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MORE INCLUSION THROUGH PARTICIPATION? ABOUT THE ACCESS, INTERACTION AND PARTICIPATION ON SOCIAL NETWORK SITES OF YOUNG PEOPLE WITH MILD INTELLECTUAL DISABILITIES

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ABSTRACT

DUE TO THEIR HIGH USER NUMBER, SOCIAL NETWORK SITES CAN BE REGARDED AS A PUBLIC SPHERE AND SHOULD BE ACCESSIBLE TO ALL DEMOCRATIC CITIZENS. NEVERTHELESS, THERE ARE SOME UNDERREPRESENTED SOCIAL GROUPS SUCH AS PEOPLE WITH MILD INTELLECTUAL DISABILITIES. THIS QUALITATIVE STUDY INVESTIGATES HOW YOUNG PEOPLE WITH MILD INTELLECTUAL DISABILITIES IN GERMANY ACCESS, INTERACT AND PARTICIPATE ON SOCIAL NETWORK SITES. THEREFORE, WE CONDUCTED 8 QUALITATIVE INTERVIEWS WITH YOUNG PEOPLE WITH MILD INTELLECTUAL DISABILITIES (AND THEIR CAREGIVERS, N=7) AND ANALYZED THE TRANSCRIBED INTERVIEWS WITH AN INDUCTIVE QUALITATIVE CONTENT ANALYSIS TECHNIQUE. OUR PARTICIPANTS DESCRIBED VARIOUS WAYS OF ACCESSING, INTERACTING AND PARTICIPATING ONLINE (E.G., SHARING THEIR OWN CONTENT). FURTHERMORE, OUR PARTICIPANTS GATHERED BOTH POSITIVE (E.G., GAINING NEW FRIENDS) AND NEGATIVE (E.G., HATE SPEECH) EXPERIENCES THERE. MOREOVER, OUR RESULTS GIVE INFORMATION ABOUT ASPECTS OF SOCIAL NETWORK SITES THAT SHOULD BE ALTERED SO THAT A POSITIVE SOCIAL CHANGE BASED ON THE INCLUSION PRINCIPLE CAN TAKE PLACE.

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Introduction

Social network sites (SNS) like Facebook, Instagram and Twitter have become increasingly popular in recent years (boyd & Ellison, 2007; Statista, 2019b, 2019a). Although high user numbers give the impression that SNS are accessible to everyone, not everyone can interact and participate on SNS. There are still some socially marginalized groups that experience various barriers while using SNS. For instance, people with intellectual disabilities (PID) are at a high disadvantage and continue to be socially excluded online and offline (Dobransky & Hargittai, 2016; Kozma et al., 2009). Studies indicate that PID have limited access to the Internet and are therefore less represented on SNS (Caton & Chapman, 2016; Chadwick et al., 2019; Fox, 2011; Guo * et al., 2005). According to the UN Convention on the Rights of People with Disabilities, participation of people with disabilities must be guaranteed in all areas of society, including media (German Federal Ministry of Labour and Social Affairs, 2011; Welke, 2012). Furthermore, Zaynel (2017) stated that successful inclusion in the Internet public sphere can lead to a "participation in social processes throughout society" (p.13). This means that successful online inclusion can contribute to a successful inclusion offline (Zaynel, 2017).

Therefore, it is essential to understand how PID use SNS as well as what the barriers are that they have to overcome. Carrying out research on the SNS usage of PID and giving them the chance to participate in a study is the first step toward overcoming the so-called *digital divide* and empowering them on their way to equality. For this reason, this study aims to get a deeper insight into this bottom-up process while investigating how young people with mild intellectual disabilities (yPmID) access, interact and participate on SNS in Germany. In the first part of the paper, we give an overview of the current research on the subject PID, the concept of inclusion, SNS use of PID and related areas. In the second part of the paper, we present a set of research questions, followed by a detailed description of our method, the results of our qualitative study, a discussion of the findings and a conclusion as well as limitations.

