

Article

# The inclusive, social space-oriented participation of people with disabilities in the Bavaria–Tyrol border region during the COVID-19 pandemic

by

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## Keywords:

COVID-19, social space, disabilities, inclusive participation, qualitative methods

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## **Abstract**

*Background:* Although some individuals in Germany and Austria's Bavaria–Tyrol border region live in one country, but work, study, shop and/or access healthcare in the other, realizing that lifestyle can be difficult for people with disabilities (PWD). Limited cross-border services currently available to PWD not only suffer from poor awareness and adoption, but also fail to meet PWD's manifold individual needs. Thus, facing restricted individual social space, especially in rural areas, the region's PWD experience various constraints to self-determined lives, which the COVID-19 pandemic's isolation and heightened border control have only aggravated.

*Aim:* Against that background, the aim was to identify factors that have enabled or constrained PWD's individual agency in the Bavaria–Tyrol border region in the wake of the pandemic.

*Methods:* Beginning in June 2020, 34 semi-structured interviews were conducted with PWD, their relatives and employers, as well as various institutional, political and administrative personnel regarding the use of cross-border education, housing, leisure and occupational services during the COVID-19 pandemic in Bavaria, Germany and Tyrol, Austria. In a qualitative content analysis, the most prevalent results were summarized into eight abstracts, which were later compiled into a qualitative online survey completed by 51 of 229 interviewees and other participants (22.27%).

*Results:* Pandemic-associated developments and policies have been external shocks to an already fragile (cross-border) support system for PWD, endangering inclusion and participation. Added to pre-pandemic obstacles, including a lack of information, consensus and options regarding cross-border activities, new deficits in mobility, housing and funding for support, along with prejudices and the effects of digitalization, have further intensified challenges for PWD.

*Keywords:* COVID-19, social space, disabilities, inclusive participation, qualitative methods

## **1. Introduction**

Since the Schengen Agreement was signed in 1985 (Convention Implementing the Schengen Agreement, 1985), followed by the establishment of the European Single Market in 1993 (Treaty on European Union, 1992) and its ‘four freedoms’,<sup>1</sup> national borders within the European Union have gradually relaxed. Likewise, in 2000, the European Union’s Lisbon Strategy (2000, section 1) initiated efforts to strengthen the path of cross-European collaboration and integration toward realizing ‘the most competitive and dynamic knowledge-based economy in the world’ (Lisbon Strategy, 2000, section 5). In the past two decades, the freedom of movement has become increasingly visible in Europe, and supported cross-border mobility among citizens in EU member states (Medeiros, 2019). Among the 190 million employed persons aged 20-64 years in the EU in 2019, two million (1%) of them commuted between member states (Eurostat, 2020). Distinct from migration (Collyer, 2012; European Commission, 2011), cross-border mobility therefore means being able to intentionally move between countries with the aim of returning to one’s country of origin after fulfilling the purpose of travel (Recchi, 2014).

In the European Union, aspirations for benefitting from open borders, free transportation and greater mobility are high, because those factors have been identified as pivotal to diminishing disparities between border regions and EU member states (Cavallaro & Dianin, 2019). According to Knippschild (2011), well-established spatial planning across the European Union’s border regions indeed bears the potential to improve ‘economic clusters, labour markets, education and training, transport, as well as tourism and public services’, among other aspects of life (p. 644). In that process, addressing the concerns, hopes and aspirations of border-adjacent populations in decision-making, as well as facilitating broad, participatory communication practices are crucial to making diverse interests heard, implementing mutually consensual decisions and demonstrating the benefits of cross-border activities (Knippschild, 2011). In time, such efforts may further loosen borders across Europe, and help to establish a broader understanding of cross-border cooperation. Although enhanced mobility can even positively impact

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<sup>1</sup> The ‘four freedoms’ are the free movement of people, capital and payments, goods and services (Treaty on European Union, 1992).

European citizens' sense of participation and cohesion (Mazzoni et al., 2018), it can never conceal the reality that maintaining borders is a social process that depends on contextual factors, including border closures to ensure a feeling of security in times of crisis (Newman, 2006) and border (re)openings to strengthen economies. Even if a 'borderless' world (Shapiro & Alker, 1996) remains a distant prospect in Europe, let alone an 'empire' with a 'decentred and deterritorializing apparatus of rules that progressively incorporate the entire global realm within its open, expanding frontiers' (Hardt & Negri, 2000, p. xii), European integration nevertheless provides the grounds 'to look to space first, and borders second' (Rumford, 2006).

Although the reduction of borders in Europe has afforded several benefits and a sense of participation and cohesion, it remains questionable as to whether people with disabilities (PWD) participate and benefit to the same extent as everyone else in the society. In 2008, Austria ratified the Convention on the Rights of Persons with Disabilities, followed by Germany in 2009, which explicitly aimed to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities' (United Nations, 2020).

