Lessons from the COVID-19 pandemic for changes in institutionalized residential settings for people with intellectual disabilities

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Introduction

During the course of the COVID-19 pandemic, social processes changed in almost all areas of life. The resulting social and political effects continue to be the subject of intense debates and legal assessments. In the following, we will look at one group of people who were particularly affected by the pandemic – people with intellectual disabilities. This was partly because key areas (such as psychosocial support, care, healthcare and education), on which they depend, were undermined by protection and care measures. These measures were particularly felt in residential institutions for people with disabilities, where people with intellectual disabilities often spend a large part of their daily lives, given their close connection to the institutions' structures (Schmidhuber, 2020, p. 273). In addition, policymakers have generally classified them as people at risk. Although not all people with intellectual disabilities necessarily belong to this group, the number of people at risk is higher among them, partly due to their form of care (centralized accommodation), which is associated with an increased risk of infection (Habermann-Horstmeier, 2023, pp. 285 f.; Felder, 2021, p. 156). In principle, even without a pandemic, there is already a risk that people with intellectual disabilities are threatened or affected by social exclusion (Trescher, 2015a, 2017a, 2017b, 2018a, 2018b). This is particularly evident in the housing sector: At present people with intellectual disabilities mainly still live in closed, specialized facilities where they receive round-the-clock care and only benefit to a limited extent from the expansion of assisted living (BMAS 2021, p. 13; Kulig and Theunissen 2016a, pp. 12–14; Seifert, 2016, pp. 65–67). This is despite research findings showing that this is often not their preferred form of living (BMAS, 2021, p. 396). Notably, these closed institutions show an unbroken, albeit transformed, proximity to Erving Goffman's ideal type of the 'total institution' (Goffman, 1973) and act as

barriers to inclusion despite all the protection and support measures they offer and provide (Trescher, 2015a, p. 316). At the same time, processes of deinstitutionalization have been and are being initiated, the result of arduous struggles that are still being waged today. Processes of deinstitutionalization are understood as the dismantling of comprehensive structures in favor of alternative and open residential structures (e.g. assisted living). This is also called for in Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD), which Germany has committed to implementing (BMAS, 2021, p. 339). This leads to the question of how the living conditions of the affected population changed during the pandemic in residential institutions, where most people with intellectual disabilities live, and what lessons can be learned for the post-pandemic period, particularly in relation to education. These two questions are examined in this article. Reference is made to the study "Institutionalized living conditions in times of Corona". The study and its findings are presented in the next two sections, followed by a discussion of the questions raised.

The study 'Institutionalized living conditions in times of Corona'

The aforementioned study was conducted as a teaching and research project at the Philipps University of Marburg (Germany) from 2020 to 2022 and was dedicated to researching the impact of the pandemic on different types of educational and care institutions. The data collection consisted of 22 interviews with staff from different institutions. Ten interviews were conducted with staff from residential homes for people with intellectual disabilities and a further 12 interviews were conducted with staff from other institutions (e.g. retirement homes, kindergartens, psychiatric institutions, etc.). The focus of this article is on residential services for people with intellectual disabilities. Care was taken to ensure that the interviewees worked in different residential settings and for different organizations and institutions throughout Germany in order to obtain the widest possible range of data. Based on the assumption that the employees, particularly of residential facilities, have a comprehensive insight into the changed requirements and processes, they were used as interview partners. The planned interviews with people with intellectual disabilities were not possible at the time due to the hygiene regulations in force. The interviews were conducted in the form of topic interviews (Trescher, 2015a, pp. 164–166). This is a hybrid form between guided interviews and narrative interviews, which assumes a conversational structure and accordingly generates narrative passages on the part of the interviewee (ibid., p. 164). At the same time, the conversation is structured by previously determined topics (ibid., pp. 164 f.). The recorded and transcribed interviews were analyzed using qualitative methods (Mayring, 2010).