People with intellectual disabilities & the concept of inclusion

Intellectual disability is one of the most common medical conditions across the world (Hazarika & Choudhury, 2016). The prevalence of this disability is estimated to be around three percent of the general population (Maulik et al., 2011; McKenzie et al., 2016). There are two main approaches, which aim to define the phenomenon considering two opposing perspectives: the *medical approach* and the *social model* (Hermes, 2006). According to the medical approach, intellectual disability is characterized by significant limitations in intellectual functioning and adaptive behaviour, which covers a broad range of everyday social and practical skills. Besides, intellectual disability is diagnosed before the age of 18 (American Psychiatric Association, 2013; Tassé et al., 2016). The severity is described and classified by the terms *mild* (e.g., IQ 50–70, slower than typical in all developmental areas, no unusual physical characteristics, able to learn practical life skills); *moderate* (e.g., IQ 35–49, noticeable developmental delays, may have physical signs of impairment, able to learn basic health and safety skills); *severe* (e.g. IQ 20–34, considerable delays in developmental areas, able to learn daily routines) and *profound* (e.g., IQ < 20, significant developmental delays in all areas, obvious physical and congenital abnormalities, requires close supervision) (American Psychiatric Association, 2013; Häßler, 2011; Saß, 2003). The *mild* and *moderate* intellectual disability are the most common forms (Bourke et al., 2016). Contrary to the medical approach, other authors claim that intellectual disability is a socially constructed phenomenon excluding particular social groups that do not live up to the socially established frame of *normality* (Waldschmidt & Bildungs- und Forschungsinstitut zum Selbstbestimmten Leben Behinderter, 2003, p. 15). In this sense, the social model argues that deficits or disabilities are not personal characteristics but are social constructs that are created and re-created in the interaction between individuals and society (Pandey & Mishra, 2016). Furthermore, some authors claim that people with disabilities are capable of learning and adapting to the outside world and thus can become a "competent subject in their surrounding area" (Theunissen, 2013, p. 28).

Irrespective of these two opposing perspectives, PID encounter a great deal of difficulties in their day-to-day lives, in particular, acquiring skills like reading and writing (Hashim et al., 2016). Since the presence of emotional and social immaturity is also possible, it is usually quite challenging for them to marry or raise children (Häßler, 2011). Due to their intellectual condition and the resulting complications, many PID depend on other people's care, such as social workers or relatives (Firdaus &

Jadeja, 2016). Even though the majority of PID have no visible disability that could allow others to identify their impairment, they often experience problems in communicating with others, suffer from isolation and loneliness and have a narrow social circle, which usually consists only of their own family and caregivers (Emerson & McVilly, 2004). One way to include PID in society is reflected in the concept of inclusion. It assumes that all people, despite their differences, are equal, thus already a part of the society (Hermes, 2006). Zaynel describes this concept as "a further development of integration" (Zaynel, 2017, p. 66) and claims that social heterogeneity can refer not only to disability but also to other factors such as gender, background, religion, et cetera (Boban & Hinz, 2003). If heterogeneity is considered the "normal state" of the society, then inclusion is congruent with "immediate social belonging" (Bielefeld, 2011, p. 70). This leads to the idea that each human being's needs are important and must therefore be taken into account so that everyone can participate in society (Hermes, 2006), including SNS as a means to communicate and share issues with the network public sphere. The basic principles of inclusion are the "rights to self-determination, participation and support" (Theunissen, 2013, p. 19) and these presuppose the development of a new social order. This means that all social and cultural systems such as social services, education and jobs must be altered in a way that they are barrier-free. Moreover, the system changes are not to be brought about *top-down* but should be initiated by the affected people themselves (Theunissen, 2013).

The concept of inclusion also lies in the foundation of the UN Convention on the Rights of Persons with Disabilities, which has been valid in Germany since 2009 (Welke, 2012). According to its articles, people with disabilities are regarded as equal citizens, whose participation in all areas of society must be promoted by adapting society to their needs (UN Disability Convention, 2017). They also place a special emphasis on the access of people with disabilities to media because it should guarantee their "participation [...] in cultural life" (German Federal Ministry of Labour and Social Affairs, 2011, p. 75). Great potential for people with disabilities is attributed to the Internet and its applications (Zaynel, 2017). Antener (2015) stated that the Internet offers people with disabilities more opportunities for participation via innovative platforms, where one can adopt new skills and can therefore gain more social independence and a better life (Schaumburg, 2010). Furthermore, impaired users also have the possibility to express themselves "in a new and creative form" to the outside world (Schaumburg, 2010, p. 16). At the same time, SNS can also pose new challenges that can lead to exclusion instead of inclusion (Aktion Mensch e.V./die Medienanstalten – ALM GbR, 2016), such as cyber-bullying or sexual abuse (Holmes & O'Loughlin, 2014).

Online access, interaction & participation of people with intellectual disabilities

German blogger Carina Kühne, who has Down's syndrome, poses a prime example of successful inclusion in the online and offline public sphere. Through her blog and Facebook profile, she regularly shares information about the rights of people with Down's syndrome as a way to empower her community (https://carinakuehne.com). To achieve a similar successful inclusion online, PID need the opportunity to participate in online environments. According to Carpentier's AIP-Model (Access-Interaction-Participation-Model, Carpentier, 2016, p. 23), two main conditions must be fulfilled so that participation can take place (on SNS): access and interaction. Access can be interpreted as the opportunity of having access to SNS, thereby giving the user a presence on this platform to co-create with other users. Interaction can be considered the possibility to communicate and consume content with others. In contrast to interaction, participation also has a political dimension (e.g., spreading information about the rights of people with disabilities) (Matikainen, 2015), but can also be defined as an interaction with others where the political dimension plays a subordinate role (e.g., creating own content, reacting on hate speech; Jenkins, 2006; Villi & Matikainen, 2016).

