individuals with intellectual disabilities regarded as the primary beneficiaries of social inclusion. Simplican et al. (2015), however, define social inclusion for people with intellectual disabilities from a contextual perspective. In line with Bronfenbrenner's theory (1986; 1994), Simplican et al. (2015) propose to understand social inclusion by capturing how individual, interpersonal, organisational, community and socio-political variables either promote or hinder social inclusion. Given that Simplican et al. (2015) consider meaningful work to be a pivotal component of social inclusion, this contextual perspective can therefore also be applied to better understand work inclusion.

Bronfenbrenner's model (1994) forms the basis of this contextual approach, which seeks to understand how both diverse social environments and the passing of time influences individuals' development. Bronfenbrenner distinguishes between the *individual level*, the *microsystem*, the *mesosystem*, the *exosystem*, the *macrosystem* and the *chronosystem*. The individual level refers to purely individual factors, such as gender. The microsystem encompasses activities, social roles, and interpersonal relationships that are within the direct environment of the individual, such as one's relationship with their parents. The mesosystem includes processes and direct interactions that occur between two or more settings within which the individual lives, such as the relationship between home and work. The exosystem designates interactions and processes within environments that indirectly influence the life of an individual, such as the work environment of a parent or partner. The macrosystem refers to the broader cultural, economic and political social system and the way in which, for example, overarching values and legislation indirectly influence the individual. Finally, the chronosystem pertains to how social and historical changes over time can influence individuals, such as technological or cultural changes. The precise way in which the different studies in this thesis are related to Bronfenbrenner's model will be outlined in the proceeding section.

Objectives of the research

Despite both growing awareness over the importance of participation within meaningful work for people with intellectual disabilities and ongoing efforts to promote work inclusion, the participation of people with intellectual disabilities within meaningful work still lags behind people without intellectual disabilities. There is a relative dearth of research within this area, and therefore specific knowledge is needed into how individual, social, organisational and community factors either facilitate or hinder the realisation of meaningful work for people with intellectual disabilities. Consequently, the aim of this thesis is to provide a more nuanced account of what meaningful work for people with intellectual disabilities entails, which conditions contribute towards its realisation, and how the factors that either promote or hinder its realisation may be related. This examination is grounded in a contextual approach and is based upon the experiences of the different stakeholders involved in the process of work inclusion. Research from this perspective can contribute towards both scientific knowledge within the field and a more comprehensive consideration of work within the context of 'broad prosperity.' Furthermore, it can help to put forward suggestions of how to improve the labour market position of people with intellectual disabilities. The studies within this thesis aimed to capture the perspectives of different stakeholders in order to gather information at the individual, micro-, meso-, exo- and macro levels (Bronfenbrenner, 1986; 1994).

First, this thesis explores the perspectives of people with intellectual disabilities themselves, which is important given the scarcity of knowledge available from their perspectives and experiences of the meaningfulness of work (Ellenkamp et al., 2016) at the individual-micro level. There is a need for more specific knowledge about both the experiences of people with intellectual disabilities who are involved in meaningful work within integrated settings and the impact and consequences of not having access to meaningful work, specifically due to the loss of work activities. Second, this thesis explores the perspectives of informal network members. Given the critical role they play in the lives of people with intellectual disabilities (Giesbers et al., 2020), they possess important knowledge at the micro-meso level that is relevant to bring to the surface. Gaining a better understanding of informal network members' perspectives upon the meaning of work for people with intellectual disabilities, as well as the role that informal network members can play in promoting work participation, can help to empower people with intellectual disabilities with respect to their labour market position. Finally, in their capacity as gatekeepers of the inclusive labour market, it is also important to explore the perspective of employers. In order to understand how barriers and facilitators at the meso-exo-macro levels can be associated with the inclusion of people with intellectual disabilities within organisations, this thesis explores how employers' perspectives can interfere with broader societal perceptions on inclusive employment. Given that customers can also be considered to be citizens, employers' perceptions of their customers' attitudes (or the 'perceived customer perspective') are explored in relation to their inclusive hiring behaviour. For the express purpose of preventing stereotyping amongst employers towards people with intellectual disabilities, the studies that investigate employers' perspectives focus upon a broader group of workers with disabilities than just people with intellectual disabilities. One reason for this is that specifically focusing upon a particular type of disability can evoke stereotypical images and responses from employers regarding the characteristics and skills of a worker (Stone & Collela, 1996). In addition, in practice many employers do not specifically focus upon hiring people with intellectual disabilities, but rather consider a broader target group of people with disabilities and, indeed, often do not have specific information about their workers' diagnoses. Moreover, adopting a broader focus can aid the gathering of knowledge that can help to increase the opportunities to engage in meaningful work for a broader group of workers who have additional support needs, and thus contribute towards a more inclusive labour market.

Outline of this thesis

This thesis comprises seven chapters, which present the results of the five research studies that captured the meaning of work for people with intellectual disabilities, the relevant conditions, obstacles and dilemmas from various perspectives and levels, that are introduced in the general introduction and then culminate in a general discussion. The present chapter establishes the context and underlying principles of the research (**Chapter 1**). The first two studies that form the basis of this dissertation explored the meaning of work for people with intellectual disabilities within the context of their broader lives. **Chapter 2** presents a study that explored the meaning of participation in integrated work from the perspective and experiences of people with intellectual disabilities themselves. Subsequently, **Chapter 3** unpacks a study that examined how a lack of access to meaningful work, specifically due to the loss of work activities, impacted upon the lives of people with intellectual disabilities during the COVID-19 pandemic, once again from the perspective and experiences of people with intellectual disabilities themselves. **Chapter 4** discusses a study that specifically focused upon both informal network members of people with intellectual disabilities and how they perceive and experience the meaning and conditions of work for their relatives with intellectual disabilities. The two final studies of this research outline a broader perspective upon the meaning and conditions of work for people with disabilities within the workplace. **Chapter 5** presents an initial exploratory study of employers' perceived customer perspective' and the role that this plays in terms of hiring and retaining workers with additional support needs due to intellectual and other disabilities. In **chapter 6,** a study is presented that further explores the role of the 'perceived customer perspective' within the hiring and retention of workers with additional support needs amongst a larger group of employers from different industries. Finally, the general discussion in **Chapter 7** summarises and interprets the results of this research as a whole, before proceeding to reflect upon these results in relation to other research in the area. Finally, based upon these results, avenues for future research are suggested, along with recommendations for policy and practice.

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Chapter 2

The value of competitive employment: In-depth accounts of people with intellectual disabilities

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Abstract

Background

Increasing the societal participation of people with intellectual disabilities via competitive employment requires a full understanding of what this means to them. This paper aims to provide an in-depth examination of the lived experiences of people with intellectual disabilities in competitive employment.

Method

Interviews were conducted with six participants with mild intellectual disability or borderline functioning and good verbal communication skills. Interviews were analysed according to the guidelines of Interpretative Phenomenological Analysis (IPA). Member checks were conducted.

Results

Analysis yielded three main themes: 1) Building on my life experiences, 2) My place at work, and 3) Being a valuable member of society, like everyone else.

Conclusions

Competitive employment could make a substantial contribution to the sense of belonging to society and quality of life of people with intellectual disabilities. Nevertheless, they must cope with stigma-related obstacles and feelings of being dependent on others in the work environment.

Introduction

In recent decades, the importance of full and effective community participation for people with intellectual disabilities has gained increasing recognition, from the perspective of both emancipation (UNCRPD, United Nations, 2006) and quality of life (Verdugo, Navas, Gómez, & Schalock, 2012). As is the case in the general population, employment is considered important for people with intellectual disabilities, as it allows them to experience community participation. Moreover, it is also thought to make a substantial contribution to people's quality of life (Beyer, Brown, Akandi, & Rapley, 2010; Lysaght, Cobigo, & Hamilton, 2012). More specifically, people who are employed experience a more structured and meaningful use of time, increased social opportunities and the possibility of using and expanding their skills (Donelly et al., 2010; Jahoda et al., 2009), in addition to benefits to their physical and mental health (Robertson, Beyer, Emerson, Baynes, & Hatton, 2019). People with intellectual disabilities perceive employment as a critical element of their community participation, as a source of social contacts and as a means by which to experience a sense of being appreciated (Cramm, Finkenflügel, Kuijsten, & van Exel, 2009; Donelly et al., 2010).

The employment of people with intellectual disabilities varies across different work environments. More specifically it can take place in a sheltered or integrated environment (Metzel, Butterworth, Sulewski, & Gilmore, 2007). Sheltered employment has been described as "employment in a facility where most people have disabilities, with ongoing work-related supports and supervision" (Metzel et al., 2007, p.151). Its forms include sheltered workshops, day centres and vocational rehabilitation centres (Metzel et al., 2007; Migliore, Mank, Grossi & Rogan, 2007). Integrated employment has been described as "taking place in a community setting in the general labour market where the proportion of workers with disabilities does not exceed the natural proportion in the community" (Migliore et al., 2007, p. 7). Its forms include competitive employment, supported employment, entrepreneurship and self-employment (Metzel et al., 2007; Visier, 1998). The specific characteristics of sheltered and integrated work environments, including wage rates and how wages are paid, can vary widely both within a country and between countries (Migliore et. al., 2007; Visier, 1998).

Several studies have examined whether the work environment affects the job satisfaction and quality of life of people with intellectual disabilities. Some studies suggest that the job satisfaction (Akkerman, Kef, & Meininger, 2018) and quality of life (Blick, Litz, Thornhill, & Goreczny, 2016) experienced by people with intellectual disabilities is similar in both sheltered and integrated employment. As indicated by systematic literature reviews, however, people with intellectual disabilities generally experience higher rates of job satisfaction in integrated employment environments (e.g. competitive employment) than they do in sheltered employment settings (Akkerman, Janssen, Kef, & Meininger, 2016; Kocman & Weber, 2016).

In line with these findings, international policies have focused on increasing the rate of competitive employment among people with intellectual disabilities. European countries are giving positive and negative incentives to both employers and people with poor job prospects (e.g. people with intellectual disabilities) (Borghouts-Van de Pas & Pennings, 2008). For example, quotas might be imposed on employers to oblige them to hire people with poor job prospects, and people with poor job prospects might receive positive incentives to find jobs (e.g. through financial and other forms of support).

Despite the focus on increasing participation in competitive employment among people with intellectual disabilities, the rate of paid employment for this group remains low in comparison to people without intellectual disabilities. In the general population, worldwide employment rates range from 42.6% to 85.5% (OECD, 2019). In contrast, the employment rates of people with intellectual disabilities in Western countries are estimated at between 7% and 49% (Holwerda, Van der Klink, De Boer, Groothoff, & Brouwer, 2013; McGlinchey, McCallion, Burke, Carroll, & McCarron, 2013; Rose, Saunders, Hensel, & Kroese, 2005). It is clear that there are still unequal employment opportunities for people with intellectual disabilities compared to people without intellectual disabilities.

In order to optimise the participation of people with intellectual disabilities in competitive employment it is essential to explore the experiences in competitive employment settings of people with intellectual disabilities themselves. However, in-depth investigations of the perceptions and experiences of people with intellectual disabilities with regard to employment participation are scarce (Ellenkamp, Brouwers, Embregts, Joosen, & Van Weeghel, 2016; Lysaght et al., 2012). The small number of qualitative studies examining the work experiences of people with intellectual disabilities revealed for example that being paid, staying busy and feeling connected to others in a community (Lysahgt et. al., 2009), feelings of belonging, a sense of contribution and enjoyment of work (Lysaght, Petner-Arrey, Howell-Moneta, & Cobigo, 2017) were experienced as the most important benefits of work by this group. However, these valuable studies, did not exclusively address the experiences of people employed in competitive work environments. A focus on competitive employment would, however, be valuable since competitive jobs in particular potentially offer the type of employment that is closest to full inclusion (Lysaght et al., 2012). In addition, establishing detailed accounts of the competitive employment experiences of people with intellectual disabilities in the context of their broader lives might result in a better understanding of how competitive employment is perceived in relation to aspects of quality of life and feelings of participation, as broadly defined by Lysaght et al. (2009; 2017). As such, scientific research might help to create competitive employment that fit the needs of people with intellectual disabilities in order to increase their emancipation and quality of life (and to prevent the negative consequences of unemployment). In addition, itmight encourage governments to adapt their policies in order to realise their effort to achieve full participation and equal opportunities in the labour market for people with intellectual disabilities.

Given the potential impact of work experiences on other life domains, it is imperative to examine the work experiences of people with intellectual disabilities in relation to the context of life beyond work (Jahoda et al., 2009). To this end, we draw on Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2008) to examine what participation in competitive employment means to people with intellectual disabilities. This qualitative research method explores in detail how small numbers of individuals make sense of their experiences in a specific situation, in consideration of their life context. The method corresponds well to the aim of this paper—to provide an in-depth exploration of the lived experiences of people with intellectual disabilities themselves with respect to their participation in competitive employment, embedded within the broader context of their lives.

Method

Participants

Prior to conducting this study, ethical approval was obtained from the Ethical Review Board of [XX] (EC-2017.101). Participants were recruited through a [country] service organisation for people with intellectual disabilities. As is common in [country], this organisation both provides residential and community-based support to people with mild to profound multiple disabilities at all ages. Psychologists and job coaches employed by this organisation were asked to select potential participants from file information, based on the following inclusion criteria: (I) a diagnosis of mild intellectual disability or borderline intellectual functioning (IQ scores between 50 and 85); (II) a paid job in a competitive employment setting and work experience of at least one year in such a setting and (III) little to no support from a job coach—

one or fewer sessions every six weeks (based on the lowest frequency of coaching offered by job coaches from that organisation to clients).

Potential participants were informed about the study by a familiar support worker and asked whether they would be willing to participate. The first author (MV) contacted those expressing willingness to participate by telephone to gather additional information and to answer any questions that arose. The job coach of one participant indicated that this individual would feel more comfortable receiving additional information about the study from someone more familiar. This participant was therefore contacted by the job coach rather than the researcher with a view to providing additional information and answering questions. Afterwards, an information and consent letter was sent to the participants, detailing the key aspects of the study and measures that would be taken to safeguard the confidentiality and rights of participants. Before starting each interview, the interviewer explained the content of the information letter to ensure that the participant understood the intention and procedure of the study and was aware of the option of terminating their participation at any time without giving a reason. Each participant signed an informed consent form.

Six individuals participated in this study. In IPA studies, a focus on a limited number of accounts is desirable. Small sample sizes allow for in-depth engagement with each individual case, and a detailed exploration of similarities and differences between participants. A sample of six is generally considered to be appropriate (Smith et. al., 2009). The research team considered the data obtained from the participants in the current study to be sufficiently rich and detailed to answer the research question in accordance with IPA guidelines. Demographic information was collected from the participants’ files (see Table 1), with their consent. Each of the participants received a salary, in some cases supplemented by state benefits. How their wages were paid depended on applicable legislation and their specific employment situations. Five participants were subject to the provisions of the [country] Disabled Assistance Act for Young Persons. This law regulates that people who are born with or who acquire a disability before the age of 18 can receive a financial benefit if they are completely or partially unable to work. The legislation is implemented by UWV, the organisation charged with administering work-related benefit schemes in [country]. The provisions of this law are tailored to reflect the needs in each individual case, depending on age, degree of disability and capacity to work. They therefore apply differently to each of the five benefit recipients who took part in this study.

Table 1. Descriptive personal data of participants

Participant (pseudonym)	**Gen-der**	**Age**	**IQ score***	**Type of work**	**Work hours (weekly)**	**Payment arrangement**	**Job coach**	**Service years**	**Work experince in years****
Mason	m	36	71	Order picker and forklift driver in a distribution centre	37	Regular payment	No	18	18
Luke	m	26	72	Host at two different restaurants	24+	Supplement to social benefits	No	6	6
Ryan	m	26	64	Short-term jobs as order picker and forklift driver via employment agencies	40	Regular payment (relapse into social benefits when unemployed)	No	0	>7
Damian	m	27	81	Car polisher at a car cleaning company	40+	Supplement to social benefits	Yes	1,5	10
Nancy	f	32	72	Supermarket employee (in addition to an unpaid job as an expert-by-experience)	16	Regular payment for working hours (supplemented to the level of social benefits)	Yes	1	>10
Elsie	f	35	74	Employee in the linen room of a nursing home and supporting tasks in day-care activities	27,5	Regular payment (employer receives wage cost compensation)	Yes	12	>12

Note.
*Based on file data
**At least one year in a paid competitive employment setting

Procedure

Semi-structured interviews were conducted according to IPA guidelines (Smith et al., 2009). The comprehensibility of the interview schedule was pilot-tested with three individuals with mild intellectual disabilities (other than the six participants), after which minor adjustments were made to the wording of the interview questions. The interview started with an open question — “Can you tell me something about your work?” —after which the interviewer followed an interview format consisting of key topics (i.e. type of work, tasks assigned, description of a workday, role in the team, support received), in order to explore the work experiences of the participants. The interviews lasted an average of 57 minutes each (range 44-80 minutes), with all but one of the participants being interviewed alone and in their own homes. One participant was interviewed at the office of the service organisation with the job coach present (but not interfering in the interview), as the participant felt more comfortable with this arrangement. Because of the iterative character of IPA, the next participant was not recruited until the interview with the previous participant had been conducted and analysed.

After the interview of a participant was analysed, the preliminary results were subjected to a member check with the participant. The member checks had a more structured character than the initial interviews. Because of the time interval between interview and member check (range 3-12 weeks; mean 7 weeks), the researcher started each member check by explicitly reminding the participant of when and where the first interview had taken place and what had been discussed. Subsequently, each personal theme identified by the research team as emerging from the initial interview was explained and presented to the participants both orally and in written format. The participants were then asked whether they recognised each theme and, if so, to provide additional information about what that theme meant to them personally. In cases where themes were not recognised, participants were given the opportunity to describe their own experiences. In addition, during the member checks, participants were asked to clarify any ambiguities that had emerged in the analysis of the main interview. With regard to the member checks we tried to minimise the risk of social desirability bias, by explaining to the participants prior to and during the member check session, the importance of telling the researcher if they did not recognise a theme or missed information. Member check sessions lasted an average of 42 minutes each (range 30-54 minutes). One participant was not able to participate in the member check due to unexpected personal circumstances. The interview with this participant was analysed and interpreted with additional care and prudence. Audio recordings were made of all interviews and member checks, with the consent of the participants, and these were transcribed verbatim by MV.

Analysis

All interviews and member checks were analysed according to the guidelines of IPA (Smit et al., 2009). The analyses were carried out by the first author, in close cooperation with the third author (SG). To ensure that interpretations made during analysis remained as close as possible to the narratives of the participant, the researchers frequently discussed the analysis until consensus was reached about interpretations and potential uncertainties. During the research process, the analyses were regularly discussed in meetings with the full research team as an extra audit and to refine the analysis. In addition, MV kept a reflective journal describing and explaining all decisions made throughout the research process.

After analysing both the interview and member check of one participant, the analysis of the member check was integrated into the analysis of the initial interview, thereby resulting in a more nuanced and in-depth elaboration of the overarching themes. In addition, several separate superordinate themes were merged into single superordinate themes after the member check. In other cases, broader superordinate themes were separated into several subordinate themes, based on additional information obtained during the member check. After all of the interviews and member checks had been analysed and integrated, the cases were compared and discussed to discover patterns (i.e. superordinate themes) in the experiences of participants in discussion with the full research team.

Results

Three interconnected superordinate themes emerged, with several subordinate themes distinguished within each. All of the themes are presented in Table 2 and elaborated below. The participants are referred to by pseudonyms, in order to protect their anonymity.

Table 2. Superordinate and subordinate themes

Superordinate themes	**Building on my life experiences**	**My place at work**	**Being a valuable member of society, like everyone else**
Subordinate themes		I feel people have a certain image of me	What I do is useful
		I don't have much choice	I don't know what I would do without my work
		I want to be treated as an equal by my co-workers	I want to earn a living, like everyone else
			I don't want to work among people with intellectual disabilities

Building on my life experiences

Participants report both positive and negative life experiences that have had a major impact on their work aspirations and their present and future working lives. Participants appreciate how previous work (and other) experiences have helped them to discover the types of work that they prefer, the job (and other) competences that they possess and the preconditions that they need within the context of work. For example, Luke's childhood memories of cooking with his grandfather inspired him to become a cook. Through several jobs as a cook, however, he has discovered that working as a cook in a kitchen does not suit him, and that he prefers the personal contact with guests he experiences when working as a restaurant host. In contrast to Luke's positive personal experience, Ryan talks about an unpleasant life event that forced him to relocate and to give up his permanent job. Years after moving, Ryan continues to work in rapidly changing, temporary jobs through employment agencies, even though he would prefer to have a permanent job, without the uncertainty of temporary employment.

Other participants also talk about obtaining or keeping a permanent job as being an important element in securing their goals for the future. Mason is determined to hold on to his current, permanent job for years to come, as he does not want to run the risk of feeling less comfortable in a new workplace. Nancy wants to obtain a permanent job, in order to build a retirement pension to ensure security for the future.

> *Nancy: I've been trying to find a permanent job somewhere for a long time, because I've also been working hard on building my future and those kinds of things, you know, but I always tell my job coach, I say that if I can only work a certain number of months each time, and then it's not renewed, you know, then I always say, 'But how? How do I build up a pension?*

In order to achieve the (future) work situations to which they aspire, all of the participants express a certain work ethic and awareness of the importance of aligning their behaviour. Participants talk about the importance of being motivated and demonstrating their drive and commitment to their employers and their willingness to accept tasks they would rather not do. Some participants exhibit their work ethic, more or less consciously, in order to influence their work environment and enhance job opportunities. For example, Ryan describes how he actively shows his motivation, flexibility and skills each time he starts a new temporary job, with the goal of ensuring that the employer will be satisfied and willing to keep him as an employee. In addition, Nancy is determined to go to work even if she feels sick, as she has been frightened by stories about other people losing their job due to illness.

For other participants, the work ethic seems to be driven purely by internalised standards or personal characteristics. For example, Elsie experiences completing her tasks as a personal responsibility. She feels uncomfortable when she fails to complete her tasks during a working day.

> *Elsie: Just the things that I'm assigned to do, I have to make sure that they're done before I go home. It's my responsibility. They assigned it to me, so... yeah, otherwise you won't feel right going home, at least I don't.*

Overall, the results reveal both similarities and differences between participants in terms of life experiences, personality, characteristics and skills. All of these aspects have an effect on how the individual participants experience employment, as well as on the ways in which they try to make an impression and sustain themselves in their jobs.

My place at work

I feel people have a certain image of me

In both their personal and work environments, participants experience stigmatising attitudes expressed by people without intellectual disabilities. For example, Elsie talks about how colleagues have disregarded her, overruled her and made her feel dependent, which has left her feeling insecure and has made her lose her focus and motivation to work.

Although experiences of stigmatisation have affected the self-confidence of Damian and Luke as well, these experiences have also strengthened their ambition to apply their capabilities to the fullest and prove other people wrong. Luke has done this by obtaining his diploma, thereby freeing himself from the negative perceptions of others and regaining his ability to believe in himself again. Luke also talks about how the unconditional support of his mother, grandfather and girlfriend has provided a base for growth and has helped him to counterbalance the negative views of other people. Additionally, Damian states that he sometimes experiences the well-intentioned behaviour of others as stigmatising and painful, as is the case when they take over his tasks. He feels an urge to prove himself in order to change such stigmatising attitudes and to build a relationship of trust with his co-workers.

> *Damian: Then it seems like, 'You can't handle it'. In other words, 'Well, sorry pal, but that? You can't do that'. That hurts me... when someone tells me, 'Someone else will do that', then I think, 'No! Heck, no! Absolutely not. I'll do it myself, even if it takes me three or four hours'. I'm just going to do it.*

> *And when it's finished three or four hours later, they come back and say, 'Is it taken care of?' or 'Is it done?' 'Yeah. Look!' Then they stand there like, 'Huh? Okay, you can do it after all'. Yeah, that gives you a kick. That gives you a kick. And again, that's the confidence that you can inspire in someone, and that someone can inspire in you!*

For Damian it is important that his employer demonstrates trust in him and his competencies when assigning new tasks. He explains how excessive efforts on the part of employers to adapt to the needs of people with intellectual disabilities could lead them to underestimate the capacities of these employees.

> *Damian: Because people do have a certain image, like, if they say, 'Yeah, he's disabled', then yeah, the first question people ask is 'What can he do?'. Right? And I think that's the wrong mindset, because I think, you shouldn't ask, 'What can he do, what can he do?' You should just ask things like 'How far is he willing to go?' Right? I can ask someone something like, 'Can you handle that?' or 'Do you want to try that?' Those are, those are two different things with, with an entirely different underlying thought.*

The experience of stigma thus triggers different feelings and responses among the participants, which subsequently have positive or negative effects on their work situations and careers.

I don't have much choice

Although all of the participants describe feelings of dependence, they experience this dependence as part of their relations with different individuals or authorities.

Elsie feels dependent on her co-workers, as she constantly needs their guidance and instructions during the course of her work, due to her lack of planning skills and insight into tasks. This nevertheless does not seem to bother her very much. In contrast, Ryan does not like the dependence he feels on the employment agencies for which he works. He experiences hardly any freedom of choice or control when it comes to choosing a temporary job. He feels that he has to take on any jobs that are offered him, because he can not run the risk of being unemployed or damaging his relationship with the employment agencies.

> *Ryan: When they, for example, if they call and say, 'We have this for you', then you almost have to accept it, because otherwise…*

Like Ryan, Damian feels dependent on the state benefit agency (UWV) and limited by the way the institute implements the government's legislation. In [country], the benefit agency determines how much salary individuals receive in addition to their social benefits. Damian does not consider this proportionate to his efforts. He feels that his capabilities and performance are undervalued financially and are not sufficiently recognised by the benefit agency. He feels unable to influence this situation.

> *Damian: The UWV… they've drawn a line, something like, yeah, someone with a disability can only do this, or can only do that, but this, no you can't ever say that… yeah, and then I think to myself, 'I drive to A. On my own. Z. on my own. I work 60 hours', but yeah, then, I could bring it up at the UWV, because you can also do that yourself, but yeah, it can be three years before you get an answer. So…*

As the observations presented above illustrate, the participants differ in terms of their characteristics and skills, particularly Damian and Elsie. These differences seem to be related to the ways in which participants deal with their work environments, which in turn seem to influence their opportunities. Damian's reflective ability and confidence in his potential seems to create a critical attitude towards employers and the benefit agency, while strengthening his capacity to create his own opportunities. In contrast, Elsie seems to be dutiful and insecure, thus rendering her more accepting of less desirable work situations.

I want to be treated as an equal by my co-workers

The participants attach considerable importance to a working atmosphere in which they experience equality, thus allowing them to feel comfortable and safe at work and to carry out their work properly. Both Nancy and Damian refer to past work experiences in which they did not feel that they were treated as equals. Nancy feels people treated her differently once they knew of her intellectual disability. Because she can not bear the feeling of not being treated as an equal, she has developed a tendency to conceal her disability from other people.

> *Nancy: I'm actually hiding my disability more, but I do that on purpose, because I just want to be treated normally, like anyone else…that happens an awful lot, because, if they know that you have a disability, they'll start treating you very differently, and that's not always good. Some people may be able to deal with that, but I can't.*

Elsie does not feel treated as an equal in her current work situation. She has nevertheless chosen to accept the current situation, as she feels that equality has improved in recent years.

> *Elsie: They accept me more, yeah, well, they, they, they react normally to me, just like they do with other people… uh, it could be a bit better [more equal], but I just think, like, 'That's how it is'.*

Being a valuable member of society, like everyone else

What I do is useful

Competitive employment makes the participants feel useful, although they differ in their perceptions of exactly what makes their work useful.

Some participants associate feeling useful with seeing concrete evidence of the added value of their efforts. For example, Damian is eager to perform tasks that are visibly useful, and he perceives this as a precondition for job satisfaction. He dislikes performing tasks that he does not feel make any substantial contribution (e.g. sweeping up leaves in autumn). Mason became aware of his added value to the company when he began to notice that less work gets done on his day off than on the days on which he works.

The participants further relate feeling useful to feeling appreciated by supervisors and customers. In particular, some participants appreciate the contribution that their work makes to the lives of other people. For example, both Luke and Elsie associate feeling valuable with caring for others. More specifically, Luke loves working as a host in a restaurant. By giving personal attention to his regular guests, he tries to make them feel welcome. In turn, he feels personally valued when guests enjoy his attentiveness. Elsie supports elderly people with daytime activities in the care home where she works, and she is aware that she can contribute to their quality of life by giving them personal attention.

> *Elsie: Then you have time for that resident, and that's what I really like about it… hmm, contact, just having a chat, for the resident, that in itself means a whole lot and, yeah, for myself, well, I think like, 'Now I've done something useful again', just because I also know that those residents get hardly any attention, and then I can do that myself, and they like it a lot.*

Thus, in addition to the actual utility of the work, the ways in which their work is appreciated by others makes the participants feel valued.

I don’t know what I would do without my work

All of the participants report that the need to spend their time working is important, although they differ in the level of importance they attach to this aspect. Luke, Ryan and Nancy note that it is difficult for them to get through holiday periods. Due to a lack of sufficient additional activities to which to devote their time, they often experience emptiness and boredom during these periods. In this regard, both Luke and Damian try to devote as much of their spare time as possible to work-related activities. For example, during holidays, Luke regularly performs chores as a volunteer at his girlfriend’s workplace.

> *Luke: I can’t live without work. I just can’t sit at home for a whole week… I’d be bored to death. No… I really can’t handle boredom. I, yeah, I just have to stay busy.*

In addition to giving them a way to spend their time, employment meets the social needs of participants. Damian, Nancy and Elsie all say that their social contacts would be reduced if they were unemployed. Damian regards work as an important place to meet people, and he therefore expects that he would not meet as many people if he were unable to work.

> *Damian: Yeah, if I didn’t work, what would I do then? I think that I would just sit at home all day. It would be harder, it would be harder to, say, just go into town or things like that, because once I’d get there, yeah, no one would strike up a conversation with me, like, ‘Hey, how’s it going?’ Yeah, right, yeah, you don’t meet people anywhere, so it gets a lot harder to, to meet people.*

Overall, the participants predict that they would experience emptiness in their lives, in terms of activities and social connectedness, if they did not work.

I want to earn a living, like everyone else

Participants say that being in competitive employment makes them feel like less of an exception. It gives them an ordinary place in society, making them feel able to participate in society like ‘everyone else’. For example, Ryan values having a job in a regular company, as it makes him feel part of the regular workforce. He expresses how important it is to him to be seen as a regular employee by emphasising that he and his co-workers regard the same issues as important. Mason considers earning a living to be the standard for every human being, including himself.

> *Mason: Yeah, [to me, an income means] the same as for anyone else, I guess. Yeah… we all have to work for our money, so, yeah. So, it's not just important to me. Any normal person probably thinks, like, 'It's important to work in order to have money'.*

Although Damian also expresses feeling connected to society through his paid job, he emphasises that his experiences differ from those of co-workers without intellectual disabilities. As noted previously, Damian experiences feelings of dependence on the benefit agency, but he also expresses feelings of injustice and inequality in the workplace. These feelings are based on the financial inequality that he experiences relative to his co-workers without intellectual disabilities.

> *Damian: Yeah [I have just as much to offer] as a regular co-worker, yeah, who earns a full salary, yeah. I don't see the difference. The only difference, and I'm not afraid to say it out loud, I think that, if you put me alongside a regular co-worker and we were both to wash a car, you wouldn't see any difference at all in terms of work, but if you put our pay slips alongside each other, you would immediately see who is on state benefit and who isn't.*

Despite their experiences of inequality, the participants regard having a competitive job as an important means through which to feel part of society.

I don't want to work among people with intellectual disabilities

Taking their place in society often seems to pose a challenge to people with intellectual disabilities (e.g. Damian's experience of unequal treatment). In some cases, participants feel a need to differentiate themselves from other people with intellectual disabilities, in order to belong to the group of co-workers without intellectual disabilities in the workplace. For example, Ryan stresses that he prefers not to work among other people with disabilities or to be identified with people with disabilities. For this reason, he regards working in a sheltered workshop as a last resort.

> *Ryan: Yeah, just… they are different people and, uh, in an […] ordinary company, the people who work there are not always 100% either, and that's not what I'm saying, but, but at [sheltered workshop], it's different from an ordinary company. At [sheltered workshop], everyone has a disability and, uh, well I'm not saying, I might be able to work there, but if I had to go to work there every day, it might just drive me crazy.*

Nancy also distances herself from other people with intellectual disabilities. She considers herself more skilled, and she does not want to be associated with the group of 'people with disabilities'. At the same time, however, she is clearly aware of her own intellectual disability, and she seems to struggle to explain her paradoxical feelings concerning working among and being associated with other people with intellectual disabilities.

> *Nancy: You know, the thing is, I've worked at B. [sheltered workshop] once now, but, you know, the thing is, I, I have, it may seem odd, but I have a problem with it, with working with people who have disabilities…, it often gets on my nerves, yeah… yeah, but for me, yeah, it sounds really odd to me, because I have a disability myself, yeah, not such a severe type, but a very, very mild type, but I just can't do that.*

The stigma that the participants experience with regard to their intellectual disabilities seems to have caused them to struggle with accepting or rejecting their identification with the group of people with intellectual disabilities, given their need to be fully recognised for their capacities and to take their proper place within society.

Discussion

The results of this study illustrate that the participants experience competitive employment as important to feeling like part of society. For them, participation in competitive employment created social value by enabling them to make a valuable contribution to society. It also protected them from experiencing emptiness in their lives. In contrast to most people without intellectual disabilities, however, the stories of the participants clearly illustrate that such social value is not always self-evident. The participants also described experiences in which they felt dependent in relation to others, in addition to having been affected by stigmatising attitudes in the work environment.

The participants had been able to achieve participation within a socially complex, competitive work environment. They recognised that previous work and life experiences had helped them to discover the types of work that they preferred, the competences that they possessed and the preconditions that they needed to successfully participate within the context of work. However, such a development process is not self-evident for people with intellectual disabilities, as their career choices are often determined by their environment rather than by themselves, at times resulting in personal wishes and goals being ignored (Lysaght et al., 2009).

The personal accounts presented in this study reveal similarities that may have contributed to their successful participation in employment. First, the participants shared a strong work ethic, as well as a desire to secure their future goals. These aspects (i.e. feeling responsible and being goal-oriented) have been associated with work performance and sustainable employability within the general population (Barrick, Mount, & Judge, 2001; Van Ruitenbeek, Zijlstra, & Hülsheger, 2019). Due to reduced cognitive and adaptive ability, unmet support needs and other factors, however, people with intellectual disabilities are less likely to develop these required skills for sustainable employability (Nouwens, Lukas, Embregts, & Van Nieuwenhuizen, 2017; Snell et al., 2009). Second, the work motivation of the participants and their ability to adapt their behaviour to the requirements of their work situations apparently contributed to their successful participation in competitive employment (Lindsay, Cagliostro, Albarico, Mortaji, & Karon, 2018; Holwerda et al., 2013). In addition to their own motivation and characteristics, simply being offered the opportunity to work also needs to be recognised as a key factor for participation in competitive employment.

The participants in this study shared the desire to occupy an ordinary place in society in general and in the workplace specifically, a place in which they strive to be treated as equal and recognised for the valuable contribution they make to the company or their customers. However, they also reported experiences of stigmatisation that seemed to impede them in realising these wishes and which triggered a variety of feelings and responses among participants. For example, the urge felt by Luke and Damian to prove their abilities when they experienced stigma contrasts with Elsie's insecurity and loss of work motivation due to stigmatisation. Other behaviours and experiences among the participants could also be linked to stigma, such as their strong work ethic and ability to adapt their behaviour, which might have been due to a desire to please others and might therefore have served as a means to feeling accepted or liked by others (Snell et al., 2009). This might have been the case for Elsie, who showed herself to be dutiful, with a tendency to be accepting of unequal situations. In addition, the participants' tendency to distance themselves from other people with intellectual disabilities—as reported in this study by Damian, Nancy and Ryan—has also been described by Snell et al. (2009), along with an adaptive response to experiences of stigma. More specifically, to reduce the experience of stigma, people with intellectual disabilities might deny their disabilities and attempt to present themselves as someone without disability. For example, Nancy talked about masking her disability in order to be treated as an equal. Similar individual strategies are also seen in people with other types of disabilities, such as physical and sensory disabilities, in response to stigma (Nario-

Redmond, Noel, & Fern, 2013). Such denial, however, could result in a reluctance to accept support in the workplace (Ali, King, Strydom, & Hassiotis, 2015), and this could have a negative effect on their success in competitive employment.

In the experience of the participants in this study, human relationships in the direct work environment sometimes entail feelings of stigma and dependence. Participants seem to experience these feelings as interconnected, and this corresponds with existing definitions of stigma. In line with studies by Pelleboer-Gunnink, Van Weeghel, & Embregts (2019) and by Cavanagh et al. (2017), the realistic needs that people with intellectual disabilities have for assistance in the workplace and the assumptions (either implicit or explicit) of co-workers, supervisors and support workers (e.g. job coaches) with regard to this need for assistance are likely to influence the opportunities that individuals are given to realise their full capacity to work. A customised work environment is therefore essential, with an inclusive attitude on the part of people without intellectual disabilities in the workplace (Lysaght et al. , 2017; Nelissen, Hülsheger, Van Ruitenbeek, & Zijlstra, 2016) and supportive relationships with supervisors and co-workers apparently being key elements (Embregts, Taminau, Heerkens, Schippers, & Van Hove, 2018; Flores, Jenaro, Orgaz, & Martin, 2011). In this study, Damian experienced the well-intended behaviour of co-workers as stigmatising and painful at times. In addition, he felt that this behaviour could lead to underestimation of the capacities of people with intellectual disabilities and, reducing their opportunities as a result. Damian’s experience is in line with the public stereotype attributed to people with disabilities. In line with studies by Fiske, Cuddy, Glick & Xu (2002) and Pelleboer-Gunnink et al. (2019) people with disabilities are viewed as a subordinate group by the general population, a view which can encompass both positive stereotyping such as 'warm' (likable) and negative stereotyping such as 'incompetent', resulting in feelings of 'pity' and ‘sympathy’ towards people with disabilities. Assigning socially desirable and non-threatening characteristics to people with disabilities serves to justify and maintain their subordinate status. This paternalistic reaction arises from a feeling of superiority and engenders a tendency to take care of the other person. At the same time, the combination of positive and negative stereotyping ensures that those who stigmatise do not experience discomfort. As such, processes of stigmatisation may maintain feelings of dependence and remove opportunities for independence for people with intellectual disabilities in the workplace. In Damian’s case, stereotyping triggered an urge to prove himself in order to change such stigmatising attitudes. However, many people with intellectual disabilities, for example Elsie, are not able to adopt such a robust attitude in these kinds of situations. This highlights the importance of defining the concept of inclusive behaviour not only from the perspective of co-workers without disabilities (Nelissen et al, 2016), but also from the perspective of people with intellectual disabilities themselves, in order to enhance their opportunities in the workplace.

This qualitative study contributes to the creation of in-depth knowledge about the experiences of people with intellectual disabilities in competitive employment. In line with previous studies (e.g. Rose, Malik, Hirata, Roughan, Aston, & Larkin, 2019; Giesbers et al., 2018), this study demonstrates the value of IPA in research on intellectual disabilities by providing rich data on their lived experiences. In this study, we subjected our findings to member checks with participants—an element that is increasingly being used for purposes of validation in IPA and other qualitative research methods (e.g., Groves, Rayner, & Muncer, 2017). The participants also experienced the member checks as valuable, indicating they provided a sense of being recognised.

The findings of this study should be interpreted within the context of its limitations. First, we examined what participation in competitive employment means to people with mild intellectual disability or borderline functioning and good verbal communication skills. However, the work experiences of people whose disabilities are more severe and who are less proficient in verbal communication might be different. Second, despite our efforts to minimise social desirability, we cannot exclude the possibility of bias, in the sense that participants may have been inclined to express agreement with the themes we proposed. A third limitation has to do with the average time of seven weeks between the interview and the member check. This period could be considered long, given the cognitive limitations of the participants. It was nevertheless necessitated by the time-consuming, in-depth analysis prescribed by IPA guidelines.

The results of this study have implications for both practice and research. First, they could help to raise awareness among public authorities and employers, with regard to the impact of stigmatising attitudes on the opportunities and position of people with intellectual disabilities in the labour market. For example, strategies of educating the general public about inequalities experienced by people with intellectual disabilities (as opposed to interventions that focus on the similarities between people with and without intellectual disabilities) have proven effective in reducing stigmatising attitudes in the general population (Walker & Scior, 2013). Second, companies might embrace human diversity and implement inclusive HR strategies that encourage openness (Bartram, Cavanagh, Meacham, & Pariona-

Cabrera, 2019), and public authorities could support and compensate employers who provide customised guidance to people with intellectual disabilities. A great deal of sensitivity is required on the part of the direct work environment in order to adjust to individuals with intellectual disabilities and to offer them opportunities to perform to the best of their ability, without under-estimating or placing excessive demands on them and, moreover, without making them feel stigmatised and dependent. Third, people with intellectual disabilities themselves should be able to receive training and support in order to increase their self-confidence and develop skills that could help them to create their own opportunities. Expert-by-experience programmes offer one example of this approach (Verbrugge & Embregts, 2013). The skills of job coaches in the accurate assessment of the capacities and personal wishes of people with intellectual disabilities could be further expanded, thereby optimising the support provided to people with intellectual disabilities (and their work environments) in the process of finding and maintaining suitable employment.

Given the relative lack of knowledge concerning the emergence and evolution of the complex process of stigma relating to intellectual disabilities in the workplace (Ellenkamp et al., 2016; Scior, 2011), this area is in need of further exploration. Future studies could focus on how interactions between people with and without intellectual disabilities are assessed and experienced from both perspectives, as well as in a variety of integrated and sheltered employment settings. They could also examine how these interactions might interfere with stigma, a sense of belonging and the position of people with intellectual disabilities.