Central findings

Hygienic concepts

Across the surveyed facilities, similar approaches were implemented in the event of a (suspected) coronavirus infection in a resident. They all followed a hygiene policy, usually designed by the facilities themselves, and although the specifications varied to some extent and the specific design depended on various factors (such as local incidence and national requirements), the affected residents were (initially) isolated in their rooms. In some cases a house quarantine was also imposed, with all residents, for the most part, remaining in their rooms. Where intensive medical treatment was not required for a confirmed infection, residents were cared for in their rooms by carers wearing protective suits. Infections were recorded in both residents and carers in all the homes studied. Some of the quarantine situations were particularly challenging for the residents, as described by an educator interviewed: "The worst thing we've experienced here was a coronavirus quarantine because of a suspected case. We had to lock the people with intellectual disability in their rooms, even though some of them didn't understand. So the rooms weren't locked, but that was blatant and also ethically questionable in my opinion" [1]. It is clear from this, that these situations were perceived as stressful by all involved, particularly for those working in education who were faced with moral conflicts as they were required to implement policies that they may not have personally supported. One respondent also reported having to work "masked as if in an intensive care unit" (I5, Pos. 138). With regard to the handling of coronavirus infections or suspected cases, it must be taken into account that while the described approach within the institution was able to effectively contain the spread of the virus, it also violated the dignity and privacy of the residents. In this context, privacy means, for example, being able to decide autonomously and free from social control about one's own room (Trescher 2015b, pp. 136–138; Thesing, 2009, p. 34). Finding the 'right' balance between protection and freedom was a fundamental challenge in dealing with the pandemic. In retrospect, it must be emphasized that the restrictions imposed on people with intellectual disabilities living in these institutions were more drastic than those experienced by many other members of society. Although the hygiene regulations of the institutions are based on government guidelines and recommendations, they are, in some cases, adapted and extended and, in rare cases, enforced and controlled in people's most private spaces: their homes.

1 The statements made by the interviewees have been translated here and below from the German into the English language.

Restrictions on free movement

In addition to the handling of coronavirus infections and suspected cases described in the previous chapter, the individual hygiene protocols also impacted how physical contact in the facilities, in cases of infection, was minimized. The key to this was rules restricting the movement of people. The way in which this was implemented varied in the facilities surveyed, which, as already mentioned, was partly due to the different requirements across the federal states. The measures taken often meant that residents were not allowed to leave the premises on their own in the interim. If they were, it was usually only in exceptional cases or for short walks, as one interviewee noted: "Arranged walks were actually the only thing that could be done outside" (I4, Pos. 74–75). Another said: "Some people were actually only in the dormitory during the lockdown" (I5, Pos. 59–60). In line with this requirement, most activities that would have meant leaving the center were suspended. This included, for example, independent or collective shopping trips. While this may sound trivial for people who do not live in an institutional environment, it is highly relevant, as one educator explained in relation to one of her clients: "He [the client] doesn't go to work anymore and can't really go anywhere else. He can't go shopping, for example. Although it has now been decided that he can do that again to give him a certain amount of freedom. But that hasn't been the case for a while and then his favorite hobby fell away" (I3, Pos. 442–444). Moreover, the workplaces of the residents, who mainly worked in workshops for people with disabilities, were (temporarily) closed or restricted, as one interviewee said: "When we were in lockdown, the residents couldn't go to work at all" (I6, Pos. 77–78). Although such restrictions generally applied to all members of society, they were particularly heightened for people with intellectual disabilities living in institutions, as the sometimes-total nature of the institutions became more pronounced (Trescher, 2015a, p. 298). Corona ultimately manifested itself in the (quasi-)imprisonment of people with intellectual disabilities living in institutions.