Although Internet access offers a plethora of opportunities for PID, they still have limited access to it compared to other social groups (Ågren et al., 2020; Chadwick et al., 2013; Chadwick & Wesson, 2016; Naslund, 2018). However, if access is granted, their Internet use does not differ significantly from people without intellectual disabilities: they communicate, play games and search for information. In contrary, special online platforms such as *Facebook Access for People with Disabilities website* are rarely used by the target group. Studies indicate that people with disabilities prefer mainstream SNS like Facebook to interact and participate (Ågren et al., 2020; Chadwick et al., 2013; Chadwick & Wesson, 2016; Naslund, 2018).

Caton and Chapmann (2016) discuss that nowadays many PID are online on SNS and their usage has a positive impact on different areas of their life, contributing to the process of socialization. Various studies demonstrate the desire of PID to have more friends, especially outside their social group (Amado et al., 2013), which becomes possible through online communication. Söderstrom's study (2009) confirms this assumption: participants with disabilities intentionally use the Internet to establish social contacts with peers outside their milieu. Additionally, some PID also use SNS to find romantic partners and build intimate relationships (Darragh et al., 2017; Löfgren-Mårtenson, 2008). SNS also serve as a means of expressing social identity as well as sharing life stories, personal experiences and opinions (Caton & Chapman, 2016; Chadwick & Wesson, 2016; Chadwick et al., 2019). Thereby, PID can also use anonymization as a stigma reduction strategy (Tsaliki & Kontogianni, 2014). Furthermore, the nature of SNS allows role-playing as means for self-discovery since the impaired users can form an entirely different online identity that does not correspond to their behaviour offline (Holmes & O'Loughlin, 2014).

Zaynel (2017) sees Internet platforms as a potential for empowering the whole social group of people with disabilities to introduce themselves to the outside world; therefore, providing them with more independence in their daily lives. Nevertheless, online interactions can also entail risks (e.g., cyber-bullying, abuse) for PID. Thereby, studies indicate that "risk may increase contingent upon higher levels of sociability, loneliness, anxiety and depression, poorer insight, judgment, discrimination and ability to detect deception online and reduced experience and life opportunities" (Chadwick, 2019, p. 180, for an overview see Chadwick, 2019). Furthermore, Salmerón and colleagues (2019) demonstrate that PID can autonomously participate on SNS, but PID are often not capable of identifying less trustworthy content online. Thus, PID usually need support while searching for less familiar topics online.

This study

This study aims to explore and describe, according to the AIP-Model, the access, interaction and participation of young people with mild intellectual disabilities (yPmID) in Germany. For this reason, we devised the following research questions: (RQ1) What SNS do yPmID have access to? (RQ2) How do they interact on the accessible SNS? (RQ3) How do they participate on SNS? Furthermore, the study investigates the impact of different experiences regarding access, interaction and participation on the inclusion of yPmID.

Note: The participants of this study were people who were diagnosed with a *mild* intellectual disability. This decision was taken since (1) finding access to people with *moderate, severe* and *profound* intellectual disability poses a great difficulty; (2) The following research aimed to go a step further into the research on yPmID based on the foundation of previous research.

In line with the Declaration of Helsinki, all participants were informed in advance about the aim of the study and signed a consent form. At the same time, participants were reassured that they could end the interview anytime, as well as call off their participation later on.

Method

Since only a few studies have addressed the use of SNS by yPmID, we decided to conduct qualitative interviews to get a deeper understanding of how yPmID access, interact and participate on SNS. Following the example of Zaynel (2017) and Schreiner (2017), our methodological approach was adapted to the participants' needs so that they would not feel overwhelmed at any part of the research process. For this reason, the qualitative interviews were conducted orally, as some of our participants experience reading and spelling difficulties due to their impairment (Schreiner, 2017). Therefore, we translated our interview guideline into plain language, which means that the language was clear, easy to understand and without difficult words. In addition to the interviews with yPmID, we decided to conduct expert interviews with their caregivers. The interviews with the caregivers served as a tool to reflect and extend the interview data obtained from the participants with *mild* intellectual disabilities. This was necessary as their condition can sometimes lead to a distorted perception of everyday situations (Holmes & O'Loughlin, 2014).

Recruitment of participants

To answer our research questions, we recruited our participants (both yPmID and their caregivers) from a German social non-profit institution that offers accommodation and social care to PID. People there receive a different type of accommodation in relation to the degree of assistance needed. The accommodation possibilities are single flats, sharing community flats and a dorm. They are adapted to meet their clients' specific needs and portray the level of independence the clients have obtained. The participants in this study lived in shared flats or their own apartments.

Participants

A total of 15 interviews were conducted (8 adults with mild intellectual disabilities, 7 males and 1 female, aged between 22 and 31; 7 caregivers, 4 males and 3 females, no age information; further information, see Table 1). Despite the small sample size, previous studies on this topic have shown that a small sample can also offer valuable insights (e.g., de Groot et al., 2019).