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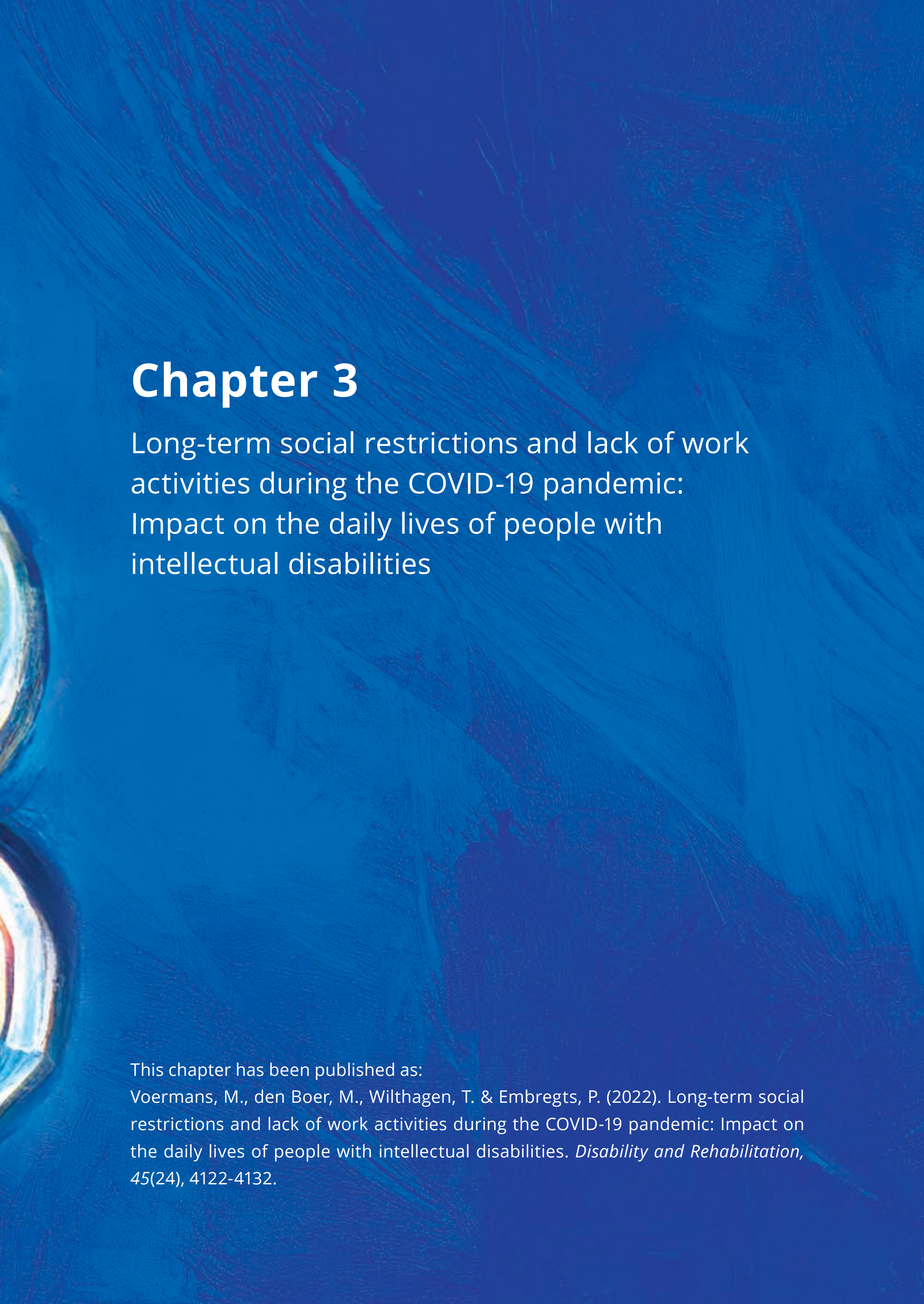

Chapter 3

Long-term social restrictions and lack of work activities during the COVID-19 pandemic: Impact on the daily lives of people with intellectual disabilities

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Abstract

Purpose

Lockkdowns due to the Covid-19 pandemic may have had a disproportionate impact on the daily lives of people with intellectual disabilities. Many of them had to deal with limited social contacts for an extended period. This study explores in depth how people with intellectual disabilities in the Netherlands experienced their daily lives, in particular due to lack of access to regular work activities.

Materials and methods

Eight participants with intellectual disabilities were interviewed. Interpretative Phenomenological Analysis (IPA) was employed in conducting and analysing interviews.

Results and conclusions

Analysis yielded three overarching themes that are conceptually linked. Participants experienced a prolonged lack of social connections that resulted in experiences of social isolation and feelings of loneliness. This led to different kinds of struggles: either internal struggles involving negative thoughts or depressive feelings, or a perceived threat to their autonomous position in society. Meanwhile participants had to sustain their sense of self-worth in the absence of work activities. The findings emphasise the importance of social opportunities through the access to work activities for people with intellectual disabilities. Interventions are suggested to help reverse the increased social inequalities and enhance rehabilitation via work activities for people with intellectual disabilities.

Introduction

The global Covid-19 pandemic has had a substantial impact on the lives of many people. Since the start of the pandemic, to a greater or lesser extent, attention was paid to vulnerabilities of specific groups in society (World Health Organisation (WHO), 2020). Among others, the pandemic has a particular impact on the lives of people with intellectual disabilities; physically, mentally and socially (Courtenay & Perera, 2020; Doody & Keenan, 2021). A large international study (Linehan et al., 2022) revealed, for example, that family members and professional caregivers experienced the pandemic to have a disproportionate negative impact on the lives of people with intellectual disabilities, due to an increase in depression and anxiety, stereotyped behaviour, aggression, and weight gain.

Social restrictions, also in terms of lockdowns, have been applied around the world for a long period of time to prevent the spread of the Covid-19 virus (Ritchie et al., 2020). As people with intellectual disabilities tend to have smaller social networks than people without intellectual disabilities (Giesbers et al., 2020) and may be more vulnerable to social isolation and loneliness (Gilmore & Cuskelly, 2014), these social restrictions may have had a substantial impact on their lives. This may be particularly true for people with intellectual disabilities living in supported or residential facilities, as they had reduced possibilities to visit or be visited by family and friends and to meet fellow residents (Linehan et al., 2022). In the Netherlands, for example, most service providers followed national advice of the branch association of professional service providers in the disability care sector (Vereniging Gehandicaptenzorg Nederland (VGN), 2020a) and therefore closed supported and residential facilities for visitors, including family, when the first lockdown was introduced. Studies conducted during the first phase of the pandemic indicated that people with intellectual disabilities perceived the Covid-19 pandemic and the restrictive measures imposed as having a major negative impact on many aspects of their lives and well-being, for example, by causing them to experience a lack of connection with significant others, and by reducing or altering the nature of their access to support (Embregts et al., 2022; Honingh et al., 2021; Lake et al., 2021). Consequently, people with intellectual disabilities may have generally experienced major obstacles in maintaining social contacts in their daily lives during the pandemic. As a result they may have experienced reduced social networks and social exclusion (Puyaltó et al., 2022).These problems were compounded by disturbing changes to and interruptions in their employment situation, such as having to interrupt employment temporarily or working remotely (Amor et al., 2021; Embregts et al., 2022).

Participation in employment, either paid or unpaid, or meaningful daytime occupation is perceived as an important aspect of the lives of people with intellectual disabilities, including the positive effect on their position in society and social contacts (Bigby et al., 2015; Blick et al., 2016; Ellenkamp et al., 2016; Simoës & Santos, 2017). Having a job or daytime occupation [from here referred to as 'work activities'] is associated with better physical and mental health of people with intellectual disabilities (Robertson et al., 2019) and enables them to experience social connections, a useful and structured spending of time, opportunities to achieve personal development, and a sense of being part of society (Donelly et al., 2010; Lysaght et al., 2017; Voermans et al., 2021). In addition to the benefits of work activities, it has been suggested (Voermans et al., 2021) that employed people with intellectual disabilities expect unemployment to lead to an experience of emptiness in their lives, in terms of activities and social connections and that a lack of access to regular daytime activities is associated with the prevalence of challenging behaviour, such as self-injurious and stereotypical behaviour, among people with intellectual disabilities (Bowring et al., 2017). Thus, among other benefits, participation in work can be an important pathway to create and maintain social capital for people with intellectual disabilities (Hall & Kramer, 2009).

Despite the perceived advantages of work, paid employment rates for people with disabilities are significantly lower compared to the general population in many countries, for example in Canada, the Netherlands, the UK and the US, even in the flourishing economic situation prior to the Covid-19 pandemic (Berendsen et al., 2021; Majnemer et al., 2021; National Governor's Association, 2021; Office for National Statistics, 2019). Unfortunately, this disability employment gap has widened further in these countries since the Covid-19 pandemic began (Berendsen et al., 2021; Holland, 2021; Majnemer et al., 2021; National Governor's Association, 2021). In addition, the Covid-19 pandemic has also had adverse effects on participation in unpaid employment options, such as daytime occupation. As lockdowns were enforced, services that provide daytime activities for people with intellectual disabilities were closed across a number of countries with higher rates of Covid-19 (Doyle, 2021; Kim et al., 2021; Linehan et al., 2022; Trip et al., 2022; VGN, 2021). As such, the pandemic has had a detrimental effect on the access of people with intellectual disabilities to work activities, both (paid) employment and daytime activities.

When restrictions were eased in the summer of 2020, day services reopened, in Ireland and the Netherlands for example, albeit with a reduced capacity (Doyle, 2021; VGN, 2021). As Covid-19 infection rates increased again in autumn 2020, stricter measures were reintroduced in many countries. In the Netherlands, for example, a partial lockdown was implemented in October 2020, with measures that included closing bars and restaurants, advising people to work from home and restricting the number of guests in the home to three a day. Subsequently, on 14 December 2020, even a stricter lockdown was imposed, which led to the closure of non-essential shops and the number of guests in the home being reduced to one a day. This inevitably led to a further prolonged interruption of day services (Boeije et al., 2021; VGN, 2020), in addition to a structural decrease in volunteering and employment options (de Klerk et al., 2021). People with intellectual disabilities therefore faced a prolonged loss of a substantial part of their social connections, as a result of their loss of work activities. This impact on social connections adds on the previously mentioned broad impact of social restrictions -and the additional measures in residential facilities- on the social connections of people with intellectual disabilities.

When considering how the initial lockdown negatively impacted upon people with intellectual disabilities, specifically with respect to their personal life and work situation, it is vital to rigorously explore how they experienced the later stages of the pandemic. These stages were characterised by broad restrictions on social contact in daily life for an extended period of time, also due to the lack of work activities. Despite widespread recognition of the negative impact that long-term unemployment can have on people's lives generally (Marrone & Swarbrick, 2020), there is a dearth of in-depth scientific knowledge about how the loss of work activities impacts upon the lives of people with intellectual disabilities. Therefore, it is essential to draw particular attention to how people with intellectual disabilities experienced the loss of work activities during this period of time. Indeed, shedding light on these experiences can enhance scientific knowledge about the disadvantages this group experiences as a result of a lack of access to work activities due to social restrictions during periods of crisis. In addition, exploring these experiences enables us to identify potential facilitators of, and barriers to, coping with the loss of work activities during contexts characterised by limited opportunities for social connection and support. The insights yielded from this research can subsequently inform public authorities about how important the social connections formed through work activities are for people with intellectual disabilities, in addition to contributing to policy-making for future crises.

Consequently, this study sets out to answer the following research questions:

1. How do people with intellectual disabilities give meaning to their daily lives when they have limited social connections, and especially when they experience a long-term lack of access to work activities during a period of crisis?
2. What facilitators and barriers do people with intellectual disabilities experience when attempting to cope with limited social connections during a crisis, particularly if this stems from the long-term loss of work activities?

Materials and methods

Study design

In this study Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) was employed. Data collection, using semi-structured interviews with the eight participants, started on 19 November 2020 during the partial lockdown in the Netherlands, and continued until the unexpected announcement of a stricter lockdown on 14 December. Before that date, five participants had already been interviewed; the interviews with the three remaining participants had been scheduled for after 14 December. In order to include data on how all of the participants experienced the stricter lockdown, a decision was taken to conduct an additional interview with the five participants who had been interviewed previously. As a result, this study consists of five participants who were interviewed twice and three participants interviewed once, with the first group being treated as the core dataset. This means that we used the interviews of the first group as a focus for the overarching analysis, after which we incorporated the experiences of the remaining three participants. The two interviews of the participants who were interviewed twice were analysed separately and subsequently merged. For this study, ethical approval was obtained from the Ethical Review Board of Tilburg University [RP 149].

Participants

Participants were recruited from a Dutch organisation that provides both residential and community-based support to people of all ages with intellectual disabilities ranging from profound multiple disabilities to borderline intellectual functioning. Professionals were asked to indicate possible participants who met the following criteria: (I) a diagnosis of mild intellectual disability or borderline intellectual functioning (IQ scores between 50 and 85); (II) an age of 18 to 50, since people with intellectual disabilities are at risk of frail health from the age of 50 (Schoufour et al., 2013), which can affect the perception of loss of work activities; (III) having lost at least one half of their (paid or unpaid) working hours since the start of the Covid-19 pandemic in the Netherlands (i.e. since March 2020); (IV) being at home without any replacement organised daytime activities for at least three working days a week.

Five men and three women aged between 21 and 40 (average age: 29.9) participated in this study. Demographic data were obtained from the participants during the first interview and from their files, with their consent (see table 1). To protect their anonymity, the participants are identified using pseudonyms. The participants' work situations were diverse. Nick and Tim both used to have a competitive paid job in the hospitality industry, with Tim being supported by a job coach of the service organisation. Tim was unemployed after his employer went bankrupt in July 2020. Nick could only work minimum hours from October 2020 due to the second hospitality industry closure in the Netherlands. Jerry used to have an unpaid daytime occupation at a day centre, run by a service organisation that went bankrupt during the first lockdown. Katie, Marvin, Melissa, Oliver and Veronica all had an unpaid daytime occupation in the community, which was organised or supported by the service organisation that also facilitated their residential support. Therefore, the work activities of these participants were, to a greater or lesser extent, affected by the measures taken by the service organisation, in line with national policy. In terms of closing and reopening day centres this meant that day centres closed in March 2020 and home-based daytime activities were sought to be provided instead. From September 2020, the day centres were gradually reopened. With the exception of Tim and Jerry, all participants were offered to return to their work activities part-time or full-time from September 2020 or before. However, Melissa and Oliver chose not to resume work activities because of concerns about possible Covid-19 infection. Marvin and Katie had partially resumed work activities, but Katie was back home again due to private circumstances. Veronica had resumed work in June 2020, but was out of work activities since the hospitality industry closed again in October 2020 and her employer could not offer her any alternative work activities. Therefore, at the first interview, six participants had no working activities, whereas two (Nick and Marvin) had been assigned replacement activities at their workplace for several hours a week. Six participants had been told that they would be able to fully resume their original work activities as soon as the Covid-19 situation permitted, whereas two (Tim and Jerry) had no prospect of returning to their job.

Two participants (Nick and Tim) were living independently, and one (Oliver) was living with his parents. Five participants (Jerry, Katie, Marvin, Melissa and Veronica) were living in community-based care facilities with support. These participants were therefore affected by the national Covid-19 policy implemented by the service organisation supporting them concerning visitors and meeting fellow residents. This meant that between March and July 2020 they were not allowed to receive any visitors at home and could only meet their fellow residents at set times. In addition, participants sometimes had to deal with their residential location being closed because a fellow resident had become infected with Covid-19. As a consequence, participants were not allowed to leave the location or receive visitors for a certain period of time. The easing of the measures from July 2020 was tailored within the organisation on a site-by-site basis, resulting in differences in measures per site. With the new restrictions in October and December 2020, the service organisation sometimes deviated from national policy with, for example, wearing a face mask becoming mandatory at these residential locations earlier than within the national policy.

Procedure

Potential participants were initially approached about participating in the study through a professional or family member. If they expressed an interest in taking part, the first author called the potential participant to check the inclusion criteria, to give them further details about the study and to answer any questions. If they still expressed interest, they were sent an information letter and informed consent form. The letter described the key aspects of the study in detail, along with measures taken to safeguard the confidentiality and rights of the participants. A first interview was planned when they agreed to participate. Before the start of the first interview, the information letter and the informed consent form were carefully reviewed with the participants to make sure that they were fully aware of their decision to participate, after which they signed the informed consent form.

An interview schedule following IPA guidelines (Smith & Osborn, 2008) was used. The interview schedule was pilot tested among three co-researchers with mild intellectual disabilities, after which minor adjustments were made in the formulation of questions. The interviews started with an open question: ‘Can you tell me something about how you are experiencing your life right now?’ Subsequently, the interviewer tried to respond to elements of the participant’s story, using open-ended questions whenever possible to give participants as much control over the conversation as possible. This allowed information to emerge that was not directly relevant to answering the research questions, but which could help to understand the participants’ experiences within their life context. To explore the participant’s experiences in detail, the interview schedule included some potential questions that could be asked when the topic did not arise spontaneously (see table 2).

Table 1. Descriptive personal data of participants

Pseudonym	Sex	Age	Living situation	Work situation before COVID	Work situation at start of study	Work prospects
Jerry	M	21	Semi-residential facility	At a day centre	None, day centre went bankrupt	Looking for new occupation
Katie	F	35	Semi-residential facility	Full-time unpaid occupation at a petting zoo	Restarted for 2 days a week	Restarted full-time in January 2021
Marvin	M	30	Semi-residential facility	Full-time unpaid occupation in catering business	Restarted for 3 mornings a week	Back to full-time work when catering business reopens
Melissa	F	38	Semi-residential facility	Part-time unpaid occupation at a nursing home	None, she has chosen not to restart yet	Return to regular working hours when situation permits
Nick	M	29	Independent, with his wife	Full-time paid job in catering business	A few hours a week at the take-away	Back to full-time work when catering business reopens
Oliver	M	22	With his parents	Full-time unpaid occupation at 3 different places (catering industry and nursing home)	None, he has chosen not to restart yet	Could return to regular working hours when situation permits, but is also looking for new occupation
Tim	M	40	Independent	Full-time job in catering business	None, his employer went bankrupt	Looking for a new job
Veronica	F	24	Semi-residential facility	Unpaid occupation in catering business	None	Back to full-time work when the catering business reopens

The second interview – if applicable – was based on the same principles and started with the open question: 'How have you been doing since our last interview?' This was followed up by questions formulated in advance with a view to exploring how participants were experiencing and coping with the stricter lockdown. In the case of the three participants who were interviewed only once, the interview schedule was supplemented with relevant topics from the other participants' second interview schedule.

The participants were given the choice of being interviewed in person or remotely using video conferencing software; all of them opted to be interviewed in person. The participants were interviewed at home, except for one participant who preferred to be interviewed at the office of the service provider. All interviews were conducted by the first author. Although employed by the participants' service provider, she had never been professionally involved with any of the participants. Interviews took place in full compliance with the Dutch government's Covid-19 guidelines as they applied at the time and any additional precautions taken by the participants' service provider. On one occasion, the second interview was conducted on Skype as the participant felt more comfortable being interviewed remotely; on another occasion, the second interview was conducted by telephone due to quarantine measures. The interviews took an average of 46.5 minutes each (range: 29-76). With the participants' consent, all of the interviews were audio-recorded and transcribed verbatim.

Table 2. Potential questions included in the interview schedule

- Can you tell me something about how you are experiencing your life right now?
- Can you describe what your days are like right now?
- Are there things that are going well in your life right now?
- Are there things that you find difficult in your life at the moment?
- Can you describe what it is like for you to be at home without work or daytime activities?
- Can you tell me what you liked about work before your work/daytime activities stopped?

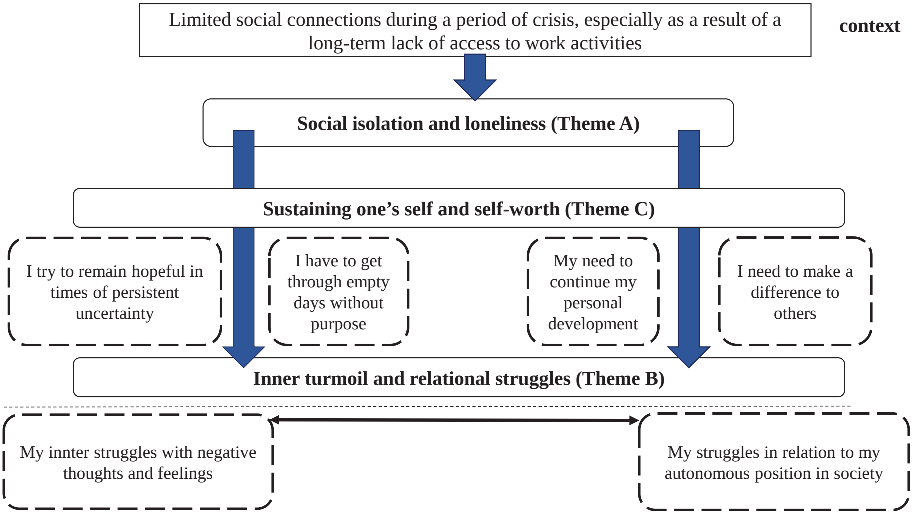
Analysis

The stages described in the IPA guidelines (Smith & Osborn, 2008) were carefully applied throughout the analysis, which was conducted by one researcher in close cooperation with a second researcher. Discussions with the full research team were held throughout the analysis process. At the first stage, the recordings of the interviews were listened to, and transcripts were read and reread by one researcher who subsequently, at the second stage, made initial notes on descriptive, linguistic and conceptual aspects. These were carefully audited by and discussed with the second researcher. The third stage involved the formulation of emergent themes by one researcher based on rereading the transcript and initial notes, which were also discussed with the second researcher until consensus was reached. At the fourth stage, the two researchers discussed possible overarching themes based on the emergent themes already formulated. The emergent themes were then clustered according to the overarching themes, audited and discussed by two researchers. At the final stage of the analysis, the overarching themes within and across cases were discussed in detail by the entire research team to identify patterns, similarities and differences. Throughout the process, a reflective journal was kept to document the decisions made.

Results

Analysis yielded three overarching themes that are conceptually linked. These themes are presented below and visualised in figure 1.

Figure 1. Model of overarching themes



Theme A: Social isolation and loneliness

Participants expressed a significant lack of social connection, which led to social isolation and loneliness. For Marvin, Katie, Tim, Veronica, Jerry and Nick, the social connection to others was significantly impacted by the unintentional loss of their work activities due to Covid-19.

Katie, for example, characterised herself as a people person for whom togetherness and physical contact, particularly cuddling, with significant others are of great importance. The loss of social contact as a result of having to stop her work at a petting zoo, combined with restrictions affecting participation in social activities with fellow residents at her supported home due to Covid-19, led to a significant loss of meaning in her life.

For Melissa and Oliver, there was a different relationship between the loss of work activities and the lack of social connections: they both decided not to resume work despite being given the opportunity to do so. As Oliver considered himself to be at high risk from Covid-19 due to a lung disease, he and his mother decided he should stop his jobs at two nursing homes and a lunchroom, even before the initial lockdown started. Oliver missed the contact with people at work, but above all he missed the personal and intimate contact with his friends, because he only rarely had the chance to meet them in person. For him, online contact via WhatsApp was not sufficient to experience this close connection.

Although Melissa also missed the contact with her colleagues and clients at her job in a nursing home, avoiding loneliness was actually one of the reasons behind her decision not to resume work at that stage in the pandemic. She perceived a high latent risk of infection at the nursing home and was worried that she could easily become infected there. Melissa therefore feared that resuming work would increase the risk of having to quarantine, which in turn would stop her participating in the social activities at her supported home and prevent her from visiting her vulnerable parents. She talked about desperately wanting to avoid the loss of contact with her small circle of significant others.

> *Melissa: Then I think I'd also ... um... feel lonely, because then all I'd do is come home and take a shower and stay in my apartment. I don't know, I've never tried to go to work and see what happens. And I don't know what arrangements would follow or what it would be like (...) But I'm like, I'm not going to risk it. I' m not... um.... I'm not going to take that chance.*

Theme B: Inner turmoil and relational struggles

The lack of social connections during the pandemic caused the participants to focus more intensely on themselves and their own situation. This affected both their emotional balance and the relational balance between themselves and others. It led them to experience inner turmoil or struggles regarding their position in society.

My inner struggles with negative thoughts and feelings

Some participants experienced inner turmoil due to the lack of social connection. Both Veronica and Nick experienced feelings of gloom. The prolonged loneliness and lack of connection with others during the dark days of winter led Veronica to express dark thoughts. However, she still had sufficient coping skills to avoid falling into depression. Nick, in contrast, experienced feelings of hopelessness and ultimately spiralled down into depression. He was prescribed medication by his general practitioner. Nick seemed to derive his own sense of identity very strongly from his connection with other people and from his identity at work. The decrease in his work activities in a restaurant and the restricted social contacts in both his work and personal life meant that important sources of meaning and aspects that defined his identity were lost to him. On his own, he was no longer able to be the person he wanted to be and slipped into a spiral of negative feelings.

> *Nick: Then it really is all down to you, and it even gets to the point where you don't want to go on anymore. You just go crazy inside, you get headaches and you get depressed.*

Although he did not slip into depression, Marvin was caught up in a pre-existing cycle of negative thoughts, exacerbated by the pandemic and the lack of work opportunities. He expressed the need for social meetings and activities outside his home (e.g. activities with friends and contacts with customers at work) as these constituted important sources of distraction from his negative thoughts. He explained that doing domestic activities on his own did not offer him sufficient distraction from and control over his negative thoughts.

> *Marvin: Yes, when I'm at home too often and I'm in my room too much (...) I don't know why it's like that in my head, but in my head I just keep thinking. I get to thinking way more about all kinds of things, about things that went wrong in the past or what could have gone better and, well, I just kind of dig a hole for myself.*

In contrast, the emotional turmoil experienced by Jerry was not caused by the limitations on social contact themselves, but the fact that these limitations were imposed on him by others. The Covid-19 restrictions, and in particular the quarantine measures imposed due to a Covid-19 infection at the supported accommodation where he lives, reminded Jerry of the years he spent in a locked facility, a time he remembered as traumatic and stressful. As a result, he did not want to be deprived of his freedom by the quarantine measures and, against the rules, he continued to visit his family.

> *Jerry: Yeah, I spent eight years in a locked facility (...) No one’s going to stop me doing that. They did that for a very long time, but not anymore. (...) No, that makes me feel like I’ve been locked up. When I think back on that, it drives me completely crazy.*

My struggles in relation to my autonomous position in society

The changes in social connections led other participants to experience difficulties with regard to the autonomy they wanted to experience in identifying with and relating to other people in society.

Melissa and Katie suffered due to missing opportunities for optimal participation in society. This confronted them once again with their status as a person with an intellectual disability, whereas before the pandemic they had been able to distance themselves from this identity. Melissa used to work in a regular nursing home. She specifically experienced her responsibilities being given to her in caring for elderly residents as things that set her apart from other people with intellectual disabilities. When, in the first phase of the pandemic, she was no longer allowed to work in the nursing home, she was offered substitute handicraft activities at a day care facility, that made her feel undervalued and treated like a child. She expressed her objections to participating in these alternative activities.

> *Melissa: Yes, and [normally] I work in the neighbourhood. (...) I'm not one for pasting and cutting and all that stuff. (...) I mean, what do they think I am? A 6-year-old kid? Get lost, that's what I say. That's not me at all.*

At the same time, being at home so much made Melissa aware of the fact that the Covid-19 measures at her supported accommodation were often different from and more restrictive than the measures for people who do not live in a facility. Like Melissa, Katie experienced her supported accommodation had become a hospitalised environment. Due to the Covid-19 measures, support staff took over tasks from all the residents (such as serving food) and also decided which fellow residents Katie was allowed to meet in the common room and at what time. Katie was also confronted with the status of 'vulnerable person': this was applied to her as a resident of a facility for people with intellectual disabilities, whereas she did not perceive herself as vulnerable.

> *Katie: Some of the people here are vulnerable, but if you take me, I am otherwise healthy (...) But I still get that label though in terms of health I am not really vulnerable at all. (...) Because it's an institution they see me as vulnerable.*

Whereas Katie's and Melissa's confrontation with their status led them to actively disassociate their personal identity from that of other people with intellectual disabilities by making comparisons, Tim's confrontation with his intellectual disability led him to speak out in favour of opportunities for people with intellectual disabilities as a group. Tim, who gives the impression of having evolved into an independent and socially engaged person, lost his regular paid job. This forced him to confront his status as an intellectually disabled person once again and face up to the difficulties of living in society while having these disabilities. He had to re-connect with himself as a person with a disability and as part of the group of people with disabilities, a group he felt he had outgrown as a result of his job. This involuntary reactivation of the connection he felt with this group made him want to do something for the group that he said he felt connected to, but not fully part of.

Theme C: Sustaining one's self and self-worth

The lack of work activities and social connections implied that several key elements in participants' lives were no longer evident, which meant that they had to work hard to maintain their sense of self and self-worth.

I try to remain hopeful in times of persistent uncertainty

The long-term lack of work activities in the context of the unclear and ever-changing situation caused by the pandemic took its toll on all of the participants. However, their abilities to adapt and keep on dealing with this situation differed.

Some participants clearly suffered due to the prolonged lack of prospects resulting from this situation. Marvin, for example, became frustrated by the government's ever-changing and fluctuating Covid-19 policy, which made him feel like he was constantly taking one step forward and two steps back. He needed more clarity and predictability.

Other participants, however, appeared to succeed better in adapting to the long-term lack of clear prospects. Tim's open-mindedness and ability to take things as they come seemed to provide a buffer when coping with the current difficulties in his life. Nevertheless, the longer the situation lasted, the more Tim began to lose hope of finding a new job. To protect himself, he tried to temper his expectations but emotionally he seemed to find it difficult to accept his unemployment.

Like Tim, Katie found it increasingly difficult to maintain hope. On the one hand Katie tried to use her experiences during the crisis as a source of support and help for the future. In other words, she felt that – with the crisis as a reference point – she would be better able to handle difficult situations in the future. On the other hand, Katie noticed that she became frustrated with the Covid-19 situation, exerted by feelings of insecurity caused by the ever-changing news about the vaccination strategy.

> *Katie: On the other hand, I'm like, "Don't splash it all over the media unless you're sure," you know (...) It makes me feel insecure and it probably makes other people insecure too.*

I have to get through empty days without purpose

Participants experienced a lack of variety in their lives that led to a sense of drudgery. Every day seemed to feel the same. The lack of purpose and structure in their lives led them to lose their grip on their personal day-night rhythm.

In the case of Veronica, for example, missing work, and the subsequent reduction of social contact, routine and purpose, made her feel that she no longer had a life.

> *Veronica: Before you used to work and you had all your colleagues around you, a good atmosphere and you could talk to your colleagues, it was nicer. Now all that's gone and you miss it. Now I actually feel like I don't really have a life because ... you know what I'm trying to say? Normally you go to work and now you don't. Now you get up and then it's like "what am I going to do now", you know?*

Nick seemed to be a person who got bored easily. When the hospitality sector and other amenities were shut down for the second time in October 2020, an increasing number of activities that might have kept him entertained were no longer possible because of the restrictions (e.g. go-karting, going to the gym). Time seemed to drag by endlessly and this drove him crazy. He noticed that boredom made him lazy and led him to postpone things, but he couldn't find a way to turn things around.

> *Nick: [Time] seems to drag on endlessly, so that time actually makes you crazy, and out of boredom you don't do anything anymore and you get all lazy and lame, so you don't feel like getting up or doing anything in the first place. You keep putting things off like "I still have to clean the bathroom ... Oh, I'll do that tomorrow." Because you feel that way every day.*

In contrast, Jerry managed to find a new purpose in his days. During a long period without work activities in the past he also fell into a vicious circle and his day-night rhythm was adversely affected, which made him feel tired of almost everything. At the time of the interview, however, Jerry was running his own internet radio station with a friend. This made him feel that he had created his own daytime activity, which made him proud and gave him a sense of having things to do every day.

I need to continue my personal development

Each in their own way, participants experienced that the lack of work activities during the pandemic deprived them of opportunities to learn new things and keep developing as a person. However, some participants found other ways to continue their personal development or even attach new value to certain aspects of their lives and development as a result of their experiences since the outbreak of the pandemic.

For Oliver, learning and personal growth were important sources of inspiration and energy, with the ultimate goal of being able to participate in society as independently as possible. He felt that this growth had come to a complete standstill.

> *Oliver: A standstill. The brakes are mostly on, I can keep moving but not a lot actually, (...) I do miss growing, continuing to grow, in the sense of learning all kinds of things and being allowed to make mistakes.*

However, he found new ways to meet his needs during the Covid-19 period by learning English through an app and attending an online course with his mother.

Katie, in contrast, put off achieving the goals she had before the pandemic. She initially regretted that the pandemic prevented her from obtaining her driver's license and doing a course to become an expert client. However, the pandemic made her aware of the importance of enjoying the small things in life, such as physical contact with significant others. She decided she wanted to focus more on these small things in life after the pandemic and postponed her more ambitious goals.

For Veronica too, life during the pandemic provided a positive learning experience. Shortly before the initial lockdown started, Veronica had moved from her parents' home to supported accommodation. In contrast to many of her fellow residents, Veronica chose to stay in her own home instead of moving back in with her parents. Even though this was a difficult and lonely time for her, she looked back on it as an experience that helped her grow as an autonomous person and to become more self-reliant.

I need to make a difference to others

Although Nick, Tim, Melissa and Katie normally work in different sectors, they all missed making a difference in the lives of their customers or clients. Katie, for example, missed working in the farm shop, where she enjoyed making her regular customers feel happy and special by giving them attention. Katie talked about one customer her colleagues did not get along with, but with whom she had a special connection. She enjoyed finding ways to keep this customer satisfied.

> *Katie: She can be blunt sometimes and some people can't cope with that. But I turn it around and just try to stay nice (...) It's very special that a customer likes me and thinks I'm nice. (...) It's great, wonderful. That makes it all worthwhile (...) keeping the customers happy.*

Despite the absence of work, Melissa found ways to continue to care for others and make a difference to their lives. This was important to her. For example, Melissa identified herself as a family caregiver for her parents and sometimes did shopping for them. She also tried to help the housekeeping staff at her supported home. In Melissa's experience, these activities helped her make more of a difference to others than the alternative handicraft activities she was given instead of her work in the nursing home. She also enjoyed the appreciation that the housekeeping staff expressed when she helped them.

Tim, by contrast, experienced working as a way to make a difference to society as a whole, for which a salary is the quid pro quo. When he became unemployed, he experienced the income from his benefits as money for nothing, a free ride without having to do anything in return. This made Tim feel bad. He felt it was unfair that others had to make a real effort to have the same amount deposited on their bank account, while his own competencies remained untapped.

> *Tim: Well, it kind of feels like you're looking for a handout, like I don't have to do anything but they give me money anyway. Yeah, that doesn't really feel right. You know, that one person, my neighbour say, has to work 40 hours a week for about 400 euros and I just sit at home and [whistles] in comes the money. Yes, it's not nice. I get it, fine, but I mean basically I can work for it.*

Discussion

This study is an in-depth exploration of how people with intellectual disabilities experience their daily lives with limited social contacts, in particular as a result of a long-term lack of access to regular work activities due to the Covid-19 pandemic. This situation made participants suffer from a prolonged lack of social connection, resulting in social isolation and feelings of loneliness. This left participants to draw on their own inner resources and ultimately confronted them with different types of personal struggles. Some participants mainly felt inner turmoil and had to focus on themselves to control the depressive feelings or negative thoughts they experienced due to severe long-term social isolation and loneliness. Other participants experienced struggles that were directly related to what they felt was a threat to their autonomous position in society and sometimes even a confrontation with or a sharp reminder of the stigmatising status of having an intellectual disability. Meanwhile participants had difficulty sustaining themselves and their sense of self-worth, as some key aspects of their lives were no longer self-evident without regular work activities and social connections to engage in. These findings shed further light on the significant value that people with intellectual disabilities attribute to meaningful social connections and work activities, and on the potentially drastic adverse effects on their quality of life when being deprived of these elements in their lives.

Participants in this study mentioned some positive effects of the pandemic, which are also reported in other studies. For example feeling more relaxed and having more time for hobbies (Honingh et al., 2021) or developing skills or personality traits, such as responsibility for themselves and others (Embregts et al., 2022) However, these positive effects by no means outweigh the psychological and social impact of the preventive measures on the lives of people with intellectual disabilities, which are both reported in this qualitative study and in various quantitative studies (Courtenay & Perera, 2020; Doody & Keenan, 2021; Linehan et al., 2022; Lunsky et al., 2022). Puyaltó et al. (2022) explored the relationships of people with intellectual disabilities during a similar phase of the pandemic and yielded comparable results. The lack of physical contact caused participants in that study to experience dehumanisation and cooling of relationships, leading to distress in some cases. The detrimental social and psychological effects of the pandemic on people with intellectual disabilities may have several reasons. First, people with mild intellectual disabilities are vulnerable to experiencing a lack of social connections, as they generally tend to have smaller social networks and less supportive resources (Giesbers et al., 2020). Yet at the same time, despite the support needs of people with intellectual disabilities (Shalock et al., 2021), the access to professional support services has deteriorated for them since the pandemic began (Parchomiuk, 2022; Purrington & Beail, 2021). Therefore, the pandemic may have further limited the availability of supportive resources to help people with intellectual disabilities cope with the social restrictions including lack of work activities. Second, people with intellectual disabilities are generally assumed to be a high risk group for mental health problems, such as depression (Nouwens et al., 2017). Social restrictions and lack of work activities may have further increased this risk, as people with intellectual disabilities are at higher risk to experience feelings of loneliness and experiences of chronic loneliness presumably exacerbate depression in people with intellectual disabilities (Gilmore & Cuskelly, 2014). In general, the sources of resilience of people with intellectual disabilities (Scheffers et al., 2020), both internal (i.e. autonomy, self-acceptance, physical health) and external (daytime activities, social network), may be diminished during a pandemic due to restrictions on freedom and loss of work activities. It is therefore essential that professionals support people with intellectual disabilities to enhance their sources of resilience and coping strategies (Scheffers et al., 2020), particularly during a pandemic.

In addition to feelings of loneliness and depression, participants in this study experienced that the long-term situation with restrictions on social contacts, particularly due to a lack of access to regular work activities, threatened their autonomous position in society. In line with the study of Puyaltó et al. (2022), our findings suggest that people living in a supported accommodation may have experienced more restrictions in their autonomy than people not living in supported accommodation, potentially leading to feelings of stigmatisation. In general, these experiences may be associated with negative attitudes towards people with intellectual disabilities in the population and the resulting segregation of society (Scior, 2011). Unfortunately, in various countries, Covid-19 measures have further reduced participation rates in various life domains and reinforced segregation of vulnerable groups in society, including people with intellectual disabilities and mental illness (Majnemer et al., 2021; Miltenburg & Schaper, 2020). Just as loss of work activities may reinforce the stigmatised identity and risk of social exclusion for people with mental illness (Oudejans et al., 2021), this may also apply to people with intellectual disabilities. That is, in Western societies having a job is perceived as a major social role for people to fulfil (Wolfensberger, 2000), while performing social roles is usually more difficult for people with intellectual disabilities due to the stigma attached to their disability (Dorozenko et al., 2015). The work activities of the participants in this study usually offered them opportunities to perform valued aspects of social roles, such as making a difference to others. These activities also contribute to their identity and self-worth. In a qualitative study, Forrester-Jones & Barnes (2008) explored how providing social support to others could help individuals with severe mental illness to forge and manage a less stigmatised identity. They found that providing social support helped participants to construct a more socially valued identity than that of being a patient. In line with their findings, making a difference to others helped participants in this study to take on an accepted social role and escape the public stigma and they tried hard to find other ways to maintain this aspect of their lives while they had limited access to work activities. Both professionals and employers can support people with intellectual disabilities to find opportunities to provide social support to others, either in or outside the work situation, for example by helping out an elderly neighbour.

There are some limitations that should be considered when interpreting the results of this study. First, due to the sudden introduction of a stricter lockdown, additional interviews were conducted and, as a result, either one or two interviews with the participants are included in this study. However, we have carefully accounted for this discrepancy in the analysis by using the data from the participants who were interviewed twice as the core dataset. Second, given the iterative nature of the IPA method, the literature recommends that the interviews should be conducted and analysed sequentially (Smith & Osborn, 2008). However, due to the unpredictability of the pandemic and subsequent shifts in policy, and the fact that we specifically aimed to collect data in a context with severe restrictions, it was not possible to conduct the interviews sequentially. Lastly, it was not possible to carry out member checks to validate the preliminary results, a procedure applied in some IPA studies (Voermans et al., 2021) and absent in others (Giesbers et al., 2019). Previous studies have proved the valuable contribution of member checks. Nevertheless, in the ever-changing context of the pandemic, member checks proved not to contribute to the research validity: in a pilot member check the participant appeared to have difficulties recalling the experiences at the time of the interviews.

The findings of this study illustrate that the loss of social connections, in particular due to the lack of access to work activities, during the pandemic has reinforced the social inequalities and disadvantages for people with intellectual disabilities (Majnemer et al., 2022; Miltenburg & Schaper, 2020). The group of people with intellectual disabilities is overlooked and forgotten in Covid-19 policies (Majnemer et al., 2022), which can be seen as a result of the public stigma attached to this group (Pelleboer-Gunnink et al., 2021). Interventions to address these inequalities and disadvantages are key, especially since a pandemic can reinforce conservative thoughts, stigmatisation and discrimination in the population (Miltenburg & Schaper, 2020) and since the pandemic has not yet been entirely resolved and new lockdowns cannot be ruled out. It is therefore important to invest in sustainable and innovative post-pandemic community participation initiatives and particularly in accessible post-pandemic employment support to reinstall meaningful work activities for people with intellectual disabilities (Majnemer et al., 2022). There are workforce gaps in several sectors, and employers, together with healthcare professionals, can create opportunities to employ people with intellectual disabilities in these fields, for example by organising paid in-company training placements. In addition, more awareness should be raised among authorities, the general public and employers about the value of participation for people with intellectual disabilities, also in regular work activities. Public policies can be based on the philosophy of contributive justice by creating opportunities for everyone to use their talents to contribute to society rather than providing benefits (Wilthagen & Stolp, 2021). Moreover, in the event of new lockdowns, the results of this study could motivate public institutions to tailor policy decisions, considering both health risks and risks of social isolation. This could imply that day services for people with intellectual disabilities can remain open and that the visiting opportunities for people living in residential facilities persist, in compliance with applicable measures. By doing so, people with intellectual disabilities can be protected from health risks, while they can continue to benefit from social connections, which are such an important aspect of their lives.