The lack of information

Throughout the facility, residents were found to be largely unaware of the coronavirus pandemic. Many residents had little access to information about the pandemic. This was partly due to inadequate access to information about the pandemic and its development. For example, residents were generally not (officially) informed about pandemic-related developments and conditions or were given uncoordinated and informal access to information through their caregivers. This is illustrated by the following statements from two carers: "There was hardly any information. You only got information from the carers and only if they had time and knew about it themselves" (I1, Pos. 349–351). As well as: "Of course the residents don't get all the information either, otherwise they get too fixated on it" (I2, Pos. 477–478). However, this perceived sense of protection also meant that residents often perceived the pro-

tective measures as (too) strict, as they were rarely adequately informed about the extent of the pandemic or, as one educator put it: "The understanding [of many residents] for the restrictions is simply not there" (I8, Pos. 173). Overall, it was possible to show the extent to which the sharing of information and decisions, that (directly or indirectly) affect the fate of those in care, was regulated by the individual institutions, making it difficult for residents to exert any influence – a feature typical of the overall nature of these institutions (Goffman, 1973, p. 20). This made it more difficult for residents to have personal agency in dealing with the limitations that non-institutionalized people without mental disabilities generally tend to have. As a result, they were unable to develop their own strategies for coping with the pandemic.

Behavioral problems

The interviewees reported that they had noticed changes in the residents' behavior. They noted an increase in aggressive, unbalanced and listless behavior. One person stated: "We have an increasing number of candidates here who are aggressive towards others or themselves" (I8, Pos. 171–172). Another person: "We already have loneliness and odd behavior during the quarantine period. People are supposed to stay in their rooms as much as possible" (I5, Pos. 527–529). This was a challenge, especially in group settings, as other respondents reported: "Basically it was always about de-escalation. How can we get through this day so that they [the residents] are well and there is no escalation?" (I2, Pos. 70–74). In addition to the limited personal agency, this can also be attributed to the fact that (personal) activities could only be promoted to a limited extent during the corona pandemic, or were canceled entirely (e.g. sports or cultural activities). Consequently, the previously highly structured everyday routines, including their opportunities for social interaction, were eroded. For example, one interviewee talked about a resident who was mentally very unwell during the lockdown: "I think the biggest problem is that he just spends too much time in the same room" (I3, Pos. 176–178). The documented behaviors can be described as hospitalization effects, negative physical and psychological consequences of deprivation (Theunissen, 2013, pp. 105 f.), and illustrate the stress people with intellectual disabilities living in institutions endured during the pandemic.

Slowing down life

One striking finding was that there was a noticeable slowing down of life in the homes during the pandemic. This was mainly due to the fact that residents' work was temporarily suspended. As a result, the homes had to be staffed 24 hours a day, as residents, unlike before, spent the whole day there. One interviewee said: "What has definitely been noticed is that you have much more time now. Because the residents no longer go to the workshop for people with disabilities" (I3, Pos. 149–150). Residents in the homes surveyed used this newfound time to reorganize in different

ways. One staff member explained: "Because the residents have to be looked after, I still start work at six o'clock. Because a lot of people still have that rhythm in their bodies and just get up early" (I4, Pos. 626–629). Overall, respondents painted a positive picture of having more time. As one interviewee pointed out: "It also meant that some of the people felt better because they didn't have to work or go to a group [i.e. the groups in the day care centers]. One person was very clear that he felt better when he wasn't out all day. It's incredibly good for him to be able to sleep longer and not be in these cramped situations when he's being transported. It was always back and forth. From one rush hour to the next" (I2, Pos. 85–92). On the other hand, however, there were also residents who did not cope well with the change in procedures. According to some interviewees, they needed a more structured daily routine and to be able to leave the facilities in between. Overall, it can be said that the previously tightly synchronized schedules within these institutions were (inevitably) broken up, resulting in more available time as well as new opportunities for personal agency.