Participants	**Age**	**Sex**	**Devices**	**Diagnosis**	**Reading and Writing skills**	**Place of residence**	**Working**
P1	22	m	Smartphone and Laptop	MID with behavioural disorders	Can read and write but does some mistakes. The participant needs assistance by comprehending of some texts	Shared community	Yes
P2	29	m	Mobile device and PC	MID with behavioural disorders; ADHS; Adjustment disorder	Can read and write, but does some mistakes	Shared community	No
P3	25	m	Smartphone	MID and depressive disorder	Can read and write, but does some mistakes	Own flat	No
P4	23	f	Smartphone	MID and depressive episodes	Can read and write	Shared community	No
P5	23	m	Smartphone and PC	MID and visual impairment	Can read and write	Shared community	No
P6	27	m	Smartphone and PC	traumatic brain injury, ID; Face problems orienting themselves in timely, chronologically and space spheres	Can read and write, but often faces problems comprehending texts	Shared community	Yes
P7	31	m	None	MID, ASD, social communication disorder	Can barely read and write	Own flat	Yes
P8	25	m	Smartphone and Tablet	MID	Can read and write	Own flat	Yes

Table 1 Participants' description

Materials

Our interview guideline for the yPmID included the following parts: 1.) A brief introduction with personal questions 2.) Explanation regarding the equipment and the usage of mobile devices (computer, laptop, mobile phone and tablet) 3.) Questions about SNS access, interaction and participation as well as positive and negative experiences, barriers and an overall evaluation of SNS.

Our interview guideline for the caregivers included the same questions, but they were primarily concentrated towards their clients. The caregivers were additionally asked to estimate the potentials of SNS for the inclusion of yPmID. Furthermore, all participants were encouraged to report everyday experiences on the topic.

Procedure

15 interviews were carried out during the period from 01.11.2018 until 14.11.2018. The most extended interview lasted 1 hour 12 minutes, while the shortest one lasted 5 minutes (mean value: 00:31 hours). All interviews were recorded as audio files and manually transcribed.

Data analysis

The interviews with yPmID were supplemented by postscripts to add further information (Schreiner, 2017). The data collected were processed via the inductive qualitative content analysis developed by Mayring (2015). In the first step, every transcript was read thoroughly by the authors several times. In the second step, the authors selected relevant statements (quotes) to answer the research questions. In the following step, all identified statements were contextually discussed. In the fourth step, the core statements were generalized (thematic frames) and embedded in a broader context.

Results

In the next section, we present the results based on the identified thematic frames (further information, see Table 2).

Access to SNS - an important part of participants' lives

7 out of 8 had various personal internet enabled devices (Table 1) and all interviewees had access to different SNS. Facebook and YouTube were the favorite SNS among our participants. All interviewees accessed and used them regularly (e.g., every day till many times a week). The usage of Instagram was slightly less common (5 out of 8 participants). Nevertheless, Instagram belonged to the SNS considered relevant by the participants. More informative SNS like Twitter were barely used. Only two participants were using Twitter at the time of our interviews. However, the interviews demonstrated that the access to SNS *"play(s) an important role"* (Caregiver No. 3) in participants' lives.

Initiating access

Even though SNS such as Facebook or Instagram were among the most widespread web applications among our participants, we wanted to know how they became aware of these platforms and what motivated them to sign up for them. Seven participants stated that they had noticed that many people in their social environment (e.g., school mates, peers) used SNS (*"I discovered YouTube through my classmates."* (Participant No. 4)). This aroused their curiosity and motivated them to try out some of them, which they found appealing.

Access barriers

Although all of our respondents had access to various SNS, they sometimes faced certain barriers while accessing and using these applications. The barriers either had a structural nature (technical and juridical) or were connected to the intellectual condition.

Limited internet data volume posed as one of the technical barriers. Although almost all participants had Internet access on their PC or their smartphone, the Internet quality varied among the participants. Those who lived in a shared community used a common router and therefore reported a poor or slow Internet connection on some days. This restricted the access to and usage of SNS, as well as the process of producing own content at home such as YouTube videos (*"YouTube mostly consumes the data volume."* (Participant No. 3)). The participants who lived in single flats did not have an Internet connection at home at all. Moreover, the Internet access was limited on all of their mobile phones (prepaid card), since our participants were not allowed to enter into Internet contracts, which indirectly restricted their Internet usage (juridical barrier).

The intellectual condition was another factor influencing the access to and usage of specific SNS such as Twitter. Only 2 out of 8 participants stated that they used Twitter. However, both of them mentioned that they preferred reading Tweets rather than tweeting themselves. All of the interviewees who had used Twitter at some point reported the same problem: Twitter was considered an overly text-intensive SNS for them (*"When you use Twitter, it's not easy to find out how to write a comment. You have to understand the texts first"* (Participant No. 1)).

Nevertheless, it is essential to note that none of the participants used any special SNS for PID, such as the *Facebook Access for People with Disabilities* webpage. Only one participant stated that he would appreciate more offers in plain language on YouTube.