This study contributes to the scientific knowledge by reporting in depth on the potentially adverse effects of long-term social restrictions on people with intellectual disabilities by depriving them from meaningful social connections through work activities. More research is needed to examine the effect of the loss of work activities, outside the context of a global pandemic with long-term social restrictions, for a larger group of people with intellectual disabilities. It would therefore be desirable to further explore the relationship between the loss of work activities, loneliness and mental health. In addition, considering the negative effect of Covid-19 on participation in employment of people with intellectual disabilities, it is important to investigate how this participation can be improved post-pandemic, for example by exploring partnerships between education, healthcare and companies. Finally, future research can examine how people with intellectual disabilities can use their ability to make a difference to other people's lives to design their social roles and promote destigmatisation, for example by studying the perceptions of the clients and customers they serve.

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Chapter 4

Informal network members' perspectives and experiences on work for people with intellectual disabilities: A thematic synthesis

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Abstract

Purpose

The level of participation of people with intellectual disabilities (ID) in various forms of work, including daytime activities, appears to be suboptimal. Informal networks of people with ID constitute crucial forms of support, as they can significantly influence occupational choices and opportunities. This review aims to synthesize existing research for the purpose of examining how informal network members perceive the meaning of employment or daytime activities for their relatives with ID.

Methods

Following the PRISMA guideline, a systematic search of scientific literature published between 1990 and July 2022 was conducted. The qualitative results from twenty-seven studies (qualitative and mixed-method) were analyzed using thematic synthesis.

Results

Four overarching themes and several subthemes were identified: I) Ensuring customized work for my relative; II) The ongoing need to collaborate and share care responsibilities with professionals; III) The meaning of work for both my relative and myself; and IV) Achieving full work participation for my relative is neither straightforward nor self-evident.

Conclusions

Informal networks place great value upon customized and sustainable work opportunities for their relatives with ID, particularly community-based work. While network members play an important role in creating these opportunities, they encounter obstacles resulting from both collaboration difficulties with professionals and employers and public and structural forms of stigma. Researchers, professionals, policy makers, and employers are encouraged to collaborate with individuals with ID as well as their networks to increase the meaningful work opportunities available to them.

Background

Social changes in Western societies over the course of the twentieth century have led to a shift away from collectivist values towards more individualistic values characterized by individuals' rights and self-determined choices (Greenfield, 2016). In line with these social changes, many Western countries also pursued policies focused on the integrated living of people with ID, and the recognition of their equal rights to citizenship, as a substitute for living and working in large-scale institutions, often outside or at the border of cities (Altermark, 2017; Simpson, 2018). These major transformations, which include, among other things, deinstitutionalization, have hitherto regrettably not resulted in equal opportunities in society for people with ID (Bigby, 2005; Greenfield, 2016).

Participation in employment represents an important pathway through which to stimulate equal rights and full participation in society for people with ID (Lysaght et al., 2012; Lysaght et al., 2017; Voermans et al., 2021). However, despite evidence and policies in many countries aimed toward promoting inclusion within the workforce for people with disabilities (International Labour Organisation (ILO), 2018; United Nations (UN), 2006), the employment rates for people with disabilities remain significantly lower compared to the general population (Berendsen et al., 2021; ILO, 2018; Office of National Statitistics (ONS), 2022;). Alongside the small proportion of people with ID who participate in competitive employment, people with ID also participate in a wide range of employment or daytime activities that can take place in either sheltered or integrated work environments (Metzel et al., 2007). Sheltered employment is defined by Metzel et. al. (2007, p. 51) as "employment in a facility where most people have disabilities with ongoing work-related support and supervision" and can take place in sheltered workshops, day centers and vocational rehabilitation centers (Metzel et al., 2007; Migliore et al., 2007). Integrated employment is defined by Migliore et al. (2007, p. 7) as "taking place in a community setting in the general labor market where the proportion of workers with disabilities does not exceed the natural proportion in the community" and can take the form of competitive employment, supported employment, entrepreneurship, or self-employment (Metzel et al., 2007; Visier, 1998). Unfortunately, the participation rates for people with ID in both integrated and sheltered employment remain suboptimal (McGlinchey et al., 2013).

People with ID themselves appear to perceive participation in integrated work activities as incredibly valuable, as far as it enables them to make a meaningful contribution to society (Akkerman et al., 2016; Kocman & Weber, 2016; Voermans et al., 2021). They also appreciate the opportunity to do work activities in a sheltered environment, because it affords them opportunities for both engaging in social relationships and growth and development (Akkerman et al., 2014; Blick et al., 2016; Voermans et al., 2022). Successfully identifying which type of work best suits a particular person with ID depends on numerous factors, such as person-level attributes, individual needs and goals, skills, educational preparation, social opportunities, societal values, and family and community support (Lysaght et al., 2017). Parents and other members of the informal network of people with ID constitute a potentially important resource in terms of identifying and sustaining suitable work options (Donelly et al., 2010; Petner-Arrey et al., 2016), insofar as people with ID might need more support than people without ID to make self-determined choices (Clegg et al., 2017). Therefore, the present systematic review focuses on informal network members' perspectives on employment or daytime activities for their relatives with ID.

People with ID can be supported in making self-determined choices by professionals as well as by people from their informal network, such as parents, relatives or friends and peers. The forms of support provided by informal networks to people with ID display particular characteristics. For example, although the social networks of people with ID frequently appear to be small and largely composed of family members and professionals (Giesbers et al., 2020; Lippold & Burns, 2009), they are often characterized by a high frequency of contact (Van Asselt-Govers et al., 2013). In many cases, parents provide most of the practical (Giesbers et al., 2020) and emotional (Sanderson et al., 2017) forms of support for their offspring with ID, but people with ID also assign important roles to others in their family and broader informal network, such as siblings and friends (Giesbers et al., 2020; Tournier et al., 2022).

When people need to make self-determined choices, the social values of a person's informal network may have a major influence on this process (Hagger et al., 2014). The values, beliefs and experiences shared by informal network members can also greatly influence people's occupational choice (Black et al., 2003). Therefore, informal network members of people with ID – and their values, beliefs, and experiences – may contribute to how people with ID experience both the meaning of and opportunities for participation in employment (Donelly et al., 2010; Petner-Arrey et al., 2016). This may be especially so given the aforementioned reliance of people with ID on and their need for support from their informal network.

Consequently, informal networks may play an important role in the occupational choice of people with ID and, in turn, their participation in society via employment opportunities and job retention (Donelly et al., 2010; Petner-Arrey et al., 2016).

Therefore, these informal networks are a vitally important resource for identifying appropriate opportunities for participation in suitable employment or daytime activities for people with ID, further enhancing their own self-determination. It is thus critically important to better understand informal network members' perspectives (i.e., values, beliefs, and experiences) on the meaning of the broad spectrum of integrated and sheltered employment and daytime activities for people with ID. Given the scarcity of research on informal network members' perspectives on this issue, this study sets out to synthesize existing research on these perspectives in a systematic review in order to answer the following research question:

> *How do informal networks perceive the meaning of participation in employment or daytime activities for their adult relatives with ID and their social environment?*

Method

In conducting and reporting on the systematic review, the guideline for Preferred Reporting Items for Systematic Reviews and Meta-Analysis (Liberati et al., 2009) were implemented.

Search strategy

First, the Population, Intervention/exposure, Comparison and Outcome (PICO) approach (Liberati et al., 2009) was used to determine the core elements for the systematic review. The Population (P) was defined as 'informal network members of people with ID.' The informal network was defined broadly, as far as it included family members as well as other (non-paid) network members who may be influential in the occupational choices of the person with ID, such as friends. This decision was based on the fact that people with ID themselves sometimes also consider non-relatives to be family members (Giesbers et al., 2020). Intervention (I) was defined as 'Participation in – paid or non-paid – employment or daytime activities by people with ID', which, as aforementioned, includes all forms of sheltered and integrated employment. Due to the descriptive character of the research question, the Comparison (C) component was deemed to be not relevant for this study. Outcome (O) was defined as 'Perspectives (i.e., values, beliefs, and experiences) of informal network members of people with ID toward employment and daytime activities.' Initially, the O component was not specified in the search strategy, as the perspective of informal network members is an underexplored research area, and hence, any and all information about their perspectives was deemed to be of interest for this study. Subsequently, a search strategy was developed and conducted, based on the Exhausted Search Method (Bramer et al., 2018), in collaboration with an experienced information specialist. Four databases (i.e., Embase, MEDLINE (Ovid), PsychINFO (Ovid), and Web of Science) were systematically searched for empirical, peer-reviewed articles, published in English between January 1, 1990, and July 5, 2022. Given that contemporary research on the employment of people with ID only started in 1990 (Kocman & Weber, 2016), articles prior to the year 1990 were excluded. The full search strategy is provided in Appendix I.

Study selection

In accordance with the PRISMA guidelines (Liberati et al., 2009), the selection process consisted of four phases: (I) identification, (II) screening, (III) eligibility, and (IV) inclusion. A flowchart of the selection process is shown in Figure I. During the first phase, duplicates were removed, along with publications prior to 1990. The second phase comprised reviewing the 6125 titles and abstracts of all remaining articles for the purpose of inclusion or exclusion. In order to refine the inclusion and exclusion criteria, fifty publications were reviewed and discussed by the first author and a second researcher. The criteria for inclusion and exclusion are represented in Table 1. All publications were independently reviewed by both the first author and a second researcher to improve inter-researcher consistency. They agreed on 97% of all titles and abstracts. Any disagreements were discussed between both reviewers until a consensus was reached. In the event of uncertainty, the article in question was included and proceeded to the next phase. During the third phase (i.e., 'eligibility'), the same researchers independently reviewed the full texts of the remaining articles (n=212). During this phase, studies were also excluded according to the criteria concerning the Outcome (O), i.e., perspectives (values ,beliefs, and experiences) of informal network members concerning employment of people with ID. Based on this broad definition, only qualitative studies that properly captured the perspectives of the participants were included as well as mixed-methods studies whose qualitative component met this criterion. Quantitative studies were thus excluded at this point. The researchers agreed on 87% of the full texts. Any disagreements were discussed until a consensus was reached, and in the event of uncertainty a senior researcher was consulted. Subsequently, the quality of the eligible studies (n=27) was assessed using the Mixed-Method Appraisal Tool (MMAT), version 2018 (Hong et al., 2018), which is applicable for the assessment of different types of research designs. The quality assessment was conducted in order to provide a proper assessment of the quality of the studies and any potential bias, and was conducted by the first author in close cooperation with a second researcher. The quality criteria for each study were discussed in detail until a full consensus was reached, which resulted in studies assessed as having high quality (n=16), medium quality (n=6) or low quality (n=5). Information on the quality of the studies is included in Table 3. All of the authors frequently discussed the selection process and were consulted in the event of any uncertainties.

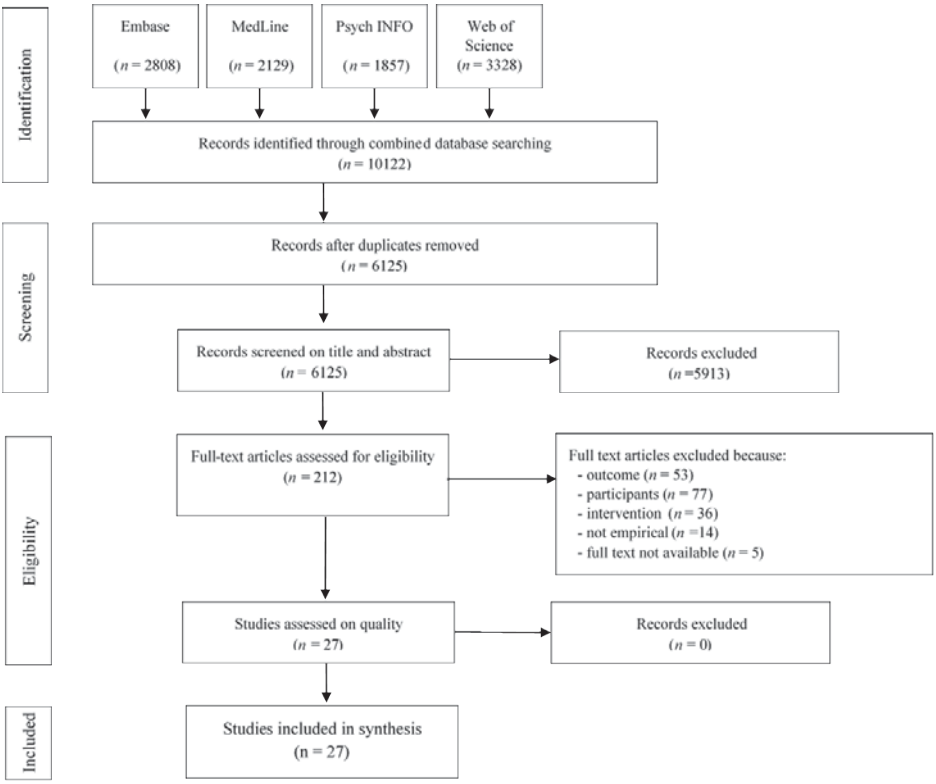
Table 1. Inclusion- and exclusion criteria

	Inclusion criteria	**Exclusion criteria**
General	Empirical articles Publications > 1990 Articles in English	Non-empirical articles, including systematic reviews Publications <1990 Articles in other languages
Population (P)	Studies concerning: (non paid) network members of adults with ID (e.g. parents, grandparens, siblings, friends, acquaintances, mentors) (non paid) network members of adults with other comorbid disorders, frequently associated with ID (i.e. autism, down syndrome, epilepsy, cerebral palsy, FASD)	Studies concerning: (paid) professional caregivers (e.g. support staff, psychologists, teachers, nurses) People with ID themselves Other populations with no reference to ID (e.g. psychiatric patients, ex-cancer patients, people with physical disabilities, autism clearly without ID, ADHD, SLI, DCD and ABI) Infants and children (< 18 years) Adults > 65 years A mixed sample of participants where separate results could not be extracted for the subgroup meeting inclusion criteria
Intervention (I)	Studies concerning informal network members of: Adults with ID participating in employment or daytime activities at present or in the past This includes all forms of work or daytime activities, including activities as an expert by experience or co-researcher	Studies concerning: Education / educational activities The transition process from education to employment/daytime activities The transition process from employment/ daytime activities to retirement Daily living Leisure activities (e.g. sports or faith communities) Therapy or therapeutic activities
Outcome (O)	Experiences, values, beliefs and attitudes of informal network members	Factual information from informal network members (e.g. the number of workplaces that their relative with ID has had) Informal network members explicitly representing the perspective of their relative as a proxy (e.g. when they had answered behavioural questionnaires)

Data extraction and analysis

Each study was read several times and summarized by the first author in order to familiarize herself with all the studies. For each study, specific information was extracted about the author, year of publication, country, aim(s), study design, participants (P), the employment situation of the relatives with ID (I), and the main results. In addition, given that not all of the results in the studies met the inclusion criteria, only data that met the inclusion criteria were extracted from the results sections of all the studies, in preparation for the thematic synthesis. Data extraction was conducted by the first author, while a second researcher independently extracted data from 20% of the studies (with a 94% level of agreement). Thematic Synthesis (Thomas & Harden, 2008) was employed as a method for data analysis.

Figure 1. Flow-chart Study Selection



To start the thematic synthesis, the extracted data were carefully studied by the first author in order to familiarize themselves with the data. Next, all data were coded line by line. Coding was conducted in a word processing program by the first author. The second researcher independently coded 20% of the data (with an 85% level of agreement). Both researchers then discussed any disagreements until a consensus was reached, and in the event of any uncertainty a senior researcher was consulted. Subsequently, themes and subthemes were identified and codes with similar content and meaning were grouped and organized. The identification of themes and subthemes was conducted by the first author and discussed with all other authors. To optimize rigor and to achieve a proper and rich understanding of the data, further meetings were organized with all authors and the previously consulted researchers involved in the data analysis.

Results

Study characteristics

After the critical selection procedure was completed, the qualitative data from 27 studies with different designs were included: qualitative studies (n=22; interviews, focus groups, observation, case study designs) and mixed-methods studies (n=5; survey and interviews, concept mapping, social network analysis and interviews). The studies were conducted in five Western countries: US (n=15), Australia (n=5), UK (n=4), Canada (n=1), Malta (n=1) and the Netherlands (n=1). In the majority of the studies (n=15), the participants were solely parents – fathers and mothers – of people with ID, but some studies also specifically focused on mothers (n=3). Some studies included, in addition to parents, other family members as participants, such as siblings (n=7). Other studies also included, in addition to parents and family members, informal network members from outside the family as participants, such as friends and acquaintances (n=2). In the majority of the studies, either the level of ID of the relatives was not reported (n=19) or relatives had various levels of ID (n=4). A minority of the studies focused on relatives with specific levels of ID: mild (n=2), severe (n=1) or visually impaired people with severe or profound (n=1) ID. In most of the studies, the relatives with ID were either in varying types of employment or daytime activities (n=15), or there was no specific information given about the type of employment or daytime activities of the relatives (n=5). A minority of the studies focused on specific types of employment: a day program (n=1), competitive employment (n=2), supported employment in the community (n=2), or self-employed people with ID (n=2). To improve readability, we use the term "work" to refer to both employment and daytime activities. This is also consistent with the large number of studies that focused on a broad range of work activities and the small number of studies that focused on specific employment types. Finally, the majority of the studies were conducted between 2011 and 2021 (n=17), eight studies were conducted between 2001 and 2010, and two studies were carried out between 1990 and 2000. The characteristics of all the included studies are shown in Table 2.

Table 2. Characteristics of the included studies

No	Author, (year) and country	Aims	Study design, (theory)	Participants	Work situation	Main findings
1	Anderson et al. (2020), *US*	Explore early employment-related expectations and experiences through first-person accounts of young adults with autism spectrum disorders (ASD) and their parents	**Qualitative:** Interviews (grounded theory)	**Parents:** fathers, mothers or couples (n=28) of young adults with ASD and young adults themselves (n=12). Nine of them had an ID (**level not reported**)	Various work situations from competitive employment without support to day programs	Three major themes emerged: a) Employment aspirations and potential; b) Challenges of job finding and keeping; and c) Differing young adult and parent work-related roles and views.
2	Bianco et al. (2009), *US*	Soliciting parents' voices to provide a better understanding of parents' experiences and perception of their roles during the post high school years for their children with developmental disabilities	**Qualitative:** semi-structured interviews (phenomenological)	**Parents** (n=9) of adults with **varying levels of ID**	Working in a vocational setting providing sheltered or supported employment	Families perceived their roles as complex. In advocating for their adult children's needs into adult life they had to balance between different roles (i.e. collaborators, decision makers, program evaluators, role models, trainers, mentors, instructors, and system change agents). Parents often felt they were the safety net for their children and the back-up plan for service agencies.
3	Butcher & Wilton (2008), *Canada*	Exploring the experiences of young adults with ID as they transition from high school in search for paid employment	**Qualitative:** Interviews and participant observations	Young adults with ID (n=6) (**level of ID not reported**). In addition their **parent(s)** and employer are interviewed.	Various work situations (vocational training center, sheltered workshop and mainstream workplaces)	While the primary goal of the youth and their parents was to make a transition to competitive employment, a lack of transition planning, a shortage of appropriate opportunities and other factors meant the youth spent considerable time in 'transitional spaces' (e.g. vocational training center, sheltered workshop, supported employment placements). While these spaces are organized around an explicitly economic goal of augmenting the youth's employability, they can play a critical role as spaces for social interaction and meaningful activity outside the home.

No	Author, (year) and country	Aims	Study design, (theory)	Participants	Work situation	Main findings
4	Callus et al (2019), *Malta*	Exploring whether and how people with ID experience overprotection in different aspects of life, especially through the actions of their parents	**Qualitative:** Focus groups	Focus groups with people with ID (n=17), **parents** of people with ID (n=14) (**level of ID not reported**) and representatives of organizations (n=18)	No specific information about work situations	Overprotection is a disabling barrier for employment, leisure activities, intimate relationships, and the use of public transport, money and mobile phones. People with ID who experience overprotection live very structured lives. They cannot develop their skills, abilities, and potential and cannot live their life on their own terms, creating a sustained dependence on others, especially the family.
5	Dague (2012), *US*	Examine selected aspects of one agency's conversion from a sheltered workshop facility to one providing community-based services for individuals with IDD	**Qualitative**: Case study design with semi-structured interviews, participant observation and archival review	People with ID (**level of ID not reported**) and their **parents** (n=12)	All currently in supported community employment (some transitioned from a sheltered workshop)	While the initial transition was difficult, most families and participants were satisfied with the conversion process as long as they could maintain previous social networks and find acceptable employment in the community. Conflicted issues emerges, as families had different histories, culture, values, philosophies, and expectations of their children and their inclusion in community.
6	Dixon & Reddacliff (2001), *Australia*	Describing the contributions families make to the vocational competence of young adults with mild ID	**Qualitative:** Semi-structured interviews	Adults with **mild ID**, in some cases supplemented with interviews with **family members**	Competitive employment	Families contribute to the individuals' efforts to maintain competitive employment. Moral support, practical assistance, role models of appropriate work ethic, protection from difficulties and exploitation, and family cohesion were family characteristics that led to more successful employment outcomes.

No	**Author, (year) and country**	**Aims**	**Study design, (theory)**	**Participants**	**Work situation**	**Main findings**
7	Docherty & Reid (2009), *UK*	Exploring the values and beliefs of mothers of young adults with Down syndrome (DS), currently involved in supporting their offspring in the transition from dependence to independence	**Qualitative**: Interviews (interpretative phenomenological analysis)	**Mothers** of adults with ID (**level of ID not reported**) (n=8)	Various work situations	The mothers described themselves as having a dynamic role as both gate-keepers and facilitators in aiding their offspring on the path of adulthood.
8	Donelly et al. (2010), *Australia*	Explore the impact of informal support networks on work opportunities of people with ID thoroughly	**Qualitative**: Case-studies with interviews and participant observations (ethnographic)	People with ID (**no level of ID reported**) (n=4) and key members of their **informal support network**	Various work situations	The insight and actions of network members created and sustained the employment and support opportunities that effectively matched the needs and interests of the relatives with ID. Paid work had a range of personal meanings and functions in the lives of the participants. There was often a mismatch between the interests and choices of the relatives with ID and the services provided by employment support organizations.
9	Eisenman (2007), *US*	Further extend the research base on how social networks function to influence careers by examining the experiences of young adults with ID	**Qualitative:** Case-studies with interviews	Adults with **varying levels of ID** (n=5) and 2 or 3 **informal network members**	Employed (n=3) or still students (n=2)	Participants who were still studying mainly had friends and acquaintances from school. Participants who were employed mainly had friends and acquaintances from work. Family members played a supportive role in many aspects of participants' career situations. Work acquaintances, primarily those in supervising roles, had a strong influence on the career situations of employed participants as did school staff.

No	Author, (year) and country	Aims	Study design, (theory)	Participants	Work situation	Main findings
10	Finch et al. (2021), *UK*	Gain a better understanding of the everyday experiences of autistic adults through first-hand accounts from adults with ASD and also from relatives interviewed from the perspective of supporting autistic adults	**Qualitative:** Interviews (thematic analysis)	Adults with ASD (n=29) with or without ID **(level of ID not reported)** were interviewed, as well as **relatives** (n=16): mothers (n=10), fathers (n=3), grandparent (n=1), spouse (n=1) or sibling (n=1) of adult with ASD with (n=9) or without ID	Various work situations	Six main themes were identified: a) Diagnosis as validating yet limiting; b) Supportive and non-supportive social agents; c) The ‘invisibility’ of the needs of autistic adults; d) Health in the context of autism; e) Staying ‘outside’ the circle; and f) Multiple lives with autism. Data from relatives about autistic adults experiences gave additional perspectives on these themes. Education and employment, whilst challenging for many, were also rewarding for some.
11	Ford et al (1995), *Australia*	A preliminary examination of parent and primary caregiver attitudes toward the employment conditions of their relatives/wards who are working in supported employment placements	**Qualitative:** semi-structured interviews	**Parents** (n=7: 4 mothers, 3 fathers) and professional caregivers (n=9) of adults with **severe ID**	All in supported employment	Respondents were generally satisfied and accepting of their child's/ward's participation in supported employment. They felt that the supported employment programs offered more normalized and beneficial work experiences than those typically provided for persons with severe disabilities. Respondents also expressed relatively low expectations for improving wages, opportunities for career advancement and social integration.
12	Francis et al. (2018), *US*	Explore the negative and positive experiences of Hispanic caregivers from a Midwestern state as they support their family members with disabilities to achieve positive post school outcomes	**Qualitative:** Interviews	Hispanic **mothers** (n=13) of people with various disabilites (age 14-25), including ID (**level of ID not reported**)	Various work situations	Three key themes emerged form analysis: a) negative experiences with school educators, b) negative experiences with community-based service providers, and c) positive experiences and strategies for overcoming barriers.

No	Author, (year) and country	Aims	Study design, (theory)	Participants	Work situation	Main findings
13	Franklin et al. (2019), *US*	Explore the health care transition experiences of parents of adolescents and young adults, with particular interest in the barriers and facilitators to the transition to adulthood within and between the medical, community and vocational systems	**Qualitative:** Semi-structured interviews	**Parents** (n=16) of adults with **various levels of ID**	Some were in work situations	Three overarching themes represented barriers and the essence of supporting the transition to adulthood of persons with ID experienced by their parents: a) Inefficient and siloed systems; b) 'Left out floundering' in adulthood; and c) Hope despite uncertainty.
14	Frounfelker & Bartone (2020), *US*	Exploring ways to increase choice for individuals in their day treatment settings and evaluate the effectiveness of a day program, 18 months after its inception, by capturing experiences of participants, family and staff	**Qualitative:** Focus groups (grounded theory)	People with ID (n=15), **family members** (n=7), i.e. mothers and sisters, and staff (n=3), and staff of people with ID (**level of ID not reported**)	All in a day program	A model was derived from the data with 'building relationships' at its core. The model describes how relationships come together and work congruently with each level of a day program, from the top administrators to the staff, the members themselves and family members. This helps create and foster a positive environment that increases members' independence and provides them with stimulating activities during the day.
15	Hall & Kramer (2009), *US*	Explore how employment creates opportunities for social capital	**Qualitative:** Interviews and observations	Adults with **various levels of ID** (n=29), professionals (n=29) and **family members** (n=23)	Sheltered workshops and community employment	A form of social capital was created through workplace connections. Community employment did not increase social capital per se, but it did produce opportunities not available in sheltered workshops. The role of family members emerged as critical in the support of community employment, increasing the potential for social capital development.

No	Author, (year) and country	Aims	Study design, (theory)	Participants	Work situation	Main findings
16	Hanzen et al. (2017), *NL*	To develop a definition and operationalization of the concept of participation for adults with visual and severe or profound ID	**Mixed Method:** Concept mapping	**Parents or family members** (n=30) of people with visual and **severe or profound ID**, professionals (n=30) and experts (n=17)	No specific information about work situations	The final cluster map of the statements contained seven clusters: (a) Experience and discover; (b) Inclusion; (c) Involvement; (d) Leisure and recreation; (e) Communication and being understood; (f) Social relations; and (g) Self-management and autonomy. On this basis a definition of participation of the population was developed.
17	Keogh et al. (2004), *US*	To document long-term outcomes for individuals with ID specifically to determine where they are and how they are	**Mixed-Method:** Interviews and surveys	**Parents** (n=30) of young adults with **mild ID**	Various work situations (competitive, assisted, sheltered workshop, volunteering, none)	There was a broad range of outcomes, with some young adults leading independent and productive lives. However, the majority of yound adults were un- or underemployed, living with and financially dependent upon their families, and socially isolated.
18	Lindstrom et al. (2014), *US*	Examine career development and early employment experiences of young adults with IDD	**Qualitative:** multiple method, multiple case study design	Adults with ID (**level of ID not reported**) (n=3) and ASD (n=1), supplemented with interviews with their **parents**	All in integrated paid employment	During the early career years, participants maintained stable employment, but earned annual wages well under the federal poverty line. Employment opportunities seemed to be influenced by family advocacy and expectations, school-based work experiences, job development services, and work environments.
19	McMahon et al. (2020), *Australia*	Explore the aspirations that young adults with intellectual disabilities and their parents hold for the future and the factors that influence their aspirations and decisions regarding support services	**Qualitative:** Interviews (thematic analysis)	Young adults with ID (n=4; **level of ID not reported**) and their **mothers**	Two young adults were still in education, one was unemployed and one was in supported employment	The four young adults held a range of aspirations themselves. Their mothers had holistic, multidimensional aspirations for their children and wanted them to 'flourish' by deriving meaning and enjoyment from employment and leisure activities, having strong supportive relationships with their family, friends and the broader community, and having a happy home environment.

No	Author, (year) and country	Aims	Study design, (theory)	Participants	Work situation	Main findings
20	Reddington & Fitzsimons (2013), *UK*	Identify lessons that could be learned about the role microenterprise might play to help people with learning disabilities to be included in the world of work	**Mixed-methods:** Questionnaire and interviews	Microenterprises (n=13) were explored, by interviewing persons with ID (**level of ID not reported**), their advocates, **family members** and staff	All in microenterprise	Data reveal how successful self-employment, or starting a microenterprise, has been for the individuals involved, and how this can be a worthwhile alternative to regular employment, training, day center attendance or volunteering.
21	Rossetti et al. (2015), *US*	Examine parents' perceptions of meaningfulness in relation to the young adult's post-school activities and supports	**Qualitative:** Interviews (Grounded Theory)	**Parents** (n=23) of adults with pervasive support needs, including ID (**level of ID not reported**)	Diverse work situations (ranging from day program to paid work)	Most of the young adults spent time in their communities, though typically without friends and not engaged in integrated employment. The participants defined meaningfulness according to three dimensions: a) community participation; b) individual indicators: and c) the nature of activities in the young adults' schedules.
22	Rossetti et al. (2016), *US*	Examine parents' involvement in meaningful post-school experiences	**Qualitative:** Semi-structured interviews	**Parents** (n=8) of young adults with IDD (**level of ID not reported**)	Various work situations	The parents were active in their children's post-school experiences as fierce advocates and creative problem solvers. They strove to achieve what they considered to be the most meaningful lives for them, describing that they often challenged existing service options to do so. The active involvement of parents included three participatory sub-themes, which contributed to their success: a) attitudinal factors, b) advocacy efforts, and c) strategic actions.
23	Spencer et al. (2021), *US*	Provide insights into the social networks of graduates of a post-secondary education program and the social network aspects that contribute to positive employment outcomes	**Mixed-methods:** Semi-structured interviews and social network analysis	Adults with ID (n=6) (**level of ID not reported**) and their **parents/guardians** (n=6)	Five participants were employed, one had recently become unemployed	Three participants displayed smaller networks than a year before. Two graduates displayed larger networks, because of new opportunities for socialization. Most parents were involved in graduates' employment decisions, thereby curbing graduates' expression of self-determination.

No	Author, (year) and country	Aims	Study design, (theory)	Participants	Work situation	Main findings
24	Thomson et al. (1995), *UK*	Reporting on the transition pathways to the adult status of young adults with DS	**Mixed-Method:** Quantitative and qualitative (case study) data	Adults with DS (**level of ID not reported**) (n=2). In the case-studies the **parent** perspective is described	day centre (n=1) and volunteering (n=1)	Results provide a disappointing picture of a narrow range of leisure opportunities, negligible placement in employment, and continuing dependency on parental caregivers in adulthood.
25	Thoresen et al. (2018), *Australia*	Explore the utility of Small Business Enterprises (SBE) as an emerging employment pathway in economic and social inclusion for adults with ID	**Qualitative:** Case study design with interviews	Case studies of people with ID and high support needs (**level of ID not reported**) (n=4) that also includes the perspective of **parents** as key informants	All self-employed	A range of strategies are described to develop and maintain SBE's and to create meaningful economic and social inclusion. The case studies illustrate different supports used in establishing and continuing these arrangements, and issues related to safeguarding and sustainability.
26	Timmons et al (2011), *US*	Exploring factors that influence the employment-related decision-making of individuals with IDD and to what extent their preferences correspond to existing employment options and choices	**Qualitative:** Interviews	Adults with ID (**level of ID not reported**) (n=16), and one of their **family members** and professional caregivers	Sheltered (n=7) and competitive (n=9) employment	Different people and factors affect the choices people with IDD make in relation to work: 1) family in the formative years, 2) school-based staff and early employment experiences, 3) community rehabilitation providers' culture, 4) the job developer and, 5) personal preferences.
27	Yuan et al. (2018), *US*	Explore parents' expectations and perceptions of academic, social and employment experiences of their children out of the first two cohorts of the Think College	**Qualitative:** Semi-structured interviews	**Parents** (n=9) of adults with ID (**level of ID not reported**)	Majority in paid employment	Parents described efforts to support their children during college and discussed hopes for employment, and evolving perceptions of their own roles in relation to the future lives of their adult children. Parents responses fell into three categories: (a) perception of their child, (b) perceptions of the program (including expectations and perceptions of employment), and (c) perceptions of their own roles of the college life of their children and beyond.

Thematic Synthesis

Thematic synthesis yielded four overarching themes with various subthemes, which are discussed in turn below. An overview of the reported themes and subthemes for each study is presented in Table 3.

Theme I: Ensuring customized work for my relative

Across the studies, informal network members expressed the importance of ensuring customized work for their relatives with ID. Within this theme, two subthemes emerged: One concerning the efforts of network members to put the needs and wishes of their relatives first in the process of finding or creating customized and person-centered work for them; and one centered on network members' experiences of the lack of support services and work options that suit their relatives' needs.

My efforts to put the wishes and needs of my relative first. Informal network members went to considerable effort to find or create work activities that their relatives preferred, in addition to work activities that suited the needs and skills of their relatives. They emphasized the value of focusing on the wishes, dreams and needs of their relative as the starting point for creating meaningful employment for them (n=11). Parents, for example, stressed the importance of putting their child's interests at the center of starting up a Small Business Enterprise (SBE) (Thoresen et al., 2018). One parent stated: *"The potential for other people to create person-centered employment is limitless, it's absolutely limitless. It just had to be looking at who is the person, what can they do, what do they want, what are they like?"* In addition, network members stressed that leveraging their knowledge about the interests, skills and choices of their relatives with ID served as an effective basis from which to create employment opportunities, identify support needs and find ways to effectively meet those needs (Donelly et al., 2010).

In some instances, it appeared to be complex for parents to distinguish between their child's wishes and their own wishes for them. For example, a parent couple expressed that they were actively trying not to determine the direction their child should take (Yuan et al., 2018). Moreover, in some of the cases from the study by Butcher & Wilton (2008), the preferences of the relatives with ID interfered with the expectations and preferences of the parents. For example, one mother felt the need for her son to do a job that would be more challenging for his brain and considered him capable of that, despite knowing that her son liked his current job in a grocery store.

A lack of support services and work options that fit my relatives' needs. Despite the fact that informal networks emphasized the importance of customized work for their relatives with ID, they indicated that existing customized work opportunities were limited, and that there was a lack of support in finding suitable options (n=17). It was common for informal network members to spend a lot of time and effort trying to obtain suitable support and work opportunities, and sometimes they had to endure years of waiting lists for support services and work. This frequently resulted in network members having to strongly advocate for their relatives with ID to obtain support and work (Anderson et al., 2020; Bianco et al., 2009; Butcher & Wilton, 2008; Dague, 2012; Donelly et al., 2010; Franklin et al., 2019; Thoresen et al., 2018; Rossetti et al., 2015]. Parents, for example, experienced having to fight to achieve employment or the necessary support for their children (Bianco et al., 2009). In the absence of existing suitable programs or because of the unavailability of programs due to long waiting lists, parents in some cases initiated suitable work opportunities for their relatives themselves, by creating micro-businesses (Reddington et al., 2013; Rossetti et al., 2015; Thoresen et al., 2018), collaborating to establish day programs (Butcher & Wilton, 2008; Dague, 2012; Donelly et al., 2010), or arranging volunteer opportunities (Anderson et al., 2020).

Theme II: My ongoing need to collaborate and share care responsibilities with professionals

Informal networks reported the need to organize sustainable work for their relatives with ID in sustainable collaboration with professionals (n=20). For example, network members emphasized that a sustainable and ongoing supportive partnership with a support worker was a precondition for sustainable work for their relatives with ID, rather than forms of support that were time-limited and focused on withdrawal (Donelly et al., 2010). However, informal network members sometimes had different expectations about the allocation of roles and tasks between network members and professionals. For example, family members perceived support workers, such as job coaches, to have greater knowledge and skills than themselves about finding work for their relatives (Timmons et al., 2011). They viewed job coaches as being responsible for finding and preparing their child for starting work. In other studies, the network members reported playing a more active role in the work support for their relatives [Anderson et al., 2020; Bianco et al., 2009; Dixon & Reddacliff, 2001; Donelly et al., 2010; Finch et al., 2022; Hall & Kramer, 2009). For example, in the study of Bianco et al. (2009), parents took on the role of teaching their children job-related skills. One mother, however, experienced that this role of being a mother and a job coach simultaneously eventually became unwieldy for her, and she chose to hand over that role to a professional. She expressed: *"I was the main support* *[for a job] and I'm also the main reason why we're not doing it still. Because it became unwieldy and I did not have enough time to be that support person."*

With respect to their collaboration with professionals and other people, such as employers and co-workers of their relatives with ID, informal network members expressed the need for shared responsibility (Bianco et al., 2009; Butcher & Wilton, 2008; Dague, 2012; Docherty & Reid, 2009; Donelly et al., 2010; Ford et al., 1995; Francis et al., 2018; Franklin et al., 2019; Rossetti et al., 2015). If and when network members felt they were able to confidently share the care and responsibilities for their relatives with ID, it brought them relief and comfort. Indeed, even the fact that their relatives with ID had a job was in some instances experienced in and of itself as a form of support by network members (Anderson et al., 2020; Butcher & Wilton, 2008; Dague, 2012; Dixon & Reddacliff, 2001 Donelly et al., 2010; Ford et al. 1995; Frounfelker & Bartone, 2021). Involvement in work activities made network members feel that their relatives were supervised for a certain number of hours during the week. In some instances, parents explicitly expressed that the work of their child released them from their caregiver duties and freed them up for their own schedules and interests (Dague, 2012; Ford et al., 1995).

Theme III: The meaning of work for both my relative and myself

It was observed across the studies that informal networks experienced work as being meaningful for their relatives with ID, in terms of providing several benefits in both their relatives' and sometimes their own lives, namely: (I) gave them routine and purpose, (II) enhanced their skill development and self-confidence, (III) provided them with social connections, and (IV) afforded them opportunities to contribute to society and perform social roles.

Work provides routine and purpose in my relative's life. Although a few parents (Rossetti et al., 2015; 2016) stated that they experienced life outside of work as more meaningful for their child, involvement in work was generally perceived as a means for the relatives with ID to spend the day performing meaningful activities (n=14). For example, parents experienced that it provided routine (Butcher & Wilton, 2008; Dague, 2012; Thoresen et al., 2018) or structure (Anderson et al., 2020; Finch et al., 2022) and a sense of purpose (Frounfelker & Bartone, 2021; Rossetti et al., 2015; Thoresen et al., 2018) in their relatives' lives. In some studies, family members noted that variation in work activities was important for experiencing meaningfulness (Ford et al., 1995; Frounfelker & Bartone, 2021; Hanzen et al., 2017; Rossetti et al., 2015).

Furthermore, in several studies informal networks reported negative effects of the absence of work for their relatives with ID (Butcher & Wilton, 2008; Donelly et al., 2010; Franklin et al., 2019). For example, network members experienced that days without work could be very long and boring for their relatives. They reported that long periods without work could also have adverse health effects for them, for example weight gain and depression (Donelly et al., 2010). Parents indicated that a lack of structure and meaningful daytime activities negatively impacted on the situation of their relatives, as a result of reversing the day-night rhythm (Butcher & Wilton, 2008). In some instances, this also had negative effects upon family members. One mother experienced significant conflict and role confusion, because her daughter was at home every day, and she considered this to be detrimental to both her daughter and the family. She said: *"I'm just trying to find something for [my daughter] to do because it is certainly detrimental to her and to everybody else that she is home every day. (…) because it gets where she is trying to reverse roles. She is trying to be the mother and telling you know, what to do, what to wear. There's been a fair amount of conflict with her and I lately…"*

Work helps my relative to keep developing skills and feel self-confident. Informal network members believed that participation in work contributed toward the development of their relatives' skills and self-confidence (n=15). For example, one father noted that his daughter's self-confidence had markedly increased since she started attending a day center (Thomson et al., 1995). In some of the studies, network members associated the development of skills and self-confidence particularly with work in the community (Dague, 2012; Donelly et al., 2010; Lindstrom et al., 2014; Thoresen et al., 2018). Dague's study (2012), for example, explored how parents experienced the transition from a sheltered workshop to community employment, with several of them reporting a remarkable increase in their children's skills since leaving the sheltered workshop, including their verbal communication skills. In the study of Donnelly et al. (2010), the opportunities that community employment afforded to develop traveling and social skills were valued. Conversely, a family member whose relative had returned to sheltered employment experienced that this relative was no longer challenged at work and consequently saw their skill diminish.