Initiation of communitization

The measures implemented throughout the pandemic had an impact on the organization of social life for all people. However, the consequences were particularly far-reaching for people with intellectual disabilities living in institutions. This is, in part, because their socialization practices are primarily organized through institutions for people with disabilities and/or their family of origin (Trescher 2017a, pp. 158 f.; 2018a, pp. 175–177). As the results have demonstrated, these practices were severely restricted during the pandemic. For example, leisure activities and contact with reference persons outside the home, such as work colleagues, friends or family members, were lost. This led to a reduction of social contacts outside the home environment. On the other hand, many respondents reported an intensification of social relationships among residents. This is highlighted in statements such as "You [i.e. the residents] were also able to make new contacts within the group, which you otherwise rarely had or avoided each other" (I1, Pos. 222–223); same person: "The willingness to help was much greater among the residents" (I1, Pos. 312–313). Another: "The bond of the group has also grown to some extent. They see it more as a home" (I2, Pos. 94–96). One staff member explained that this is because otherwise "everyone only had time to do something at the weekend. But because a lot of people were picked up at the weekend, there wasn't as much of a sense of community" (I4, Pos. 434–438). One employee continued: "Now that we've been in this house exclusively for months, we [the staff] can't compete with the residents. They stick together, conspire wherever they can" (I6, Pos. 326–329). The potential of the initiated communitization practices to lead to participatory empowerment can be seen here, as residents (more) collectively formed a community of interest that shared similar experiences, represented interests, and demanded the opportunity to co-design

and exert influence within the institutions. On the other hand, it is also problematic that these communitization practices only took place because of the greater unity of the institution and, moreover, only within the sphere of disability care. This situation has fueled the segregation of living environments for people with intellectual disabilities in institutions.

On the professional relationship with educational staff

The interpersonal relationships between residents and carers intensified during the pandemic, according to the results of the study. This was because more time was available and other interpersonal contacts (e.g. with friends or family) were limited. The extent of this is illustrated by the statement of one interviewee: "We are sometimes the last remaining contact for many people" (I5, Pos. 728–729). A carer also said: "At some point the staff became an absolute substitute for the families during the months of closure" (I6, Pos. 171–173). Conversely, this also led to (more) pedagogical counselling sessions, which also focused more on the biographies of the residents, some of which had previously been omitted due to lack of time or trust. As a result, they experienced greater personal agency and were able to become freer and more active pedagogical agents. For example, one staff member reported: "We have been able to work much more intensively than before with residents who have communication difficulties and find it difficult to express their needs or who quickly slip into auto-aggression or aggression towards others" (I8, Pos. 77–80). Another person stated: "There are definitely issues that were there before, but now, because [of] the pandemic, there is more time to get behind them and talk about them" (I3, Pos. 482–487). These developments can be discussed in two ways: first, the intensification of the interpersonal relationship between carers and residents means that the latter were viewed less as mere objects of care practices. Second, residents were pushed into new or different relationships of dependency.

Separation processes from parents

The relationship between people with intellectual disabilities living in institutions and their parents also changed during the pandemic. This relationship often plays a central role for both parties, characterized by a high degree of intensity (Trescher 2017b, pp. 253 f.; 2015a, pp. 212 f.), yet it remains ambivalent. Although contact with the family of origin offers people with intellectual disabilities living in institutions scope for action beyond the organizational structure of the institution – acting as a counterbalance – and is often where they experience interpersonal closeness, a strong attachment to the family can also complicate detachment and self-empowerment processes. This attachment can perpetuate (often lifelong) dependency relationships (Trescher 2017b, pp. 253 f.). During the pandemic, there were (initial) processes of separation from families, as physical contact in some cases ceased completely, necessitating alternative ways of maintaining contact. This was very bad for

many, as one interviewee reported: "What was really bad was that the residents could no longer see their relatives. But they still need affection sometimes" (I7, Pos. 277 f.). Another said: "It was also very difficult that they [the residents] were not allowed to see their relatives. It was a very drastic change" (I6, Pos. 10–12). Overall, the (albeit temporary) limited contact was subjectively perceived by the residents as a burden; however, it also represented a medium- to long-term opportunity for people with intellectual disabilities to gain (more) independence from their families.