> *Yeah, it would be cool if YouTube had stuff in plain language (…) more content in plain language to make certain topics more understandable. For example, how can I download a program properly?* (Participant No. 1)

They interact like people without handicaps

In the next part of the interviews, we talked with our participants about how and with whom they interacted online. In most cases (7 out of 8 participants), our interviewees primarily communicated (e.g., writing with familiar people), reacted or commented on social network content (e.g., liking photos of friends) and followed other people or various pages (e.g., following Influencers):

> *Facebook, I just check from time to time what friends and family members have posted or written, but I'm not so active anymore. I also don't post that actively anymore.* (Participant No. 5)

Communication is the most common usage motive mentioned

Communication with others posed the main reason for using SNS for our respondents. As one participant stated, *"You have to communicate somehow"* (Participant No. 3). Thereby, they mainly communicated with familiar people, such as family and friends. For this purpose, they primarily used the Facebook messenger app to write and receive messages from other users easily. Besides, five participants mentioned Instagram as a tool for communication. In comparison to Facebook, Instagram was primarily used to communicate with unfamiliar people (e.g., texting with Influencers).

> *Yes, indeed. I use Facebook-Messenger. I got the app on my mobile phone.* (Participant No. 2)

> *I use Instagram, because there are so many great artists there whose pictures I look at. I am inspired by them. That's really cool. And also, because I can talk to people there [on Instagram], even live. (…) You can go live there and talk to people for maybe an hour or two. It's really cool.* (Participant No. 4)

The desire to meet new people

Apart from interacting with close connections, most of the participants (6 out of 8 participants) mentioned that they used SNS to get to know new people, who did not belong to their social group (e.g., people without a handicap). One of the caregivers confirmed that socializing with new people and expanding their social circle was one of his clients' main motives for using SNS (Caregiver No. 2).

> *To make contact. The larger the circle of contacts, the bigger the network. Through contacts you can sometimes discover good things or more to learn, or to know how the people are doing, or how people in a certain area live.* (Participant No. 3)

However, texting with or sending a friend request to strangers took a lot of effort for the participants, which is why they often shied away from it. Whether they did it or not depended on their personal characteristics and interests. Only one of the participants shared that he was not interested in meeting new people at all as he did not have the time for this (Participant No. 6). Nevertheless, some of those who dared contact new people, benefited from their decision:

> *Sometimes I ask myself: 'Should I send him or her a friend request or not, or should I leave it as it is?', but again, somehow one doesn't dare, one is not brave enough. Instead, you write a comment like 'You did a great job, it looks cool', but getting to talk to strangers [an unknown user] is difficult.* (Participant No. 1)

Less politically coloured participation

Besides interacting, we wanted to find out whether and how our respondents participated (e.g., sharing photos) on SNS. For this reason, we talked with them about the process of creating their own content (e.g., uploading photos, sharing information). The majority of our respondents stated that they participated actively on SNS by producing and posting their own content. They posted private photos and edited images or self-made videos on SNS (7 out of 8 participants). According to them, this allowed them to present themselves online (5 out of 8 participants).

> *I joined Instagram, because I wanted to show people what I draw, since they might be interested and might like to talk to me.* (Participant No. 4)

In addition, 5 out of 8 people stated that they participated or had participated in Facebook groups with other people. Contrary to the political dimension of participation, none of our participants aimed to express or comment on political issues while sharing their own content or entering a Facebook group. Nevertheless, some participants mentioned that they intervened when they came across content that they perceived inappropriate. In such cases, they expressed their opinion through a comment or an emoji.

> *When I find something really, really bad, I click on the 'angry-faced emoji '(...) and then write something underneath, sometimes in an angry tone.* (Participant No. 2)

Facebook as an interactive diary

3 of our 8 participants stated that they used Facebook as a personal interactive diary. Their timelines enabled them to share pictures or mark special events. For one of the participants, this process had a special significance, since it helped him keep track of his own memories. Due to his impairment, his short-term memory was damaged. Therefore, he experienced persistent memory blank spots. The pictures on Facebook were the narratives that accompany his everyday life. Facebook enabled him to share photos with friends and relatives in Germany and abroad and regularly reminded him of moments he might have forgotten. In this manner, Facebook served as a chronological diary, where he could observe his son growing up by regularly posting photos of him (his son was a baby at the time of the research interview).

> *Due to my short-term memory problem, I use Facebook as my diary (...). It is nice because I can see photos that I have uploaded, especially the development of my son, how beautiful and big he has become.* (Participant No. 6)

Meet new friends and gain positive feedback

In the next step of our interview, we asked about the experiences (both positive and negative) our participants gained on SNS. Even though, according to the caregivers, making contact with new people took much effort for the respondents, there were also new friendships formed from these virtual interactions:

> *Yes, I found a good friend on Facebook (...).* (Participant No. 8)

Besides making new friends, many participants gained social gratification by receiving positive reactions on the content they shared on SNS such as private photos, edited images or self-made videos (5 out of 8 participants).