However, the exportability of disability benefits and entitlements remains limited (Waddington, 2010), faces numerous legal preconditions (Waddington 2014), is often confined to state of citizenship or residence (Bayrisches Behindertengleichstellungsgesetz, 2003/2020; Tiroler Teilhabegesetz, 2018/2020) and neglects to address the diverse needs of individuals (Waddington, 2012). Among those individuals, PWD already face multiple constraints to self-determined lives, not only on a national scale (Crowther, 2019), and face relatively high risks of social exclusion and poverty (European Union, 2019), both exacerbated in rural versus urban areas due to remoteness and the lack of infrastructure (European Commission, 2008). As a consequence, the mobility and social capital of PWD have been limited (Gray et al., 2006), and access to social services made scarce (Dassah et al., 2018). But to think that challenges for PWD are limited to border areas would be wrong, although Pallisera et al. (2016) state that family networks support the transition into education and training, and build the basis for 'sociopersonal skills that lead to autonomy in the workplace' (Pallisera et al., 2012, p. 1118). Langford et al. (2013) point out that certain network features such as tie strength or centrality, as well as the

composition of social networks, which in the case of PWD are often compromised of unemployed, underemployed or low-status positions, negatively influence the quality of employment for PWD. The importance of social networks and the contact to peer groups is crucial for the psychological well-being of PWD (Woodgate et al., 2019), but constantly endangered by narrow intuitional paths and non-inclusive educational systems (Raghavan & Pawson, 2008). Furthermore, several PWD are dependent on their relatives' support in negotiating the required services with providers, or in providing advice for professionals (Koelewijn et al., 2020). Although PWD are often in need of institutional support, participation and utilization is dependent upon the quality of counselling offers and amenability (Albuquerque & Carvalho, 2020; Sabatello, 2020), as well as the quality, accuracy and the fit (such as barrier-free information (Courtenay & Perera, 2020)) of given information to identify appropriate services (Braddock et al., 2013). The most common problems for PWD in the use of services are waiting times, costs, adequacy and the availability of services in an appropriate vicinity (McColl et al., 2010). In addition to the service structures in place, the process of utilization, such as navigating through the social landscape and identifying suitable services, can already be problematic and restrain service utilization (Albuquerque & Carvalho, 2020; Waddington, 2012, 2014). Additionally, McColl et al. (2010) identified that the lack of mobility infrastructure is already a problem in order to reach provided services at all. Pallisera et al. (2016) further point to the issue of insufficient guidance and the referrals of PWD between different professionals and services, with Sebrechts (2018) referring to the problem of transitioning into the first labour market due to being stuck in sheltered-workshops and the lack of appropriate labour market services.

More recently, unprecedented measures taken due to the COVID-19 pandemic have further aggravated pre-existing inequalities, and showcased the extent of the exclusion of PWD in today's societies (Doeblich et al., 2020; United Nations, 2020; World Health Organization, 2020). Although the pandemic's effects—the reintroduction of national borders (European Commission, 2020), social isolation and multiple lockdowns (Pollack et al., 2021)—have affected all of European society, PWD are recognized as being particularly vulnerable to its physical, mental and social effects (Courtenay & Perera, 2020), due to pre-existing forms of social injustice and discrimination against PWD (McQuillen & Terry, 2020), their higher prevalence of

comorbidities (Turk et al., 2020), a general lack of data to inform disability-inclusive pandemic responses (Reed et al., 2020) and various ethical, legal and medical dilemmas in emergency frameworks (Sabatello et al., 2020). To help mitigate such vulnerability, we aimed to identify factors enabling or constraining the individual agency of PWD in Germany's and Austria's Bavaria–Tyrol border region in the wake of COVID-19.

## 2. Methods

Within that scope of research, data collection proceeded in two phases. The first phase, from June to September 2020, involved 34 qualitative-centred interviews (Witzel & Reiter, 2012). The applied interview guideline was derived from the most prevalent topics discussed in the literature review, continuously including an open, explorative approach, and incorporating narrative elements (Scheibelhofer, 2008). Each participant agreed on being part of the survey, and the informed consent was signed by themselves or the legal representative.

Table 1: Interview Guideline

<b>Introduction</b>	
<b>Participation</b>	<ul style="list-style-type: none"> <li>• <b>Inclusion and Exclusion</b> (Crowther, 2019; European Union, 2019; Doebrich et al., 2020; United Nations, 2020; World Health Organization, 2020; McQuillen &amp; Terry, 2020)</li> </ul>
<b>Network components</b>	<ul style="list-style-type: none"> <li>• <b>Social networks</b> (Langford et al., 2013; Raghavan &amp; Pawson, 2008)</li> <li>• <b>Peers</b> (Woodgate et al., 2019)</li> <li>• <b>Relatives</b> (Koelewijn et al., 2020)</li> <li>• <b>Professionals and Administration</b> (Koelewijn et al., 2020)</li> </ul>