Nevertheless, parents sometimes felt that there were insufficient career opportunities for their relatives to continue to develop their skills (Ford et al., 1995; Keogh et al., 2004; Rossetti et al., 2015; Spencer et al., 2021). One father, for example, noted that there were no actual further positions his son could grow to occupy, with the exception of supervisor positions that he personally felt would be too demanding in view of his son's capabilities (Ford et al., 1995). In his words: *"There is nowhere to go except maybe a supervisor position, but [son] doesn't have the ability for that."*

Employment improves my relatives' social connections in the community. Informal networks experienced that work participation improved their relatives' social connections in the community, beyond their families (n=9). One mother, for example, expressed that she felt it was crucial that work in the community made her son meet people besides his own family (Lindstrom et al., 2014). She said: *"He sees a whole different world of people besides family and it's just crucial to his whole [being]. It seems the healthy thing to do for any adult with a disability."* Another mother noticed that her son developed relationships with his co-workers, who started monitoring and helping him outside of working hours, as well as including him in social events outside work (Francis et al., 2018). Some parents found it very difficult that their child had to make the transition from a sheltered workshop to work in the community (Dague, 2012). They wanted to maintain the sense of community and connection that had developed in the sheltered workshop over 35 years and were concerned about losing this, not only for the sake of their relatives with ID, but also for their families. They experienced a sense of togetherness with other parents and feared the loss of these friendships among families.

I want my relative to make a contribution to society and perform a valued social role. Participation in employment was perceived by informal networks as a means through which their relatives with ID could make a productive contribution to and perform a valued social role in society (n=9). Besides making a productive contribution, network members considered it as meaningful when their child could make a difference to other people's lives and receive recognition for this (Dague, 2012; Donelly et al., 2010; Rossetti et al., 2015). One mother, for example, expressed that her daughter was recognized for her ability to help day care children go to sleep (Dague, 2012). She said:

> *She's the lunch lady there. She does the tables, cleans them all up, pours the milk, sweeps the flours, takes the garbage out, and she's been known to put twenty children on the back and put them all to sleep there.*

However, making a contribution to society was not only perceived as being valuable for their relatives with ID, rather it also brought relief to family members (Ford et al., 1995; Thoresen et al., 2018). Parents experienced a sense of relief as their children became productive members of society (Ford et al., 1995). For example, one mother felt less guilty since her son was involved in meaningful work activities, as opposed to before when he was just sitting at home and benefitting from society. She even felt that in a similar way other family members' previous feelings of guilt had been replaced by pride in her son's achievements.

Theme IV: Achieving full work participation for my relative is neither straightforward nor self-evident

Although many informal network members wanted their relatives with ID to be able to experience full participation in society via work, they also experienced many societal barriers that hindered this.

Moving a continuum: ideals for participation in community jobs vs. barriers and concrete experiences in society. Many network members in the studies were focused on achieving a full job and experiencing a sense of belonging to society for their relatives with ID (n=25). They routinely expressed a strong preference for community jobs and valued normalization for their relatives (Anderson et al., 2020; Bianco et al., 2009; Butcher & Wilton, 2008; Dague, 2012; Donelly et al., 2010; Ford et al., 1995; Francis et al., 2018; Frounfelker & Bartone, 2021; Hall & Kramer, 2009; McMahon et al., 2020; Rossetti et al., 2016; Thoresen et al., 2018; Timmons et al., 2011). Mothers, for example, wanted to ensure that their children with ID felt integrated in society like any other individual (Francis et al., 2018). They believed that they themselves, as parents, could help make this happen by maintaining high expectations and a positive outlook on participation.

Furthermore, network members in some instances even expressed strong disapproval toward work in sheltered environments (Butcher & Wilton, 2008; Dague, 2012; Donelly et al., 2010; Ford et al., 1995). For example, some parents considered working in a sheltered workshop as working in a closeted box, saw sheltered workshop tasks as both menial and redundant or thought that working in a sheltered workshop added to the stigma toward people with ID (Dague, 2012). Moreover, there were concerned that placement in sheltered employment would limit the future opportunities of relatives with ID to grow into competitive employment (Butcher & Wilton, 2008; Donelly et al., 2012). Informal networks, however, encountered obstacles in realizing their aspirations for participation. Indeed, sometimes it took considerable effort to achieve participation in community jobs (Anderson et al., 2020; Bianco et al., 2009; Butcher & Wilton, 2008; Donelly et al., 2010).

Conversely, there were family members who expressed a clear preference for sheltered work environments (Callus et al., 2019; Dague, 2012; Dixon & Reddacliff, 2001; Donelly et al., 2012; Frounfelker & Bartone, 2021; Hall & Kramer, 2009). These family members expressed concerns about unfair treatment and wanted to protect their vulnerable relatives from exclusion, negative experiences, and high demands in community jobs. There were fears and concerns about exploitation of their relatives with ID by employers or co-workers, by, for example, assigning them too heavy tasks or by asking them to borrow money, or about bullying by co-workers, discrimination or dismissal from jobs on the grounds of their disability (Butcher & Wilton, 2008; Callus et al., 2019; Dague, 2012; Dixon & Reddacliff, 2001). Therefore, some parents felt that their children were better off in sheltered employment situations or staying at home instead of doing community jobs (Callus et al., 2019).

However, the preferences of network members for community or sheltered work sometimes changed over time. These changes might have been driven by advanced insights through experiences or observations of their child's experiences and abilities. For example, parents who feared the closure of the sheltered workshop in the study of Dague (2012) reported after four years that their initial fears of abuse and ridicule in a community job did not materialize. Rather, they experienced that community-based jobs were tailored to the needs of their children and caused their children to be considered 'regulars' and be recognized in the community. Conversely, one mother, who initially feared the placement of her daughter in a sheltered workshop, saw after six months of the placement the various benefits of the sheltered workshop for her daughters' wellbeing, as well as the risks and barriers of working in the community (Butcher & Wilton, 2008). She subsequently abandoned her ideal for participation in society and changed her belief in seeing separation as positive. Moreover, the study of Dague (2012) indicated that the preferences of network members for sheltered vs. community work might also derive from the spirit of the time in which their relatives with ID had grown up. Some parents thought it was too late for their children with ID to make the shift from the sheltered workshop to community employment. These parents had noticed that people with ID today are better prepared and educated for community jobs, while their children did not have that option during their younger years. One mother thought it was unfair to expect her child to go into a community job, because her child did not know any better. She said: *"We didn't prepare them for this. The younger kids have the potential, our kids don't. They have been too taken care of. It's not fair to them."*

Basic income insecurity hinders my relative's full participation in the workforce. Across several of the studies, informal networks expressed concerns about the effects of full participation in paid employment upon their relatives' eligibility for social benefits and the financial risks this entailed (n=8). As a result, network members experienced struggles and sometimes had to make paradoxical decisions in order to protect the financial situation and social benefits of their relatives.

Network members in the study of Donnelly et al. (2010), for example, experienced a huge struggle, as their relative worked far too few hours, purely due to the risk of losing her benefits. They experienced a paradox, insofar as working the desirable number of additional hours represented a potential threat to the social security of their relative. Family members in other studies also took paradoxical decisions about the work situations and earnings of their relatives (Hall & Kramer, 2009; Lindstrom et al., 2014; Yuan et al., 2018). For example, parents decided to limit their son's working hours to protect his benefits, despite having an offer for full-time paid employment. They were concerned that he would not recover his benefits when he lost his job and feared financial hardship, with a view to their own mortality (Yuan et al., 2016). Intense fear over losing benefits led some parents to suggest that their children should work without getting paid (Hall & Kramer, 2009), while other parents protected their children's benefits by instructing employers to pay their children low wages. As one mother said: *"I had said to [his supervisor] don't pay him much now because I don't want to go over that limit and go through that again….and [his job coach] did say he can't make too much money…."*

Table 3. Themes and quality assessment per study
* Low quality score on MMAT
** Medium quality score on MMAT
*** High quality score on MMAT

Study	**I: Ensuring customized work for my relative**		**II: The ongoing need to collaborate and share care responsibilities**	**III; The meaning of participation in work for my relative and for myself**				**IV: Achieving full employment participation for my relative is not easy and self-evident**	
	a): My efforts to put the wishes and needs of my relative first	b): A lack of support services and work options that fit my relatives' needs		a): Meaningful and varied work provides routine and purpose in my relative's life	b): Work helps my relative to keep developing skills and feel self-confident	c): Employment improves my relatives' social connections in the community	d): I want my relative to make a contribution to society and perform a valued social role	a): Moving a continuum: Ideals for participation in community jobs vs. barriers and concrete experiences in society	b): Basic income insecurity hinders full labour force participation of my relative
Anderson et al.***		x	x	x	x	x	x	x	
Bianco et al.***		x	x		x			x	
Butcher & Wilton*	x	x	x	x		x	x	x	
Callus et al.*								x	
Dague**	x	x	x	x	x	x	x	x	
Dixon & Reddacliff***			x					x	
Docherty & Reid**			x		x				
Donnelly et al.***	x	x	x	x	x		x	x	x
Eisenman***			x					x	
Finch et al.***		x	x	x				x	
Ford et al.***	x	x	x	x	x		x	x	x
Francis et al.***		x	x			x		x	x
Franklin et al.***		x	x	x	x	x		x	
Frounfelker & Bartone***	x	x	x	x	x			x	
Hall & Kramer**		x	x					x	x

Study	I: Ensuring customized work for my relative		II: The ongoing need to collaborate and share care responsibilities	III; The meaning of participation in work for my relative and for myself				IV: Achieving full employment participation for my relative is not easy and self-evident	
	a): My efforts to put the wishes and needs of my relative first	b): A lack of support services and work options that fit my relatives' needs		a): Meaningful and varied work provides routine and purpose in my relative's life	b): Work helps my relative to keep developing skills and feel self-confident	c): Employment improves my relatives' social connections in the community	d): I want my relative to make a contribution to society and perform a valued social role	a): Moving a continuum: Ideals for participation in community jobs vs. barriers and concrete experiences in society	b): Basic income insecurity hinders full labour force participation of my relative
Hanzen et al.***	x			x	x	x	x	x	
Keogh et al.**		x			x				
Lindstrom et al.***	x		x		x	x		x	x
McMahon et al.**	x		x	x				x	
Reddington & Fitzsimons*		x							x
Rossetti et al. (2015)**	x	x	x	x	x		x	x	
Rossetti et al. (2016)***				x				x	
Spencer et al.***			x		x	x		x	x
Thomson et al.*					x			x	
Thoresen et al.*	x	x	x	x	x	x	x	x	
Timmons et al.***		x	x	x			x	x	
Yuan et al.***	x	x						x	x

Discussion

The present study systematically reviewed qualitative data from qualitative and mixed-methods studies (n=27) to explore how informal networks of adults with ID perceive and experience the meaning of participation in work for their relatives with ID. The thematic synthesis revealed four overarching themes: I) Ensuring customized work for my relative; II) The ongoing need to collaborate and share care responsibilities with professionals; III) The meaning of work for both my relative and myself; and IV) Achieving full work participation for my relative is neither straightforward nor self-evident. The results suggest that informal network members place significant value on the customization and maintenance of work opportunities for their relatives with ID, particularly community-based work.

The first two themes of the present review revealed that in finding sustainable and fitting work, informal networks considered it an important precondition to always position the preferences, skills and needs of their relatives with ID at the forefront of their choices. However, informal network members experienced a lack of support services and work opportunities that matched their relatives' preferences, skills and needs, which, in turn, hindered the needed customization. Network members believed that realizing sustainable work that matches the preferences, skills and needs of their relatives with ID, requires ongoing collaboration with professionals, employers and co-workers. In their estimation, this involves sharing responsibilities and considering the informal network as a partner, which is in line with previous research findings (Petner-Arrey et al., 2016). However, network members experienced two types of problems in creating this partnership in practice. On the one hand, network members experienced that their knowledge of their relatives' preferences, skills and needs is sometimes underutilized by professionals. On the other hand, in some instances too many tasks, such as job coaching, fall on the shoulders of network members, which can overburden them or cause confusion about their role as either a loved one or a professional. Nevertheless, if collaboration and shared responsibility between professionals and informal network members are well-balanced, then this can promote the resilience of informal networks (Lafferty et al., 2016). Petner-Arrey et al. (2016) also found that continued advocacy for and investment in supporting informal networks to achieve suitable work for their relatives with ID could lead them to experience fatigue and frustration. Therefore, it is recommended that professionals and employers take note of the experiential knowledge of network members of people with ID, seek to utilize their experiential knowledge and collaborate with them in partnership. It is equally important for professionals to be sensitive to the capacity and workload of network members in the process of securing work for their relatives with ID.

Professionals might consider whether, if necessary, they can take over certain tasks from network members and, particularly in the case of parents, help strengthen the support from the social network (Petner-Arrey et al., 2016). Given the growing recognition of the importance of experiential knowledge of informal networks of people with ID in terms of collaborating with professionals and engaging in shared decision-making (Shogren et al., 2017), it is important that research continually acknowledges the voices of informal networks.

The third theme showed that informal network members experienced suitable work to be meaningful for their relatives, and in some instances also for themselves and the broader social network. Most of the benefits attributed to work by informal networks were related to their relatives' position in society. They experienced that skill development and self-confidence were positively associated with work in the community. Moreover, they valued the way in which work increased their relatives' social connections and social capital through affording them contact outside of their family and immediate environment, and, in so doing, enabled them to contribute to society through either their productivity or by doing something meaningful for other people. These perceptions of informal networks are consistent with how people with ID themselves experience the meaning of work (Voermans et al., 2021; 2022) as well as how those without ID perceive work (Abma et al., 2016). However, the difficulties that the informal networks in this study experienced in ensuring community-based work may hinder people with ID from benefitting from work as the primary means through which to experience social connections, inclusion, feelings of belonging, and social relevance (Lysaght et al., 2017).

The fourth theme revealed that, consistent with the benefits of work experienced by informal network members, many of them had a clear preference for community-based work and the associated normalization and equality. Indeed, in some instances they even expressed strong disapproval toward sheltered work. Other network members, however, preferred sheltered work because of the risks and dangers they perceived in society. This difference touches upon the ongoing debate in the field of ID about the appropriate balance between protection and empowerment (Altermark, 2017). Informal networks of people with ID have to strike a balance between protection and empowerment when supporting their relatives. The findings further revealed that network members' preferences for either sheltered work or work in the community may change over time, as a result of their experiences or due to societal developments and shifts in prevailing norms and values, the related societal image of people with ID and thus the prevailing public stigma (Babik & Gardner, 2021). As a result, network members could potentially experience courtesy stigma, even though they did not explicitly report it in the studies. Courtesy stigma occurs when the stigma also affects persons closely related to the stigmatized person (Ali et al., 2012). This, in turn, can impact upon the wellbeing of network members, especially when courtesy stigma leads to the development of negative self-evaluations and negative emotions, which is referred to as affiliate stigma (Ali et al., 2012; Mitter et al., 2019). Given that self-esteem and social support are found to be potential buffers against the internalization of stigma for network members (Mitter et al., 2019), this further emphasizes the need to strengthen the support from their social network. To strengthen the social network, professionals can, for example, use the strategy of Family Group Conferencing (Bredewold & Tonkens, 2021; Pennell et al., 2005). However, future research is needed to better understand the effect of (courtesy) stigma on informal network members of people with ID.

The findings point to informal networks experiencing one clearly distressing barrier: the potential impact of work participation on their relatives' basic income (in)security. Network members in studies from the US, Australia and the UK report on this issue, with specific experiences varying depending on different national social security systems. These experiences sometimes forced network members to make paradoxical decisions regarding their relative's work, such as, for example, advising them to turn down an offer for a full-time job. In so doing, they unintentionally reproduced the deficient work participation of people with ID. This finding indicates that legislation and social security systems are not in line with the participation and autonomy of people with ID. Moreover, this is an example of structural stigma, which is ingrained in the political system and hinders people with ID from fully participating in society (Mitchell et al., 2021; Pelleboer-Gunnink et al., 2019). It raises the question of to what extent the ideals of 'independence', 'autonomy', 'citizenship', and 'inclusion' actually fit the way people with ID are viewed by the general population (Altermark, 2017; Dekker et al., 2021), and even care professionals (Pelleboer-Gunnink et al., 2019), in a performance-oriented system defined by ableism (Mitchell et al., 2021). Reforming these types of systems is necessary for overcoming structural stigma, starting with a recognition by public institutions of the deleterious impact that structural stigma can have on the well-being of people with ID as well as their livelihood security (Mitchell et al., 2021). In collaboration with people with ID, their networks, and experts-by-experience, policy makers can find approaches to adopt legislation in such a way that promotes full work participation by people with ID, while, simultaneously, providing them with a financial safety net for when they are unable – temporarily or for an extended period – to engage in paid work. Ideas of 'contributive justice' rather than merely 'distributive justice' can be involved in these new approaches to creating work opportunities for everyone, thus allowing society to make use of everyone's talents rather than providing benefits (Wilthagen & Stolp, 2021).

This thematic synthesis of qualitative data makes an important scientific contribution by bringing together extant knowledge about informal network members' perspectives toward work for their relatives with ID. Specifically, by applying thematic synthesis, the perspectives of participants from a range of study contexts can be examined both deeply and broadly, thus providing evidence for the development and implementation of interventions (Lachal et al., 2017). However, consideration should also be given to the limitations of this synthesis. First, some of the studies (n=5; 19%) in this synthesis received low quality ratings. The results of these studies may therefore have a lower reliability. However, both the considerable number of studies included in this synthesis (n=27) and the good representation of these studies within the themes and subthemes found, may have positively affected the reliability of the synthesis. Next, although this study focused on informal networks, most of the included studies appeared to address the perspective of parents of people with ID, which is in line with the fact that most of the practical and emotional support provided to people with ID comes from their parents (Giesbers et al., 2020; Sanderson et al., 2017). The results should therefore be interpreted accordingly. Future empirical studies could focus on the perspective of other network members, such as siblings, friends, and acquaintances, in order to gain more insight into the potential role of peer groups in finding and retaining work for people with ID. The ways in which the informal networks of people with ID contribute to finding and retaining work could also be compared to the way informal networks and reference systems of the general population function in the labor market, from the viewpoint of labor market and job search theory. A further limitation pertains to the fact that all the studies were conducted in Western countries, with the vast majority being from the US (n=15, 56%). Consequently, the results of this synthesis cannot be directly generalized to non-Western contexts or even to European welfare states. Moreover, the specific context should be considered at all times when interpreting the results. One of the studies was conducted in Malta (Callus et al., 2019), explicitly stating that protection is characteristic of Maltese culture. Indeed, the results of this study reveal more (over)protection by informal network members than the results from other studies.

This thematic synthesis enhances our understanding of the value of work for individuals with ID through the lens of informal networks, highlighting the important role that network members play in creating sustainable and appropriate work opportunities for their relatives. This deeper understanding may inspire researchers, professionals, policy makers, and employers to strengthen collaboration with individuals with ID as well as their networks to increase the meaningful work opportunities available to them.

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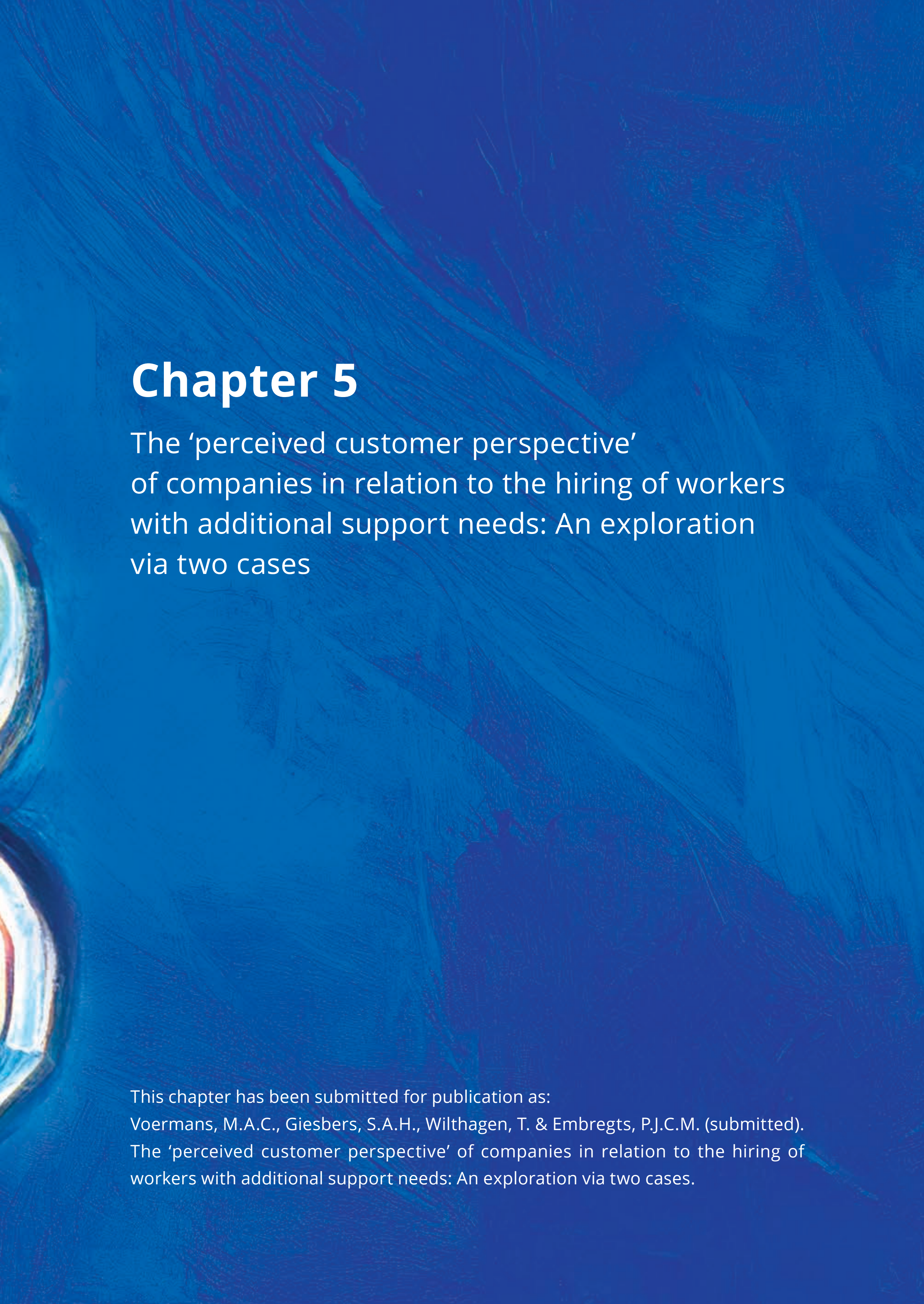

Chapter 5

The ‘perceived customer perspective’ of companies in relation to the hiring of workers with additional support needs: An exploration via two cases

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Abstract

Introduction

Despite legislation promoting an inclusive labour market, employment of workers with additional support needs (WWASN) within regular companies continues to lag behind. Influencing companies' hiring strategies is complex and the role of companies' perceived customer perspective in their hiring decisions is underexplored in the literature.

Methods

A supermarket and a hospitality company were studied as two cases. Data were collected by participatory observations and interviews within the companies and publicly available information about the companies, to cross-validate findings. Reflexive thematic analysis guided the across-case analysis.

Results

Findings suggest that customer-related factors influence companies' choices and behaviour in hiring WWASNs. Moreover, the study revealed dilemmas companies experienced, such as how to profile their inclusive employment practices to customers.

Conclusion

Creating jobs within companies for WWASNs can benefit the workers, the companies, and their customers. However, the deployment of WWASNs within companies poses several customer-and worker related dilemmas that require further research.

Introduction

Since the early 2000s, the important contribution that employment makes to the community participation and well-being of people with work-limiting disabilities, including people with intellectual and developmental disabilities, has been increasingly recognised (e.g. Robertson et al., 2019; UNCRPD, United Nations, 2006). The goal of international and national agreements and policies is to enhance employment rates of people with work-limiting disabilities, for example by giving positive and negative incentives to employers to stimulate them to hire people with work-limiting disabilities (Vornholt et al., 2018). In the Netherlands, the Participation Act promotes employment rates for people with work-limiting disabilities by introducing tools such as wage cost subsidies and job coaches to employers. Eligibility is assessed by the Dutch employee insurance organisation as having 'low work capacity' and places them in a 'target group register'. This register includes, for example, people with physical or intellectual disabilities or mental illnesses, who, despite their condition, have the capacity to work with adapted working conditions and support (Van Echtelt, 2019). We therefore refer to this group as 'workers with additional support needs in the workplace' (WWASNs).

Despite the international policies for increasing labour participation, the employment rates of WWASNs are still significantly lower compared to the general population in, among others, the Netherlands, the United Kingdom and the United States (Berendsen et al., 2021; National Governors Association, 2021; Office for National Statistics, 2022). An evaluation of the Dutch Participation Act indicates that the legislation only had a meagre positive effect on the finding and retention of work to a small group of WWASNs and even negative effects for other groups of WWASNs (Van Echtelt et al., 2019). These lagging participation rates of WWASNs stand in stark contrast to the major shortages in the current Dutch labour market as experienced in many industries, such as education, healthcare, childcare, ICT, and technology (Olsthoorn & Roeters, 2023; Peters et al., 2024).

Evidently, the effectiveness of legislation such as the Participation Act is closely related to the willingness of employers to provide job opportunities to WWASNs (Bredgaard & Salado-Rasmussen, 2020; Van Echtelt et al., 2019). Although companies have expressed positive attitudes towards hiring and retaining WWASNs, there seems to be a gap between their positive attitudes and their actual hiring behaviour (Bredgaard & Salado-Rasmussen, 2020). Several variables are indicated as related to companies' attitudes, willingness and actual behaviour to hire WWASNs, but the correlations between attitudes and behaviour are still difficult to interpret. Factors that positively related to the willingness and actual hiring behaviour of companies were: prior experience and familiarity with WWASNs, having a Corporate Social Responsibility (CSR) strategy, larger organisations, perceiving competitive benefits of hiring WWASNs, positive perceptions of the work performance of WWASNs, and motivation to help others (Borghouts-van de Pas & Freese, 2020; Bredgaard & Salado-Rasmussen, 2020; Dean et al., 2022; Nagtegaal et al., 2023). Factors that negatively related to the willingness and hiring behaviour were: expectations of high costs, ideas about the unproductivity of WWASNs, and a lack of knowledge about what additional support needs entail (Borghouts-van de Pas & Freese, 2020; Nagtegaal et al, 2023). Despite the increased scientific knowledge about barriers and facilitators to the hiring and retention of WWASNs from the perspective of companies, promoting inclusive hiring behaviour remains a difficult issue.

Besides the employer's own attitude, customers are key for the success and survival of companies (Chen et al., 2012). As such, companies' perception of customers' attitudes and behaviour might also play a role in the decisions they make when hiring WWASNs, specifically in companies that have direct service-oriented interactions with their customers, such as restaurants (Houtenville & Kalargyrou, 2015). The 'perceived customer perspective' of companies is, however, considered a context-dependent complex concept that is relatively unexplored in the literature (Zauner et al., 2015).

Customers continuously evaluate the service provided by a company in pursuit of high value when purchasing products and services (Oliver, 2015). Service quality for customers is therefore considered a significant business aspect by companies (Awad et al., 2023), that has been described as the extent to which a customer's expectations correspond to the actual delivered service (Churchill & Suprenant, 1982). Service quality has also been linked to a customer's intention to purchase a service or product in the future (Han et al., 2020). Therefore, to implement marketing strategies and optimise customer satisfaction, it is important for companies to properly assess and understand the needs, expectations, and experiences of customers. Also when it comes to CSR and inclusive employment practices (Hult et al., 2016).

Several studies indicate that customers have positive attitudes to and are willing to support companies that execute CSR and hire WWASNs (Dwertmann et al., 2021; Kuo & Kalargyrou, 2014; Siperstein et al, 2006). For example, because these companies are perceived as caring about their workers and helping WWASNs live more productive lives. However, negative customer reactions to and experiences with WWASNs may also be a significant concern for companies (Dwertmann et al., 2021), although little is known about the extent to which companies' assessment of their customers' expectations and experiences affects the behaviour of companies in hiring WWASNs. One of the few studies in this area suggested that service-selling companies with direct customer interactions, especially companies in hospitality, leisure, and retail industries, might be more concerned about customers' attitudes to hiring WWASNs than employers elsewhere. Possibly because these industries place a high value on physical attractiveness and presentation of workers in frontline positions (Houtenville & Kalargyrou, 2015).

To better understand companies' choices to hire and retain WWASNs and to help companies further design their inclusive employment strategies and practices, it is critical to explore whether and how the 'perceived customer perspective' of companies contributes to their decisions. 'Perceived', here means that it is about employers' perception of customers' perspective and attitude. Particularly, researching customer interactions within and from the perspective of inclusive companies can help to understand the actual impact of the 'perceived customer perspective' on the hiring and retention of WWASNs and can provide directions for systematic future research. This study aims to explore activities and experiences in real work contexts where WWASNs and customers interact, taking into account the company's context and specific characteristics. It aims to answer the research question whether and how customer-related factors play a role in these company's decisions to hire and retain WWASNs.

Methods

Following the aim of the study, two case studies were employed within which participatory workplace observations and in-depth interviews were conducted, to study the real world as it unfolds (Patton, 2002). Approval of the Ethical Review Board of Tilburg University (TSB_RP829) was received.

Preparation of the study

To explore the research topic, the first author visited four hospitality establishments hiring WWASNs – as a customer – and had exploratory interviews with three inclusive employers in a diversity of industries (i.e., hospitality, retail, and construction). Based on the gathered information and scientific knowledge (Houtenville & Kalargyrou, 2015), the research team decided to study a hospitality company and a retail company. Furthermore, companies were included that employed a large number of WWASNs compared to others, and were actively pursuing policies accordingly. By including companies explicitly known for hiring WWASNs from an inclusive strategy, we aimed to catch illuminative and information-rich situations, in line with intensity and purposeful sampling (Patton, 2002). A targeted search for companies that met these criteria was made, after which two companies were approached for participation in the study.

Recruitment

The two companies were recruited via an HR officer. The first author contacted the HR officers, informed them verbally and in writing about the study and asked them if their company would be interested in participating. Both companies expressed interest and were asked to mark a site within their company that would be information-rich for participatory observation and was employing at least two WWASNs. The researcher asked the HR officers to inform all employees (WWASNs and their co-workers) at the respective sites about the purpose, method, and conditions of the study through an information letter. All participants were, for example, informed about the voluntary nature of participation and their right to withdraw from the study at any time without giving a reason. If any employees expressed concerns regarding the study and observations, the participatory observations would be scheduled at times when the respective employees were not present at the site. There were, however, no employees who raised objections. Via the HR officer, an appointment was made for a participatory observation at the respective sites. All employees (WWASNs and their co-workers) that were observed and interviewed were asked for their written informed consent. To avoid traceability of the participants and the data collected within the cases, only brief personal information about the participants was collected, which can be found in Figure 1.

Two cases

A supermarket chain and a hospitality company were included in the study and studied as two different cases, as a company can be considered an information-rich entity within which the phenomenon under study is manifested (Patton, 2002). Participatory observations and interviews were conducted at sites within these companies where several WWASNs were deployed and had direct interactions with customers.

The first company (Case I) was a large supermarket chain. On their website they publicise that two percent of their workforce was characterised as WWASNs. The participatory observations were conducted at one supermarket that was known within the company as having a high inclusive climate and had employed WWASNs for years, with six WWASNs in their workforce at the time of study. The second company (Case II) was a medium-sized hospitality company with a diversity of hospitality establishments (such as restaurants, bars, event venues); 14.2 percent of their permanent employees were WWASNs. For the participatory observations, two hospitality establishments were chosen that both employed two permanent WWASNs: an establishment next to a golf course (Site A) and an establishment in the midst of an urban forest (Site B)[1].

Data collection

Data were collected by the first author via participatory observations, in-depth interviews and the collection of publicly available information of the companies on their websites and social media accounts.

Participatory observations. Scientific knowledge as well as information gathered during the preparation of the study was used to develop a topic list to guide the participatory observations containing the following topics: 1) 'Perceived customer perspective' of the company (needs, wishes, and expectations of customers; directness of customers interactions; customer responses), 2) Perspective and context of the company itself (location; CSR policy; knowledge and experience with WWASNs; specific support needs of WWASNs). Focus on the first topic was important to gather targeted information related to the research question, i.e. the perception of the customer through the eyes of various employees at the site. In addition, focus on the second topic was relevant in order to properly understand the collected information on the first topic in the particular context.

The researcher observed the locations for two days, except for Site B. As Site B was included later in the research process, only one day of observation was conducted there. Observations were scheduled on days when at least two WWASNs were present and when medium crowds were expected. That is, days with sufficient patronage to observe direct customer interactions , but not overly crowded to ensure that workers would experience sufficient space to accommodate the researcher. During the participatory observations, the researcher observed a broad range of activities in the work context, of which the researcher took anonymous field notes. When possible, verbatim quotations were noted. Directly after the observations, the field notes were elaborated in rich descriptions. During the observations, the researcher observed work

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[1] It was during the research process the research team decided, in consultation with the HR officer of Case II, to include a second establishment (Site B), to further enrich the data by gathering information from a site with a different character, purpose and types of customers as compared to Site A. This was not an issue for the supermarket. Although there was some variation in customer types between locations, the purpose and offer among supermarkets was largely similar.

activities and had informal conversations with employees (WWASNs, team leads, HR officers). The researcher used direct observations, for example interactions between WWASNs and customers, as input to ask further questions to employees. For example, after observing an interaction of a WWASN with a customer that made a familiar impression to the researcher, the WWASN was asked whether he knew the customer in question and how he felt about interacting with familiar customers. Depending on the context, the observations were more or less participatory. That is, in Case I the researcher was able to actually help workers to get their work done and thus observed actively, while in Case II this could not be realised and the researcher observed more passively.

In depth-interviews. After the sites (Case I and Site A) were observed for one day, the captured data were studied, analysed, and discussed within the research team. The research team identified initial themes across observations. These themes were incorporated into an interview guide with open-ended questions and prompts (Patton, 2002), which served as the basis for an in-depth interview with the team leads at the respective sites during the second day of observation[2]. At this time Site B was included as an additional location for observations and interviews. The interview was conducted at a time during the second day of observation (or the first day of observation in the case of Site B) when the team lead was able to take some time to talk to the researcher. The interview guide consisted of general questions as well as questions related to the deployment of WWASNs, organised into the following topics: 1) Gradations of customer interactions; 2) Regular vs. new customers; 3) Diversity in customer types; 4) Quality of customer interactions; 5) Importance of customer satisfaction and quality of customer interactions; 6) Visibility of impairment of WWASNs; and 7) Perspective on inclusiveness. The interviews were conducted as a triangulation to check and further explore the initial themes. In line with the participant observations and to allow the interviews to flow as naturally as possible, the interviews were not recorded. The extensive field notes from the interviews were transcribed by the researcher and presented to the interviewees as rich descriptions to check their consistency and veracity.

Publicly available information. Publicly available information was used as an extra source to validate findings. Therefore, the first author collected available data related to the research topic on the websites and searched the companies' social media accounts on Facebook, Instagram and LinkedIn for up to one year prior to the data collection. In addition, news reports about the companies over the last

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[2] Observations were conducted using a similar approach to the first day of observation.

three years were searched via Google, as well as posts on Google Reviews about the sites observed, paying specific attention to customer experiences regarding their interaction with staff at the site. The collected information was studied extensively by the first researcher, while taking field notes.

Observations, interviews and publicly available information were used to cross-validate findings, patterns, and conclusions.

Analysis

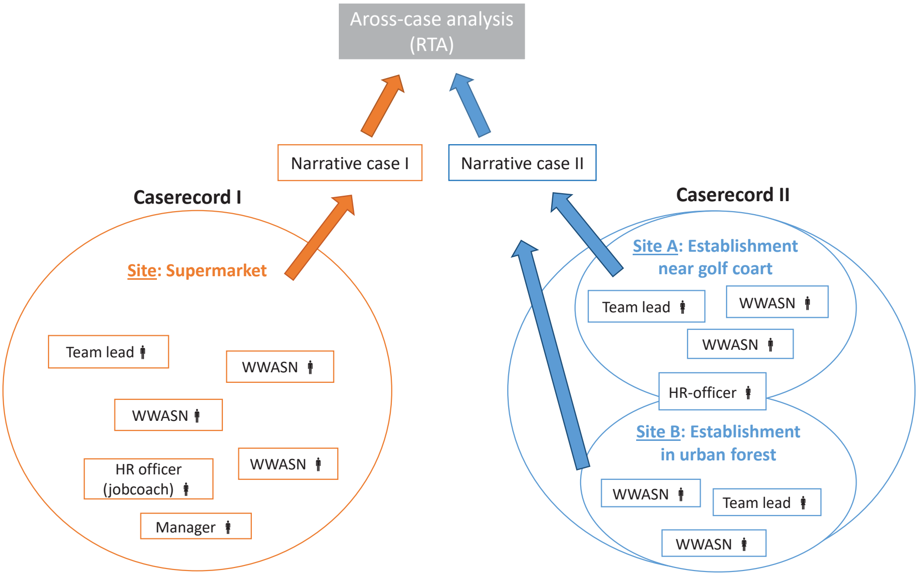
After all participatory observations and in-depth interviews were carried out, the data, as captured in field notes and rich descriptions, were structured and analysed. The two case studies were structured in three layers, in accordance with Patton (2002). The first layer was to construct individual cases within one case by collecting and structuring the information pertaining to specific individuals within the case. In the second layer, case records were constructed by compiling all the individual case information within one case, and describing both cases as a whole. In the third layer, an analysis across cases was carried out. A visual representation of the process is shown in Figure 1. Across case analysis was based on the principles of Reflexive Thematic Analysis (RTA: Braun & Clarke, 2022).

The six stages of RTA were implemented:

1. The first author familiarised herself with the data by reading and re-reading the data and taking notes of salient issues.
2. The first author systematically coded the dataset, which was critically reflected upon with the second author, a senior researcher with extensive experience in qualitative research.
3. Initial themes were generated by clustering codes, based on reflections on the codes.
4. Themes were developed and reviewed by refining the first themes while carefully reflecting on the original and complete dataset.
5. Themes were refined, defined and named, built around a strong key concept.
6. Themes were written down.

Each stage was carried out in close cooperation between the first and second author and all observations and decisions were kept in a reflective journal. When constructing the themes, it was ensured that all data sources were adequately represented within a theme. All stages were extensively discussed in the full interdisciplinary research team to check for interpretations, biases, and unwarranted conclusions, until consensus was reached. From the philosophy of RTA, the concept of data saturation is considered problematic and it is recommended, instead of determining data saturation, to reflect upon the richness of the dataset (Braun & Clarke, 2022). The dataset was considered as sufficiently rich by the research team.

Figure 1. Participants and process of analysis



Results

Following Patton (2002), first the context of each case is described separately to guide the reader through the different cases. Subsequently, the across case analysis is presented.

Case I – Supermarket

The observed site was part of a large supermarket chain, which profiled itself on its website as a socially engaged company with a strong focus on sustainability, the development of workers and to an employee base that broadly reflects society. Diversity and inclusion were described as important values and the company emphasised a responsibility to promote these values. On social media the company mainly shared activities related to sustainability and social involvement (e.g., activities to reduce plastic packaging material). In the year prior to data collection no posts related to inclusion and diversity were found on social media.

The supermarket observed was characterised as a relatively small, but busy supermarket by the manager. The store is located in a medium-sized city in the Netherlands, situated between a more-advantaged and less-advantaged neighbourhood. The supermarket had a staff of 160 employees in diverse roles such as shelf stacker, cashier and warehouse worker, including many part-time workers, such as students. The shelf-stacker crew employed six WWASNs. In Google reviews, customers expressed their appreciation for the supermarket's friendly staff

Case II

Case II was a hospitality company that operates ten different venues in and around another medium-sized city in the Netherlands, all of which have their own character and purpose. For example, locations focused on events such as conferences, on fast food, and on luxurious dining. The company had 77 permanent workers in addition to a flexible supply of 150 workers. On its website, the company demonstrated a desire to contribute to sustainability and the website showed signs of their inclusive strategy, for example by explicitly naming that the company cooperates with a hospitality school for WWASN, and by applying the principles of 'open hiring' to certain vacancies. However, expressions about the company's contribution to sustainability were more prominent on the website. The website also stated that enjoying a wonderful experience is the central mission on all locations, and to realise this mission, employees are considered the most important resource. Given the diversity of contexts within the company, observations were conducted at two different sites.

Site A: Establishment next to golf course

Site A was an establishment located next to a golf course, just outside a city, on the outskirts of a more advantaged neighbourhood. There was a restaurant with seating for about 50 people and next to it a terrace, where people could have lunch, dinner, or a drink. There were also separate rooms for gatherings. Golf club members made extensive use of the establishment. The clientele were characterised by the team lead as somewhat old and elite, but undergoing rejuvenation. During the observations, there were several employees working in the kitchen, service, and behind the bar, two of whom were WWASNs. Customers rated the friendly and helpful staff in Google reviews.

Site B: Establishment in urban forest

Site B was a small-scale establishment on the outskirts of town, in the midst of an urban forest. The site was much smaller than Site A and had a compact interior space with a few tables and a very small kitchen. According to the HR officer, the indoor space was hardly used by customers and operating the terrace was their main business, as the clientele were mostly walkers who came down for a drink, including many regular customers. Three people were working at the site during observation, two of them were WWASNs.. The reviews on Google showed varying reactions: A large number of customers experienced the staff as good and friendly, but some complained about waiting times or rushed and unfriendly staff.

