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# **Studying Problematic Online Behavior** of Adolescents With Mild Intellectual **Disabilities and Borderline Intellectual** Functioning: Methodological and Ethical **Considerations for Data Collection**

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#### **Abstract**

The aim of this study is to find a research method that results in capturing lived experiences of problematic online behavior of adolescents with mild intellectual disabilities and borderline intellectual functioning within four risk domains: commercial interests, aggression, sexuality, and values/ideology. Three research methods were examined and field-tested in small sample pilot studies: an online questionnaire (N = 16), two focus group interviews (N = 6 and N = 14), and a combination of participatory observations and visual elicitation (N=2). Both the questionnaire and the focus group studies were not able to generate sufficient knowledge to capture lived experiences. Key issues that arose were the respondents' comprehension of the research questions, their tendency to give socially desirable answers, the influence of group dynamics, and a lack of rapport between researcher and respondent. Results generated from the third pilot study were more promising. Participatory observations in the form of deep hanging out combined with conversational interviewing and elements of visual elicitation mended these issues and helped to create an authentic research environment, build real relationships, and level the playing field between researcher and respondents. Additionally, it invited the respondents to voice their opinions and feelings about their online experiences. Finally, the study inspires to use different communicational means with the adolescents to increase the understanding of their virtual world. Some important ethical and methodological limitations to these findings are discussed.

#### **Keywords**

ethnography, focus groups, methods in qualitative inquiry, photo elicitation, photovoice

#### Introduction

The online (problematic) behavior of adolescents frequently receives attention in youth studies (recent examples: Anderson, Steen, & Stavropoulos, 2017; Kerstens, 2015). In accordance with Hasebrink, Livingstone, and Haddon (2008), problematic online behavior is categorized into four risk domains: commercial interests, aggression, sexuality, and values/ideology. While the literature acknowledges that adolescents with Mild Intellectual Disabilities and Borderline Intellectual Functioning (MID/BIF<sup>1</sup>) experience specific problems due to their cognitive limitations in general (Boertjes & Lever, 2007), assumptions are sometimes made that they experience specific problems concerning online safety as well (Nikken, Berns, & Beekhoven, 2018; de Cocq & Boot, 2014).

However, these assumptions are often based on opinions of experts, parents, and field practitioners (Chadwick, Wesson, & Fullwood, 2013; Löfgren-Mårtenson, 2008), while adolescents with intellectual disabilities (IDs) themselves are often not sought out as respondents (Caton & Chapman, 2016; Chadwick, Quinn, & Fullwood, 2016). This could have significant consequences, as the views of professionals and parents on

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online safety and risk may make it more difficult for people with IDs to fully access the Internet (Gutiérrez & Martorell, 2011, Seale, 2007).

Seale and Chadwick (2017) and Caton and Chapman (2016) state, considering the above, that future research needs to include the lived online experiences of people with IDs. Especially the viewpoints of adolescents with IDs are underrepresented (Caton & Chapman, 2016; Chadwick et al., 2016). By denying people with IDs an active voice in the knowledge construction on their own behavior, they may be marginalized (Nunkoosing, 2000) and risk getting support that is unnecessary, unproductive, or even counterproductive to their needs.

To gain insight into the lived online experiences of people with IDs, a wider, more robust range of methodologies is essential (Caton & Chapman, 2016; Seale & Chadwick, 2017). The question which methodology is suitable to gain insight into these lived online experiences with regard to the earlier described domains of problematic online behavior arose while setting up a broader study designed to gather data on problematic online behavior of adolescents with MID/BIF. As research on people with IDs mostly has a deficit-based approach and often does not include the perspective of care recipients (Claes, 2016; Gabel, 2005), it was key to find a research method that gives care recipients an active voice and does not rely on proxies or experts as the primary source of information. There is a growing body of studies on creative research techniques like photo elicitation and photovoice that aim to better document the experiences of people with IDs in their everyday life (e.g., Boxall & Ralph, 2009; Jurkowski, 2008; Povee, Bishop, & Roberts, 2014), but the researcher has no knowledge of studies that fully capture the lived online experiences of people with IDs.

The limited knowledge base on lived online experiences might be due to difficulties in accessing adolescents with MID/BIF in an online environment and documenting their online behavior. This is in many ways no different when studying online behavior of adolescents in general, for example, regarding the unwillingness to disclose experiences and opinions to adults and strangers (Dedding, 2009). However, since user profiles do not contain information on IQ or behavioral histories, data collection by (participatory) observation of online communities or by searching for a is not an option. Making direct observations of, for example (problematic), conversations via social media is even more difficult. Collecting data retrospectively is almost unavoidable but increases the risk of recall bias. Finally, questionnaires or interviews on online behavior may be unfit for purpose as requirements for and assumptions of verbal, social, and cognitive skills could lead to a mismatch between these approaches and respondents with MID/BIF and raise the risk of interviewer and respondent bias.

The main research question presented here is what methodology results in capturing the lived experiences in the four risk domains of problematic online behavior, while providing scientific rigor and being ethically sound. Therefore, this article describes some attempts to develop fitting techniques to study actual online behavior of adolescents. It does so by (1)

describing the background and methods of three pilot studies testing different techniques, (2) discussing ethical considerations, and (3) reflecting on the applied techniques and methodology and their yield. Analysis of the actual data gathered on online (problematic) behavior of adolescents with MID/BIF as obtained by the final approach (as described in Pilot Study 3) will be presented in a different paper.