> *I have posted things that were pretty well received. I have been getting pretty good comments for them.* (Participant No. 1)

Yet, it is not only the feedback that had a positive influence on the respondents. As one caregiver reported, several people worked together to create content, such as YouTube videos about video games (e.g., Let's Play videos). The mutual exchange of ideas and the joint implementation of projects promoted our participants' creativity and helped them gain confidence in their abilities and be a part of a small community.

> *I've noticed that two of my clients use their hobbies as a subject to post on Instagram, so that they could be a part of a small community where they exchange ideas and give each other feedback.* (Caregiver No. 4)

Social network sites as a helpful tool in their everyday lives

Our respondents faced different challenges every day. Still, seven participants mentioned that using SNS helped them to overcome various daily obstacles. For example, thanks to "DIY"-YouTube Videos, they managed to obtain information about relevant topics, acquire new knowledge as well as become more independent while handling some new or challenging life situations. Thereby, YouTube also served as a means for self-improvement. Caregivers also considered SNS, especially YouTube, a source of inspiration or advice for their clients.

> *(...) it's inspiring to watch the videos of some Youtubers. They can even inspire you to say: 'I also want to do YouTube and show the people what I can, because you can also inspire people.* (Participant No. 4)

Gaining public attention due to social network sites

The majority of caregivers shared the opinion that SNS served as a tool for self-representation for some of their clients (*"There are one or two people who use it intensively. Because they just want to have a lot of followers. It's about recognition, boosting the own self-esteem (...)"* (Caregiver 1)). In this way, yPmID could get public attention, build up their identity, gain confidence and compare themselves with people in the public network sphere. Therefore, SNS could help yPmID gain the recognition or appreciation that they often lack in their real life.

For example, one of our participants had around 3,000 followers on Instagram, where he mainly posted artistic photos taken by him. Even though his posts did not have any political messages, they enabled him to present his interests and talents publicly and therefore gain self-confidence.

Virtual fights and hate speech

Besides the positive experience gained through SNS, both caregivers and participants also reported some negative experiences. For instance, caregivers mentioned that some of their clients participated in various SNS groups, where interactions often escalated in virtual fights leaving their clients insulted or anxious. Some participants experienced hate comments from other users regarding their own content. One stated that despite trying not to take hate comments personally, they still upset her every time (*"I don't get along with criticism so well (...) I feel hurt every time."* (Participant No. 4)). As a consequence, she altered her behaviour in order not to receive further hate comments (e.g., posting photos only with makeup). Furthermore, some of the caregivers mentioned that such conflicts were also challenging for them, because they had to support their clients in situations, which are often difficult to observe, since they took place online.

> *Otherwise, there is also a great conflict potential, especially when it comes to emotions. This is apparent and comes directly or indirectly to us [caregivers].* (Caregiver No. 3)

Superficial contacts

As already mentioned, a huge part of our participants had the desire to establish new social contacts online. Yet, many of these virtual contacts never crossed the online borders and remained on a rather superficial level. According to Participant No. 2, the communication in such SNS groups barely lived up to the expectations one had in the beginning.

Fake profiles

Five of the participants communicated with other people in Facebook as a way to encounter a potential romantic partner. These attempts confronted them with some problems such as fake profiles or people who were only interested in sexual encounters. Based on these experiences, one of the respondents shared having lost faith in Facebook as a platform for finding a serious relationship.

> *They [unknown Facebook users] either mess around with you, they have a fake profile picture, or they just want ***. Those are the three main things I have experienced so far.* (Participant No. 8)

Inclusion through participation?

At the end of the interview, we asked the caregivers whether and how SNS could contribute to the inclusion of PID. Most of them agreed that SNS such as Facebook supported the social inclusion of their clients. According to them, SNS raised awareness of PID by granting them the opportunity of having a personal profile and sharing content with familiar as well as unfamiliar people.

> *I use Facebook and I already know many groups of people with disabilities who advocate for themselves through it.* (Caregiver No. 2)
>
> *Through such Facebook profiles, one finds out that such people [with disability] exist.* (Caregiver No. 5)

Nevertheless, one caregiver pointed out that SNS routines such as Facebook events (e.g., Inclusion disco) could indirectly lead to exclusion rather than inclusion.