New technologies

In order to avoid a complete breakdown of residents' social contacts, alternative means of communication were increasingly used in the institutions, mostly in the form of increased use of new technologies. For example, more telephone calls were made, short messages or voice messages were sent via online messenger services, and contact was established via online tools on the computer or tablet computer. Previously, such services were used less frequently or only by those residents who had learned to use such devices independently. In addition, many homes do not have open Wi-Fi and shared computers are usually located in the carers' rooms, primarily reserved for their use. This was resolved during the pandemic. For example, in one residential home, extra tablets were purchased, as one carer reported: "During the restrictions, residents could be visited by their contacts via the tablet. They were even provided by the provider. We then Skyped with the relatives every day. Through this way we already had a bit of social connection" (I6, Pos. 306–308). Another respondent explained: "The residents also got to know technology a bit more through Corona by doing something with the computer. For some it was really the first time they had seen and used a computer" (I1, Pos. 225–228). According to the report, during the pandemic, some residents participated in the digital society to some extent, learning to use new technology for the first time. As one carer explained: "There was a lot of Facetime on the tablets. It was strange for a lot of clients at first because they didn't know how to use it. But they got used to it quite quickly and it went down really well" (I4, Pos. 120–123). Here we can see the potential for participation in technological achievements to have an inclusive effect and widen the scope of possibilities for individuals (Dederich, 2012, p. 103). It sometimes is the case that people with intellectual disabilities in particular have less access to digital technologies than the general population (Etges and Renner, 2022; Reichstein, 2016, pp. 80–82). Digitalization can create (new virtual) spaces and opportunities for residents to participate and overcome physical boundaries. However, these developments tend to benefit those who are already 'more empowered', meaning that the people with complex disabilities are less likely to gain from them. This development also raises the question or need for media literacy support, as the uncontrolled use of digital media can be associated with risks of dependency or addiction, (financial) fraud, escapism or digital violence. Overall, it should be

noted that issues related to new technologies have become more pressing in the context of intellectual disabilities (for more details on digital participation during the coronavirus pandemic, see Menschik, Kunze and Renner, 2024).

Inclusion, crises and lessons from the COVID-19 pandemic

The results presented have made it clear that existing structural frameworks in residential institutions for people with disabilities were disrupted by the pandemic and had to be adapted within a short period of time. Accordingly, the following considerations are in no way intended to euphemistically glorify the effects of the pandemic. Rather, the aim is to discuss whether, despite all the effects of the pandemic, Covid can (also) be seen as an opportunity for inclusion. Here, inclusion should be thought of as 'disability as practice, inclusion as critique' (Trescher, 2015a, pp. 333 f.; 2017b, pp. 47–49; 2018b). Disability is understood as a practice that takes place whenever people are excluded from or within the discourses of mainstream society or specific sub-discourses. It can therefore be assigned to a cultural understanding of disability which, in contrast to other understandings (such as the medical model on which disability care is based (Rathgeb, 2014, p. 42), which sees disability as a form of individual damage that needs to be remedied), views disability in the context of social values, norms and power structures (Waldschmidt, 2005, pp. 24 f.). Conversely in the theorem 'disability as practice, inclusion as critique', inclusion is a processual practice that stands in contrast to 'disability'. It takes place when barriers to participation in discourse are deconstructed. According to Butler (1991), deconstruction is a process of questioning that reveals ambivalences and contradictions (Zima, 2016, p. 1). Accordingly, deconstruction questions discourse and is therefore characterized as a crisis-ridden practice. Based on the concept of crisis chosen here, as defined by Oevermann (1996), who understands crisis as a mode in which routine actions no longer function and new ones have to be created, it must be noted that extreme crises, such as the pandemic, despite all the negative effects they (can) bring, always fundamentally challenge the norm, creating new practices in the process (White and McCallum, 2021). With regard to the connection between Covid and inclusion, it can then be argued that Covid has brought about deconstructivist elements; the structures of institutions were disrupted and spaces for action were closed but also opened, requiring unprecedented ways of thinking and acting. Contrary to the commonly held view, supported by research (like Trescher, 2017a; 2018a; Kremsner, 2017; Seifert, 2016), that many closed residential institutions have a very rigid functional framework, it has been demonstrated that this is not necessarily an incontrovertible truth – institutions are, at least in principle, capable of changing routines. However, they cannot do this alone; the social and legal framework in which these institutions operate must also (co-)change, as they are in a state of mutual production.