Across-case analysis

Seven themes could be identified. The first three themes address dilemmas within the companies concerning the relationship between the perceived customer perspective and the deployment of WWASNs, across various organisational layers. The next three themes concern the companies' dilemmas related to the deployment of WWASNs, also on different layers of the organisation, but not directly related to the perceived customer perspective. However, to properly understand the context of the research topic, it is relevant to describe these themes. The seventh theme serves as the link between the two sets of themes, focusing on the significance of familiarity for the sustainable employability of WWASNs, encompassing both the work context and interactions with customers. Theme 2 consists of two interrelated subthemes.

Theme 1: Balancing between ideals, commercial goals, and customer expectations

Although both companies mentioned their social engagement and inclusive attitude on their websites, observations also indicated a focus on worker performance to achieve commercial goals. Ideals, commercial goals and customer expectations sometimes seemed at odds with each other with respect to the deployment of WWASNs, but this was reflected in different ways within the companies. Observations in Case I suggested that the company's performance culture sometimes conflicted with the adjusted expectations of WWASNs. The internal job coach in Case I experienced co-workers sometimes projected the same targets onto WWASNs, even though adjusted targets were agreed with the job coach and management. The team lead in Case I also experienced that when he wanted to provide WWASNs with new tasks, managers were sometimes reluctant due to financial risks, i.e. giving a WWASN the responsibility over stock counting.

Within Case II it was experienced that the capabilities of WWASNs sometimes clashed with keeping customers satisfied, particularly during peak times. For example as customers felt impatient when they had to wait too long, as experienced by the team lead of Site B. In addition, both team leads of Sites A and B found it difficult that WWASNs frequently could not meet their own standards for the optimal quality of customer interactions, although they also realised that their expectations might be too high..

From different data sources, the customer perspective appears to be important to both companies, but observations indicated that this was characterised differently within the companies. The resulting different expectations of workers with respect to customer interactions is further elaborated in Theme 3.

Theme 2: Profiling inclusive employment vs. normalisation and destigmatisation

Prudent profiling of inclusive vision and activities

Both companies seemed cautious in profiling their inclusive vision and activities to stakeholders outside the company, as compared to the attention they gave to other topics, such as sustainability. That is, both companies' websites covered the topic, but did not actively post on social media about employing WWASNs. Observations and interviews showed that both companies did not proactively inform their customers about the deployment of WWASNs. They only responded reactively when they had reason to do so, for example when customers had complaints about the service.

Dealing with customers' expectations and reactions in relation to stigmatisation

Not proactively informing customers seemed, based on the observations and interviews, related to both companies' goals for equality and normalisation of WWASNs. However, both companies also encountered dilemmas in communicating openly in the case of negative reactions of customers. These dilemmas seemed more prominent for Case II. In Case I hardly any negative customer reactions to the presence of WWASNs were experienced, but some specific examples were mentioned by the team lead of Case I concerning difficulties in customer interactions. One example concerned a deaf worker who was touched unsolicited by customers, because she did not respond to verbal questions, which the worker experienced as unpleasant. In cases such as these, the team lead and the WWASN concerned sought a suitable solution that provided clarity about the disability to the customer, making the interaction between customer and WWASN more pleasant and smooth from both perspectives. In the case of the deaf worker, the solution was agreed to have her wear a T-shirt that stated that she was deaf. It is important to note that the specific examples mentioned in Case I were concerned with disabilities that could be explained in concrete terms to customers (as opposed to, for example, behavioural disorders).

In Case II, however, the team leads and the HR officer more frequently experienced negative reactions of customers. Previously, WWASNs who worked within the company wore badges including their status as WWASNs to make their position clear to customers. Due to stereotyping, however, this no longer felt the right strategy for the company and the WWASNs themselves. Nevertheless, the badges were experienced to help in some situations to influence customer expectations and prevent negative reactions. Both team leads of Case II sometimes experienced customers saying afterwards: "If we had known the worker has a disability, we would have reacted differently". These reported situations in Case II involved WWASNs with limitations that were less concrete to explain, such as a worker with behavioural problems who sometimes responded oddly or irritably to customers. In Case II, the HR officer and team lead of Site A were reluctant to deploy WWASNs in situations with mainly new, unfamiliar customers, as they experienced that new customers in particular could react negatively. Therefore, they preferred to deploy WWASNs to a permanent clientele with knowledge of the situation. However, negative responses were also sometimes experienced among regular customers by the team lead. In the event of negative customer responses, team leads explained the company's inclusive vision and asked for understanding from the customer in question.

Theme 3: Customer-related conditions require customised deployment

Within the three sites differences were observed in the expectations of workers, for example regarding customers interactions and the degree of independence of workers. As the competencies of WWASNs also differed significantly, the deployment of WWASNs required customisation.

Within the observed sites, workers were, in addition to direct interaction moments, consistently in indirect contact with customers as in their working environment customers were continuously present. Therefore, workers had to be constantly aware of this presence and be able to adapt their behaviour accordingly. However, each site seemed to hold distinct expectations for their employees regarding customer interactions.

In Case I, workers' service orientation to customers was considered important, but the team lead and manager also considered it as an accepted reality that customers sometimes had complaints. The requirements in terms of customer interaction by workers appeared somewhat lower in Case I than in Case II, as contact was usually more fleeting and functional within a supermarket than in a hospitality establishment. Team leads and the HR officer in Case II perceived customer interactions as highly important, so the type of customer at a given location (and their perceived needs and wishes) was explicitly taken into account when employing WWASNs. For example, WWASNs were deliberately not deployed during lunch time at a location visited by students that wanted to be served quickly. They were more frequently deployed at Site A, as this was visited by older customers who had more time to spare.

Within the two sites of Case II, the researcher observed that different levels of independence and stress resistance were required of workers. That is, at Site B only two workers were deployed at the same time, limiting the ability for WWASNs to rely on a co-worker for support. In addition, due to the small scale of the site, little opportunity existed for workers to withdraw from customer interactions when briefly needed. The HR officer expressed that Site A had more physical space for WWASNs to perform tasks behind the scenes, such as setting a dining room, when WWASNs were unable to handle customer interactions. Because multiple activities took place within one location, such as meetings and private dinners, a more targeted choice could be made in which tasks a WWSANs could be deployed.

The competences of WWASNs in terms of independent working and interactions with customers varied widely. For example, the researcher observed that some WWASNs were functional in their contact with customers, while others were able to connect to customers more naturally.

Theme 4: Equal vs. customised approach

Information from websites and observations suggested that both companies strove for an equal approach and position of WWASNs. Team leads recognised that they played a key role in facilitating equality, but also experienced they had to balance between approaching WWASNs equally and adapting their approach given their support needs. They noticed that some WWASNs did not appreciate an adapted approach, and wanted to be treated the same way as their regular co-workers.

Nevertheless, the approach of WWASNs did not always differ from regular workers. Within both companies comparisons were made between WWASNs and student-employees in terms of competences and support needs. For example, the team lead of Site B mentioned she had to keep pushing both WWASNs and student-employees to polish the tables. WWASNs even sometimes excelled compared to regular workers.

Within both cases, the value of WWASNs to the company was acknowledged by the team leads and HR officers, for example for their willingness to perform repetitive tasks. Within Case I WWASNs were valued as they were willing and comfortable to work shorter shifts.

Theme 5: Inclusive employment implementation at all organisational layers

Information from the websites and observations made evident that both companies focused on inclusive employment practices at all layers of their organisation (e.g., within the workplace and at different management layers), although the size, and thus the organisational structure, of both companies differed significantly. In both cases, the HR department was pivotal in this process. In Case I there was an in-house job coach department that supervised all WWASNs. Job coaches were trained in-house and developed staff training within their department for supporting WWASNs. In Case II, the HR officer stated they were closely involved in both the application process of WWASNs and their subsequent deployment within the company. The HR officer monitored them in the workplace and strove to create an inclusive atmosphere through this involvement. Within both cases, the team leads involved had no influence in the placement of WWASNs. One of the team leads indicated difficulty with the placement of a WWASN in which they had no say.

Theme 6: Collaborating with and supervising WWASNs requires dedication and knowledge

Observations and interviews revealed that supervising WWASNs required affinity and capabilities of team leads and co-workers. The team leads of Case I and Site B expressed they had an explicit affinity for supervising WWASNs and both experienced it as an aspect of their work that gave them extra satisfaction. The team lead in Case I was specifically focused on development of the WWASNs and encouraged this in them. The job coach of Case I experienced that affinity and capabilities of team leads and direct co-workers might determine the success of a WWASN’s placement.

However, both team leads in Case II experienced that mentoring WWASNs could also be intensive. The team lead of Site A expressed that, despite her affinity, she felt that supervising two WWASNs was intensive. She spent a lot of time monitoring their work and experienced she had to work hard to keep one of them connected to the team. The team lead of Site B experienced it as demanding that she had to stay alert at all times and could never completely detach from one of her WWASNs. In addition, she hesitantly indicated that she experienced less job satisfaction while working with one of the WWASNs, because of less smooth interactions.

Theme 7: Familiarity promotes employability of WWASNs

It was experienced by the team leads and HR officers within both cases that WWASNs needed to grow into customers interactions as well as interactions with co-workers. A familiar environment with familiar people seemed to be important for the sustainable employability of many WWASNs. However, In Case I, the job coach noted that frequent team lead changes, driven by the company's growth culture, limited efforts to build a stable work environment for WWASNs.

In addition to working with familiar co-workers, WWASNs appeared to enjoy contact with regular customers. In both cases, team leads and HR officers expressed that sometimes WWASNs had to start working behind the scenes, for example in the kitchen or warehouse, to gain confidence and to get used to the work and the environment before they could make the transition to interaction with customers.

Discussion

This study explored whether and how the perceived customer perspective of companies plays a role in the deployment of WWASNs within the inclusive work contexts of two companies in the hospitality and retail industry. The results of this study provide additional knowledge regarding factors that determine whether or not companies hire and deploy WWASNs within their company related to the perceived customer perspective. In addition to previously detected barriers and facilitators such as prosocial motivation, and fears for high costs and low productivity of WWASNs (e.g. Bredgaard & Salado-Rasmussen, 2020; Nagtegaal et al., 2022), the results of this study suggest that customer-related factors may also influence companies' choices and behaviour regarding the deployment of WWASNs in specific industries. In addition, the study provided knowledge regarding other barriers and facilitators, such as the difficult balance that companies experience between achieving commercial goals and their prosocial motivation to implement inclusive employment practices, how to profile their inclusive employment practices to customers, and the contribution and dedication that implementing inclusive employment practices requires from workers. Although the latter barrier was not directly related to the customer perspective, it is relevant knowledge to properly understand the context of the research topic. In addition to the dilemmas experienced within the companies, the value of WWASNs was also highlighted in their willingness to work short shifts, perform repetitive tasks, and excellence in certain tasks. The meaning of these findings in relation to research and practice is further discussed below.

First, the results of the current study showed that within the inclusive work contexts of the two cases, both customer-related and non-customer-related factors were taken into account when making decisions about the deployment of WWASNs. Companies struggled to find the right balance between their inclusive vision and ideals, commercial goals, and customer expectations when deploying WWASNs in tasks that suit their capacities. The extent to which the customer perspective was considered in deploying WWASNs seemed to depend partly on the way the customer relationship was perceived within the company and the importance that was attached to the quality of customer interactions. Consistent with earlier studies, greater value seemed to be attached to customer satisfaction and the quality of customer interactions in the hospitality company than in the supermarket chain (Margutti et al., 2024), resulting in higher demands on WWASNs when deployed in customer interactions. Companies implement hospitality strategies to achieve higher customer satisfaction and better commercial results (Pizam, 2020). Following hospitality theory (Camargo, 2021), the desired level of hospitality in customer interactions within the supermarket in this study might be characterised as a pleasant and professional ‘staged’ encounter based on extrinsic motivation from both the side of the customer and the service provider. In the hospitality company an additional form of hospitality in customer interactions was sought by creating a memorable encounter based on ‘genuineness’, in which the personal qualities, attitude, and behaviour of the service provider play a role (Camargo, 2021), which may be more challenging for the workers involved than achieving staged hospitality. In line with other research (Cheah et al., 2023; Helena et al., 2022), this study emphasises that customisation in support and in the allocation of (customer-related) work tasks is required to sustainably create a work context in which the competencies of WWASNs match employers’ expectations, also with regard to customer interactions.

The different emphasis on hospitality between the two cases might be related to the different service expectations of the customers in these different business contexts (Margutti et al., 2024) and may also explain the different strategies the companies use in their struggle whether or not to openly communicate with customers about the deployment of WWASNs. The hospitality company explicitly aimed to prevent negative reactions from customers by preferring to deploy WWASNs with regular guests who were familiar with the deployment of WWASNs. The supermarket chain, however, only informed customers about the deployment of WWASNs when this made customer interactions more pleasant for the WWASNs. The struggle companies experienced in communication with customers mainly concerned WWASNs with disabilities that were not immediately visible to customers, and is therefore related to the disclosure dilemma that people with invisible disabilities frequently experience in the workplace and while seeking employment (Ysasi et al., 2018). People with invisible disabilities are viewed by the public as part of the majority group, with related expectations of their competencies, which can lead to a mismatch between expectations and reality in interactions. This mismatch can also result in less willingness among employers to offer jobs to people with invisible disabilities compared to people with visible disabilities (Ysasi et al., 2018). To avoid stigmatisation and discrimination in the workplace based on disability, people often deliberately conceal their invisible disability and try to pass as an individual without disability (Vornholt et al, 2018). Employers in this study seem to experience a similar disclosure dilemma with regard to their customers who consider the WWASNs with invisible disabilities as part of the majority group, potentially resulting in a mismatch between customer expectations and reality. However, although they experienced that communication with customers about the deployment of WWASNs could lead to more understanding, this could lead to stigmatisation, which was at odds with their strive for normalisation.

In addition, the results revealed that implementing an inclusive climate within companies, also in relation to their customers, required effort of employees at all levels of the company with key roles for HR stakeholders and managers. Regardless of the size of the company, in creating an inclusive climate the HR department may take a coordinating key position and appointing an HR stakeholder specialised in inclusion strategies for WWASNs might be effective (Beatty et al., 2019). Also, managers may have a key position in creating an inclusive climate by increasing social connections and facilitating conversations about inclusion among workers (Nair & Vohra, 2015). Findings showed that supporting and supervising WWASNs may be challenging. Therefore, targeted training of supervisors and co-workers is needed, for example by workshops and support of HR stakeholders (Beatty et al., 2019; Ysasi, et al, 2018). However, in line with Boccalandro (2021) findings also emphasised that supervising WWASNs can add purpose to the work lives and contribute to job satisfaction for co-workers. Moreover, engaging regular customers in inclusive employment practices may increase their appreciation for the company (Dwertmann et al., 2023).

The results of this study should be considered a brief exploration of the topic. Given the small scale and sectoral scope of this study regarding the number of cases and the extent of the participatory observations, broader conclusions cannot be drawn. Nevertheless, the exploration did provide information to better understand the role of the perceived customer perspective within this complex issue, which can be further investigated in systematic follow-up research within a wider range of business contexts. This could, for example, include large-scale and long-term participatory observations or focus group research among a diversity of companies to better understand the complex subject in work contexts that extend beyond retail and hospitality. Future research can specifically examine the disclosure dilemma that companies experience in relation to their customers.

To conclude, creating jobs within companies for WWASNs can benefit the workers, the companies and their customers. However, the deployment of WWASNs within companies may pose customer- and worker-related dilemmas and implementing inclusive employment practices is not always straightforward and requires attention on various organisational levels. The results of this study provide an explorative view on the role of the perceived customer perspective in inclusive employment practices that deserves further elaboration in future research and may inspire companies in the implementations of inclusive employment.

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Chapter 6

Employer perceptions of customer attitudes and their impact on the employment of workers with additional support needs

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Abstract

Introduction

The inclusion of workers with additional support needs, due to work-limiting disabilities, in the labour market remains challenging. It has proved difficult to influence employers' decisions to hire these workers. Employers might be concerned about attitudes and reactions from customers. This study explored the perceived customer perspective of organisations employing workers with additional support needs in relation to their hiring decisions and dilemmas related to the customer perspective.

Materials and methods

Two focus groups were conducted comprising team leads of workers with additional support needs and employees involved in inclusive HR policy and strategy. Reflexive thematic analysis was employed.

Results

Four overarching themes and several subthemes were identified. Findings showed that organisations across a diversity of industries considered perceived customer expectations as well as the complexity of customer interactions when deploying workers with additional support needs. Also, they encountered dilemmas in addressing stigmatising attitudes on the part of customers. Furthermore, they experienced challenges in creating customised working environments and an inclusive climate, with personal motivation emerging as a key facilitating factor.

Conclusions

Achieving inclusive employment, especially in customer-facing roles, is a nuanced process that requires ongoing adaptation and thoughtful decision-making. Next to challenges, there are opportunities for growth on the part of employers, employees and customers.

Introduction

There is increasing recognition of the right to participate in regular employment for people with additional support needs due to work-limiting disabilities, such as physical or intellectual disabilities or mental illnesses and the health benefits of this participation (UNCRPD, 2006). However, a significant gap remains between these aspirations and reality (UN, 2024). Workers with additional support needs, who often wish to participate in the labour market, continue to be underrepresented in regular employment. The non-participation of workers with additional support needs can have a profoundly negative impact on their health and well-being, increasing the risks of social isolation, poverty and reduced mental health (Paul & Moser, 2009). Furthermore, this exclusion represents a significant loss of human capital and potential (Wilthagen & Stolp, 2021), particularly at a time when many countries face labour shortages across key industries such as healthcare, childcare, education and technology (Olsthoorn & Roeters, 2023; Peters et al., 2024).

To address the challenges faced by workers with additional support needs, many European and North American governments have shifted their policies from traditional models – such as promoting sheltered employment and mandating quota systems for hiring individuals with disabilities – to more inclusive and active labour market policies (Shima et al., 2008). These policies aim to create equal opportunities and provide the necessary support for workers with additional support needs to enable them to participate meaningfully in the labour market (Shima et al., 2008; Vornholt et al., 2018). For instance, in Canada, a variety of funding programmes have been implemented to empower workers with additional support needs to participate in regular employment, alongside initiatives encouraging organisations to promote equity in the workplace by creating job opportunities for these workers (Vornholt et al., 2018). In the Netherlands, the Participation Act, or *Participatiewet* in Dutch, was introduced in 2015 to increase job opportunities for people with additional support needs who are listed in the so-called 'target group register'. This target group register includes people with physical or intellectual disabilities or mental illnesses who are assessed as having limited work capacity and often require adapted working conditions and additional support to make full use of their existing skills and capabilities (Van Echtelt 2019). The Participation Act offers various instruments to encourage employers to hire workers with additional support needs, including wage cost subsidies, other financial incentives, such as compensation for workplace accommodations, and job coaches. In addition to the Participation Act, a Social Agreement between trade unions, employers and the Dutch government was negotiated with the aim of creating 125,000 additional jobs for workers with additional support needs by 2026, including 100,000 in the private sector and 25,000 in the public sector (Van Echtelt, 2019).

Despite these efforts, however, the employment rates for workers with additional support needs in many countries, including the United States, the United Kingdom and the Netherlands, continue to lag significantly behind those of the general population. In the United States, for example, only 27% of people with additional support needs are employed in regular jobs, compared to 78% of the general population (Winsor et al., 2019). The situation is comparable in the Netherlands, where 43% of people with additional support needs are employed, compared to 86% of the general population (Bottenheft et al., 2023). An evaluation of the Participation Act in the Netherlands revealed that only a small proportion of workers with additional support needs had benefited from the interventions and that job creation under the Social Agreement was progressing at a slower pace than expected in both the private and public sectors (Schouten, 2021). These findings highlight the persistent challenges in achieving meaningful labour market inclusion for workers with additional support needs, despite targeted policy initiatives. Concerns about the high incidence of unemployment among workers with additional support needs were further emphasised by the recent visit of the UN Committee on the Rights of Persons with Disabilities to the Netherlands (United Nations, 2024).

A key obstacle to progress in the labour market position of workers with additional support needs may be employers' limited willingness to actively engage with workers with additional support needs as part of their workforce, despite a growing number of firms embracing Corporate Social Responsibility (CSR) strategies (Bredgaard & Salado-Rasmussen, 2020). Evidently, employers play a crucial role as gatekeepers of the labour market, and their attitudes toward hiring workers with additional support needs are a major determinant of the success of inclusive employment policies (Van Echtelt, 2019; Bredgaard & Salado-Rasmussen, 2020). While many employers express positive attitudes towards the idea of hiring workers with additional support needs, only a small fraction take the necessary steps to actually do so. This discrepancy between stated intentions and actual hiring practices remains poorly understood, as existing research has yet to offer a comprehensive explanation (Bredgaard & Salado-Rasmussen, 2020; Van Echtelt, 2019).

Several factors have been identified as potentially influencing whether an organisation hires workers with additional support needs, including the size of the organisation, the existence of a formal CSR strategy, expectations regarding the costs associated with employing workers with additional support needs and perceptions of their work performance (Borghouts-van de Pas & Freese, 2020; Bredgaard & Salado-Rasmussen, 2019; Dean et al., 2022; Nagtegaal et al., 2023). In addition, employers' (in)familiarity with workers with additional support needs and the (in)availability of support programmes to assist organisations in adapting the workplace can also play a role. Given the critical importance organisations place on their customers, how organisations perceive customer attitudes towards the employment of workers with additional support needs may also influence their hiring decisions, especially in the case of companies operating in customer-facing industries (Houtenville & Kalargyrou, 2015).

However, research by organisations into the actual customer perspective as well as the ‘perceived customer perspective’ remains limited, although some studies have begun to explore the issue. A systematic review by Essa (2023) summarised existing research into customers’ actual view of workers with additional support needs and its influence on their purchasing behaviour. The review found eight studies with contrasting results: some reported that workers with additional support needs had a neutral effect on customer behaviour and others indicated positive effects, while a few studies highlighted negative reactions from customers. However, organisations’ perceptions of their customers’ expectations and satisfaction are not always in line with actual customer expectations and behaviour (Hult et al., 2016). As customers are a crucial party for an organisation’s success and survival (Chen, 2012), negative customer reactions may be a major concern to organisations and their perceptions of customer attitudes may affect decisions about hiring and deploying workers with additional support needs (Dwertmann et al., 2023). Therefore, it is crucial to expand the existing scarce knowledge about how organisations assess their customers’ expectations in relation to services provided by workers with additional support needs. Houtenville & Kalargyrou (2015) found that organisations in different industries perceive the customer perspective differently, with the retail and hospitality sectors specifically viewing it as a more significant challenge to hiring workers with additional support needs. Building on this, Voermans et al. (2025) conducted an exploratory study of two organisations in the retail and hospitality industries and found that the perceived customer perspective did play a role in shaping organisations’ decisions about employing workers with additional support needs. Companies often faced dilemmas, such as whether to emphasise their inclusive hiring practices in their marketing or to promote the normalisation of workers with additional support needs without drawing attention to it. Voermans et al. (2025) also found that customisation was often required to ensure that workers with additional support needs were placed in roles suited to their skills and that effectively deploying them required attention at all organisational levels, both in management and the HR department as well as in the workplace. While hiring decisions were made at HR or management level, support for workers with additional support needs, including in customer interactions, was provided by the team leads in the workplace.

A deeper understanding of corporate attitudes, choices and behaviours towards employing workers with additional support needs may help identify factors that influence organisational hiring practices (Bredgaard & Salado-Rasmussen, 2020). Specifically, more research is needed into how the perceived customer perspective influences employers' decisions about hiring, deploying and retaining workers with additional support needs (Houtenville & Kalargyrou, 2015). While customer attitudes are now receiving more attention in the research literature, detailed investigations of the interactions between customers and workers with additional support needs from the corporate perspective remain scarce (Essa, 2023). The present study aims to address this gap by exploring how multiple organisations with considerable experience in inclusive employment perceive the customer perspective and whether and how this influences their employment of workers with additional support needs across a diversity of industries, to further deepen knowledge from previous research in the retail and hospitality industries (Voermans et al., 2025). Additionally, this research aimed to investigate the facilitators and barriers these organisations encounter when employing workers with additional support needs, as well as how they manage dilemmas related to the perceived customer perspective. This exploratory study seeks to answer the following research questions:

- What are the similarities and differences across industries in how organisations perceive the customer perspective regarding the employment of workers with additional support needs?
- What facilitators and barriers do organisations encounter when hiring, deploying and retaining workers with additional support needs in relation to their perceived customer perspective, and how do they navigate these challenges?

Materials and methods

Study design

To address the research questions, a qualitative and descriptive research design utilising focus groups was implemented. Focus groups are structured discussions centred on specific aspects of a topic and are facilitated by an experienced moderator (Krueger & Casey, 2015). The group dynamics foster interaction, which helps participants explore and deepen their perceptions and experiences (Kitzinger & Barbour, 1999). The design of these focus groups was informed by previous exploratory studies (Essa, 2023; Houtenville & Kalargyrou, 2015; Voermans et al., 2025). These studies emphasised the importance of involving people at different levels of the organisation in implementing inclusive employment practices, in particular team leads directly managing workers with additional support needs and staff involved in organisational policy-making. As a result, two separate focus groups were conducted: one with team leads managing workers with additional support needs in the workplace, and the other with people involved in inclusive policy and strategy, such as HR professionals or directors responsible for inclusive practices.

The composition of the focus groups aimed to capture a diversity of work contexts by including participants from organisations across different industries with various types of customer interactions, i.e. education, retail, leisure, hospitality, cleaning, transport and the public sector. The composition was intended to enable the study to identify similarities and differences across industries. In addition, exploratory discussions with companies in preparation for the study revealed that participants might feel more comfortable discussing these topics with peers from other industries where there are no competitive tensions. Purposeful sampling (Patton, 2002) was applied to ensure the selection of information-rich cases with specific knowledge and experience relevant to the study. The reporting of this study follows the Consolidated Criteria for Reporting on Qualitative Research (COREQ) guidelines, and the checklist can be accessed in the supplementary materials.

Table 1. Participants focus groups

Team Leads Focus Group					**Policy and Strategy Focus Group**				
R	*Sex*	*Position*	*Industry*	*Business context*	*R*	*Sex*	*Position*	*Industry*	*Business context*
R1	f	Secretary (managing workers)	Education	Large organisation for higher education	R8	f	HR staff	Education	Large organisation for higher education
R2	m	Site manager	Retail	Supermarket, part of a large supermarket chain	R9	m	HR staff	Retail	Large supermarket chain
R3	f	Site manager	Retail	Construction shop, part of a medium-sized construction company	R10	f	Business owner	Hospitality	Hospitality company operating two locations (restaurant and hotel)
R4	m	Site manager	Leisure	Cinema, part of a large company	R11	f	Business owner	Cleaning	Small-scale company for specialist cleaning
R5	f	Cook (managing workers)	Leisure / hospitality	Bowling alley with catering facilities (small company)	R12	m	Operations manager	Transport	Medium-sized company for cab transportation
R6	f	Site manager	Hospitality	Company restaurant, operated by a large catering company	R13	f	HR staff, team lead intern job coaches	Public sector	Large company for public administration
R7	f	Site manager	Hospitality	Company restaurant, operated by a large catering company					

Participants and recruitment

The study was approved by the Ethical Review Board of Tilburg University (TSB_RP829). Participants were recruited through two business associations in the south of the Netherlands, both of which focus on inclusive entrepreneurship. Coordinators from the associations distributed information about the study to their members via email and explained the inclusion criteria. Organisations interested in participating contacted the researcher by telephone. Additionally, snowball sampling was used to recruit more participants, based on recommendations from organisations that had already shown interest.

The selection process aimed to ensure a balanced representation of various industries within the focus groups. Inclusion criteria required organisations to employ workers with additional support needs (operationalised for the Dutch situation as 'listed in the target group register'[1]) and to have direct customer contact. Customers were considered as a broad group, including customers in retail, guests in hospitality, clients in healthcare, students in education and customers in service sectors, such as cleaning and construction companies. The first author contacted interested organisations by telephone to confirm eligibility and determine which individuals within the organisation had the appropriate knowledge and experience to participate in one of the focus groups. In some cases, the initial contact person was the best candidate, while in others the contact person identified another colleague with greater expertise in either developing or implementing inclusion policies or supervising workers with additional support needs.

As two participants were unable to attend the focus groups due to unforeseen circumstances, a total of 13 individuals participated in the focus groups, representing 11 organisations. See Table 1 for an overview of the participants and their organisations. One organisation contributed participants to both focus groups, while in another case two individuals from the same organisation attended the team leads focus group. In total, seven participants attended the focus group for team leads and six participants the focus group for inclusive policy and strategy officers. Prior to the focus group discussions, participants were briefed on the study and given an opportunity to ask questions. All participants signed informed consent forms. As a token of appreciation, all participants received a small gift made at a day care centre for people with intellectual disabilities.

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[1] The Dutch target group register includes people with physical or intellectual disabilities or mental illnesses who are assessed as having limited work capacity and often require adapted working conditions and additional support to make full use of their existing skills and capabilities (Van Echtelt, 2019)

Interview and materials

The focus groups took place in February 2024 in a conference room at Tilburg University with the participants and two experienced researchers that facilitated the discussions. The first author, a female PhD candidate with extensive knowledge of the study context, led the discussions and ensured that all key topics were covered. A second female PhD candidate, with significant experience of conducting focus groups, kept time, raised clarifying questions, ensured that all participants had an opportunity to contribute and took notes on both verbal and non-verbal interactions. The sessions began with an introduction to the researchers' profession, research interests and experience and the participants' roles within their organisations in relation to managing workers with additional support needs. Consent was obtained from all participants for audio recording. The findings from a previous exploratory study (Voermans et al., 2025) were then presented in an accessible manner to introduce the interview topics. The semi-structured interview guide, developed on the basis of literature (Borghouts-van de Pas & Freese, 2017; Dean et al., 2022; Houtenville & Kalargyrou, 2012; Voermans et al., 2025), framed the discussions. The interview guide was not pilot-tested. The interview guide was used to explore four key topics: perceived customer perspectives in different industries; strategic dilemmas related to customer perspectives and the employment of workers with additional support needs; customer responses; and familiarity with customers and co-workers.

The researchers encouraged participants to share what stood out to them regarding the themes presented, allowing for open discussion of the topics that they found most significant. While the conversation was guided to ensure all themes were covered, participants were given room to question one another. The guide included questions such as, "Is the customer perspective considered when deploying workers with additional support needs in different departments?" and "How does your organisation communicate its inclusive business practices to customers?". The questions sought to elicit rich information, exploring considerations, barriers and facilitators, and concrete examples. Both focus groups followed the same interview guide, and each session lasted two hours.

Analysis

The audio recordings from the focus groups were transcribed verbatim. Transcripts were not returned to participants for comments, but in case of any ambiguity participants were asked for clarification by email. Reflexive thematic analysis (Braun & Clarke, 2022) was used to analyse the data, which is an interpretative approach designed to identify and analyse patterns in participants' experiences, focusing on themes, similarities, differences and unexpected insights. Instead of focusing on achieving ‘data saturation’, which is considered problematic in the reflexive thematic analysis approach, during a meeting the research team discussed and evaluated the dataset to determine its richness and sufficiency. Based on this assessment, the dataset was deemed sufficiently rich to support the analysis (Braun & Clarke, 2022). The analysis was conducted in six phases (Braun & Clarke, 2022) using Microsoft Word. The first phase involved familiarisation with the data, during which the first author read and reread the transcripts, making notes of salient themes and issues. In the second phase, initial codes were generated and critically reflected upon with the second author, a male senior researcher who has extensive experience in both quantitative and qualitative research. The third phase involved grouping initial codes into themes, informed by the reflections of the first and second authors. In the fourth phase, the themes were reviewed by the entire research team and compared against the full dataset to ensure consistency, leading to further refinement of the themes. In the fifth phase, the themes were defined, named and organised into a thematic framework. Finally, in the sixth phase, the themes were written up, with ongoing refinement during the writing process.

Results

Using reflexive thematic analysis, four overarching themes, each with two or three subthemes, could be identified.

Theme 1: At the front: Taking customer expectations and complexity of customer interactions into account

Participants reported considering perceived customer expectations when deciding whether or not to deploy workers with additional support needs for front-office tasks, noting that the complexity of customer interactions in relation to competencies of workers with additional support needs played a significant role.

Considering differences in customers’ service expectations in demand-driven matching for front-office tasks

As the participating organisations operated in a wide range of industries, they were confronted with a diversity of customer expectations and behaviours that were perceived and assessed in different ways, resulting in different choices among organisations regarding the deployment of workers with additional support needs in front-office roles with customer interaction. For example, within a higher education institution with students being viewed as customers, the HR officer hardly took the customer perspective into account, frequently placing workers with additional support needs in positions with customer interaction. However, for the team lead in a cinema the perceived expectations of the visitors regarding fast and high-quality service and competent staff was an important principle in the placement and assignment of tasks of workers with additional support needs. Several participants applied demand-driven and person-oriented matching by determining where workers with additional support needs would best fit within the company on the basis of their competencies and needs, rather than solely on the basis of existing vacancies. In doing so, they sometimes also considered the customer perspective in this alignment.

Delineating customer interactions when complexity increases

The complexity of the customer interactions appeared to vary between and within the participating organisations. The more complex the customer interactions were, for example due to complaint and conflict management or customers with high expectations, the more difficulty the participants experienced in matching and deploying workers with additional support needs. The operations manager of a taxi company talks about this issue:

> *R12: Of course. Quite honestly, if a world-famous artist arrived from abroad today to sing at [the festival] for an hour, you couldn't [deploy] someone from the target group register. They would have expectations and it would have to be 100 percent right.*

Participants experienced that the deployment of workers with additional support needs in roles with more complex customer contact required training and development of workers and phased development of customer-related work tasks and was not always feasible given their competencies. In some cases, explicit restrictions on interaction with customers were agreed upon with a worker. In a supermarket, for example, the team lead had agreed that workers with additional support needs must involve a colleague if a customer's complaint was complicated. The HR officer of a large government organisation experienced the challenge that the complexity of customer interactions could increase during a work process from a simple email to a telephone contact requiring conflict management, complicating the matching of workers with additional support needs in customer-related roles. In addition, team leads perceived it as difficult for workers with additional support needs to set boundaries for customers, such as holding customers accountable for behaviour or rules, for example when an eloquent student or professor at a higher education institution had to be spoken to about the rules or when customers at a hardware store asked the workers with additional support needs to carry their purchases to their car when they were perfectly capable themselves.

Theme 2: Customer attitudes towards workers with additional support needs and how organisations deal with these

When deploying workers with additional support needs, stigmatising attitudes on the part of customers were regularly experienced and posed dilemmas for organisations. Participants reported different strategies to involve customers in their inclusive employment practices.

Different attitudes of customers towards inclusive employment practices

Across organisations, participants experienced different attitudes on the part of customers towards inclusive employment practices and the deployment of workers with additional support needs, with participants sometimes observing stereotypical attitudes among customers. The HR officer of a higher education institution experienced that customers (i.e. students and teachers) did not always understand the behaviour of workers with additional support needs and often held stereotypical and limited beliefs about their competencies. The owner of a hospitality company, however, experienced that customers greatly appreciated the inclusive employment practices and came back precisely because they wanted to make a difference by contributing to inclusion as a customer. The team lead of a hardware store experienced customers having greater and lesser affinity with workers with additional support needs, with customers she knew to have a relative with a disability responding more positively, for example.

Participants' experiences, along with those of their organisations, regarding customers' attitudes appeared to be related to how organisations communicated their vision of inclusive employment practices to the outside world. The owner of a cleaning company and the team lead of a cinema, for example, believed that knowledge about the deployment of workers with additional support needs tended to have a negative rather than a positive effect on the attitudes and experiences of the majority of their customers and therefore only communicated about their inclusive employment practices to customers when there was a specific reason.

Knowledge about a worker's disability can enhance customers' understanding while also contributing to stigmatisation

Regardless of customers' positive, neutral or negative attitudes toward inclusive employment practices, participants experienced a relationship between customers' knowledge of the deployment of workers with additional support needs within a company and their expectations and reactions. This was particularly evident in examples of customer responses to interactions with workers with disabilities that were not directly visible. Participants cited situations of customers who were unaware of the deployment of workers with additional support needs within the company and complained about the behaviour or service of a worker without visible disability. After the organisation's inclusive employment practices were explained, they expressed understanding of the situation and withdrew their complaint. At the same time, participants strove for diversity and inclusion and therefore regretted that customers needed this explanation and knowledge to understand and adjust their judgments and expectations, creating a dilemma. Participants noticed that informing customers contributed to understanding and preventing dissatisfaction, while informing was at the same time perceived as conflicting with their efforts to normalise diversity.

Specifically, team leads experienced that customers had entirely different expectations of workers with and without visible disabilities, as shown in the excerpt below:

> *R6: But if someone has a visible disability, it's certainly different.[...]*
> *R7: Then it's taken into account more quickly.*
> *R3: Yes, because people can see it.*
> *R1: The expectation changes immediately.*
> *R6: Yes. It might sound very disrespectful when I put it that way, but it's true.*

Team leads experienced that customers were more likely to judge the behaviour of workers with invisible disabilities negatively, because their expectations and the – in their eyes – deviant behaviour did not match. The team lead of a supermarket experienced that such a mismatch could easily lead to difficult situations and overestimation of a worker with invisible disabilities, as customers did not understand why a 'normal' worker was not able to answer their question. In the case of visible disabilities, however, participants experienced that customers could underestimate a worker and could, for example, be inclined to direct their question to a co-worker. Participants perceived this as a potential barrier to the development opportunities of workers with visible disabilities, as they could not always demonstrate their competencies, as a result of which stigmatising images could be perpetuated.

Communicating with customers about and involving them in inclusive employment practices

Participants employed various methods to communicate with customers about their inclusive employment practices, engage them in these initiatives or even attempt to change stigmatising attitudes. The extent to which organisations communicated proactively and broadly about the deployment of workers with additional support needs varied: from not actively informing customers to sharing information on a website and communicating more explicitly. The higher education institution, for example, portrayed workers with additional support needs positively in interviews to influence stereotypical images of co-workers and students. Noteworthy was the strategy of the owner of a cleaning company who, despite considering inclusive employment practices as the most important core value internally, explicitly chose not to communicate this to the customers, based on the experience that customers punished rather than rewarded this inclusive vision.

All participants, however, experienced that not all customers were reached with a generic form of communication, for example through a website, and that customised information to customers at the case level was sometimes necessary. Participants perceived informing customers about individual workers as necessary in specific situations, with the guiding principle being that customers were not informed about a worker's disability, but about the additional support someone needed. Proactive strategies were sometimes used to meet customer needs in the relationship with workers with additional support needs. For example, the manager of a taxi company built trust among parents of children who received a worker with additional support needs as a new taxi driver by having this worker accompanied by a familiar driver for the first few days. In addition, some participants talked about using strategies to actively influence a customer's attitude and behaviour. For example, the owner of a cleaning company shared an experience with a business customer who doubted the competencies of a worker with additional support needs. The owner addressed the customer's concerns by creating the conditions that the customer needed to give the worker an opportunity, aiming to create a positive experience that would challenge the customer's stereotypes. This approach ultimately resulted in increased customer confidence in the worker's capacities.

An important issue was whether or not to specifically indicate workers with additional support needs, for example by having them wear a badge or a vest, making it immediately clear and visible to customers that they were dealing with a worker with additional support needs. Several team leads indicated that they had considered this as a helpful way to inform customers and proactively influence their expectations and thus avoid difficult situations. Team leads, however, unanimously agreed that they did not want to implement this strategy, as it was contrary to their drive for inclusion:

R2: As an employer you can't say to such an employee: you're part of the team. You just have to wear a badge.

Theme 3: The challenge of creating a customised work environment

Participants experienced that accommodations and customised support in the workplace were pivotal aspects to sustainably employ workers with additional support needs and to improve their contact with customers. The customised support was, however, experienced as challenging.

The challenge of customised support

Participants experienced a wide variety of support needs among workers, resulting in the need to offer tailor-made support that, at the same time, sometimes made the support complex and time- and energy-consuming.

Challenges in supporting workers with additional support needs arose when they pushed boundaries with colleagues and customers or sent different signals to colleagues, supervisors and people in their informal network. Specifically, team leads very regularly experienced challenges, as workers with additional support needs overestimated their own competencies or had a different perspective on their own competencies than the participants had. Team leads experienced that this self-overestimation and the desire to demonstrate competencies could lead workers to deviate from the agreements made about customer contact and perform tasks that were not agreed. This could lead to difficult situations in interactions with customers and several team leads experienced it as challenging to support and set boundaries for workers with additional support needs in these situations.

> *R4: That guy who works for me, who thinks he can do more than I think he can. It always ends up with a confrontation. (..) But he wants to show that he can do it. So he does it secretly, behind your back. And then you know you'll have to deal with an angry visitor again.*

Preconditions promoting employability and smooth customer interactions

Participants experienced stability in the working environment, a good working atmosphere and the prevention of stress among workers with additional support needs as important preconditions for sustainable employability as well as smooth customer interactions. One participant reflected on how overburdening workers with tasks could lead them to experience stress, which could ultimately negatively impact the quality of customer interactions:

> *R2: If, as an employer, I ask too much of my two employees, or ask things that I may know about beforehand, they actually can't handle it (..) then they immediately get a bit upset. And you see it immediately in their customer contact afterwards. They're abrupt, resentful, irritated. So things must be right at the front, otherwise they'll never be right at the back.*

A permanent supervisor, proactive agreements and setting boundaries were perceived as key ingredients for the creation of a fitting environment. Specifically, a permanent and continuously available supervisor with whom the worker with additional support needs felt a connection was experienced as helpful. This supervisor could also help the worker set boundaries to prevent overburdening or exploitation by co-workers or clients. Not all co-workers were perceived as capable for this role, as it required empathy, flexibility and an affinity with supporting workers with additional support needs. In the monitoring of agreements, participants perceived active cooperation with the network of workers with additional support needs, such as a job coach and parents, as important in some situations. In general, the continued availability of job coaches was experienced as helpful, while this was not always possible within current practice and legislation.