> *Things like the 'Inclusion disco' are also offered on Facebook as an event, but I find it rather excluding. The idea itself is nice, but it does not fall under the motto of inclusion. For me, inclusion means normality.* (Caregiver No. 3)

Thematic frames	**Participants (P) Caregivers (C)**	**Quote**
Access to SNS - an important part in participants' lives	P1, P2, P3, P4, P5, P6, P7, P8 C1, C2, C3, C4, C6, C7	Authors: "Can you give up on Facebook?" P3: "No, I can't without Facebook."
Initiating access	P1, P2, P3, P4, P5, P6, P8 C2, C3, C7	P4: "I signed up for Instagram because I wanted to show people what I drew, and they might be interested and want to talk to me."
Access barriers	P1, P2, P3, P4, P5, P6, P7, P8 C1, C2, C3, C5, C6, C7	Authors: "How is the WLAN in your shared flat?" P1: "Not that good. There are always some restrictions."
They interact like people without handicaps	P1, P2, P3, P4, P5, P6, P8 C2 C7	P4: "I also had other contacts on Instagram, whom I used to exchange manga-books and posters with. It was interesting."
Communication is the most common usage motive mentioned	P1, P2, P3, P4, P5, P6, P8 C1, C2, C6, C7	Authors: "Why do you use Facebook?" P3: "Because there one can exchange with other people, friends and family and one can also write. You have everybody there."
The desire to meet new people	P1, P2, P3, P4, P5, P8, C1, C2, C7	Authors: "So, you have two Facebook profiles?" P8: "Yeah, one of them is only for partner search."
Less politically coloured participation	P1, P2, P3, P4, P5, P6, P8 C2, C3	P4: "When I like the pictures (on SNS), I often comment how awesome they look."
Facebook as an interactive diary	P1, P4, P6 C3	P4: "[regarding Facebook posts] I always write a description to the picture as well as the date, when it was taken, so that the people can see, but only those ones who are my friends on Facebook."
Meet new friends and gain positive feedback	P1, P2, P3, P4, P5, P8, C1, C2, C3, C4, C5, C7	P3: "I already uploaded some videos on Instagram, and someone told me: 'You should apply for 'Germany looks for the superstar'"
Social network sites as a helpful tool in their everyday lives	P1, P2, P3, P4, P5, P6, P8 C5, C6, C7	P2: "There are also short videos that you can watch only on YouTube, so that you find out how a particular thing works. One should just learn."
Gaining public attention due to social network sites	P1, P3, P4, P5 C1, C2, C3, C4, C7	P1 "[talking about his Let's Play videos] I would like to show what I can a bit."
Virtual fights and hate speech	P4, P8 C1, C3, C6, C7, C8	P4: "I sometimes find the hate-comments just awful."
Superficial contacts	P1, P2, P6, P8, C1, C2, C6, C7	P6: "I used to watch the photos of my dear Facebook friends earlier. But these are no true friends…"
Fake profiles	P3, P4, P5, P6, P8, C1, C2	P5: "What really gets on my nerves are the fake profiles."
Inclusion through participation?	C1, C2, C3, C4, C5, C6, C7	C3: "It makes it easier for people who have intellectual difficulties (…) to communicate with the world."

Table 2 Thematic frames

Discussion

In accordance with the present results, previous studies demonstrated how the access, interaction and participation to SNS affect the lives of PID in various ways. Thereby, many authors discussed the motives of PID for using SNS (e.g., desire to meet new people or romantic partner; (Amado et al., 2013; Darragh et al., 2017; Löfgren-Mårtenson, 2008), the potentials of SNS for the impaired individuals (e.g., expressing a social identity online by self-generating content (Holmes & O'Loughlin, 2014) as well as the challenges regarding the SNS usage (e.g., cyberbullying; Holmes & O'Loughlin, 2014).

Despite the relatively limited sample, this study offers valuable insights into the access, interaction and participation of yPmID on SNS as well as their unique personal experiences and perspectives on the topic. A new positive point gained through our study is that 3 of our 8 participants use Facebook as an interactive diary. For one of them, this function plays a pivotal role in organizing his everyday life. This means that SNS can support PID leading an ordinary life despite the challenges caused by their impairment. To our knowledge, previous studies only investigated why people share photos or private information on SNS in a broader context (e.g., seeking attention, self-disclosure; Eftekhar et al., 2014; Malik et al., 2016). However, memorizing lifetime events on SNS due to the impact of cognitive needs seems to be a new usage motive, which was never reported before.

Furthermore, SNS are used by our participants as a helpful tool to overcome daily difficulties. Thereby, our participants, for instance, use DIY YouTube Videos to acquire various skills. Nevertheless, SNS can be very beneficial for our participants, especially if their content is in plain language. This result indicates that SNS need to be further adapted so that they enable PID access, interaction and barrier-free participation on such platforms. Only in this fashion, the principle of inclusion could actually take place (Chadwick et al., 2017; Holmes & O'Loughlin, 2014).

Besides, our study gives further insight into the experiences of yPmID with finding new friends or romantic partners on SNS. Although the desire to find new friends and establish romantic relationships was a subject investigated in previous studies (Amado et al., 2013; Darragh et al., 2017; Löfgren-Mårtenson, 2008; Söderström, 2009), our research indicates that fulfilling these desires might also bring risks. Besides fake profiles, some of our participants described the interaction with unfamiliar people on SNS as rather insufficient. In consequence, our results show that the interactions with unfamiliar people also have a negative impact on the self-esteem of our yPmID and that the gathering of frustrating experiences can result in losing trust on SNS. This points to the significance of online dating for yPmID as well as the importance of media literacy in this regard and emotional support by caregivers, so that PID can profit from the online dating platforms.