<p><b>Service structures</b></p>	<ul style="list-style-type: none"> <li>• <b>Services</b> (Albuquerque &amp; Carvalho, 2020) <ul style="list-style-type: none"> <li>○ Navigation and Identification</li> <li>○ Needs</li> </ul> </li> <li>• <b>Information structures</b> (Braddock et al., 2013)</li> <li>• <b>Counselling</b> (Lindsay, 2011)</li> <li>• <b>Self-determination</b> (Crowther, 2019)</li> <li>• <b>Service Deficits</b> (Pallisera et al., 2016; McColl et al., 2010)</li> </ul>
<p><b>Service utilization</b></p>	<ul style="list-style-type: none"> <li>• <b>Service acquisition (referral, bureaucracy, social networks)</b></li> <li>• <b>Mobility and Infrastructure</b> (European Commission, 2008; Gray et al., 2006)</li> <li>• <b>Service mediation</b> (Pallisera et al., 2016)</li> <li>• <b>Labour market services</b> (Sebrechts, 2018)</li> <li>• <b>Barriers to services</b> <ul style="list-style-type: none"> <li>○ Accessibility (Sabatello, 2020)</li> <li>○ Information (Courtenay &amp; Perera, 2020)</li> </ul> </li> <li>• <b>Benefits</b> (Waddington, 2010, 2012, 2014)</li> </ul>
<p><b>Legal structures</b></p>	<ul style="list-style-type: none"> <li>• <b>Contact points</b> (international, European, federal &amp; state law)</li> <li>• <b>Advocacy</b> (international, European, federal and state law) <ul style="list-style-type: none"> <li>○ Legislation for services and labour market (tax, compulsory employment, dismissal protection) (international, European, federal and state law)</li> </ul> </li> </ul>
<p><b>COVID-19</b></p>	<ul style="list-style-type: none"> <li>• <b>Vulnerability</b> (Courtenay &amp; Perera, 2020)</li> <li>• <b>Service deficits &amp; restrictions</b> (Sabatello 2020)</li> <li>• <b>Information and contact points</b> (Reed et al. 2020; Courtenay &amp; Perera, 2020)</li> <li>• <b>Discriminatory practices</b> (McQuillen &amp; Terry, 2020)</li> </ul>
<p><b>Closure</b></p>	<ul style="list-style-type: none"> <li>• <b>Wishes, suggestions and feedback</b></li> </ul>

The interview sample should be contrastive, therefore we targeted (1) PWD, as well as (2) their relatives, (3) employers and (4) various institutional, political and administrative personnel in rehabilitation, social and integration services of the Bavaria–Tyrol border region experienced in using cross-border educational, social, healthcare, housing, leisure and occupational services. The second phase involved compiling the most prevalent results from interviews into a qualitative online survey to be completed by the interviewees and an extended number of contacts from the above-mentioned target groups.

Historically and even today, using proxies instead of the people affected has been an all-too-common practice (Doody, 2012; Hartnett et al., 2008), one that has limited the collection of insights from PWD and risked prioritizing the perspectives of proxies at the expense of individuals who have experienced the phenomena (Lloyd et al., 2006). Hence, in both phases, it was important to afford people affected by the studied phenomenon the opportunity to participate in the research process (Atkinson, 1997). Consequently, the utilized approach followed the definition of Orton (2019), who distinguished between the traditional definition of experts as ‘people with learned expertise’ and experts as ‘people with lived experience’ (Orton, 2019, p. 132). Therefore, experts with both learned expertise and lived experience found entrance into the research.

Existing and potential difficulties in collecting data from people with intellectual disability should thus not promote the avoidance of complications, but instead the embracement of possibilities for increasing their participation in different aspects of research (Beail & Williams, 2014). As a result, flexibility is crucial in acquiring information from PWD, which itself requires a dynamic interview process that will ‘neither overestimate nor underestimate participants’ abilities and communication preferences’ (Teachman & Gibson, 2013, p. 272). We particularly benefitted from having a trained social care worker specializing in assisting PWD on our research team. With that expert’s knowledge and abilities in augmentative and alternative communication, our qualitative research became ‘a valuable window through which to view the lived experiences of individuals with disabilities’ (O’Day & Killeen, 2020). For instance, pictograms, drawings and plain language in spoken communication were utilized for better understanding. Moreover, we learned, given the appropriate



preparation, setting and techniques, it is entirely possible to conduct qualitative interviews with people who have difficulties with expressing themselves (Hollomotz, 2018).