This clearly identifies a potential for advancing inclusive practices within institutions, something which now needs to be fully realized post pandemic. The pandemic should therefore not only be understood as a crisis that disrupted existing routines, but also as a catalyst for the renegotiation of new crises and routines, with the experience serving as a valuable future reference point. These experiences, in turn, can also create new perspectives on educational frameworks. Such free frameworks and spaces are necessary because pedagogical action takes place in discourses, is correspondingly changeable and must always be understood in the context of external conditions and reflected accordingly in its reciprocal (re)production relations (Trescher, 2018a, p. 51). This requires thinking and acting in ambivalence (ibid., pp. 51–53; Oevermann, 1996, pp. 22–24), which can only unfold if the relevant people are given personal responsibility and opportunities to act spontaneously. Ongoing practices of reflection, reflexive action, and dialectical understanding need one thing above all: time and space. It is then the responsibility of educational practice to use the post-pandemic conditions as a starting point to make support structures for people with disabilities more open and flexible in the future, ensuring that these two resources are available. Sometimes, due to cost-cutting measures and the prioritization of administrative and bureaucratic activities, pedagogy takes a back seat in residential institutions for people with intellectual disabilities, ultimately at the expense of the recipients of this practice. They are thus produced as objects of care and, above all, of administration. It is therefore necessary to strengthen pedagogical perspectives in order to establish a working alliance between pedagogical practitioners and their clients (ibid., pp. 115–117). Although the practice of relationships in this context cannot be standardized (ibid., p. 122) and is fundamentally open to the future, as the management of a crisis is always related to the specifics of a case, including its historical peculiarity and logic (Oevermann, 2002, p. 30), the prerequisites for entering into this alliance must first be created. Only then can joint crisis management be achieved in a working alliance (Oevermann, 1996, p. 138; Rieger-Ladich, 2014, pp. 285–287). In addition to measures that ensure the freest possible pedagogical action in institutions, concepts are also needed that ensure that people with intellectual disabilities who are being cared for are placed more at the center of attention. In addition to embedding reflexive practices within the institutions, a central aspect of this is to focus on the person being cared for, which requires the dismantling of overall structures within the institutions (keywords deinstitutionalization and promotion of alternative housing concepts), that were already present before the pandemic but have now become more apparent. The dismantling of the comprehensive structural framework of institutions (e.g. the need for consent to leave the institution, a very rigid and inflexible daily routine, excessive documentation requirements, the spatial design of the residential facilities primarily aligned with pragmatic principles, etc.) entails a technical risk of uncertainty, which runs counter to the ideas of protection and care, but would ultimately mean more pri-

vacy and dignity for the residents. Although such advances are always met with resistance from regulatory and legal levels, it is essential for the dismantling of the totality of institutions; to overcome the tightly synchronized, omnipresent action plans and schedules, to enable and promote community processes among people with intellectual disabilities, and to break down the social boundary that sometimes still exists between people with and without intellectual disabilities. However, this approach cannot be the sole responsibility of disability service providers or of people with intellectual disabilities themselves; it also requires the attention and awareness of the needs of people with intellectual disabilities by society as a whole. After all, it is not only the barriers of the support system that directly or indirectly restrict the participation of people with intellectual disabilities, but also latent barriers such as insecurities, fears, and prejudices.

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