The preconditions required to create a fitting environment sometimes meant that exceptions to general working agreements were made for workers with additional support needs, such as exemption from cash register work or the allocation of fixed working days, which sometimes caused friction with co-workers who felt disadvantaged. Participants experienced that proactively informing co-workers could help prevent this friction.

Theme 4: Creating an inclusive climate with all stakeholders from an intrinsic motivation

In addition to providing tailored support for workers with additional support needs, participants found that fostering an inclusive climate within the organisation was essential for sustainable inclusive employment, though also challenging. They identified intrinsic motivation at various levels of the organisation as a key driving force behind inclusive employment practices, necessitating extra effort from management, direct supervisors, co-workers and customers.

Personal drive to make a difference

A difference was observed in how the participants characterised the objective and core values of their organisations. For example, both supermarkets and the cinema were explicitly presented as commercial companies, while within the cleaning company and both hospitality companies inclusive employer practices were presented as part of the company's core values. In the companies characterised as commercial, the participants perceived their own intrinsic motivation as crucial to embed inclusive employment practices within the workplace, as they had to deal with strong commercial expectations from management. For example, the team leads of a supermarket and a cinema were expected to achieve the same financial results despite deploying workers with additional support needs within their teams, which they experienced as challenging. This led the team lead of the supermarket to ask other team members to increase production. The team lead of the cinema emphasised the importance of his own intrinsic motivation in commercial companies:

> *R4: My subsidy also goes to head office. I don't see any of it. But you do it because you want to. And commercial companies also have a commercial CSR policy.*

In addition, several participants expressed a personal affinity with workers with additional support needs and therefore wanted to go the extra mile for them. Sometimes the affinity arose from personal experiences, such as being raised in a disadvantaged neighbourhood or having a son with autism, and sometimes from previous, successful work experiences with workers with additional support needs. In addition, it was observed that many participants were explicitly focused on helping workers with additional support needs to develop further in their work, but also to achieve goals in their private lives, such as buying a house.

Positioning workers with additional support needs; normalisation versus an exclusive position

The participants experienced that not all co-workers shared their drive to offer opportunities to workers with additional support needs. They frequently experienced difficulties in creating understanding among co-workers about the needs of workers and the associated more tolerant boundaries and adjusted working agreements. The HR officer of a supermarket cited an example of co-workers who had difficulty with a worker who was allowed to take breaks at the agreed time, including in busy situations, forcing them to work harder. Some participants even talked about colleagues who tried to take advantage of workers with additional support needs, for example by giving them tasks they did not feel like doing themselves, such as taking out garbage bags and cleaning up the kitchen.

A number of participants indicated that they took diversity within their team as a starting point, placing less emphasis on the disabilities of workers. They discussed within their diverse teams what each team member needed and experienced positive effects of this approach, for example because co-workers became more aware of each other's needs, regardless of whether they had a disability. The owner of a hospitality company expressed her positive experiences:

> *R10: I notice that among our colleagues who supposedly have no issues. They look out for each other much more. Like: how come it doesn't work out tonight? Is there something wrong? Or can I help you with something?*

Participants also mentioned situations in which workers with additional support needs had a special positive position with co-workers and customers. For example, some team leads noticed that co-workers and customers were more concerned about workers with additional support needs than about regular workers and, for example, immediately asked about the worker with additional support needs when absent. The team lead of a supermarket even perceived one of his workers with additional support needs as a figurehead of his supermarket who was highly appreciated by customers and co-workers.

Discussion

This study investigated whether and how organisations across diverse industries perceive the customer perspective as influencing inclusive employment practices and explored the facilitators and barriers encountered when employing workers with additional support needs. Analysis of focus group data revealed four themes, each highlighting aspects of hiring and retention for these workers, with varying relevance of the customer perspective. This discussion considers these themes and their implications for research and practice.

Findings indicate that organisations across industries often consider customer expectations and the nature of customer interactions during the selection process, particularly when hiring for customer-facing roles. These insights expand the existing knowledge of the factors influencing organisations' decisions to hire workers with additional support needs. Previous research has shown that customer attitudes can pose challenges, particularly in customer-focused industries such as retail and hospitality (Houtenville & Kalargyrou, 2015). Our study, however, suggests that the extent to which customer perspectives are considered depends not only on the industry but also on factors such as the degree of commercial objectives and the core values of the organisation. For instance, team leads from highly commercial organisations felt compelled to prioritise the speed and efficiency expected by customers, while those from organisations with a core commitment to inclusion did not regard this factor as significant in their decision-making.

Additionally, the complexity of customer interactions emerged as a relevant factor in hiring decisions, especially in determining suitable roles for workers with additional support needs. Increased complexity in customer interactions – such as conflict resolution or the need for product expertise – appeared to influence how organisations approach hiring. According to Margutti et al. (2024), different service orientations require varying degrees of customer interaction, ranging from self-service to complete service, with the latter requiring more engagement and knowledge on the part of employees. For example, supermarkets in this study represent a self-service model focused on cost reduction, with limited direct customer assistance. By contrast, environments such as hardware stores or cinemas operate closer to a complete-service model, where workers may need specific product knowledge to assist customers effectively. This variation in service orientation points to an important consideration for future research: investigating how different levels of service demand and customer interaction requirements influence the deployment of workers with additional support needs across industries. Understanding these relationships could better inform matching strategies and skill development programmes for these workers.

The customer perspective also affects the social integration of workers with additional support needs within the workplace. Customised support, tailored to individual workers, was reported by participants as essential not only for promoting sustainable job performance but also for fostering smooth customer interactions. In line with the goals of inclusive employment, many organisations in this study aimed to create a sense of normalisation for these workers. However, the drive for normalisation was sometimes at odds with stigmatising attitudes on the part of customers. Participants described a delicate balance between communicating their inclusive employment practices and avoiding actions that might draw undue attention to the workers' support needs. For example, while some customers reacted positively to these inclusive practices, others held biases or stigma. Most participants strongly opposed identifying workers with additional support needs through badges or vests, as such indicators were seen as counterproductive to normalisation efforts (Dearing, 2021).

Personal motivation and empathy were also found to be crucial facilitators for supporting workers with additional support needs. Many participants expressed a personal commitment to inclusion and empathy toward these workers, which aligned with findings from Carpenter and Paetzold (2013) indicating that positive attitudes can foster job accommodations. However, some participants experienced challenges in fostering an inclusive workplace climate, as they encountered resistance from co-workers who felt adjustments for workers with additional support needs were “unfair” or an “easy way out”. This resistance reflects findings by Ysasi et al. (2018), who note that co-workers often hold stigmatising attitudes, perceiving accommodations as special treatment rather than necessary adjustments.

To address these stigmatising attitudes and promote inclusivity, organisations may benefit from educational initiatives, such as workshops, conferences or structured support from job coaches and HR professionals (Beatty et al., 2019; Ysasi et al., 2018). Job coaching in particular was valued by participants as a supportive intervention, although it is not always available on a permanent basis. Public funding is therefore essential to provide the resources necessary for ongoing job coaching and other forms of support, ensuring that organisations can sustain these inclusive practices over time (Beatty et al., 2019; Morris et al., 2024). Additionally, HR departments might consider identifying and involving co-workers who are personally motivated to assist workers with additional support needs, as this could enhance team satisfaction, increase a sense of purpose and contribute to a more inclusive workplace climate (Boccalandro, 2021).

Within teams, fostering an inclusive environment also involves de-emphasising disabilities and instead centring diversity and individual strengths. Participants shared positive experiences in which diversity discussions allowed all team members to voice their needs, thus creating an environment where the needs of workers with additional support needs did not stand out. Managers can support these discussions by facilitating open dialogues on capabilities and requirements for all team members, as recommended by Scoppetta et al. (2019), to further promote an inclusive workplace climate.HR departments play a pivotal role in coordinating and advancing inclusive employment practices. Designating an HR manager focused on inclusion strategies, as identified in the study, was reported as an enabling factor for successful implementation of these practices (Beatty et al., 2019). Moreover, establishing regional partnerships among inclusive employers could provide valuable peer support, facilitate knowledge sharing and enhance access to resources for smaller organisations. Such partnerships could allow smaller companies to benefit from shared resources, HR support and best practices (Lewis & Dijkema, 2022), ultimately fostering a broader culture of inclusion.

This study contributes to the literature by provid ing in-depth insights into the role of the perceived customer perspective in inclusive employment practices across diverse organisational contexts. Future research should incorporate the customer perspective as a variable when examining factors that hinder or facilitate inclusive employment, such as organisational size, service orientation and prosocial motivation. While this study addressed a wide range of organisational contexts, its scope limited the exploration of specific factors such as industry type, service orientation and core values. Future research employing methods such as focus groups or participatory observations within organisations that have distinct service orientations or core values may yield more nuanced insights into how the perceived customer perspective interacts with these organisational characteristics. It is important to note that the generalisability of the present findings may be limited, as only two focus groups were conducted. To validate and expand upon these results, a larger-scale survey involving a greater number of organisations across various industries is needed. This would allow for broader generalisation and enable a more comprehensive examination of the relationships between customer expectations, service demands and inclusive employment practices.

This study is among the first to examine how the perceived customer perspective influences hiring and retention decisions for workers with additional support needs. Findings show that organisations do consider customer expectations and the complexity of customer interactions, with factors such as service orientation, commercial objectives and core values playing a significant role. The dilemmas organisations face in managing customer attitudes and fostering inclusive environments highlight the complexity of maintaining normalisation while at the same time providing customised support. These findings suggest that creating and sustaining an inclusive workplace, especially in customer-facing roles, is a nuanced and sometime ambivalent process that requires ongoing adaptation and thoughtful decision-making. Despite the challenges, there are clear opportunities for growth and development on the part of employers, employees and customers alike. By engaging in open dialogues, sharing resources and best practices, and committing to education, organisations can create more inclusive climates that benefit both workers and customers.

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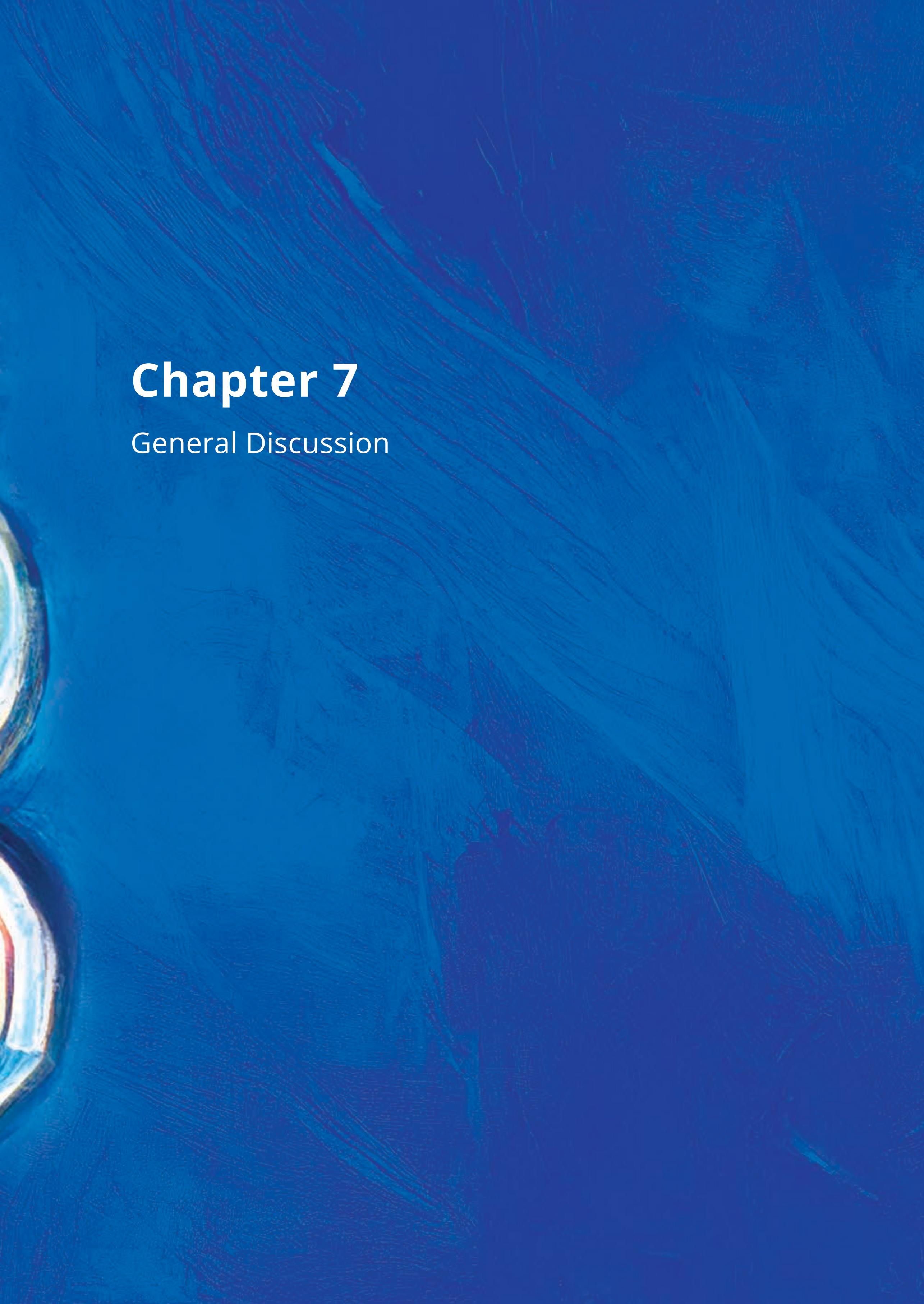


Chapter 7

General Discussion

Aim of the thesis

The meaning of work has undergone a profound transformation within Western societies, both individually and collectively. Whereas work was once primarily seen as a burden, it is now increasingly regarded as being pivotal to people's overall health and well-being (Roeters et al., 2021; van der Klink et al., 2016). Work is also considered to be a key pathway to social participation (Wilthagen & Stolp, 2021), whilst access to meaningful work is increasingly recognised as an essential component of ‘broad prosperity’ - a concept that encompasses more than mere economic indicators and is embedded within the UN’s Sustainable Development Goals (Stiglitz et al., 2009; Tilburg University, 2023).

However, not everyone has equal access to meaningful work - especially people with vulnerabilities such as intellectual disabilities. In recent decades, societal attitudes towards, and policies related to, people with intellectual disabilities have shifted due to growing recognition of their right to full citizenship (Verdonschot et al., 2009; Meininger, 2013; United Nations, 2006). In line with this recognition, work models for this group have gradually moved from segregated settings towards community-based, integrated work (Wehman et al., 2007), with an increased emphasis upon supported employment (Dague, 2012; Meininger, 2013).

Despite these developments, people with intellectual disabilities continue to face considerable barriers in accessing integrated work (Lysaght et al., 2009; Vigna et al., 2023). Whilst several Western countries have implemented inclusive labour policies (Shima, 2008; Vornholt et al., 2018), research consistently shows low participation rates within integrated work amongst this group compared to average participation rates (Berendsen et al., 2023; Hennessey & Goreczny, 2022; Winsor et al., 2019). This persistent ‘inclusion deficit’ sidelines many people with intellectual disabilities and has negative consequences for their well-being as well as resulting in an underutilisation of talent and human capital, which is especially problematic given current labour shortages within the Dutch labour market (Olsthoorn & Roeters, 2023).

Promoting social participation through meaningful work for people with intellectual disabilities is a complex challenge. Extant research in this area is limited and hitherto does not offer sufficient insight into what such participation entails or requires. Therefore, this thesis set out to develop a more nuanced understanding of 1) the meaning of work for people with intellectual disabilities; and 2) the conditions that either enable or hinder their participation within meaningful work.

A contextual approach was adopted within this thesis in order to examine how factors at the individual, interpersonal, and societal levels interact to either support or impede access to work. The research includes the perspectives of key stakeholders: people with intellectual disabilities, their informal networks, and employers. In doing so, this thesis both contributes towards our understanding of work within the context of broad prosperity and offers potential directions for interventions across multiple levels to help improve work participation for people with intellectual disabilities.

The thesis focuses primarily upon the experiences and perspectives of people with intellectual disabilities related to their participation in regular paid work (Chapter 2) and the impact of losing work and social restrictions during the COVID-19 pandemic (Chapter 3) within their broader lives. Given the pivotal role of informal networks in supporting people with intellectual disabilities (Giesbers et al., 2020), their views of meaningful work were also explored (Chapter 4). Furthermore, the perspectives of employers – who play a crucial gatekeeping role within inclusive employment – were also examined (Chapters 5 and 6). These latter studies paid specific attention to the influence of the perceived customer perspective upon employer behaviour, a topic that remains underexplored in extant literature. Given that employers tend to adopt inclusive practices geared towards a broad group of workers with disabilities, the studies in Chapters 5 and 6 focused upon this wider population. Accordingly, the term ‘intellectual’ is placed in parentheses when referring to these findings.

This final chapter summarises, integrates, and reflects upon the main findings in relation to extant literature, before proceeding to discuss the strengths and limitations of the research and outline the implications for future research, policy, and practice.

Main findings and interpretations

The findings are structured around two core themes: 1) the benefits of, and conditions for, meaningful work for people with intellectual disabilities; and 2) frictions in achieving meaningful work for people with intellectual disabilities. Both of these themes are organised using Bronfenbrenner’s contextual framework (1994, 1996), which was introduced in Chapter 1. Figures 1 and 2 visually summarise the findings.

Figure 1. Findings; Benefits of, and Conditions for, Meaningful Work
Benefits are in bold. Conditions are in italics. The chapter(s) in which the finding was presented are referenced in brackets.

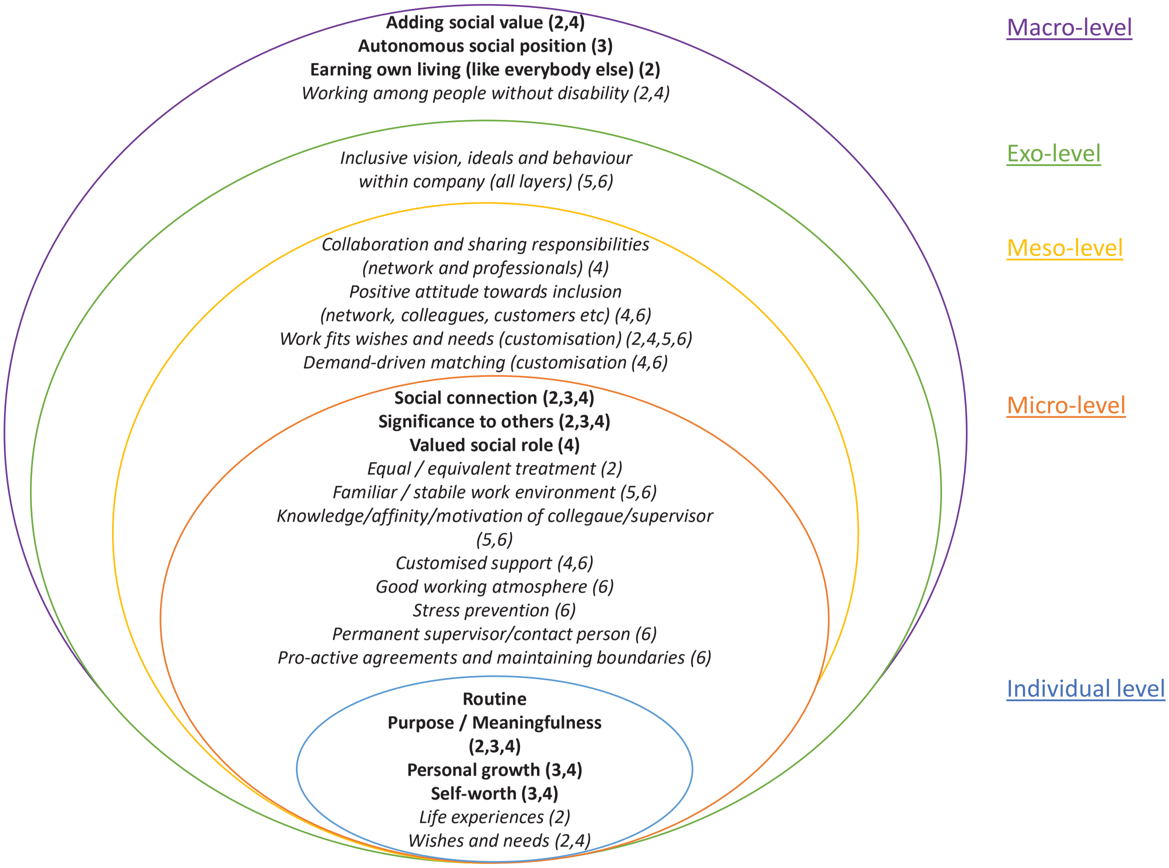
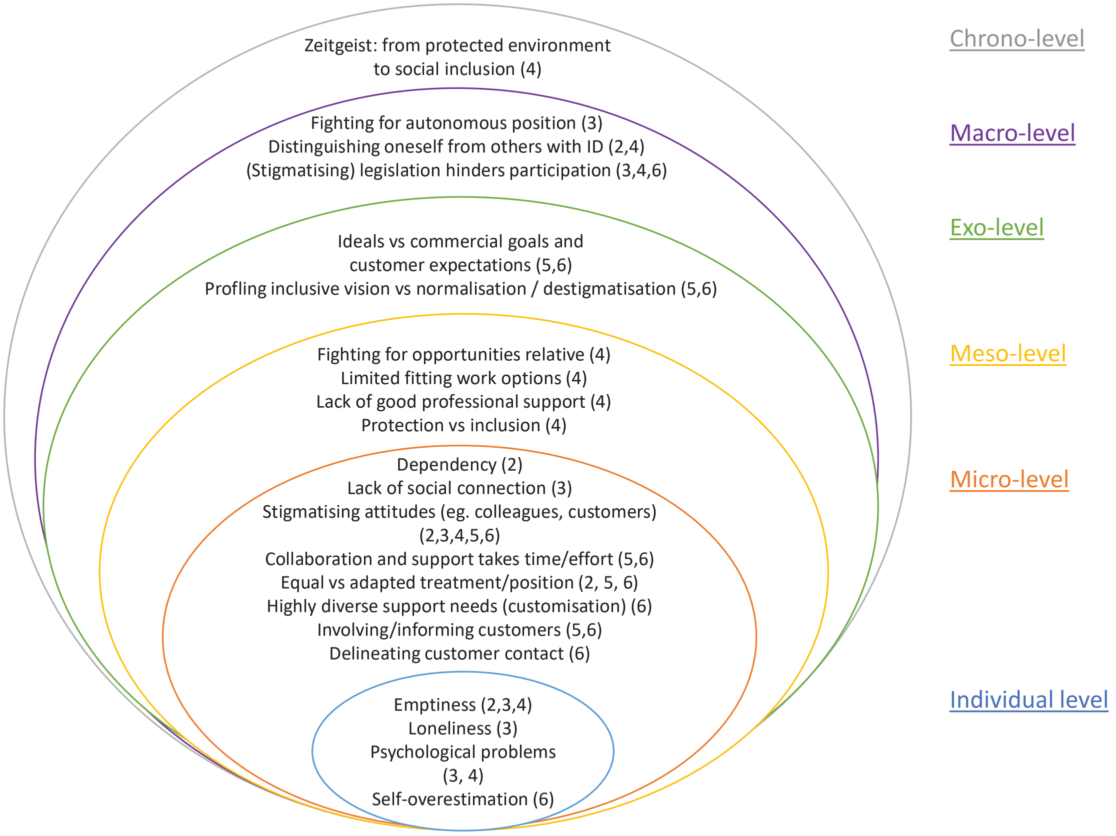


Figure 2. Findings; Frictions that Potentially Hinder Meaningful Work
The chapter(s) in which the finding was presented are referenced in brackets.



Individual-level factors

At the individual level, the *benefits* of meaningful work were reported by people with intellectual disabilities and their informal network members. They experienced that participation within work contributed towards daily routine, a sense of purpose, personal growth and a sense of self-worth. A key *condition* to realise these benefits was the need to match individual wishes and needs to appropriate work tasks and environments. Both informal network members and employers considered this alignment to be of paramount importance. People with intellectual disabilities also indicated that having opportunities to explore different work experiences was an important condition for helping them discover their preferences and capabilities.

Frictions at the individual level emerged when access to meaningful work was either lacking or lost. People with intellectual disabilities anticipated a sense of emptiness, namely in terms of activities and social connections, without work, which was confirmed during the COVID-19 pandemic. Those who lost their work experienced loneliness and psychological issues, including depressive symptoms. Informal network members observed how the absence of work led to long, uneventful days and in some instances physical and mental health problems for their relatives.

Micro-level factors

At the micro level, the *benefits* of work primarily emerged from the perspectives of people with intellectual disabilities and their informal networks and included expanded social networks and opportunities for people with intellectual disabilities to feel of significance to others. The informal network members appreciated that work provided their relatives with a meaningful social role, which also strengthened their own sense of purpose. An important *condition* mentioned by people with intellectual disabilities was receiving equal or at least equivalent treatment within the workplace, although this was not always realised in practice. Informal network members and employers stressed the condition of customised support, a stable and familiar work environment, and the involvement of co-workers and supervisors who had an affinity for and were motivated to support workers with (intellectual) disabilities. Other essential conditions included a positive working atmosphere, proactive stress prevention, and a designated supervisor who could monitor agreements and provide continuity.

Micro-level *frictions* were typically related to stigma. People with intellectual disabilities experienced limiting beliefs from both their co-workers and supervisors regarding their competencies, for example. They also reported feelings of dependency. Employers identified stigmatising attitudes and expectations of customers, which were also related to the visibility of a worker's disability. They also reported that the time and effort needed to collaborate with and customise the highly diverse support needs for workers with (intellectual) disabilities was a limiting factor, along with dilemmas around involving customers in a normalised yet inclusive way. They particularly struggled with involving workers with (intellectual) disabilities within customer-facing roles that involved complex customer interactions. Employers and workers alike struggled with finding the right balance between equal treatment and making the necessary individual accommodations. Employers in particular attempted to strike a balance between a normalised position or rather a more exclusive position for workers with (intellectual) disabilities within their organisation.

Meso-level factors

At the meso level, several *conditions* were identified that support the realisation and continuation of meaningful work for people with intellectual disabilities. Informal network members and employers considered demand-driven matching processes to be a critical condition for identifying and maintaining suitable job placements. Some employers also explicitly considered customer perspectives within this process. Positive attitudes towards social inclusion amongst care professionals, co-workers, customers and informal network members were regarded as a supportive condition. The long-term involvement of job coaches, or at least the possibility of re-engaging them when required, was considered to be essential. Informal network members stressed the importance of collaboration and shared responsibility with professionals and supervisors in sustaining employment for their relatives.

Frictions at this level included a lack of suitable job opportunities and insufficient professional support. Indeed, informal network members often felt they had to fight for their relatives to get opportunities. They also experienced a tension between promoting inclusion and providing protection, based upon the fact that they perceived risks such as exploitation or exclusion within integrated work environments.

Exo-level factors

At the exo level, Chapters 5 and 6 identified both enabling conditions and frictions from the perspective of employers. A key - but complex – *condition* was the need to establish an inclusive vision, supported by inclusive ideals and behaviours, across all organisational levels and stakeholders. The employers emphasised that such a foundation is essential for successfully integrating workers with (intellectual) disabilities into the workplace.

However, employers also encountered *frictions* at this level. Specifically, they often had to navigate the trade-off between pursuing inclusive goals and meeting commercial objectives or customer expectations. Moreover, they encountered a dilemma with respect to how to publicly position themselves as an inclusive organisation. Whilst they wished to highlight their commitment to inclusivity and the employment of workers with (intellectual) disabilities, they were also cautious not to single out these workers in order to normalise their presence within the workforce.

Macro-level factors

The benefits, conditions, and frictions addressed at this level by both people with intellectual disabilities and their informal network members are intertwined with the experienced benefits of work at the individual level. That is to say, the wish of people with intellectual disabilities and their informal network members to experience an autonomous social position at the macro level is related to individual benefits, such as gaining a sense of purpose and self-worth, and sometimes interferes with prevailing social attitudes, expectations and standards that hinder the realisation of this social position.

At the macro level, the *benefits* of work included a strengthened sense of social belonging for people with intellectual disabilities, alongside the opportunity to contribute towards society rather than merely receiving support. Informal network members viewed this shift positively. People with intellectual disabilities valued having an autonomous position within society and being able to earn their own income, particularly when working alongside people without disabilities. Some people with intellectual disabilities and their informal network members expressed a strong preference for this type of inclusive setting over more segregated options.

However, *frictions* were also present in the participants' accounts. By virtue of striving to be part of society, some individuals and informal network members distanced themselves from the label of disability due to potential stigmatisation. The COVID-19 pandemic underscored how fragile the autonomous societal position provided by participating in meaningful work can be, insofar as losing work led to a perceived loss of their autonomous position within society. Structural frictions were also evident. Certain legislation that intended to promote inclusion generated unintended negative effects, such as making people hesitant to accept paid work as a result of the perceived risk of losing their benefits due to a lack of options to fall back on. Employers noted that, from their perspective, so-called wage value assessments often underestimated the actual contribution of workers.

Chrono-level factors

Finally, at the chrono level, *frictions* emerged that pertained to shifting societal expectations. Informal network members described how it was difficult to align with changing norms, especially when their relatives were content with working in sheltered work environments but were increasingly expected to transition to integrated settings. This created a tension between respecting personal choice and keeping up with evolving societal ideals.

Reflection upon the findings

In line with the structuring of the findings, the core themes will be reflected upon below: The *benefits* of meaningful work, *conditions* for meaningful work and *frictions* in achieving meaningful work for people with intellectual disabilities.

Why people with intellectual disabilities benefit from participation in meaningful work

This thesis underscores why people with intellectual disabilities benefit from participation within meaningful work. At an individual level, work fosters personal growth and a sense of self-worth, whilst socially it enables the fulfilment of valued social roles. These insights, especially from the perspective of people with intellectual disabilities themselves, deepen our understanding of how meaningful work positively impacts upon their lives more broadly. These findings are in accordance with research on the general population (e.g., Jahoda, 1981; Abma et al., 2016) and extend disability-focused studies (Cheah et al., 2022; Donnelly et al., 2010; Lysaght et al., 2017; Schaap et al., 2023) by specifically demonstrating how work participation fosters personal growth, a sense of significance to others, and an autonomous social position amongst people without disabilities. Given the unique challenges faced by people with intellectual disabilities with respect to achieving the social value associated with paid work, this in-depth knowledge is crucially important.

Conversely, the findings show the negative impact upon autonomy and social status stemming from the loss of work. Although these negative effects of long-term unemployment have also been reported in the general population (Marrone & Swarbrick, 2020; Paul & Moser, 2009), this topic remains underexplored within disability literature (Jahoda et al., 2009; Lysaght et al., 2017), which underscores the need for further research into the impact of job loss.

The required customised conditions to access and sustain meaningful work

Below, reflections are made on two key topics related to the required conditions for meaningful work: first, connecting with the strengths of people with intellectual disabilities from the selection and recruitment stage onwards; and secondly, providing customised support within the workplace.

Demand-driven matching and strengths-based support within the workplace

With respect to realising meaningful work for people with intellectual disabilities, this thesis further emphasised the critical role of connecting to their own wishes and needs during the recruitment and selection process in order to help them find a suitable work position. The findings point to the need for people with intellectual disabilities themselves to try and experience different work situations and types of work in order to understand their own work-related wishes and needs, which is consistent with the findings of Helena et al.'s (2022) research. The findings of this thesis extend Helena et al.'s (2022) findings by providing further evidence for customised and demand-driven matching processes as key factors for employers and other stakeholders, such as job coaches, to create both suitable and sustainable work positions for people with intellectual disabilities and adapt tasks to their needs. However, demand-driven matching does not appear to be commonplace in practice. A Dutch evaluation of the implementation of the Participation Act suggested that most employers preferred to rely upon their existing vacancies when placing workers with (intellectual) disabilities and made few adjustments (Adelmeijer et al., 2017). This is an interesting finding, as the need for demand-driven matching aligns with contemporary research within Human Resource Management (HRM). Demand-driven matching is also in line with the contemporary focus upon job carving and job crafting strategies which seek to increase the employability and productivity of all workers and find a better fit between job demands and worker skills (Scoppetta et al., 2019).

Beyond recruitment, sustaining meaningful employment requires customised workplace support and adjusted workplace conditions. This includes, amongst other things, appointing supervisors with relevant expertise and motivation, proactively managing interactions (e.g., with customers), and ensuring collaboration amongst employers, job coaches, and informal networks (Cheah et al., 2023; Morris et al., 2023; Schaap et al., 2023). However, it may pose risks when supervisors seeking to create inclusive work situations overly rely upon knowledge about accommodations that people with intellectual disabilities may need, such as a reduced focus upon individual needs or making unnecessary adjustments

(Morris et al., 2023). Adopting a strengths-based approach, which focuses upon competencies rather than limitations, can help foster a more inclusive work climate and counteract disability-related stereotypes (Pulla, 2017). Stakeholders, such as job coaches and supervisors, that adopt a strengths-based approach, they work from the assumption that every person has strengths, capacities and the potential to grow. Based upon this assumption, elements can then be built into the current work situation that worked well for the person in a prior work situation. Damian, one of the participants in the study presented in Chapter 2, emphasised the potential power of a strengths-based approach in this extract below:

> *Because I think, you shouldn't ask, 'What can he do?' You should just ask things like 'How far is he willing to go?' Right? I can ask someone something like, 'Can you handle that?' or 'Do you want to try that?' Those are two different things with an entirely different underlying thought.*

Challenges in realising customised support

Challenges in providing customised support include the time and effort required by co-workers and supervisors, differing views on equal treatment, the attitudes of co-workers towards adjustments (Beatty et al., 2019), and maintaining a trusted work environment, such as, for example, in the case of turnover in supervisory roles. Whilst people with intellectual disabilities emphasise equal treatment (Helena et al., 2022; Morris et al.,2023; Schaap et al., 2023), employers and informal networks stress the need for adapted support alongside normalisation, which creates a dilemma between equality and tailored assistance. Both under- and over-estimation can hinder sustainable employment, reflecting the tension between protection and empowerment within disability discourse (Altermark, 2017). Customised solutions are necessary, insofar as there is no 'one size fits all' – for example, shorter shifts might help some but frustrate others (Helena et al., 2022). Employers, however, may be reluctant to implement adjustments, due to the perceived high costs (Lewis & Dijkema, 2016) or because co-workers may feel unfairly treated (Beatty et al., 2018). Clear communication and agreements with workers with intellectual disabilities, their networks and co-workers are therefore crucial (Stone & Colella, 1996), as well as increasing contact between employees with and without disabilities and providing diversity training across all levels of an organisation (Carmen Triana et al., 2021). However, further research is needed to explore effective solutions.

Social frictions that hinder participation within meaningful work

With respect to achieving meaningful work, there are societal frictions that extend beyond an individual's workplace that require further reflection.

Stigmatising attitudes as a main barrier

Stigmatising attitudes remain a significant barrier to full participation within work by people with intellectual disabilities. This thesis demonstrates the complexity of stigma and the multiple forms it takes – public, structural, self, and courtesy stigma (Rasset et al., 2022). People with intellectual disabilities often face public stigma from co-workers and customers, due, in part, to the (in)visibility of their disability. This affects the expectations of co-workers and customers and potentially causes either under- or over-estimation. In some instances, experiencing public stigma has prompted people with intellectual disabilities – and their informal networks -– to distance themselves from others with disabilities (Vornholt et al., 2018), which, amongst other things, can result in a strong desire to work in environments in which there are no people with disabilities. Structural stigma is evident within legislation that, despite its attempts towards creating greater inclusion, sometimes hinders full participation, due to, for example, the perceived risks of losing benefits when accepting paid work.

Negative societal stereotypes – perceptions of dependence and incompetence – also limit job opportunities and inclusive workplace climates (Bonaccio et al., 2020; Vornholt et al., 2018; Fiske, 2012; Pelleboer-Gunnink, 2020). This is especially problematic given that stigmatising attitudes and behaviour are persistent and difficult to change, as social structures tend to reproduce themselves (Giddens, 1984; Stone & Collela, 1996). The stereotypical perceptions that co-workers and supervisors attach to people with intellectual disabilities can therefore become a 'master status' that overshadows other characteristics and skills and is difficult to overcome (Beatty et al., 2019; Stone & Colella, 1996). It is therefore essential that from the outset a positive and strengths-based image is created when positioning a worker with intellectual disabilities within an organisation, highlighting their talents and capacities instead of focusing on disabilities (Stone & Collella, 1996).

Inclusive climate within and beyond organisations

Organisations are still struggling to implement effective diversity and inclusion strategies (Murphy, 2018). An inclusive climate within organisations benefits from the personal motivation of co-workers and supervisors, which is often fostered by familiarity with disabilities (Ellenkamp et al., 2016; Stone & Colella, 1996). Workers might experience inclusion when their needs for a sense of belonging and to feel unique are met. That is to say, when a worker feels treated as an insider within a workplace and their uniqueness is simultaneously accepted and encouraged. However, specific knowledge on how to create an inclusive climate both for and from the perspective of people with (intellectual) disabilities is scarce, since this group remains underrepresented within inclusion literature in comparison to other groups (Carmen Triana et al., 2021; Garg & Sanwan, 2021; Lindsay et al., 2023), which underscores the need for further research from their perspective.

In addition, this thesis sheds light upon a key dilemma within inclusive employment: how organisations can involve and inform customers about the presence of workers with (intellectual) disabilities in such a way that normalises diversity without reinforcing stigma. Whilst staff members are often aware of a worker's disability, customers generally are not. Customers' reactions are influenced by the visible attributes of a disability—more apparent or aesthetically stigmatised disabilities (e.g., facial abnormalities, uncontrolled movements) tend to evoke more negative or anxious responses (Rasset et al., 2022; Stone & Colella, 1996; Kalargyrou et al., 2021). In contrast, although concealed or invisible disabilities are less likely to trigger stereotyping (Stone & Colella, 1996), they may lead to unexpected customer experiences and complaints if expectations are not met. Employers perceived that although when customers were informed about a worker's disability — especially in the case of invisible disabilities — their responses generally became more understanding, they also evoked stigmatised reactions and certain expectations amongst customers. This reflects a broader organisational tension that requires further exploration within future research: the desire to visibly promote inclusive values versus the goal of normalising disability without drawing undue attention.

The fight to contribute within a performance role

Both people with intellectual disabilities and their networks often described the need to "fight" to occupy a contributing and autonomous societal role. Luhmann's theory of inclusion and exclusion helps explain this: individuals participate as possessors of a specific ability that is relevant for having a contributing role or function within society (Schirmer & Michailakis, 2015). Inclusion occurs through these specific functional roles – performance roles (e.g., entrepreneurs, all types of workers, health care professionals) or layman roles (e.g., customers or patients) who receive services provided by people working in performance roles. Performance roles are financially, socially and psychologically rewarding, but often inaccessible to people with intellectual disabilities due to prevailing societal standards and stigma. Whilst exclusion from performance roles is not problematic per se, it becomes so when individuals are deemed either not interesting enough or irrelevant to these systems altogether (Schirmer & Michailakis, 2015). Inclusion through performance roles demands skills and education that may be out of reach, yet these roles are more valued than layman roles which might be available to everyone (Schirmer & Michailakis, 2015). This issues is compounded by the prevailing Western societal norm that equates paid work with fulfilling a valued social role (Wolfensberger, 2000), which, in turn, serves to make labour market inclusion particularly challenging for people with intellectual disabilities.

The struggle of inclusion within a competitive society

This struggle occurs within increasingly competitive and meritocratic social and institutional contexts, particularly within the labour market (Drissen, 2024; Young, 1958). The distribution of goods within society is based upon performance rather than age, gender or social class (Elshout, 2016). Although competition motivates, it can also reduce solidarity by pitting people against each other (Hussain, 2020). Moreover, it can induce a series of psychological burdens due to failure and the perception of ‘not being good enough’ (Drissen, 2024), which intensifies exclusion risks for people with intellectual disabilities. Within our performance-driven and competitive society, people with intellectual disabilities are often disadvantaged from the outset and experience a heightened risk of exclusion (Kolen, 2017). Consequently, securing a socially valued role is neither straightforward nor self-evident. Recognition of their talents demands both changes to the prevailing societal attitudes and behaviour and greater solidarity across all levels of society.

Not everyone with an intellectual disability can secure paid work or work enough hours to leave the benefits system (Dearing, 2021). Nevertheless, many are both able and motivated to contribute through unpaid roles such as volunteer work or informal care (Bos & Elshout, 2023). These activities can offer similar benefits to paid work – fulfilling roles, satisfaction, and enhanced self-respect (Bos & Elshout, 2023; Cheah et al., 2023; Elshout, 2016; Jahoda, 1982). However, within a meritocratic society, unpaid contributions are still undervalued and may not yield the same recognition or sense of accomplishment as paid work (Bos & Elshout, 2023; Elshout, 2016). This is the phenomenon Mason is referring to in the study reported in Chapter 2 of this thesis:

> *Yeah, [to me, an income means] the same as for anyone else, I guess. Yeah... we all have to work for our money, so, yeah. So, it's not just important to me. Any normal person probably thinks, like, ‘It's important to work in order to have money’.*

Strengths, limitations and implications for future research

The qualitative and contextual approach of this thesis provides valuable insights into the complex issue of participation within meaningful work for people with intellectual disabilities. By applying diverse qualitative methods – including interviews, focus groups, observations, and various analytical strategies, such as interpretative phenomenological analysis and reflexive thematic analysis – this research has sought to offer a rich and nuanced understanding of barriers and facilitators within the work domain. Methodological triangulation (Green & Thorogood, 2014; Wilson, 2014) and the inclusion of diverse stakeholder perspectives (people with intellectual disabilities, informal network members, and employers) enhanced the study’s validity and reduced bias. Research was conducted by a multidisciplinary team, with methodological expertise tailored to each of the respective studies, which helped to further strengthen both the data quality and analysis (Wilson, 2014). The findings contribute towards phronetic knowledge – value-based and context-dependent insights (Carminati, 2018) – which are not universally transferable but nevertheless remain relevant within the Western socio-political context in which the research was situated.