Because the heterogeneity, complexity and individuality of disability makes determining a generally viable definition of *disability* impossible (World Health Organization, 2011), people with psychological or mental disorders and people with physical, intellectual and sensory disabilities were included, in addition to providers, employers and institutional agents of- and for people with long-term impairments.<sup>2</sup> The World Health Organization defines a psychological or mental disorder as generally characterized by a combination of abnormal thoughts, perceptions, emotions, behaviour and relationships with others. This covers depression, bipolar disorder, schizophrenia and other psychoses, dementia and developmental disorders, including autism (World Health Organization, 2019). We did not further distinguish between people with psychological or mental disorders and neuro-divergent people (e.g. autism, ADHD), since the interviews focused on experiences of PWD in their respective social space, and not on their disabilities. Furthermore, exact allocations to the given groups proved to be a difficult task, as there were several intersections. Project partners such as the Diakonie Rosenheim, the Diakoniewerk Tirol<sup>3</sup> and representatives of specialized social service units in Bavaria and Tyrol supported the recruitment of PWD. Thus, during the research's first phase, we conducted interviews with 13 PWD, seven women and six men with physical, psychological, intellectual and sensory disabilities living in Bavaria or Tyrol, two relatives, 10 employers and nine political, administrative or social service associates.

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<sup>2</sup> We are referring to international law (United Nations, 2006), European law (European Union, 2012), Austrian and German federal law (Bundesbehindertengesetz, 1990/2018; Sozialgesetzbuch Neuntes Buch, 2016/2020) and state law in Bavaria (Bayrisches Behindertengleichstellungsgesetz, 2003/2020) and Tyrol (Tiroler Teilhabegesetz, 2018/2020).

<sup>3</sup> The Diakonie Rosenheim, an independent welfare association, offers several social services for PWD related to employment, housing, addiction, nursing and leisure. The Diakoniewerk Tirol, a non-profit association, supports PWD in meeting their housing, employment and occupational needs.

Table 2: Sample

<b>Participants</b>	<b>Interviews (Phase 1)</b>	<b>Qualitative online survey (Phase 2)</b>
People with disabilities	13	7
• <i>Physical</i>	2	2
• <i>Psychological</i>	8	0
• <i>Intellectual</i>	1	3
• <i>Sensory disabilities</i>	2	2
Relatives of people with disabilities	2	5
Employers and employment-related institutions	10	3
Political, administrative and social service associates	9	33
Non-categorizable	-	3
	34	51

Although qualitative interviews are traditionally conducted face-to-face (Shuy, 2007), the COVID-19 pandemic's exceptional circumstances (e.g. closed borders and the risk of COVID-19 infection) required interviews to be partly conducted via telephone (Vogl, 2013) or online via Skype, Zoom or CLICKDOC (Weller 2017) according to the interviewee's request. In sum, 16 interviews were conducted this way. The rest (n=18) remained with the face-to-face mode. After transcribing the interviews, an inductive qualitative content analysis was performed (Mayring, 2014) aiming at generating categories according to the discussed content. After this first step, summarizing a qualitative content analysis was applied for cases delivering the most categories to validate the first inductive approach. In the end, two phases of a reduction of the whole results delivered the most prevalent categories, and enabled the focus on interdependencies between different topics and its impact on the different target groups (Mayring, 2014). Finally, the qualitative content analyses delivered the core topics for the second phase of the qualitative online survey: (1) information management, (2) service deficits-mobility, (3) definitions of authority, (4)

funding, (5) labour market inclusion, (6) digitalization, (7) legal barriers for cross-border inclusion and (8) the impact of COVID-19.

In the second phase, these results were transferred into eight thematic abstracts later compiled in a qualitative online survey, available for four weeks in November 2020. This approach was inspired by the basic principles of participatory consensus building of the Delphi method, in which participants reflected on the condensed results of a prior survey, and delivered a second assessment (von der Gracht, 2012). In this case, eight core topics from the interview phase were provided as statements within the qualitative online survey, which could be commented on, validated or rejected according to reasoning. In the following, the abstract on the topic of 'information management' is displayed:

In Tyrol and Bavaria, there are information gaps on offers, funding opportunities and support for employers, as well as on the legal basis for the cross-border use of services, training and employment opportunities for people with disabilities.

What do you think is needed to counteract this?

To make the survey available for people with intellectual disabilities, we utilized the online survey tool '2ask', validated its user-friendliness among people with visual impairment and members of the 'Association of the Blind and visually impaired Tyrol', and provided professional translations into easy-to-read texts of the short abstracts. Like every translation of scientific transcripts in different languages, the provided abstracts in easy to read language needed to be as understandable as possible without distorting the content and meaning (Nikander, 2008). Temple and Young (2004) argue that language has inclusive and exclusive powers, and 'although the conversation with people who use other languages is difficult, it is possible, and probably essential, if we are to move on from the objectifying gaze on difference' (p. 174). They generally plead for more efforts in qualitative research to include different languages, and therefore different perspectives, which was attempted to be implemented in the qualitative online survey. The translation should facilitate easy access to the survey, and thus increase the motivation for the participation of people with disabilities, especially for those who are dependent on plain or easy language

(Maaß, 2020). The following excerpt shows the beginning of the translated topic of information management<sup>4</sup>:

Many affected people do not know,  
what support is available,  
in their area.  
Many also do not know,  
that there are ways  
to get support across the border.  
In Bavaria and Tyrol there are,  
grants and financial support.  
This enables organizations  
for people with disabilities  
to make offers of support.  
[...]  
What do you think can be done about it?