Furthermore, our results give information about how our participants interact in conflict situations. When they are confronted with virtual fights or hate speech, they often react to it, for instance, responding with an angry emoji to an inappropriate context. However, some of these interactions lead to negative consequences in the long run, since some of the participants feel hurt and try to avoid other conflicting situations and negative experiences (e.g., posting only photos with make-up). Nevertheless, other studies show that such risks are influenced by certain factors (e.g., depression, reduced life opportunities) and may not affect all PIDs who use SNS (overview see Chadwick, 2019). Besides, such conflict situations and their consequences in our case are also pretty challenging for the caregivers, since they should deal with them without violating their clients' privacy. Furthermore, caregivers themselves should get familiar with SNS to be able to use and comprehend them to offer adequate support to their clients. All in all, caregivers should be provided with special training regarding media literacy as well as dealing with challenging situations based on online experiences. For example, Chadwick (2019) claims that it is important to help PIDs learn how to deal with risk situations, so digital inclusion prevails.

Nevertheless, as previously mentioned, Zaynel (2017) sees great potential in Internet platforms for empowering the social group of people with disabilities by giving them the chance to introduce themselves to the online public. Our results demonstrate that – in our case – the inclusion through participation on SNS represents a slow bottom-up process, which can be pretty beneficial for PID. Even though they do not use SNS for advocating for their social group, our participants manage to gain new skills and even more important more confidence in themselves through creating their own content. Moreover, SNS allow participants to exercise the same online behaviour as any other average SNS user. They post photos, express artistic ideas, have followers and interact with them. The fact that one of our participants has around 3,000 followers can be seen as an indication that PID, especially yPmID, are up-to-date with the new technologies and are much more independent in their use as expected by many. This conclusion questions the existing practice of patronizing and preventing PID from using Internet and SNS. There are indeed certain risks regarding the social media usage of PID (overview see Chadwick, 2019; Holmes & O'Loughlin, 2014), but rather than ignoring them, inclusion requires that our society addresses them and finds new appropriate solutions. However, our study like the research conducted by Salmerón and colleagues (Salmerón et al., 2019) also demonstrates that PID can find their way around in familiar online environments. For this reason, yPmID should be more supported by caregivers and relatives in order to become a part of the networked public sphere.

Answering the question whether participation in SNS might lead to inclusion is rather complicated given the complex nature of the inclusion phenomenon. Yet, the present study shows that our participants are interested in SNS and are eager to participate on these social platforms. Moreover, they show self-initiative and independence by their SNS use. On the one hand, SNS provoke them to acquire new knowledge needed for the SNS participation (such as how to create videos on their own). On the other hand, SNS accompany a bigger transition through an autonomous search for information to gaining new skills and confidence required for leading a more independent life. This statement supports the core idea of the 'social model' that all people despite their impairment and limitations are capable of learning and adapting to their surrounding area (Pandey & Mishra, 2016; Theunissen, 2013). Nevertheless, it should be taken into consideration that our participants are cared for by a German non-profit organization, which stands for the offline as well as the online inclusions of their clients. Accordingly, the organization supports the access and participation of their clients on all social platforms. Yet, the majority of PID in Germany still face many barriers regarding their Internet participation, starting from their very access to this virtual public sphere. This indicates that a structural change is highly necessary, so that these people can make further progress in the online world.

Conclusion and limitations

Our study aimed to investigate the access, interaction and participation of yPmID on SNS. Furthermore, we aimed to find out more about their experiences in these online spaces as a way to comprehend the challenges they face on such platforms. This knowledge should contribute to the further development of SNS by adapting them according to the needs of PID. However, our study design faces several limitations that should be addressed in further research.

1. Due to the qualitative research design, a small, non-representative sample was generated. Therefore, any generalization of the results is not possible.

2. Some authors question the quality criteria of qualitative research methods such as objectivity, reliability and validity (Meyen et al., 2011). In order to overcome this limitation, the working process was held in a precise and a transparent manner so that it could live up to certain quality and ethical standards. Nevertheless, it should be mentioned that dissecting the text into paraphrases and reducing them into thematic frames can cause the complexity of individual passages getting lost (Ramsenthaler, 2013).

3. It was very challenging to recruit illiterate participants with mild intellectual disabilities who use SNS. Interviewing such participants would have been of great significance for understanding the challenges of a particular group of yPmID that were barely addressed in research before.

4. One interview (P7) lasted only about 5 minutes since the interviewee was not able to conduct a longer interview due to personal characteristics. We tried to take the person's statements fully into account for our analysis and at the same time tried not to give too much weight to them due to the short duration of the interview itself.

5. The statements given by the caregivers should also be critically observed. Even though they spend a lot of time with their clients, their personal views are subjective and can therefore be biased.

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