One major strength of this thesis is its inclusion of the voices of people with intellectual disabilities themselves, which is still not standard practice despite the increased recognition afforded to experiential knowledge within academic research (Embregts & Frielink, 2023; Hall, 2013). These perspectives helped to deepen our understanding of both the value of paid work and the personal impact of losing it. Continued research into their lived experiences, especially in relation to rapid societal changes, is essential. Specifically, attention should be paid to the impact of job loss and unemployment, and its relationship with loneliness and mental health – areas where extant knowledge remains limited, despite evidence of increased vulnerability amongst this population (Gilmore & Cuskelly, 2014; Nouwens et al., 2016). More strengths-based research is needed to both underscore the capabilities of people with intellectual disabilities and explore the societal and economic value of their participation within work – potentially building a business case by comparing employment outcomes to mental healthcare costs (Vornholt et al., 2018).

Whilst this thesis also incorporated the perspectives of informal network members and employers, it lacked input from other key stakeholders. Most studies included within the systematic review focused upon parents, thus neglecting the potential roles of peers such as siblings or friends. Comparing the informal networks of people with intellectual disabilities to those of the general population could yield new insights in terms of support mechanisms to help them both find and retain jobs. Job coaching emerged as a recurring theme across the studies. Both the informal network members and employers emphasised the importance of ongoing job coaching to maintain sustainable work situations. In light of this finding, future research should include job coaches' perspectives and examine cross-stakeholder collaboration in supporting employment. Legislation and policy were also identified as barriers due to stigmatising or counterproductive structures. Further research, preferably from an international perspective, into how laws and regulations support or hinder work participation is therefore needed. The views of policymakers should also be included to help design more effective, inclusive policies (Vornholt et al., 2018).

By exploring the perspectives of employers within various organisational contexts, this thesis identified factors that can promote labour participation for people with (intellectual) disabilities. However, given the relatively small-scale nature of the studies, the findings should be viewed as exploratory in nature. Broader qualitative and quantitative research, including field experiments and larger surveys, is needed to generalise the results and address context-specific differences within work conditions. To avoid reinforcing stereotypes, the employer studies deliberately focused upon disabilities in the broadest sense of the term, rather than singling out specific types. Whilst this helped to both reduce specific instances of stigmatisation towards intellectual disabilities (Stone & Colella, 1996) and broaden the applicability of the findings, it also means that the findings may not fully capture issues that are unique to intellectual disabilities. Therefore, future research should focus more specifically upon employer, co-worker, and customer perceptions of intellectual disabilities compared to other disabilities, especially regarding the visibility of these challenging conditions (Essa, 2023; Vornholt et al., 2018). Having said that, a broader, non-categorical approach – aligned with a personalised, strengths-based perspective – remains invaluable (Cheah et al., 2023; Pulla, 2017; Stone & Colella, 1996). Ultimately, understanding the participation of people with intellectual disabilities within work requires an interdisciplinary approach that draws from multiple scientific domains and integrates both professional and experiential knowledge (Beatty et al., 2018; Wilthagen & Stolp, 2021; Frielink & Embregts, 2023).

Implications for policy and practice

The findings of this thesis have important implications for policies and practices that aim to both support the creation of an inclusive workforce and promote the participation of people with intellectual disabilities within the labour market. These insights can, in turn, help foster conditions that benefit individuals, employers, and society at large through meaningful work. However, the heterogeneity of national legislation, labour market structures, and work contexts - both within and beyond Europe – serves to limit the provision of generally applicable recommendations (Beatty et al., 2019; Vornholt et al., 2018). Since the empirical studies discussed in this thesis were conducted in the Netherlands, the implications outlined here apply primarily to the Dutch context and to people with intellectual disabilities, even though the last two studies addressed a broader group of people with disabilities. The implications are structured around three core themes: strategies to improve labour market access, promoting inclusion within organisations, and broader implications for policy and practice. Within these core themes various strategies are discussed.

Improving labour market access: key strategies

In order to improve labour market access for people with intellectual disabilities four key strategies are suggested and elaborated: 1) Demand-Driven Matching; 2) A Focus upon Strengths-based Skills; 3) Reducing Stigma Through Positive Encounters; and 4) Job Carving.

Demand-driven matching

This thesis underscores the potential of demand-driven (people-centred) matching to enhance access to the labour market for people with intellectual disabilities. Whilst employers often recruit based on existing vacancies (Adelmeijer et al., 2017), it is more effective to create tailored roles that align with individual strengths (Vornholt et al., 2018). Employers frequently overestimate the costs of adjustments, despite evidence that these are typically low-cost and enhance productivity, satisfaction, and retention—e.g., flexible hours or shift adjustments (Lewis & Dijkema, 2022). Employment specialists, such as job coaches and specialised professionals from support services for people with intellectual disabilities, can play a vitally important role in terms of informing employers, facilitating onboarding, and supporting the first stages of employment (Morris et al., 2024). More specifically, their involvement helps in terms of both aligning expectations and effectively communicating the purpose and benefits of accommodations.

Strengths-based skills focus

In order to counteract the persistent effects of stereotyping in hiring (Bonnaccio et al., 2020; Stone & Colella, 1996), a strengths-based approach to demand-driven matching is recommended. This approach emphasises individuals' abilities and prior successes rather than focusing solely upon their limitations (Pulla, 2017). Involved stakeholders collaborate to identify individuals' strengths and utilise these as the basis for purposefully creating a work environment characterised by appropriate tasks and conditions, without losing focus of the associated challenges and necessary accommodations. Successful prior experiences are also used for this purpose and, where possible, applied to the current work situation (Pulla, 2017). Here, supervisors and co-workers do not need to have full information about individuals' diagnoses. Adopting work ability descriptions based upon someone's functional capacity (rather than their specific diagnosis) allows for clearer communication about which tasks individuals are capable of performing (Vornholt et al., 2018). Thorough assessment is essential for accurately mapping these capabilities.

The concept of a skills passport – which communicates workers' knowledge, attitudes, motivations, interests, and career goals – has gained increased attention as a flexible alternative to traditional diplomas that can enhance tailor-made and successful matching (Ballafkih et al., 2021). Although this approach is certainly promising, it requires both significant systemic change to a 'skills driven economy' and further research. Its development aligns with proposed Dutch labour market reforms that prioritise a strengths-based, skills-focused strategy (Ministerie SZW, 2023; OCTAS, 2024).

Reducing stigma through positive encounters

Stigmatising attitudes remain a significant barrier to labour market inclusion for people with intellectual disabilities. Whilst there is emergent research into stigma and interventions, our understanding of effective workplace strategies remains limited (Fitzpatrick et al., 2022; Lewis & Dijkema, 2022; Pelleboer-Gunnink, 2020). One of the most effective tools through which to combat stigma is establishing positive contact between employers and people with intellectual disabilities. Studies have shown that familiarity through personal or professional relationships enhances employers' attitudes (Duvdevany et al., 2016; Ellenkamp et al., 2015; Vornholt et al., 2018). These positive encounters should ideally be frequent, but unstructured, informal and positive, and based upon equal status if they are to reduce prejudice (Fitzpatrick et al., 2022). Examples of such positive encounters include: 1) Conversations with experts by experience; 2) Informal regional events such as inclusive job fairs; and 3) Structured formats like community conversations, which engage local stakeholders in discussions to promote inclusion (Carter & Bumble, 2018; Trainor et al., 2012).

Job carving

Job carving, that is, creating customised roles by reorganising tasks in order to build new positions within organisations based upon individuals' talents, needs and interests can also help to facilitate inclusive employment (Scopetta et al., 2019). It not only supports people with intellectual disabilities, whose skills may not align with traditional roles (Griffin & Sherron, 2006) but also addresses workforce challenges like labour shortages and high turnover rates. Whilst typically top-down in nature, job carving for people with intellectual disabilities benefits from collaboration between employers, employment specialists, such as job coaches, and workers themselves. It can involve training, workplace accommodations, and ongoing support to ensure success, and provides an opportunity to create jobs that require fewer complex skills that are suitable for people with intellectual disabilities. In conjunction with this, this also means that less interesting tasks for other workers can be removed, which, in turn, also helps to promote sustainable employability. A strengths-based lens is, however, critical for avoiding the creation of undervalued roles (Scopetta et al., 2019). Since actually implementing job carving within organisations is a complex issue, it may be beneficial to use specific methods for task differentiation to analyse and redistribute tasks based upon complexity, in order to allow people with varying capacities to contribute meaningfully (Van Ruitenbeek et al., 2013; Zijlstra et al., 2017). For example, within a care facility facing staffing shortages, non-nursing tasks could be reassigned to new roles that are suited to people without medical training, thereby improving both staff wellbeing and care quality (Mulders et al., 2021).

Promoting sustainable social inclusion within organisations

To promote sustainable social inclusion for people with intellectual disabilities who are employed within organisations, three strategies are proposed: 1) Fostering an Inclusive Climate for All Workers; 2) Targeted Support for Workers with Intellectual Disabilities; and 3) Ensuring Ongoing Employment Support.

Fostering an inclusive climate for all workers

To address the pervasive impact of stigmatising attitudes within the workplace, fostering an inclusive organisational climate is of paramount importance (Beattie et al., 2019; Vornholt et al., 2018). A strengths-based approach – focusing upon capabilities rather than limitations – can help cultivate such a climate and encourage the inclusion of workers with intellectual disabilities (Vornholt et al., 2018).

Creating inclusive environments not only benefits people with intellectual disabilities, but also the broader and increasingly diverse workforce that characterises the contemporary labour market. An ageing population, with more chronic conditions, rising incidences of mental health issues (ten Have et al., 2023), and a growing number of employees who have to balance work with caregiving responsibilities (Roeters et al., 2021) all necessitate more tailored support and flexible working conditions (UN Convention, 2006; Scopetta et al., 2019). Organisations must proactively understand and respond to the needs of all employees, irrespective of their disability status (Beattie et al., 2019). Managers have a pivotal role to play in terms of initiating open discussions about employees' needs, facilitating conversations about diversity within their teams, and adapting behavioural norms, where necessary, from a commitment to, and belief in, the power of diversity (Nair & Vohra, 2015; Wasserman et al., 2007). A culture that values individual differences and facilitates dialogue can significantly enhance overall employability, performance and inclusion, which is a lesson that appears to be wholly misunderstood within the contemporary political climate.

Targeted support for workers with intellectual disabilities

Whilst fostering an inclusive climate for all workers is crucial, targeted attention for individuals with intellectual and other disabilities is also necessary, given that this group is often overlooked in diversity initiatives that tend to prioritise race, gender, or sexual orientation (Garg & Sanwan, 2021; Lindsay et al., 2023; Nair & Vohra, 2015). Organisations that have formal disability hiring policies – particularly those that include training for colleagues – are more likely to successfully employ and support workers with disabilities (Beatty et al., 2019). Therefore, involving individuals with intellectual disabilities in the development of these policies could help to further strengthen their impact.

Inclusive hiring could be reinforced by engaging those managers and co-workers who demonstrate a personal commitment towards diversity and inclusion (Boccalandro, 2021). Such involvement often enhances job satisfaction and fosters a sense of purpose. Managers can also facilitate social integration by organising shared activities and ensuring that workplace accommodations are clearly communicated so as to avoid any perceptions of unfair treatment (Stone & Colella, 1996; Carmen Triana et al., 2021).

Furthermore, implementing inclusive policies that benefit all employees —such as flexible working arrangements — could also help to normalise individualised support and reduce stigma. HR professionals have a vital role to play in terms of promoting inclusion by both emphasising the strengths of workers with intellectual disabilities and facilitating their advancement within organisations. Publicising the achievements of individuals within higher-level positions can also help to counter stereotypes and promote broader acceptance (Fitzpatrick et al., 2022). Larger organisations may benefit from appointing dedicated disability inclusion officers (Beattie et al., 2019), whilst smaller companies could access support via regional partnerships that share best practices and resources (Lewis & Dijkema, 2022).

Ensuring ongoing employment support

Sustainable employment for people with intellectual disabilities often requires continued access to individualised support, which is typically provided by job coaches (Ellenkamp et al., 2015; Morris et al., 2024; Vornholt et al., 2018). Job coaches often implement the supported employment model, which has proven to be effective in terms of helping individuals discover their strengths and interests, secure meaningful jobs, and maintain long-term employment via on-the-job support and using workers' networks (Duyvestein, 2012). Successful job coaches not only assist people with intellectual disabilities but also support employers and facilitate positive employer–employee relationships (Vornholt et al., 2018). This is especially beneficial for smaller businesses that lack the internal capacity for such services. Whilst the impact of programmes grounded in the supported employment model is difficult to quantify, their practical benefits have been widely recognised, especially when support services for people with intellectual disabilities are also involved in the implementation (Lewis & Dijkema, 2022). Although the goal is to gradually shift support responsibilities onto natural workplace resources, consistent funding from national and municipal governments is necessary to ensure accessibility to external support if and when needed (Morris et al., 2024).

An extension of the supported employment model is the individual placement and support (IPS) approach, which was originally developed for individuals with severe mental health challenges (Baxter et al., 2024; Van Weeghel & Michon, 2017). IPS distinguishes itself by virtue of placing individuals within regular employment first, before then providing on-the-job training ('place then train'), and by fully integrating employment support with healthcare services (Michon & Van der Sanden, 2024). Although research into IPS for people with intellectual disabilities is limited, initial findings in the Netherlands appear to be promising. Adjustments are necessary, however, as implementation is more time-intensive and requires closer collaboration with formal and informal support networks. Further research is required to both validate and refine the IPS model for this particular population and explore its broader application within the Dutch context (Michon & Van der Sanden, 2024).

Towards policy and practice based on broad prosperity and contributive justice

Ensuring access to work for everyone, including individuals with intellectual disabilities, is essential within the broader framework of broad prosperity. Besides the individual benefits of meaningful work—as underscored throughout this thesis—a thriving and inclusive labour market is a key pillar of broad prosperity (Olsthoorn & Roeters, 2023; Tilburg University, 2023; Wilthagen & Stolp, 2021). The findings of this thesis point towards the need for substantial shifts within both policy and practice in order to realise contributive justice, that is, a society where all individuals can actively contribute through paid or unpaid work, rather than relying solely upon distributive justice (i.e., the provision of social benefits for those who find themselves excluded).

In order to achieve such justice, a secure and predictable system is needed for people with intellectual disabilities who wish to work. Legislation and procedures must be understandable and accessible — both for individuals and employers — and comprehensive support must be available throughout the employment process. These needs are in line with the recommendations of a recent UN review of the Netherlands' implementation of the UN Convention on the Rights of Persons with Disabilities (UN, 2024). Ongoing legislative reforms striving to build a more inclusive, future-proof labour market (Ministerie SZW, 2023; OCTAS, 2024) also offer a promising framework through which to meet these needs. Furthermore, this thesis confirms that whilst employers often express a genuine willingness to employ individuals with intellectual disabilities, they frequently encounter barriers and dilemmas in the process. The following proposed directions aim to support employers and strengthen contributive justice in practice: 1) Policies to Better Support Employers; 2) Measuring Wage Value from a Strengths-Based Approach; 3) A Reflection upon the Dutch Target Group Register; and 4) A Social Re-Evaluation of Unpaid Work.

Policies to better support employers

Employers are key gatekeepers of an inclusive labour market (Salado-Rasmussen & Bredgaard, 2020; OCTAS, 2024). Whilst the UN recommends stronger policies to help force the hiring of people with disabilities (UN, 2024), this thesis indicates that there is a willingness amongst employers to be inclusive. Therefore, rather than coercive measures, it is recommended to introduce a more supportive approach that empowers employers with knowledge, tools, and resources.

In addition to simplifying legislation (Ministerie SZW, 2023; OCTAS, 2024), governments and municipalities can also improve employers' awareness of the available support. Employment specialists, for example, can assist employers in both navigating regulations and implementing inclusive hiring practices. Municipalities and provinces could also establish regional networks where employers share best practices and support each other. One example in this regard is *Brabants Besten* (Brabants Bests) in the province of North Brabant, The Netherlands. Crucially, government funding must ensure sustained access to job coaching and tailored employment support for both organisations and employees (Morris et al., 2024).

Measuring wage value from a strengths-based approach

Although wage value assessments within the Netherlands are formally conducted by labour experts, the employers who participated in this thesis reported experiencing challenges with the current system that is used to determine the wage value of workers with intellectual disabilities. Specifically, they reported that the assessed wage value often did not align with their own – typically more positive – perception of the worker's contribution, which in some cases negatively affected the worker's self-esteem and well-being. One reason for this is that these assessments tend to rely heavily upon quantitative criteria, such as work pace, hours, and productivity, whilst potentially overlooking other relevant qualities and contributions.

It may therefore be valuable to reflect upon the current system and explore ways to improve it. This could include better integration of input from various stakeholders – including both employers and workers – and the development of more collaborative methods of assessment (Vornholt et al., 2018). Furthermore, there could be greater recognition of employers' qualitative experiences as well as the broader value that individuals bring to the workplace. Such a shift would align well with the aforementioned recommendation to focus upon individuals' capacities rather than their limitations when describing their work potential (Vornholt et al., 2018), as well as the implementation of a strengths-based approach within organisations (Pulla, 2017).

A reflection upon the dutch target group register

Although Dutch legislative reforms aim to shift the focus onto people's strengths and capacities (Ministry of Social Affairs and Employment, 2023; OCTAS, 2024), access to disability-related employment support continues to be determined by impairment-based criteria within the so-called *target group register*. This model is rooted in the medical paradigm and may hinder participation by emphasising limitations over potential (Lewis & Dijkema, 2022). This also echoes the UN review (2024) that criticises the predominance of the medical model and the use of the term 'occupational disability' within current Dutch legislation and proposes to make appropriate reference to people with disabilities. The register, although intended to increase employment, can in fact reinforce stigma, create unequal pay, and limit professional development. It may also exclude those with mild impairments, by making them less appealing to employers and restricting their opportunities (Borghouts & Freese, 2022). A national debate is therefore warranted to reconsider this system. Engaging a diverse range of stakeholders—including people with disabilities, family members, policymakers, professionals, and researchers—can help guide reforms towards a more inclusive, capacity-oriented model. Importantly, any new system must allow for tailored support, in recognition of the fact that different disabilities may require different approaches (Lewis & Dijkema, 2022).

A social re-evaluation of unpaid work

This thesis also underscores the significant personal benefits that unpaid work can provide to people with intellectual disabilities. Specifically, work can help enhance their self-esteem, dignity and social capital providing them with a sense of being a valued community member (Dearing, 2021). However, paid work may not always be feasible or desirable, and in some cases, people with intellectual disabilities and their networks prefer that they engage in segregated or unpaid roles due to lower pressure and expectations about their performance. Unpaid work can also function as a developmental pathway — helping individuals discover and grow their talents — and help people with intellectual disabilities to contribute meaningfully to society (e.g., within childcare or informal care). Ultimately, then, addressing labour shortages calls for inclusive policies that support participation within both paid and unpaid roles (Olsthoorn & Roeters, 2023).

Currently, our meritocratic society tends to undervalue unpaid work, often framing it as a failure of the labour market (Dearing, 2021). A cultural and policy shift is therefore needed to better value unpaid contributions, which would include making it easier to engage in unpaid work without fear of losing benefits (Olsthoorn & Roeters, 2023). However, it is important to stress that there is a fine line between unpaid contributions and exploitation. This is especially important given that research has shown that individuals with intellectual disabilities often perceive unpaid roles as full employment (McGlinchey et al., 2013). Whilst this suggests that not everyone prioritises monetary compensation, it also raises concerns, especially given the history of underpaid or unpaid sheltered employment. In order to prevent exploitation, there must be greater financial recognition for the contributions of people with intellectual disabilities — on an equal footing with others (Dearing, 2021; Lewis & Dijkema, 2022). A robust, predictable social safety net is also essential for mitigating fears over benefit reductions. Ultimately, a broader political and societal debate is needed to shape a vision of a future society in which both paid and unpaid work are valued and accessible for all (Olsthoorn & Roeters, 2023).

In conclusion

Participation within meaningful work that is fully integrated into society is vital for the well-being of people with intellectual disabilities and their wider social environment. From a societal perspective, such participation is equally important within the broader context of *broad prosperity* and challenges within the contemporary labour market — including those posed by ageing populations, robotisation, and artificial intelligence. Meaningful work should not be regarded merely as a means to an end, but rather as an end in itself, that is, as a foundational element of well-being and a thriving, inclusive society.

Nonetheless, multiple societal and systemic barriers continue to hinder access to meaningful work for people with intellectual disabilities, including persistent stigma from co-workers and customers, competitive societal norms that set unrealistic expectations, and policy and legislation that reinforce exclusion. Addressing these challenges requires both broad social reform and targeted changes to legislation and regulations related to work participation. Additional support is also required for employers who are often motivated to hire inclusively but encounter significant practical and regulatory obstacles to doing so in practice.

Fostering inclusion within the labour market calls for a shift in attitudes, behaviours, and structures across every level of society. More specifically, it demands greater solidarity and adaptability — from relatives, employers, co-workers, customers, and citizens alike — not only to recognise the talents of people with intellectual disabilities, but also to make efforts to transform these into social value. One meaningful step towards this shift is to adopt more inclusive and empowering language. That is to say, rather than referring to 'people with disabilities' or 'people at a distance from the labour market', using terms like *workers with additional support needs*—as used in Chapters 5 and 6—can help to reframe how we view talent, contribution, and social value.

The challenges of the contemporary labour market present a unique opportunity for transformation. Demographic trends and persistent workforce shortages can serve as a catalyst for real change. Realising a form of contributive justice, where every individual can contribute meaningfully through either paid or unpaid work, will require ambitious policy and practice reforms. Key areas of focus should include rethinking wage value assessments, revisiting eligibility criteria tied to the current Dutch target group register, and re-evaluating the social value of unpaid work. Crucially, national and local governments should invest in sustained and practical support for employers, who serve as gatekeepers of an inclusive labour market. Continuous access to job coaches can make a significant difference in enabling sustainable inclusive hiring practices.These reforms are not only essential for improving the labour market position of people with intellectual disabilities, but they also are vital for building a future-proof, inclusive labour market within which every individual in the Netherlands can participate in a way that is meaningful, valued, and sustainable.

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Appendices

Scientific summary

Wetenschappelijke samenvatting

Public summary

Publiekssamenvatting

Easy to read summary

Makkelijk lezen samenvatting

Dankwoord (aknowledgements)

Curriculum Vitae

Publications

SCIENTIFIC SUMMARY

Chapter 1

Meaningful work for people with intellectual disabilities, the research topic of this thesis, is introduced within a historical, social, and scientific context. Meaningful work is defined as activities that create valuable goods, which individuals can enjoy and to which they attribute a sense of dignity. Throughout the thesis, we use the term people with intellectual disabilities, even though the two final studies involve a broader group of people with disabilities.

Work and its meaning for people

Over recent decades, the meaning of work has evolved from a purely economic necessity to a life domain that contributes to quality of life, identity and social participation. Access to work is now considered a key element of the concept of ‘broad prosperity’, which views wellbeing from a holistic perspective, in contrast to traditional economic definitions. Scientific research shows that participation in meaningful work positively affects people's happiness and health, whereas the absence of work is linked to adverse physical and mental health outcomes.

Work for people with intellectual disabilities

The social position of people with intellectual disabilities has changed significantly in recent decades, driven by the recognition of citizenship rights, the deinstitutionalisation movement and the shift from work in sheltered settings to -supported- workplaces within society. Today, people with intellectual disabilities work in a range of environments: from fully integrated work in mainstream companies to sheltered settings such as day programs and sheltered workshops. Research suggests that integrated work can benefit physical and mental health and quality of life of people with intellectual disabilities, although findings are not always consistent. There is limited research on the impact of losing meaningful work or experiencing unemployment among this group. Inclusion can also benefit employers—for example by fostering an inclusive work culture. Nonetheless, relatively few people with intellectual disabilities work in mainstream companies, partly due to practical challenges in creating suitable work environments.

Ongoing challenges in realising work for people with intellectual disabilities

To promote labour market inclusion, various Western countries have implemented targeted policies, such as the Dutch Participation Act, which aims to create more jobs for people with disabilities. However, international statistics consistently show that the participation of people with intellectual disabilities in integrated work lags behind. This represents a waste of talent—especially in the light of current labour shortages. Although more employers are adopting inclusion strategies, influencing their hiring behaviour remains challenging. Research has indicated several factors linked to inclusive employment, but the role of employer perceptions of the customer perspective in the hiring and retention of people with disabilities in underexplored. Since customers are crucial to businesses, this factor warrants further investigation. In addition, social barriers, such as stigma, limited social networks and increased societal complexity hinder labour market inclusion of people with intellectual disabilities.

Research approach and objectives

This thesis adopts a contextual approach, drawing on Bronfenbrenner’s ecological systems theory, to understand how individual, interpersonal, and community-related factors interact in realising meaningful work for people with intellectual disabilities. The research aims to gain a more nuanced understanding of 1) the meaning of work for people with intellectual disabilities, and 2) the conditions required to enable meaningful work for this group. Multiple studies explore the perspectives of key stakeholders: individuals with intellectual disabilities themselves, their relatives, and employers. Chapter 2 examines the perspective of people with intellectual disabilities who participate in regular, paid work. Chapter 3 examines the perspective of people with intellectual disabilities who lost a majority or all of their work activities during the COVID-19 pandemic. Chapter 4 describes a systematic literature study on how relatives of people with intellectual disabilities view the meaning of and preconditions for work for people with intellectual disabilities. Chapter 5 describes a study that explores how the customer perspective of employers plays a role in hiring and retaining workers with additional support needs. Chapter 6 examines the role of the customer perspective in hiring and retaining workers with additional support needs within a larger group of employers. In order to avoid stigmatising attitudes among employers and as employers in practice are often unaware of their workers’ diagnoses, these last two studies chose to look at a broader group of workers with additional support needs than just people with intellectual disabilities. Finally, Chapter 7 reflects on the research results and the research itself, and describes implications for policy and practice.

Chapter 2

This chapter describes a study that explored the meaning of participation in regular, paid work for people with mild intellectual disabilities. Six people with a mild intellectual disability or borderline functioning who had a paid job in a mainstream company were interviewed. Their experiences were analysed using the qualitative research method ‘Interpretative Phenomenological Analysis’. A second interview was conducted with the participants to check the researchers’ interpretations and to further explore information from the initial interview.

First, the results of the study revealed that positive and negative life experiences influenced the current working life of people with intellectual disabilities and their future wishes. These experiences helped them discover what kind of work they wanted to do, what competencies they had and what preconditions they needed in their work environment. Secondly, people with intellectual disabilities had challenges in their work environment, such as stigmatising attitudes among people without intellectual disabilities. They responded to these attitudes in different ways, which had both positive and negative consequences for their work situation and career. Also, they indicated that they sometimes felt dependent to different people or authorities, such as employers or employment agencies, and that they needed a work atmosphere characterised by equality. Such an atmosphere gave them a pleasant and safe feeling, which allowed them to do their work properly. Finally, people with intellectual disabilities experienced that participation in paid work enabled them to fully participate in society. Paid work made them feel useful, as they could add value to the company or could be of significance to others (e.g. customers). In addition, they experienced work as an important way to spend their time and feared emptiness in their lives without work. Paid work offered people with intellectual disabilities a normal place in society, which made them feel less like an exception. Paid work among co-workers without intellectual disabilities gave some of the participants the opportunity to distinguish themselves from other people with intellectual disabilities.

The study shows that participation in paid work can make an important contribution to a sense of community for people with intellectual disabilities and to their quality of life. However, they regularly encounter obstacles, such as feelings of dependency or stigmatising attitudes from others in their work environment.

Chapter 3

This chapter describes a study that explored how people with intellectual disabilities experienced their daily lives during the Covid-19 pandemic, in particular with regard to a lack of work activities. Eight people with a mild intellectual disability or borderline functioning who had lost their work activities completely or partially for a longer period of time during the Covid-19 pandemic were interviewed. The interviews were qualitatively analysed using the method 'Interpretative Phenomenological Analysis'.

The results of the study showed that people with intellectual disabilities experienced a prolonged lack of social connections with people in their lives due to the social restrictions and lack of work activities, resulting in experiences of social isolation and feelings of loneliness. The situation meant that people with intellectual disabilities had to rely more on themselves which led them to experience different kinds of personal struggles. Some participants experienced internal struggles, as the long-term social isolation and loneliness resulted in depressive feelings or negative thoughts. Other participants experienced that their autonomous position in society was threatened by the loss of work activities and the social restrictions. For example, because the measures for people in residential facilities were stricter than elsewhere in society. Sometimes participants were also (re)confronted with the stigma of having an intellectual disability. Meanwhile, the participants had difficulty to sustain their sense-of-selfworth, as a number of important aspects in their lives were no longer self-evident in the absence of work. For example, they suffered from the uncertain and unpredictable times and found it difficult to maintain hope and get through their empty days without purpose. In addition, they missed work-related opportunities to continue developing themselves (e.g. because they could not follow training) and to be of significance to others (e.g. due to the lack of contact with customers).

The results of this study show that people with intellectual disabilities attach great value upon meaningful work. The loss of this work activities, at a time when lockdowns and social restrictions were in force, appears to lead to feelings of loneliness and social isolation, which can negatively affect their well-being, mental health and their sense of participation in society.

Chapter 4

Given the important role of informal networks in the support of people with intellectual disabilities, also concerning work, the study in this chapter aimed to identify existing knowledge about how informal network members of people with intellectual disabilities perceive and experience the meaning of work or daytime activities for their relatives with an intellectual disability. A systematic literature review according to the PRISMA guideline was therefore conducted and 27 qualitative and mixed-methods studies were analysed using the research method ‘thematic synthesis’.

The results indicated that informal network members considered work to be important for their relatives with intellectual disabilities, suited to their wishes, needs and skills. There was a need for more suitable workplaces for people with intellectual disabilities in society and appropriate support in finding and maintaining suitable work. Informal network members felt a continuous need to collaborate and share care responsibilities with professionals (such as support staff and job coaches) in maintaining meaningful work and believed that the continued involvement of professionals (such as job coaches) was important to create a sustainable work situation. Close cooperation between informal network members and professionals was perceived to be important in finding and maintaining work. For several reasons, informal network members attached great value upon work for their relatives with intellectual disabilities: It was perceived to contribute to routine and purpose in life, personal development and self-confidence, social connections with others and a valued and autonomous position in society. Finally, informal network members experienced that realising meaningful work in society for their relatives was not self-evident and took sometimes a lot of effort, partly due to stigma in legislation and attitudes of others, such as employers. Although many informal network members preferred integrated work, some of them also feared exclusion or exploitation. Specifically, there were concerns about cuts to benefits and financial risks associated with accepting paid work.

In conclusion, informal network members attach great value upon meaningful work for their relatives with intellectual disabilities, particularly to work among co-workers without intellectual disabilities. The balance between protection and promoting autonomy is a point of attention in the support of people with intellectual disabilities and a continuous search. Informal network members experienced stigmatisation of their relatives with intellectual disabilities in society, in legislation and policy, hindering full work participation and autonomy.

Chapter 5

This chapter describes an explorative study that aimed to initially explore to what extent the customer perspective of employers plays a role in hiring and retaining workers with additional support needs, such as people with intellectual or physical disabilities or people with mental illnesses. Two companies (a supermarket and a hospitality company) were studied as two cases, both with extensive experience in deploying workers with additional support needs. Participatory observations were conducted in workplaces, team leads were interviewed and public information was collected trough company websites and social media channels. The case studies were analysed using reflexive thematic analysis.

The results show that customer-related factors played a role in the decisions of the participating companies regarding the deployment of workers with additional support needs, which could pose dilemmas. The companies sometimes had to balance between their inclusive ideals, commercial goals and the expectations of customers, for example since workers with additional support needs could not always meet customers' expectations. Another dilemma was whether or not to proactively inform customers about the deployment of these workers, as they sought to avoid this based on normalisation principles, but at the same time realised that not informing customers could lead to undesirable situations and customer dissatisfaction. The companies applied a tailored approach when deploying workers with additional support needs in customer facing contexts, dependent on the type of customer interactions in a given context and the competencies of the worker, such as stress resistance. In addition, familiarity with co-workers and customers in the work environment seemed to contribute to the sustainable employability of workers with additional support needs. However, offering tailored support and creating an inclusive climate within the company required attention and was sometimes a challenge, for example due to the required knowledge among co-workers.

The results indicate that the participating employers experienced benefits of employing workers with additional support needs. However, they also encountered customer-related dilemmas and challenges in the implementation of an inclusive climate at multiple levels within their company.

Chapter 6

This chapter describes a study that also explored the perspective of employers: Specifically how their customer perspective was related to decisions to hire and retain workers with additional support needs and how they dealt with customer-related dilemmas. Two focus group interviews were conducted with a variety of employers facing direct customer interactions. Team leads of workers with additional support needs were interviewed, as well as employees involved in inclusion policies and strategies, such as HR advisors. The focus group interviews were analysed using reflexive thematic analysis.

The study found that employers took their customer perspective into account when deciding whether to employ workers with additional support needs. They considered demand-driven matching strategies -adapting work to the wishes and needs of the worker- to be crucial in creating a suitable working environment for workers with additional support needs with appropriate customer interactions. In addition, they experienced that customer interactions required additional attention when the complexity of interactions increased. They also encountered dilemmas regarding managing stigmatising attitudes and behaviour of customers. They experienced that knowledge among customers about the support needs of workers could contribute to understanding, but could at the same time reinforce stigmatisation. The visibility of a worker’s disability seemed to play an important role. Employers mostly involved customers in their inclusive vision in a generic way and tried to prevent exceptional positions of workers with additional support needs. In addition, employers experienced it as challenging to create a working environment tailored to the needs of workers, as it was sometimes difficult to frame work tasks and create the right preconditions, such as a permanent supervisor. Finally, it was experienced as complicated to create an inclusive climate within organisations, due to resistance and stigmatising attitudes among co-workers. Employers experienced personal motivation of themselves and co-workers as a key facilitator in achieving an inclusive climate.

In summary, this study shows that employers take customer expectations and interactions into account when deploying workers with additional support needs, whereby the service orientation, the commercial objectives and the core values of an organisation also seem to play a role. The dilemmas that employers experience in managing customer reactions and creating an inclusive work environment demonstrate that it is complicated to pursue both normalisation and customisation and that sustainably creating an inclusive work environment – especially in customer-facing contexts– is a nuanced process.

Chapter 7

The discussion section of the thesis provides an overview and reflection on the research findings, as well as suggestions for future research and implications for policy and practice.

Main Findings

In order to understand the findings of the study from different perspectives and within various contexts, the results are organised according to Bronfenbrenner's model. The benefits of meaningful work, as well as the necessary conditions and barriers to creating meaningful work, are described at various levels.

- *Individual level*: Meaningful work provides structure, purpose, personal growth, and a sense of self-worth for people with intellectual disabilities. Work that aligns with personal wishes and needs is essential, as well as opportunities to gain diverse work experiences. Loss of work (such as during the COVID-19 pandemic) can lead to feelings of emptiness, loneliness, depressive symptoms, and mental health problems.
- *Micro level* (direct environment): Meaningful work fosters social contacts and a sense of fulfilling a valued social role. Key conditions include equal treatment, tailored support, a stable work environment, involved supervisors, and a positive work atmosphere. Stigma and negative expectations from co-workers and supervisors act as barriers. Employers face dilemmas regarding customer interactions and providing tailored support.
- *Meso level* (organisation): Demand-driven matching, availability of job coaches, and collaboration between employers, professionals, and relatives are experienced as necessary conditions. A lack of suitable jobs and support are perceived as barriers.
- *Exo level* (organisational policy and external context): An inclusive vision and policy that is embraced at all organisational levels is essential. Within organisations, inclusive policy and commercial interests can sometimes conflict. Employers also struggle with how to profile themselves as inclusive organisations without stigmatising workers with intellectual disabilities.
- *Macro level* (society and policy): Results indicate that meaningful work enhances social connectedness of people with intellectual disabilities and grants them an autonomous position in society. Stigma and negative societal attitudes remain significant barriers.

Reflection on the findings

The research highlights the significance of meaningful work for people with intellectual disabilities: personal growth, self-worth and social meaning. These aspects mirror the meaning of work in the general population, but are often more difficult to reach for people with intellectual disabilities. The loss of work has a significant impact on them due to their limited alternatives and greater vulnerability.

The results of this thesis show that several conditions are important to achieving meaningful work for people with intellectual disabilities. An important condition is the application of demand-driven matching to tailor work to the wishes, talents, and abilities of the individual with an intellectual disability. In practice, however, employers often continue to focus on filling existing vacancies. In addition, customised support is essential to ensure sustainable employment. A key dilemma is the tension between equal treatment and necessary adjustments: too much emphasis on equality can undermine support, while too much emphasis on differences can reinforce stigma. A strength-based approach may help balance this.

Several societal frictions undermine meaningful work for people with intellectual disabilities. Stigmatisation is an important barrier in various forms. It involves public stigma, for example when co-workers and customers doubt the competences of people with intellectual disabilities. It involves structural stigma, embedded in legislation that is discouraging for employers as well as people with intellectual disabilities and their relatives. In addition, it involves self-stigma and courtesy stigma, where people with intellectual disabilities and their relatives may distance themselves from the group to avoid negative labeling. Additionally, employers face challenges in creating an inclusive climate and struggle with how to involve customers in their inclusive strategies. Finally, people with intellectual disabilities often face difficulties fulfilling a valued role in our performance-driven society where paid work is the norm, but not desirable or achievable for everyone, and unpaid work undervalued.

Strengths and limitations of the research

Strengths of the research include the rich qualitative approach (interviews, focus groups, observations) and the emphasis on the voices of people with intellectual disabilities themselves in two studies, providing contextual, experience-based knowledge. The involvement of networks and employers also yielded valuable insights. However, the perspectives of other stakeholders, such as siblings, job coaches, and policymakers, were not included in the research. The results of this research emphasise the importance of the involvement of job coaches as well as barriers in policy and legislation. Therefore, the perspectives of particularly job coaches and policy are essential in future research. In addition, the generalizability of the employer studies is limited, given their small-scale nature. Future research needs to be larger in scale and multidisciplinary, with a focus on the role of legislation and regulations in promoting labour inclusion, stigma interventions, and the specific experiences of employers and customers regarding the employment of people with intellectual disabilities.

Implications for policy and practice

To improve access to the labour market for people with intellectual disabilities, it is important to apply demand-driven matching strategies from a strength-based perspective. This means focusing on a person's qualities rather than their limitations. Job carving -creating job positions based on an individual's talents, needs and interests- can also be used as a strategy to better align positions to people with intellectual disabilities. Furthermore, addressing stigma is important. Although combatting stigma is complicated, creating positive encounters between employers and people with intellectual disabilities can be helpful.

For sustainable social inclusion within organisations, it is essential to foster an inclusive work climate for all employees by valuing and openly discussing individual differences. At the same time, targeted policies must continue to support the inclusion and needs of workers with intellectual disabilities. Continuous availability of and access to job coaching is key.

Finally, it is important to create a society in which everyone can participate in the labour market and contribute, including through unpaid work. It is therefore essential to take measures that support employers in hiring people with intellectual disabilities. A critical reflection on current policy is needed, to ensure that people are assessed on their qualities rather than their limitations, that unpaid work is better valued, and that people can retain their livelihood security and benefits when performing unpaid work.

In conclusion

Access to meaningful work can make a significant contribution to the personal wellbeing of people with intellectual disabilities as well as for society as a whole. It provides autonomy, social value, and purpose to life. At the same time, barriers exist at all levels—from the individual to policy—particularly due to stigma, meritocratic norms, and obstructive legislation.

Promoting an inclusive labour market requires a shift in attitudes, behaviours, and structures across all levels of society. The current labour shortages provide unique opportunities for inclusive reforms. With targeted employer support, broad reflection on legislation and regulations, and societal revaluation of work (both paid and unpaid), the Netherlands can take steps toward an inclusive labour market in which everyone can contribute.

WETENSCHAPPELIJKE SAMENVATTING

Hoofdstuk 1

Betekenisvol werk voor mensen met een verstandelijke beperking, het onderzoeksthema van dit proefschrift, wordt in de inleiding binnen een historische, maatschappelijke en wetenschappelijke context geplaatst. Betekenisvol werk wordt gedefinieerd als activiteiten die waardevolle goederen creëren waarvan iemand kan genieten en waaraan de betreffende persoon een positieve waardigheid verbindt. Over het gehele proefschrift gebruiken we de term ‘mensen met een verstandelijke beperking’, ondanks dat in de laatste twee studies een bredere groep mensen met beperkingen wordt onderzocht.

De betekenis van werk

De betekenis van werk is in de afgelopen decennia geëvolueerd van een puur economische noodzaak tot een levensdomein dat bijdraagt aan kwaliteit van leven, identiteit en sociale participatie. Toegang tot werk wordt nu als een belangrijk aspect gezien van het concept ‘brede welvaart’, dat welvaart vanuit een holistisch perspectief beschouwt in tegenstelling tot de traditioneel economische definitie. Wetenschappelijk onderzoek laat zien dat deelname aan betekenisvol werk een positieve invloed heeft op het geluk en de gezondheid van mensen, terwijl een gebrek aan werk negatieve effecten heeft op de fysieke en mentale gezondheid.