The example presented of the content of the qualitative online survey only contains 45 words, the translation in easy or plain language contains 159 words. The extended word count reduces the complexity and density of the given information, and therefore facilitates a better understanding of the content. At the end of every abstract, a free-text field that invited statements, experiences and assessments in relation to the commentary was provided. It was limited to 150 words. Participants made extensive use of this opportunity to validate and assess the given statements, and to share their own experiences and thoughts. Data of the qualitative online survey was used to supplement, adjust and triangulate (Denzin, 1970) the findings derived from the interviews. The sample for the qualitative online survey was expanded to include next to the existing interviewees all available service providers, associations and self-help groups in the Bavaria–Tyrol border region according to official databases, as well as the region’s political and administrative actors. The survey was completed by 51 of the 229 individuals invited (response rate: 22.27%), who identified themselves as PWD ( $n = 7$ ), their relatives ( $n = 5$ ), their employers or members of employment-related institutions ( $n = 3$ ), institutional, political and administrative associates ( $n = 33$ ) and non-categorizable ( $n = 3$ ). Although the qualitative online survey was as low-threshold as possible, previous interview participants were decidedly addressed, and people with physical, intellectual and sensory disabilities participated, whereas people with psychological disabilities did not. We do not have an explanation for this besides the hypothesis of lacking face-to-

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<sup>4</sup> This is translated from the original German easy to read text to English, so it may not meet all criteria.

face interactions that could be of great importance for this specific group. As we combined findings from both phases, it is ensured that this group was appropriately represented.

### **3. Findings**

Despite inherently differing in structure and organization, such as service and assistance provision, benefits, legal frameworks, service providers, healthcare offerings, funding and administrative catchment areas, Bavaria and Tyrol exhibited quite a few similarities in effects for PWD. In general, the results displayed in the literature review were confirmed by the sample. In the following, only the topics 1 to 6 (information management, service deficits-mobility, definitions of authority, funding, labour market inclusion and digitalization) are displayed separately, as they all partially relate to and include (topic 7) legal barriers for cross-border inclusion, and (topic 8) the impact of COVID-19.

#### *3.1 Information Management*

Participants from both phases and all target groups showed various information deficits, regarding cross-border service offerings and providers, funding for services, support measures, legal preconditions for cross-border service utilization, education and employment. Of particular concern were the scope, quality and accuracy of information, which, from the perspectives of the participants strongly depend on the responsible unit or advising consultant, which often narrows the information and seldom covers the full spectrum of cross-border services available. The responses indicate that the events and measures due to COVID-19 have broadened information deficits and gaps: 'Getting information is really difficult because there's no place where you can go or you aren't told where to go' (Interview\_PWD). The phenomenon of transferring filtered information found a resemblance during the pandemic due to the lack of transparency in communication and crisis management from authorities: 'It [crisis management] was a disaster, because every county and state, each border official, acted differently. [...] It [border closing] was never communicated but it was the practice' (Interview\_Employer). In particular, employers and service providers reported that: 'We have been bombarded by emails, and it is difficult to filter out which information is relevant. You only get recommendations and no guidelines' (Interview\_Associate). From the perspective of PWD and their relatives:

'Transparency is almost non-existent [...] and impossible to see through' (Online\_Relative) and '[we need] uniform information materials. These should be prepared barrier-free according to all types of disabilities [...] people must feel they are being met and well informed about it [pandemic]' (Online\_PWD). During the pandemic it was hardly possible to get up-to-date barrier-free information (e.g. easy to read texts, sign and braille language) on the COVID-19 situation and regulations.

### *3.2 Service Deficits-Mobility*

Participants from both phases and all target groups recounted various examples of service deficits in the areas of work, education, leisure and housing, even before the COVID-19 pandemic, consistent with the previously discussed literature. Particularly pronounced as limiting were service deficits regarding mobility in the rather rural border region of Bavaria-Tyrol. Specific issues to the border region were differences in regional tariff systems for public transport, and the lack of cross-border recognition of disability cards and associated benefits. Beyond that, the poor quality, strong centrality, lack of barrier-free accessibility to information about funding structures and intense bureaucratism in the application process constrained PWD's individual agency, and therefore their mobility. COVID-19 further aggravated some of the pre-pandemic service deficits in the area of cross-border mobility. This exacerbation was primarily triggered by measures to contain the pandemic, such as the reduction of public transport services due to passenger limits and the decrease of available assistance for accompaniment due to contact restrictions: '[...] we had to change the care structure to an emergency operation [...] mobile structures were reduced to a minimum' (Interview\_Associate). Furthermore, the border closing between Austria and Germany led to a shutdown of cross-border public transportation: 'Yes, today I walked here (workplace) for an hour [...] otherwise by train, but it is that way [now]' (Interview\_PWD). Especially for commuters, these restrictions meant that they had to look for alternative transport options, such as contracting additional assistance services or relying on family members: 'I always commute. I suddenly had to schedule all the time with assistance. It would never have been possible to cover my needs. I [had] a family in the background without whom I would not have made it' (Interview\_PWD). Social contacts were particularly affected by border closures and the restrictions on public transport. Participants reported that visits from friends and family members were cancelled because either the border could not be crossed or

transport was not available: 'Especially in the beginning with the border closures. No more trips. My girlfriend is in Salzburg, so no visits were possible either. I really got tired of it' (Online\_PWD).

### *3.3 Definitions of Authority - Classification Process*

The type and severity or existence of a disability is subject to the respective state's legal definition; as a consequence, entitlements to benefits differ between countries. In short, what is eligible in Bavaria is not necessarily recognized or funded in Tyrol. Thus, cross-border service provision can mean that disabilities have to be separately recognized in each country: 'I'm not disabled in Germany, but I am in Austria. To get a disability certificate, I would need to go through the German classification process. [...] It's a mess' (Interview\_PWD). Further complications arise owing to differences in the process for the classification of the degree of disability and the associated benefits in the respective state. Moreover, PWD perceive the definition or classification of their disability as arbitrary: 'The classification process always depends on where and by whom the classification is done and how well the people at the other end give advice' (Online\_Associate), and deficit-oriented medical criteria, and not competence-oriented practice, also usually determine classification: 'The classification process heavily depends on diseases. It's the degree of diseases that's evaluated, not the disability. [...] We don't need additional symptoms' (Interview\_PWD). Although the legal basis or structures and systems for such classification have not inherently changed due to the COVID-19 pandemic, a highly similar issue has nevertheless arisen—namely, that PWD are categorized as an at-risk group without distinction: 'Not all people should be lumped together. I have a learning disability, there is nothing wrong with my lungs, so why do I have to be treated like everyone else? You have to look at who has what disability and whether they are really at risk' (Online\_PWD). PWD and their relatives have felt abandoned, angry and restricted in their self-determination: 'They (service providers) all cancelled during Corona. We experienced that we are a forgotten species. It can't go on like this because 80% of those in need of care are cared for at home' (Interview\_Relative), or 'I was not allowed to leave the house during the lockdown' (Online\_PWD). For assisted living arrangements in particular, the general at-risk attribution introduced an ethical dilemma between self-determination and paternalism: 'It was a dilemma between implementing protective measures and

individual freedom' (Interview\_Associate), or as one employment service aptly described, 'If someone belongs to the risk group, then they are not allowed to do any more training with us. Especially PWD who would have liked to have had the conversation were neglected' (Interview\_Employer).

### *3.4 Funding*

The general risk group attribution introduced far reaching problems for service providers and employers including to '[...] provide codes of conduct in easy language' (Interview\_Associate), and the funding of additional services '[...] since the workshops have been closed we simply had more work and more time with the clients. When the hourly quota is used up nothing more is paid. Some are now through for the year but there is still a lot of year left' (Online\_Associate). Even before the pandemic, service providers had very tight budgets, as they were not able to increase those budgets according to the additional expenses and efforts in the wake of COVID-19 (e.g. single treatment). To maintain basic service provision some other services were suspended, and 'carers did not feel properly protected by employers by being frequently so close to the PWD through care' and further '[...] the situation could only be settled with relatives who came to support' (Interview\_Associate)

### *3.5 Labour Market Inclusion*

From the perspective of the participants of both phases, fear, prejudice and an aversion to additional responsibilities generally constrain the employment of PWD. Meanwhile, employers discussed the lack of resources for adaptations in the workplace or on-the-job assistance. Making matters worse, misinformation circulated among employers regarding the increased job protection and support services in place: 'The rumour that "If I hire him [PWD], I won't get rid of him" persists. [...] There remains a lot of work to do so that the private sector comes off that track' (Interview\_Associate). In interviews, PWD stated that finding and securing cross-border employment has been difficult, owing to a shortage of appropriate, inclusive occupations. From their perspectives, fines imposed upon companies that fail to comply with legal recruitment obligations are either not extensive enough to create incentives or else redundant. Furthermore, corresponding support systems and the necessary information were described by participants as lacking or being incompatible between Bavaria and Tyrol. Consequently, PWD distance themselves



from applications, especially for cross-border employment: 'We've been able to send a person to Bavaria for distance education. However, that undertaking is very difficult and complicated due to different legal regulations, and therefore requires many exemptions' (Interview\_Employer).

The measures of both countries to counteract the pandemic have been perceived to endanger established employment arrangements and made new employment difficult, if not impossible. Participants described PWD's general inclusion in the group at risk of COVID-19, constructed as a protective measure, as facilitating a new form of exclusion. Relatives terminated their jobs to cover missing or suspended institutional care, as caregiving institutions were overburdened with the situation due to changed and altered demands in service provision due to COVID-19. Meanwhile, employers reported feeling responsible for caring for their employees, but often seeing no alternative to ensure security but to lay off PWD. Reported job losses occurred mostly during transitions from institutional structures to the primary labour market, and participants were generally ambivalent about the acceleration of digitalization during the pandemic. Some reported the expansion of their independence as an opportunity for labour market inclusion, whereas others encountered new barriers, including barrier-free accessibility or higher thresholds for qualifications. Participants also stated that the trend had increased social isolation among PWD, as home offices have now become mandatory for them as members of the at-risk group.