Werk voor mensen met een verstandelijke beperking

De maatschappelijke positie van mensen met een verstandelijke beperking is fors veranderd in de afgelopen decennia door de erkenning van het recht op burgerschap, de deïnstitutionalisatie en de verplaatsing van werk in beschermde settingen naar -al dan niet begeleide- werkplekken in de maatschappij. Mensen met een verstandelijke beperking werken in verschillende settingen: van volledig geïntegreerd werk binnen reguliere bedrijven tot aan beschermde settingen, zoals dagbesteding en sociale werkplaatsen. Resultaten van wetenschappelijk onderzoek suggereren dat geïntegreerde werkplekken een gunstig effect hebben op de fysieke en mentale gezondheid en kwaliteit van leven van mensen met een verstandelijke beperking, maar zijn niet eenduidig. Er is nog weinig onderzoek gedaan naar de impact van het verlies van betekenisvol werk of werkloosheid op mensen met een verstandelijke beperking. Ook voor werkgevers kan inclusie van mensen met een verstandelijke beperking voordelen bieden, bijvoorbeeld omdat het bijdraagt aan een positieve werkcultuur. Toch zijn er nog relatief weinig mensen met een verstandelijke beperking die binnen reguliere bedrijven werken, mede door praktische uitdagingen in het creëren van passende werkomgevingen.

Het realiseren van geïntegreerd werk voor mensen met een verstandelijke beperking

Om arbeidsinclusie te realiseren is er in verschillende Westerse landen specifiek beleid geïmplementeerd, zoals de Participatiewet in Nederland die beoogt meer banen te creëren voor mensen met een beperking. Internationale cijfers laten echter zien dat de participatie van mensen met een verstandelijke beperking in geïntegreerd werk achter blijft. Dit leidt tot een verspilling van talent, zeker gezien de huidige personeelstekorten. Hoewel steeds meer werkgevers inclusiestrategieën implementeren, blijft het lastig hun gedrag te beïnvloeden. Wetenschappelijk onderzoek heeft verschillende factoren geïdentificeerd die gerelateerd zijn aan inclusief werkgeverschap, maar de rol van het klantperspectief van werkgevers bij het inhuren van mensen met een beperking is een onderbelichte factor in onderzoek. Omdat klanten van cruciaal belang zijn voor bedrijven is het van belang deze factor verder te onderzoeken. Daarnaast bemoeilijken sociale factoren, zoals stigma, beperkte sociale netwerken en de toenemende maatschappelijke complexiteit de inclusie van mensen met een verstandelijke beperking op de arbeidsmarkt.

Benadering en doel van het onderzoek

Dit proefschrift hanteert een contextuele benadering, gebaseerd op Bronfenbrenner’s ecologische systeemtheorie, om de verwevenheid van individuele, interpersoonlijke en meer maatschappelijke factoren op het realiseren van betekenisvol werk voor mensen met een verstandelijke beperking te begrijpen. Het onderzoek beoogt een meer genuanceerd begrip te krijgen van 1) de betekenis van werk voor mensen met een verstandelijke beperking en 2) de randvoorwaarden voor betekenisvol werk voor mensen met een verstandelijke beperking. In verschillende studies worden de perspectieven van belanghebbende betrokkenen onderzocht: mensen met een verstandelijke beperking zelf, hun naasten en werkgevers. In hoofdstuk 2 wordt het perspectief van mensen met een verstandelijke beperking onderzocht die deelnemen aan regulier, betaald werk. In hoofdstuk 3 wordt het perspectief van mensen met een verstandelijke beperking onderzocht die hun werkactiviteiten gedurende de Covid-19 pandemie grotendeels of volledig verloren. Hoofdstuk 4 beschrijft een literatuurstudie naar hoe naasten van mensen met een verstandelijke beperking de betekenis van en randvoorwaarden voor werk voor mensen met een verstandelijke beperking beschouwen. In hoofdstuk 5 wordt een studie beschreven die exploreert hoe het klantperspectief van werkgevers een rol speelt in het aannemen en behouden van werknemers met extra ondersteuningsbehoeften.

In hoofdstuk 6 wordt binnen een grotere groep van werkgevers de rol van het klantperspectief onderzocht bij het aannemen en behouden van werknemers met extra ondersteuningsbehoeften. Om stigmatiserende attitudes bij werkgevers te vermijden en omdat werkgevers in de praktijk meestal niet specifiek op de hoogte zijn van de diagnoses van hun werknemers, is ervoor gekozen in deze laatste twee studies naar een bredere groep werknemers met extra ondersteuningsbehoeften te kijken dan enkel mensen met een verstandelijke beperking. In hoofdstuk 7 volgt tenslotte een reflectie op de onderzoeksresultaten en het onderzoek zelf en worden implicaties voor beleid en praktijk beschreven.

Hoofdstuk 2

In dit hoofdstuk wordt een studie beschreven die in beeld bracht wat deelname aan regulier, betaald werk betekent voor mensen met een licht verstandelijke beperking. Voor het onderzoek zijn zes mensen met een lichte verstandelijke beperking of zwakbegaafd niveau van functioneren geïnterviewd, die een betaalde baan hadden in een regulier bedrijf. Hun ervaringen zijn geanalyseerd middels de kwalitatieve onderzoeksmethode ‘Interpretatieve Fenomenologische Analyse’. Er werd een tweede interview met de deelnemers gehouden om de interpretaties van de onderzoekers te checken en verdere verdieping van informatie uit het eerste interview.

Ten eerste lieten de resultaten van het onderzoek zien dat positieve en negatieve levenservaringen het huidige arbeidsleven van mensen met een verstandelijke beperking beïnvloedde evenals hun toekomstwensen. Deze ervaringen hielpen hen te ontdekken welk werk ze willen doen, over welke competenties ze beschikken en welke randvoorwaarden ze nodig hebben in hun werkomgeving. Ten tweede kwamen mensen met een verstandelijke beperking uitdagingen tegen in hun werkomgeving, zoals stigmatiserende attitudes bij mensen zonder verstandelijke beperking Zij reageerden daar verschillend op, wat zowel positieve als negatieve gevolgen had voor hun werksituatie en loopbaan. Ook voelden zij zich soms afhankelijk van verschillende personen of autoriteiten, zoals werkgevers of uitzendbureaus. Daarnaast vonden zij een werksfeer gekenmerkt door gelijkheid van belang, wat hen een prettig en veilig gevoel gaf waardoor zij hun werk naar behoren konden doen. Tenslotte ervaarden mensen met een verstandelijke beperking dat zij door betaald werk volwaardig konden deelnemen aan de samenleving. Betaald werk gaf hen het gevoel nuttig te zijn doordat ze waarde konden toevoegen aan het bedrijf of iets konden betekenen voor anderen (bv. klanten). Daarnaast zagen zij werk als een belangrijk middel om hun tijd te besteden en vreesden zij voor leegte in hun leven als zij geen werk zouden hebben. Betaald werk bood mensen met een verstandelijke beperking een gewone plaats in de samenleving, waardoor zij zich minder een uitzondering voelden. Betaald werk te midden van collega's zonder verstandelijke beperking gaf sommigen van hen de kans om zich te onderscheiden van andere mensen met een verstandelijke beperking.

De studie laat zien dat deelname aan betaald werk een belangrijke bijdrage kan leveren aan een gevoel van verbondenheid met de samenleving voor mensen met een verstandelijke beperking en aan hun kwaliteit van leven. Zij komen daarbij echter regelmatig obstakels tegen, zoals gevoelens van afhankelijkheid of stigmatiserende attitudes van anderen in hun werkomgeving.

Hoofdstuk 3

Dit hoofdstuk beschrijft een studie die onderzocht hoe mensen met een lichte verstandelijke beperking of zwakbegaafd niveau van functioneren hun dagelijks leven ervaarden gedurende de Covid-19 pandemie, in het bijzonder met betrekking tot het gebrek aan werk. Voor het onderzoek zijn acht mensen met een licht verstandelijke beperking of zwakbegaafd niveau van functioneren geïnterviewd die hun werk tijdens de Covid-19 pandemie voor langere tijd geheel of gedeeltelijk waren verloren. De interviews zijn kwalitatief geanalyseerd middels de methode 'Interpretatieve Fenomenologische Analyse.

De resultaten van de studie lieten zien dat mensen met een verstandelijke beperking - door de contactbeperkende maatregelen en het niet kunnen werken - een langdurig gebrek aan verbondenheid en contact met mensen in hun leven ervaren. Dit had soms een sociaal isolement en gevoelens van eenzaamheid tot gevolg. Door de situatie waren mensen met een verstandelijke beperking meer aangewezen op zichzelf. Ze ervaarden verschillende soorten persoonlijke worstelingen. Sommigen hadden vooral moeite met gevoelens in zichzelf. Het langdurige sociale isolement en de eenzaamheid leidde tot depressieve gevoelens of negatieve gedachten. Anderen ervaarden dat hun autonome positie in de samenleving werd bedreigd door het verlies van werk en de contactbeperkende maatregelen. Bijvoorbeeld omdat de maatregelen voor mensen in woonvoorzieningen strenger waren dan daarbuiten. Soms werden ze hierdoor ook (opnieuw) geconfronteerd met het stigma van het hebben van een verstandelijke beperking. Tegelijkertijd hadden mensen met een verstandelijke beperking moeite om hun gevoel van eigenwaarde in stand te houden, omdat een aantal belangrijke zaken in hun leven niet meer vanzelfsprekend waren zonder werk. Zo hadden ze last van de onzekere en onvoorspelbare tijd en vonden ze het moeilijk om hoop te houden en hun lege dagen door te komen zonder doel. Daarnaast misten ze aan werk gerelateerde kansen om zichzelf te blijven ontwikkelen (bijvoorbeeld omdat ze geen opleiding konden volgen) en om van betekenis te zijn voor anderen (bijvoorbeeld door het gebrek aan contact met klanten).

Resultaten van deze studie laten zien dat mensen met een verstandelijke beperking een belangrijke waarde toekennen aan werk. Het verlies van dit werk, in een tijd waarin lockdowns en contactbeperkende maatregelen van kracht waren, blijkt bij hen te kunnen leiden tot gevoelens van eenzaamheid en sociaal isolement. Dit kan gevolgen hebben voor hun welbevinden, mentale gezondheid én hun gevoel van deelname aan de samenleving.

Hoofdstuk 4

Omdat informele netwerken van mensen met een verstandelijke beperking een belangrijke rol spelen in de ondersteuning, ook met betrekking tot werk, werd in de studie die in dit hoofdstuk wordt beschreven de bestaande kennis in beeld gebracht over hoe informele netwerkleden van mensen met een verstandelijke beperking de betekenis van werk of dagbesteding voor hun naaste met een verstandelijke beperking beschouwen en ervaren. Dit werd gedaan middels een systematische literatuurreview volgens de PRISMA-richtlijn. Er werden 27 kwalitatieve en mixed-methods studies geanalyseerd middels de onderzoeksmethode ‘thematische synthese’.

Uit de resultaten bleek dat informele netwerkleden het creëren van passend werk van belang vonden voor hun naaste met een verstandelijke beperking, met diens wensen, behoeften en vaardigheden als uitgangspunt. Er was behoefte aan meer passende werkplekken voor mensen met een verstandelijke beperking in de samenleving en goede ondersteuning bij het vinden en behouden van passend werk. Informele netwerkleden voelden een voortdurende noodzaak om samen te werken en zorgtaken te delen met professionals (zoals begeleiders en jobcoaches) bij het vinden en behouden van passend werk en vonden het belangrijk dat professionals (zoals jobcoaches) langdurig betrokken konden blijven om een duurzame werksituatie te creëren. Goede afstemming en samenwerking tussen informele netwerkleden van mensen met een verstandelijke beperking en professionals werd als essentieel ervaren bij het vinden en behouden van passend werk. Echter verliep deze samenwerking niet altijd naar wens van de informele netwerkleden. Om verschillende redenen kenden informele netwerkleden een belangrijke waarde toe aan passend werk voor hun naaste met een verstandelijke beperking, omdat het bijdroeg aan routine en een doel in het leven, persoonlijke ontwikkeling en zelfverzekerdheid, sociale verbindingen met anderen en een gewaardeerde en autonome positie in de samenleving. Tenslotte ervaarden zij dat het realiseren van passend werk in de samenleving voor hun naaste niet vanzelfsprekend was en dat het soms veel inspanning kostte om dit te realiseren, mede door stigma in attitudes van anderen en wetgeving. Hoewel veel informele netwerkleden de voorkeur gaven aan reguliere werkplekken, bestond soms ook angst voor uitsluiting en uitbuiting. Specifiek waren zij bang voor korting op uitkeringen en financiële risico's bij het aanvaarden van betaald werk.

Concluderend kennen informele netwerkleden een belangrijke waarde toe aan passend werk voor hun naaste met een verstandelijke beperking, vooral aan werk te midden van collega's zonder verstandelijke beperking. Bij de ondersteuning is de balans tussen beschermen en autonomie bevorderen een aandachtspunt en een voortdurende zoektocht. Informele netwerkleden ervaren stigmatisering van hun naaste met een verstandelijke beperking in de maatschappij en in wetgeving en beleid, wat de volledige (arbeids)participatie en autonomie kan belemmeren.

Hoofdstuk 5

Dit hoofdstuk beschrijft een eerste exploratieve studie naar de rol van het klantperspectief van werkgevers bij het aannemen en behouden van werknemers met extra ondersteuningsbehoeften, zoals mensen met een verstandelijke of lichamelijke beperking of psychische problemen. Twee bedrijven (een supermarkt en een horecabedrijf) dienden als casus, beide met ruime ervaring in het werken met deze groep werknemers. We voerden participerende observaties uit op werkplekken, interviewden teamleiders en verzamelden publieke informatie via bedrijfswebsites en sociale mediakanalen. De gegevens zijn geanalyseerd met reflexieve thematische analyse.

De resultaten lieten zien dat aan de klant-gerelateerde factoren meespeelden bij keuzes van de deelnemende bedrijven betreft de inzet van werknemers met extra ondersteuningsbehoeften en dat dit dilemma's kon opleveren. De bedrijven balanceerden soms tussen hun inclusie idealen, commerciële doelen en de verwachtingen van klanten, bv. omdat werknemers met extra ondersteuningsbehoeften niet altijd konden voldoen aan de verwachtingen van klanten. Een ander dilemma was het al dan niet proactief informeren van klanten over de inzet van deze werknemers, omdat ze dit wilden vermijden vanuit normalisatie principes, maar tegelijkertijd ervaarden dat het niet informeren van klanten kon leiden tot ongewenste situaties en ontevredenheid van klanten.

De bedrijven hanteerden maatwerk bij de inzet van werknemers met extra ondersteuningsbehoeften in klantcontact, afhankelijk van het soort klantcontact in een context en de competenties van de medewerker, zoals stressbestendigheid. Daarnaast leek bekendheid en vertrouwdheid met collega's en klanten in de werkomgeving bij te dragen aan de duurzame inzetbaarheid van werknemers met extra ondersteuningsbehoeften. Echter, het bieden van passende begeleiding en het creëren van een inclusief klimaat binnen het bedrijf vroegen de nodige aandacht en waren soms een uitdaging, bv. vanwege de benodigde kennis bij collega's.

Op basis van de resultaten kan worden gezegd dat het tewerk stellen van werknemers met extra ondersteuningsbehoeften door de deelnemende werkgevers als voordelig werd ervaren Echter ervaarden zij ook klant-gerelateerde dilemma's en uitdagingen betreft de implementatie van een inclusief klimaat op meerdere lagen binnen een bedrijf.

Hoofdstuk 6

In dit hoofdstuk wordt een studie beschreven die eveneens het perspectief van werkgevers onderzocht: specifiek hoe hun klantperspectief de keuze om werknemers met extra ondersteuningsbehoeften in dienst te nemen en te houden beïnvloedde en hoe zij omgingen met klant-gerelateerde dilemma's. Er werden twee focusgroep interviews gehouden met diverse werkgevers die te maken hadden met direct klantcontact. Teamleiders van werknemers met extra ondersteuningsbehoeften werden geïnterviewd, evenals werknemers die betrokken waren bij inclusiebeleid en strategieën, zoals HR-adviseurs. De focusgroep data werden geanalyseerd middels reflexieve thematische analyse.

De studie liet zien dat werkgevers hun klantperspectief meewogen bij de beslissing om mensen met extra ondersteuningsbehoeften al dan niet in te zetten. Vraaggerichte matching - het aanpassen van werk aan de wensen en competenties van de werknemer- vonden zij daarbij van groot belang om een passende werkomgeving met passende interacties met klanten te creëren voor mensen met extra ondersteuningsbehoeften. Daarnaast ervaarden ze dat klantinteracties extra aandacht vroegen wanneer de complexiteit van het klantcontact toenam. Ze kwamen daarnaast dilemma's tegen met betrekking tot het omgaan met stigmatiserende attituden en gedrag van klanten. Ze ervaarden daarbij dat kennis bij klanten over de ondersteuningsbehoeften van werknemers kon bijdragen aan begrip, maar tegelijkertijd ook stigmatisering kon versterken. De zichtbaarheid van de beperking bij de werknemer leek daarbij een belangrijke rol te spelen.

Werkgevers namen klanten over het algemeen op een generieke manier mee in hun inclusieve visie en probeerden uitzonderingsposities van werknemers met extra ondersteuningsbehoeften te voorkomen. Daarnaast ervaarden werkgevers het als uitdagend om een aangepast en op maat gesneden werkomgeving te creëren voor deze werknemers, doordat het soms moeilijk was de werkzaamheden te kaderen en de juiste randvoorwaarden te creëren, zoals een vaste supervisor. Tenslotte werd het als ingewikkeld ervaren om een inclusief klimaat binnen hun organisatie te creëren, vanwege weerstand en stigmatiserende attitudes bij collega's. Werkgevers ervaarden daarbij persoonlijke motivatie van henzelf en collega's als een vooraanstaande faciliterende factor om een inclusief klimaat te bereiken.

Samengevat laat deze studie zien dat werkgevers klantverwachtingen en klantcontact meewegen bij de plaatsing van werknemers met extra ondersteuningsbehoeften, waarbij ook de servicegerichtheid, de mate van commercialiteit en de kernwaarden van een werkgever een rol leken te spelen. De dilemma's die werkgevers ervaren in het omgaan met reacties van klanten en het creëren van een inclusieve werkomgeving laten zien dat het ingewikkeld is om tegelijkertijd normalisatie en maatwerk in begeleiding na te streven en dat het duurzaam creëren van een inclusieve werkomgeving –vooral in situaties met direct klantcontact– een genuanceerd proces is.

Hoofdstuk 7

Tenslotte wordt in de discussie van het proefschrift een overzicht en reflectie gegeven van de bevindingen van het onderzoek en worden suggesties gedaan voor toekomstig onderzoek en implicaties voor beleid en praktijk.

Belangrijkste bevindingen

Om de bevindingen van het onderzoek vanuit verschillende perspectieven en binnen diverse contexten te begrijpen, worden de resultaten geordend aan de hand van het model van Bronfenbrenner. Op de verschillende niveaus worden de voordelen van betekenisvol werk, alsmede de voorwaarden voor en belemmeringen ten aanzien van (het creëren van) betekenisvol werk beschreven.

- Op *individueel niveau* biedt betekenisvol werk structuur, zingeving, persoonlijke groei en eigenwaarde aan mensen met een verstandelijke beperking. Daarbij is werk dat aansluit bij persoonlijke wensen en behoeften een voorwaarde, evenals dat er mogelijkheden zijn om verschillende werkervaringen op te doen. Bij verlies van werk (zoals tijdens de coronapandemie) kunnen gevoelens van leegte, eenzaamheid, depressieve klachten en fysieke/mentale gezondheidsproblemen ontstaan.

- Op *micro-niveau* (directe omgeving) draagt betekenisvol werk bij aan sociale contacten en het ervaren van een gewaardeerde rol. Belangrijke voorwaarden zijn gelijkwaardige behandeling, passende ondersteuning, stabiele werkomgeving, betrokken leidinggevenden en een positieve werksfeer. Stigma en verwachtingen vanuit collega's en leidinggevenden zijn belemmerend. Werkgevers ervaren dilemma's rond klantcontact en het bieden van ondersteuning op maat.
- Op *meso-niveau* (organisatie) worden vraaggestuurde matching, beschikbaarheid van jobcoaches, en samenwerking tussen werkgevers, professionals en naasten als voorwaarden gezien. Een gebrek aan passende banen en ondersteuning worden als belemmerend ervaren.
- Op *exo-niveau* (organisatiebeleid en externe context) blijkt een inclusieve visie en gedragen beleid door alle lagen van een organisatie een voorwaarde. Binnen organisaties staan inclusieve doelen en commerciële belangen soms op gespannen voet met elkaar. Werkgevers worstelen ook met hoe zij zich als inclusieve organisatie profileren zonder werknemers te stigmatiseren.
- Op *macro-niveau* (maatschappij en beleid) laten resultaten zien dat betekenisvol werk sociale verbondenheid van mensen met een verstandelijke beperking versterkt en hen een autonome positie in de samenleving geeft. Stigma en negatieve maatschappelijke attitudes blijven een forse barrière.

Reflectie op de bevindingen

Het onderzoek benadrukt de waardevolle betekenis van werk voor mensen met een verstandelijke beperking: persoonlijke groei, eigenwaarde en sociale betekenis. Deze betekenis is vergelijkbaar met de waarde van werk in de algemene bevolking, maar voor mensen met een verstandelijke beperking vaak moeilijker bereikbaar. Het verlies van werk weegt voor hen zwaar, door de beperkte alternatieven en grotere kwetsbaarheid.

Het proefschrift laat zien dat bij het realiseren van betekenisvol werk voor mensen met een verstandelijke beperking een aantal voorwaarden van belang zijn. Een belangrijke voorwaarde is de toepassing van vraag gestuurde matching om werk te kunnen afstemmen op de wensen, talenten en mogelijkheden van de persoon met een verstandelijke beperking. In de praktijk gaan werkgevers echter vaak nog te werk vanuit bestaande vacatures. Daarnaast is maatwerk in de ondersteuning van belang om werknemers met een verstandelijke beperking een duurzame werkplek te bieden. Een belangrijk dilemma is de spanning tussen gelijke behandeling en noodzakelijke aanpassingen. Te veel nadruk op gelijkheid kan de benodigde ondersteuning in de weg staan, terwijl te veel nadruk op verschillen stigmatisering kan bevorderen. Het werken vanuit een krachtgerichte benadering kan daarbij helpen.

Er zijn een aantal belangrijke maatschappelijke fricties die betekenisvol werk voor mensen met een verstandelijke beperking belemmeren. Stigmatisering is een belangrijke barrière in verschillende vormen. Er is sprake van publiek stigma, bv doordat collega's en klanten twijfelen aan de competenties van mensen met een verstandelijke beperking. Er is sprake van structureel stigma door wetgeving die ontmoedigend werkt voor zowel werkgevers als mensen met een verstandelijke beperking en hun naasten. Daarnaast is er sprake van zelfstigma en courtesy stigma, waardoor mensen met een verstandelijke beperking en hun naasten neigen zich te distantiëren van de groep om negatieve labels te vermijden. Daarnaast is het voor werkgevers een uitdaging om een inclusief klimaat te creëren en ervaren zij een dilemma hoe zij hun klanten het beste kunnen meenemen in hun inclusieve strategieën. Tenslotte worstelen mensen met een verstandelijke beperking om een gewaardeerde positie te verkrijgen? in onze prestatiegerichte samenleving waar betaald werk de norm is, maar niet voor iedereen wenselijk of bereikbaar, en onbetaald werk wordt ondergewaardeerd.

Sterke en zwakke punten van het onderzoek

Sterktes van het onderzoek zijn de rijke kwalitatieve aanpak (interviews, focusgroepen, observaties) en de nadruk op de stem van mensen met een verstandelijke beperking zelf in twee van de vijf studies. Dit levert contextuele, ervaringsgerichte kennis op. Ook de betrokkenheid van netwerken en werkgevers biedt waardevolle inzichten. Het perspectief van andere stakeholders zoals broers/zussen, jobcoaches en beleidsmakers, is echter niet meegenomen in dit onderzoek. De onderzoeksresultaten benadrukken het belang van de betrokkenheid van jobcoaches, evenals barrières in beleid en wetgeving. Daarom is specifiek het perspectief van jobcoaches en beleidsmakers van belang in toekomstig onderzoek. Daarnaast is de generaliseerbaarheid van de resultaten van de werkgeversstudies beperkt, gezien de kleinschaligheid. Toekomstig onderzoek zou grootschaliger en multidisciplinair moeten zijn, met nadruk op de rol van wet- en regelgeving bij het bevorderen van arbeidsinclusie, stigma-interventies en de specifieke ervaringen van werkgevers en klanten met betrekking tot de inzet van mensen met een verstandelijke beperking.

Implicaties voor beleid en praktijk

Wat betreft het verbeteren van de toegang tot de arbeidsmarkt voor mensen met een verstandelijke beperking is het van belang om vraag gestuurde matching vanuit een krachtgerichte benadering toe te passen. Dit betekent dat men zich richt op de kwaliteiten van een persoon in plaats van op de beperkingen. Job carving -het creëren van werkposities op basis van iemands talenten, behoeften en interesses- kan als strategie worden gebruikt om functies beter af te stemmen op mensen met een verstandelijke beperking. Daarnaast is het aanpakken van stigma van belang. Hoewel het doorbreken van stigma ingewikkeld is, kan het creëren van positieve ontmoetingen tussen werkgevers en mensen met een verstandelijke beperking helpen.

Om duurzame sociale inclusie in organisaties te bereiken is het van belang om binnen organisaties een inclusieve werkcultuur te bevorderen voor álle werknemers door individuele verschillen te waarderen en bespreekbaar te maken. Daarbij blijft het van belang dat er ook gericht beleid wordt gemaakt op de inclusie en ondersteuning van werknemers met een verstandelijke beperking. Voortdurende beschikbaarheid van en toegang tot jobcoaching is daarbij van belang.

Tenslotte is het van belang om een maatschappij te creëren waarin iedereen mee kan doen op de arbeidsmarkt en kan bijdragen, ook via onbetaald werk. Het is daarbij essentieel om maatregelen te treffen die werkgevers ondersteunen bij het in dienst nemen van mensen met een verstandelijke beperking. Een kritische reflectie op het huidige beleid is gewenst, zodat mensen worden beoordeeld op hun kwaliteiten in plaats van op hun beperkingen, zodat ook onbetaald werk beter wordt gewaardeerd en mensen hun bestaanszekerheid en uitkeringen kunnen behouden bij het uitvoeren van onbetaald werk.

Conclusie

Toegang tot betekenisvol werk kan een belangrijke bijdrage leveren aan het persoonlijke welzijn van mensen met een verstandelijke beperking en aan de samenleving als geheel. Het biedt autonomie, sociale waarde en geeft betekenis aan het leven. Tegelijkertijd bestaan er op alle niveaus – van individu tot beleid – barrières die dit bemoeilijken, vooral door stigma, meritocratische normen en beperkende regelgeving. Het bevorderen van een inclusieve arbeidsmarkt vraagt een omslag in attitudes, gedrag en structuren op alle niveaus in de samenleving. De huidige arbeidsmarktkrapte biedt kansen voor inclusieve hervormingen. Met gerichte ondersteuning van werkgevers, een brede reflectie op wet- en regelgeving en maatschappelijke herwaardering van werk (zowel betaald als onbetaald), kan Nederland stappen zetten naar een inclusieve arbeidsmarkt waarin iedereen kan bijdragen.

PUBLIC SUMMARY

Why this research?

In recent years, work has increasingly been recognised as a way to participate in society that positively influences people's wellbeing. However, access to meaningful work is not self-evident for people with intellectual disabilities. Their position in the labour market has improved through the recognition of citizenship and policies such as the Dutch Participation Act. Although more supported workplaces have been created within mainstream organisations, participation in meaningful work by people with intellectual disabilities remains limited. This has negative consequences for their wellbeing and represents a loss of talent—especially in light of current labour shortages in the Netherlands.

What did we study?

This thesis explored what work means to people with intellectual disabilities and what is needed to enable their participation in meaningful work. The research involved various stakeholders: people with intellectual disabilities themselves, their relatives, and employers.

What did we find?

Meaningful work contributes to structure, purpose, personal growth, self-worth, social connection, and a valued social role for people with intellectual disabilities. Losing work negatively affects daily life and can lead to feelings of emptiness, loneliness, and psychological distress.

To support participation in work, several conditions are essential. Work must align with individual preferences, talents, and abilities, and people should be given opportunities to explore suitable roles and environments. Key workplace factors include equal treatment, stability, engaged leadership, and a positive atmosphere. Long-term availability of job coaches and collaboration between employers, professionals, and relatives are also crucial. Tailored support is necessary.

Social frictions hinder access to meaningful work, such as stigmatising attitudes from co-workers, customers, and within legislation. Employers often struggle to foster an inclusive culture where everyone feels valued and to engage their customers in this process.

Conclusion

Work holds great value for people with intellectual disabilities, as it gives them the opportunity to truly belong, to be appreciated, and to make a meaningful contribution. As a society, we still have steps to take to make this possible for everyone. This requires tailored support, inclusive workplace cultures, and breaking down persistent prejudices.

PUBLIEKSSAMENVATTING

Waarom dit onderzoek?

Werk wordt de afgelopen jaren steeds meer erkend als een manier om deel te nemen aan de samenleving die het welzijn van mensen positief beïnvloed. Voor mensen met een verstandelijke beperking is toegang tot betekenisvol werk echter niet vanzelfsprekend. Hun positie op de arbeidsmarkt verbeterde door erkenning van burgerschap en beleid, zoals de Participatiewet. Hoewel meer begeleide werkplekken binnen reguliere bedrijven werden gecreëerd, blijft de deelname aan betekenisvol werk door mensen met een verstandelijke beperking achter. Dit heeft negatieve gevolgen voor hun welzijn en leidt tot verspilling van talent. Zeker nu Nederland kampt met personeelstekorten.

Wat hebben we onderzocht?

In dit proefschrift onderzochten we wat het voor mensen met een verstandelijke beperking betekent om te kunnen werken. Daarnaast onderzochten we wat er nodig is om ervoor te zorgen dat mensen met een verstandelijke beperking mee kunnen doen aan betekenisvol werk. We betrokken verschillende belanghebbenden bij het onderzoek: mensen met een verstandelijke beperking zelf, hun naasten en werkgevers.

Wat hebben we gevonden?

Betekenisvol werk is belangrijk voor mensen met een verstandelijke beperking, omdat het bijdraagt aan structuur, zingeving, persoonlijke groei, eigenwaarde, sociale verbinding en het leveren van een gewaarde maatschappelijke bijdrage. Het verlies van werk heeft een negatieve invloed op hun dagelijks leven, en kan leiden tot gevoelens van leegte, eenzaamheid en psychische klachten.

Om ervoor te zorgen dat mensen met een verstandelijke beperking kunnen meedoen aan werk in de samenleving zijn een aantal voorwaarden belangrijk. Het is belangrijk dat werk aansluit bij wensen, talenten en mogelijkheden en dat mensen met een verstandelijke beperking de kans krijgen om te ontdekken wat voor soort werk en werkomgeving bij hen past. In de werkomgeving is het belangrijk aandacht te besteden aan gelijkwaardige behandeling, stabiliteit, betrokken leidinggevenden en een positieve werksfeer. Langdurige beschikbaarheid van jobcoaches en samenwerking tussen werkgevers, professionals (zoals jobcoaches) en naasten van mensen met een verstandelijke beperking zijn ook van belang. In de ondersteuning is maatwerk noodzakelijk.

Maatschappelijke fricties belemmeren betekenisvol werk voor mensen met een verstandelijke beperking, zoals stigmatiserende gedachten en houdingen van collega's en klanten, en stigmatiserende wetgeving. Werkgevers vinden het moeilijk om een inclusieve sfeer te creëren in hun bedrijf waarin iedereen zich gewaardeerd voelt en om hun klanten daarin mee te nemen.

Conclusie

Werk is van grote waarde voor mensen met een verstandelijke beperking, omdat het hen de kans geeft er echt bij te horen, gewaardeerd te worden en een zinvolle bijdrage te leveren. Als samenleving hebben we nog stappen te zetten om dit voor iedereen mogelijk te maken. Dat vraagt om maatwerk in begeleiding, een inclusieve sfeer binnen bedrijven en het doorbreken van hardnekkige vooroordelen.

Easy-to-read summary

Why this research?

Work is important for people. In the past, work was mainly seen as something you had to do to earn money. Now, work is also seen as something that helps people to be part of society.

Not everyone can easily take part in work. For people with intellectual disabilities, it can be difficult. Over the years many things have changed. People with intellectual disabilities have now more rights, like the right to be included in society. This right was in 2006 written down in an important agreement of the United Nations. The United Nations are a group of countries that work together to make the world safer and better.

There are now more supported jobs for people with intellectual disabilities, also in regular companies. In the past, most people with intellectual disabilities worked in protected workplaces with extra support, such as sheltered workshops. In the Netherlands, the Participation Act was introduced in 2015. That law was meant to help more people with disabilities get regular jobs.

However, research still shows that people with intellectual disabilities work less often in regular companies than people without intellectual disabilities. That makes it harder for them to participate and feel good. It also means that their talents are not being used—especially now that many companies need more workers.

What was studied?

In this research we looked at what work means to people with intellectual disabilities. We also looked at what is needed to help them take part in meaningful work.

We studied people with intellectual disabilities, their families, and employers. The research had five parts:

1. Interviews with people with an intellectual disability who have paid jobs.
2. Interviews with people with an intellectual disability who lost their work during the COVID-19 pandemic.
3. A study of how families of people with an intellectual disability see the meaning of work.
4. Visits to companies who employ people with disabilities. To see how they think about workers with additional support needs in relation to their customers.
5. Group interviews with employers about their experiences with workers with disabilities with special attention for their experiences with customers.

What did we find?

- Work is very important for people with intellectual disabilities. It gives them structure, purpose, confidence, social contact, and the feeling that they are making a difference.
- Losing work can make people feel sad, lonely, and empty.
- To help people with intellectual disabilities work well, the job must match their wishes and talents. They need chances to try different jobs and find out what suits them.
- Workplaces should treat people fairly, offer stability, have caring managers, and a positive atmosphere. Job coaches and teamwork between families, employers, and professionals are also important. As each person is different, support should be tailored to what a person needs.
- There are still many negative ideas about people with intellectual disabilities. Some co-workers or customers doubt their abilities. Laws and rules can also make it harder to work.
- Employers find it difficult to create an inclusive workplace, as many people have different wishes. They also find it difficult to explain to customers why they hire people with disabilities. Sometimes, the wish to include people with disabilities doesn’t match the business goals.

Main message and advice

Work is very valuable for people with intellectual disabilities. It helps them feel included, appreciated, and useful.

As a society, we still have work to do to make this possible for everyone. That means that:

- We should offer support that matches the needs of people with intellectual disabilities
- We make friendly workplaces where everyone feels welcome
- All people (such as co-workers and customers) should notice what people with intellectual are good at and help them with it

MAKKELIJK LEZEN SAMENVATTING

Waarom dit onderzoek?

Werk is belangrijk voor mensen. Vroeger zagen mensen werk vooral als iets dat moest, om geld te verdienen. Nu zien we werk ook als iets dat helpt om mee te doen in de samenleving.

Niet iedereen kan zomaar meedoen aan werk. Voor mensen met een verstandelijke beperking is dat vaak lastig. De afgelopen jaren is er veel veranderd. Mensen met een verstandelijke beperking kregen meer rechten, zoals het recht om mee te doen in de samenleving. Dit recht staat sinds 2006 in een belangrijk verdrag van de Verenigde Naties. De Verenigde Naties is een groep landen die samenwerkt om de wereld beter en veiliger te maken voor iedereen.

Er zijn nu meer begeleide werkplekken waar mensen met een verstandelijke beperking kunnen werken, ook in gewone bedrijven. Vroeger werkten zij vooral op beschermde plekken met extra begeleiding, zoals sociale werkplaatsen. In 2015 kwam in Nederland de Participatiewet. Die wet moest ervoor zorgen dat meer mensen met een beperking een gewone baan krijgen.

Toch laat onderzoek zien dat nog steeds veel minder mensen met een verstandelijke beperking werken in gewone bedrijven dan mensen zonder verstandelijke beperking. Daardoor is het voor hen moeilijker om mee te doen en zich goed te voelen. En het is zonde van hun talent, zeker nu er veel personeel nodig is.

Wat is onderzocht?

In dit onderzoek hebben we gekeken naar wat werk betekent voor mensen met een verstandelijke beperking. Ook keken we wat nodig is om hen te helpen bij het vinden van werk dat ertoe doet.

We deden onderzoek bij mensen met een verstandelijke beperking, hun familie en werkgevers. Het onderzoek bestond uit vijf delen:

1. Gesprekken met mensen met een verstandelijke beperking die een betaalde baan hebben.
2. Gesprekken met mensen met een verstandelijke beperking die door corona hun werk of dagbesteding kwijt waren.
3. Een studie over hoe familie werk ziet voor hun naaste met een verstandelijke beperking.

4. Bezoeken aan bedrijven die mensen met een beperking in dienst hebben, om te zien hoe zij denken over werknemers met een beperking in relatie tot hun klanten.
5. Groepsgesprekken met werkgevers over hun ervaringen met werknemers met een beperking met speciaal aandacht voor hun ervaringen met klanten.

Wat is gevonden?

- Werk is voor mensen met een verstandelijke beperking heel belangrijk. Het geeft hen structuur, zin in het leven, zelfvertrouwen, contact met anderen en het gevoel dat ze iets bijdragen.
- Als ze hun werk verliezen, kunnen ze zich leeg, eenzaam en verdrietig voelen.
- Om goed te kunnen werken, moet het werk passen bij de wensen en talenten van mensen met een verstandelijke beperking. Ze moeten ook de kans krijgen om uit te proberen wat bij hen past.
- Op de werkplek is het belangrijk dat ze eerlijk worden behandeld, dat er rust en duidelijkheid is, en dat leidinggevenden betrokken zijn.
- Jobcoaches zijn belangrijk, en samenwerking tussen familie, werkgevers en hulpverleners helpt ook. Iedereen heeft andere hulp nodig, dus het is belangrijk om de hulp aan te passen aan wat iemand nodig heeft.
- Er zijn nog steeds veel vooroordelen. Sommige mensen denken dat mensen met een beperking niet goed kunnen werken. Ook wetten en regels maken het soms moeilijk.
- Werkgevers vinden het lastig om een fijne sfeer te maken voor iedereen. Omdat iedereen andere wensen heeft. Ze weten ook niet goed hoe ze hun klanten moeten uitleggen dat ze mensen met een beperking in dienst hebben. Soms past het idee van inclusie niet goed bij de doelen van het bedrijf.

Belangrijkste boodschap en advies

Werk is van grote waarde voor mensen met een verstandelijke beperking. Het helpt hen om erbij te horen, zich nuttig te voelen en gewaardeerd te worden.

Als samenleving moeten we zorgen dat iedereen mee kan doen. Dat vraagt om:
- begeleiding die past bij wat een werknemer met een verstandelijke beperking nodig heeft
- een fijne werksfeer in bedrijven zodat iedereen zich welkom voelt
- dat alle mensen (bv. collega’s en klanten) zien wat mensen met een verstandelijke beperking goed kunnen en hen daarbij helpen

DANKWOORD (AKNOWLEDGEMENTS)

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CURRICULUM VITAE

Moniek was born on February 23, 1984, in Tilburg. In 2002, she obtained her pre-university (VWO) diploma at the Pius-X College in Bladel. She then went on to study Pedagogical Sciences at Radboud University in Nijmegen, specialising in Orthopedagogy: Learning and Development. In 2007, she earned her master's degree with a specialisation in Pediatric Rehabilitation. After initially exploring the possibility of pursuing a PhD, she began working with people with intellectual disabilities. After gaining experience as a support worker, she started working as a behavioural scientist at Amarant. In 2010, Moniek began the training to become a registered Orthopedagoog-Generalist at RINO Zuid, which she completed in 2012. In 2017, she started a PhD research project as a science-practitioner at the Academic Collaborative Center Living with an Intellectual Disability (Tranzo, Tilburg University). Alongside this, she continued working at Amarant as a coordinating therapist (*regiebehandelaar* in Dutch) and policy advisor. In 2023, Moniek transitioned to Novadic-Kentron, a facility for addiction care, where she took on the role of program manager for long-term recovery and coordinating therapist. In addition, she completed her PhD research in collaboration with Amarant and the Academic Collaborative Center. Since 2025, Moniek has also been affiliated as a senior lecturer with the training program for Orthopedagoog-Generalist in the Southeast Netherlands region.

Moniek werd op 23 februari 1984 geboren in Tilburg. In 2002 behaalde zij haar VWO diploma aan het Pius-X college in Bladel. Vervolgens ging zij Pedagosiche Wetenschappen studeren aan de Radboud Universiteit in Nijmegen in de richting Orthopedagogiek: Leren en Ontwikkeling. In 2007 behaalde zij haar masterdiploma binnen de specialisatie Kinderrevalidatie. Na een aanvankelijke oriëntatie op een promotieonderzoek ging zij werken in de zorg voor mensen met een verstandelijke beperking. Na korte tijd als begeleider ervaring op te hebben gedaan, startte zij als gedragskundige bij Amarant. In 2010 begon Moniek aan de opleiding tot Orthopedagoog-Generalist bij Rino Zuid, welke zij in 2012 afrondde. In 2017 startte zij als science-practitioner een promotieonderzoek bij de Academische Werkplaats Leven met een Verstandelijke Beperking (Tranzo, Tilburg University). Daarnaast bleef zij binenn Amarant werken als regiebehandelaar en beleidsadviseur. In 2023 maakte Moniek de overstap naar Novadic-Kentron waar zij ging werken als programmamanger langdurig herstel en regiebehandelaar. Daarnaast rondde zij in samenwerking met Amarant en de AWVB het promotieonderzoek af. Naast haar werk bij Novadic-Kentron, is Moniek sinds 2025 als hoofddocent verbonden aan de opleiding tot Orthopedagoog-Generalist Zuid-Oost Nederland.

PUBLICATIONS

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Voermans, M., Taminau, E., Giesbers, S. & Embregts, P. (2021). The value of competitive employment: In-depth accounts of people with intellectual disabilities. *Journal of Applied Research in Intellectal Disabilities, 34*(1), 239-249. https://doi.org/10.1111/jar.12802

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