### *3.6 Digitalization*

The transferral of many activities of daily life into the virtual world was challenging for PWD and their relatives; moreover, the acceleration of digitalization in the spheres of work, education and social relations had a massive impact in service provision and utilization. The shift of the employment and education into a virtual space meant the loss of regular social interactions for many PWD. Participants stated that the workplace, university or training place functions as a social hub. The previously mentioned general perception of PWD as an at-risk group due to COVID-19 provoked a situation in which PWD were expected to stick to digital solutions rather than face-to-face interactions as protective measure. Therefore, digitalization exacerbated the social isolation of PWD. Additionally, digital participation in the

spheres of work and training requires higher qualification levels and the necessary technical equipment. As one participant from a vocational placement service explained, 'Important topic, depending on qualifications, level of education, social status, there were possibilities but many who did not have a PC or laptop apart from a smartphone. It was difficult [...] to deal with bureaucracy by writing or just phoning' (Interview\_Associate). Furthermore, the risk of excluding people with learning disabilities from this development was frequently expressed within our sample, primarily due to the lack of barrier-free access (e.g. plain language), technical knowledge or digital literacy. In addition, service providers reported in this context that digital literacy is not always present among their staff accompanying PWD. Therefore, appropriately trained assistants, who are necessary to accompany PWD in this digital transition, pose another barrier for digital participation.

#### **4. Discussion**

As a consequence of the European Disability Strategy 2010–2020 (European Commission, 2010), Bavaria and Tyrol share much in their regulatory frameworks to foster the inclusion of PWD. Nevertheless, established inclusive structures and practices were set aside facing the unprecedented events that followed the COVID-19 pandemic, exposing not only pre-existing inequalities in the border region, but also introducing discriminatory practices (Uldry & Leenknecht, 2012).

Throughout both phases and among all target groups, information deficits and insufficient information quality were reported as key to influence individual agency and participation of PWD, which both further deteriorated with the outbreak of COVID-19. As the reports of the participants in both phases show, information in accessible formats, such as sign language, easy-to read information or braille were scarce to non-existent, thereby leading to an increased dependency of PWD on support and administrative staff (Sabatello et al., 2020). Particularly problematic is such a dependency on information from service providers and professionals, because it amplifies the practice of the pre-selection of services offered (Courtenay & Perera, 2020; Goggin & Ellis, 2020). The absence of a disability inclusive crisis response (Armitage & Nellums, 2020; Boyle et al., 2020) not only imposed new restrictions on the self-determination of PWD in the border region, but also stirred feelings of uncertainty. To help enable individual agency during the pandemic,

inclusive public health messaging disseminating all information in 'plain language and across all accessible formats' (Armitage & Nellums, 2020) is pivotal. Administrative and social service associates, as well as employers and employment-related institutions, experienced what Doyle and O'Brien (2020) described as a 'cacophony of guidelines' (Doyle & O'Brien, 2020, p. 372), and already 'complex, underfunded, and fragmented' (Yates & Dickinson, 2021, p. 3) service systems were further burdened. As a result, this led to uncertainties, and thus to the unpredictability of the further course of action during the crisis.

Although service deficits were reported in several areas, mobility among PWD proved to be particularly restricting in self-determination and participation in the border region during COVID-19 among PWD. The pre-existing lack of barrier-free options for public transport between Bavaria and Tyrol, accompanied by differences in regional tariff systems, benefits, eligibility requirements, application processes and the recognition of the disability card, was expanded to include frequency limitations of public transport, heightened restrictions on passengers and the cancellations of cross-border public transport during the pandemic. This confined the individuals' agency to their home countries instead of promoting cohesion and elevating a sense of participation (Mazzoni et al., 2018), but also reduced the already scarce social participation of PWD (Kim, 2021); this further impoverished the social networks of PWD and their social interactions (Brunelli et al., 2021) via a decreased contact with family and friends and participation in the community (Koon et al., 2021).

Furthermore, such mobility deficits during the pandemic can lead to a decrease in access to healthcare services (Lebrasseur et al., 2021), groceries, food and employment (Koon et al., 2021), while increasing loneliness (Ling & Lixia, 2021).

Inflexible criteria and general classification systems have categorized all PWD as being at risk of COVID-19, even though disability 'is not inherently linked to increased risk of getting COVID-19 infection or in experiencing more severe disease' (Boyle et al., 2020, p. 1). This reflects general shortcomings in the public discourse and debates, which are focused on disabilities and impairments rather than abilities (Harpur, 2012). Harpur (2009, p. 163) advocates the use of ableism to overcome the 'focus upon the person with a disability as a contributing factor to the discriminatory act'. As defined by Harpur (2009, p. 163), ableism 'should concentrate upon the act

of the discriminator and not upon the characteristics of the victim or the different abilities of the person with a disability'. Gappmayer (2021, p. 10) points out that discrimination 'occurs when the social interaction excludes a person with intellectual disability and social partners reduce a person to the sole membership of the category dis/ability'. Considering this in relation to our findings, the COVID-19 pandemic has had severe impacts on self-determination and participation to the point that PWD living in institutions were locked up, often with no social interaction with the outside world (Uldry & Leenknecht, 2021; Felix, 2020). For service providers, such an approach was often the only way to secure the increased efforts and demand in service provision under uncertain circumstances regarding the costs and responsibility for protective measures; this has led to issues in funding (cross-border) services during the pandemic, further undermining the goals, efforts and achievements in line with the Convention on the Rights of Persons with Disabilities.

Funding for cross-border services were already scarce before the COVID-19 pandemic, and faced numerous legal preconditions (Waddington, 2010, 2014). The pandemic hit already-fragile service systems, with caregivers in precarious positions and partly insufficient training (Rotarou et al., 2021) already feeling challenged to the edge of their capacity before COVID-19 (Quilliam et al., 2018). The findings also indicate the development of what Yates and Dickinson (2021) referred to as a 'gig economy' (Yates & Dickinson, 2021, p. 4), identifying a shift to individual service models, while increasing already precarious conditions, in which relatives had to intervene to ensure the provision of care or the additional employment of personal assistants to fulfil neglected services.

PWD experienced lower rates of employment (Diby et al., 2021), and faced restricted employment opportunities (Wegscheider & Guével, 2021) before the pandemic. The disorganized and chaotic crisis communication during the pandemic (Goggin & Ellis, 2020) made it close to impossible for employers or employment-related institutions to employ or place PWD in the labour market. Furthermore, the general at-risk group attribution meant a barrier to labour market inclusion, since employment services, which were already inhibited from placing persons at risk or transition into the labour market, were cancelled due to a lack of necessary workplace adaptations to guarantee protection.

As shown in the findings, the perception of digitalization was thoroughly ambivalent. On the one hand, digitalization was perceived as an opportunity for inclusion that increased the ability to act independently, particularly regarding restrictions to mobility. On the other hand, digitalization was perceived as introducing new barriers (van Holstein et al., 2021), with participants referring to issues of higher qualification thresholds, gaps in digital literacy (Jeste, 2020), barrier-free accessibility to technologies and digital content and the resource-intensive acquisition of hardware and skills. Additionally, the COVID-19 pandemic only served to accelerate the labour market's digital shift (Soto-Acosta, 2020). In conjunction with the general at-risk attribution, PWD were forced to work from home or receive services in online modes. Within the sample, this development led to fears of further social isolation among PWD.

## **5. Conclusion**

Despite differences in the support structures for PWD in Bavaria and Tyrol, neither system has proven to be more resilient amid the measures required due to the COVID-19 pandemic. The fragility of support and service systems for PWD in both states has been extensively demonstrated with our sample, even to the point that PWD in both countries have faced the same difficulties in perceived barriers and constraints due to COVID-19. Pre-existing issues revolving around information management, infrastructural and service deficits, classification processes, inclusion in the labour market and education, funding limitations, legal barriers and digitalization all became more acute during the pandemic. Derived factors influencing the individual agency of PWD are attributable to several trends, including information availability, accessibility, bureaucratism and legal preconditions. The factors ultimately discovered are not unique to the COVID-19 pandemic, but merely excesses of existing hurdles to inclusion. Despite general progress in the cross-border exchange between Tyrol and Bavaria, social space, and therefore the reality of life for PWD, is still limited. The COVID-19 pandemic showed that challenges for health and social services did not necessarily recognize or acknowledge borders. It could therefore be used as a turning point for sustainable changes and national collaborations in (cross-border) social service utilization, since in theory social space has nothing to do with national borders, but in practice has very limited chances to

overcome them. Learning from the pandemic would therefore mean to not circle back and try to re-establish and maintain the status that existed before COVID-19.

Currently, our findings indicate that the institutional approach to the pandemic is a limiting, restricting and disabling factor in the lives of people with disabilities. This is not due to COVID-19 measures, such as social distancing, but instead based on the narrow perspectives of disabilities without considering or recognizing their abilities (Harpur, 2009; 2012), in addition to the normative power of those who determine and decide what is considered a disability (Gappmayer, 2021).

## **6. Limitations**

Although a relatively large sample was available for expert interviews and the online survey, generalizability is not assured, due to the findings being confined to the participants' subjective perceptions and experiences. Furthermore, though our research combined an open, explorative approach with narrative elements and sampling guided by the principle of contrastivity, the sample did not represent all groups of persons affected by the studied phenomenon.

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