## Three Pilot Studies: Research Design

The researcher was presented with limited conceptual knowledge of online behavior of adolescents with MID/BIF and a lack of methodological solutions to gain insight into their behavior. In order to design a study that captures and gives voice to the online experiences of adolescents with MID/BIF, an explorative approach was taken, which will be presented here. Initially, two research methods were examined and field-tested in small sample pilot studies: an online questionnaire and a focus group interview. As these methods were both found insufficient in capturing the lived experiences of adolescents with MID/BIF, a third pilot study was conducted based on participatory observations and visual elicitation. The pilots were approved by the research committee of the Leiden University of Applied Sciences. Background and methods of the pilot studies will be presented first, findings with regard to the methodological weaknesses and strengths follow in a subsequent paragraph.

#### Pilot Study 1: Online Questionnaires

Research using a deductive quantitative approach is the basis of most studies on problematic Internet behavior of adolescents in general (e.g., Kerstens, 2015; Livingstone, Görzig, & Ólafsson, 2011). As mentioned, it was also applied in research involving people with IDs by Didden et al. (2009) and Salafranque-St-Louis and Normand (2017). A logical first step, therefore, was to explore whether survey research is feasible and valuable to study online behavior of adolescents with MID/BIF.

This pilot used an online questionnaire developed by Kerstens (2015) to collect data on what has been classified as problematic online behavior of adolescents aged between 12 and 18 in the Netherlands. This questionnaire was considered both valid and reliable to measure online experiences of young Dutch people, including lower educated adolescents. Items in the questionnaire were short and simple and the estimated time for completion was 10 min. Before filling in the questions, a short video was shown, which introduced the main topics of the questionnaire. In theory, this questionnaire also could be suitable for adolescents with MID/BIF. The Dutch MID/BIF guidelines on diagnostic research (Douma, Moonen, Noordhof, & Ponsioen, 2012) partly support this assumption by suggesting that in case of people with MID/BIF, the use of questionnaires can be feasible if the questionnaire is tailor-made for the target group. According to these guidelines, short, specific multiple-choice items should be used and presented visually.

Two applied psychology students of Leiden University of Applied Sciences assisted in finding 16 respondents with MID/BIF between the ages of 12 and 23. Eight participants were recruited through a special education school and eight through informal networks. According to the school and parents, all participants were diagnosed with MID or BIF. Before contacting research participants, the student assistant researchers were instructed on how to inform respondents on the study and their rights and how to guide them in filling out the questionnaire.

# Pilot Study 2: Focus Group Interview

Focus group interviews are organized discussions where, ideally, a group of six to eight people with similar profiles share opinions and experiences (Schuurman, Speet, & Kersten, 2004). As a well-established method in IDs research, the focus group interview has been found useful in studying sensitive topics with children (e.g., Hoppe, Wells, Morrison, Gillmore, & Wilsdon, 1995; Jacobs, Goossens, Dehue, Völlink, & Lechner, 2015) and might be useful when talking about topics like online aggression or sexting. Moonen (2006) used focus group interviews in combination with peer research to find out how adolescents with MID/BIF living in remedial treatment centers experienced their stay. He concludes that focus group interviews can be useful to measure experiences, opinions, feelings, and preferences of adolescents with MID/BIF; can yield results quickly, and can provide flexibility in what topics are being discussed.

Literature also mentions several disadvantages of conducting focus group interviews with people with IDs. For example, participating in focus groups can be a cognitive challenge for people with IDs because the ability to verbally reflect upon oneself and others, engage communicatively, and explore issues with minimal guidance from a moderator are prerequisite (Kaehne & O'Connell, 2010). Furthermore, adolescents in general (e.g., Norris, Aroian, & Warren, 2012) and people with IDs in particular (e.g., Kroll, Barbour, & Harris, 2007) are prone to lose concentration during focus group interviews. Also, although having advocates present during a focus group is often seen as an aid for getting to know and understand research participants, their presence could also influence the groups' dynamic process and trigger social desirable or prerehearsed answers from participants (Kaehne & O'Connoll, 2010). Another potential disadvantage of a focus group is that discussing sensitive topics may trigger past experiences and cause discomfort (Decker, Naugle, Carter-Visscher, Bell, & Seifert, 2011; Kaehne & O'Connell, 2010). Finally, focus group interviews can be challenging for the researchers as well if a focus group is heterogeneous, if some participants dominate the sessions, or if individuals use different means of communication (Kroll, Barbour, & Harris, 2007).

Two special education services participated in this second pilot study: (1) an academy where adolescents with disabilities live, learn, and work and (2) a special education school. In both locations, focus groups were organized with students with

MID/BIF. Four graduating applied psychology students assisted as part of their bachelor's thesis.

The first focus group comprised a class of six students with MID/BIF aged between 14 and 18: three girls, two boys, and one transgender person. In four different sessions, the group was introduced to and talked about several topics related to their online behavior. Their teacher was present during all sessions as the safety of the students was considered of greater importance than the influence of her presence on the social desirability of the group discussions. Some students could not attend all sessions. To improve the validity and reliability of the focus group interviews, one graduate student took notes of all sessions and observed the group dynamics. When not leading a session, the researcher and the other graduates also took notes and observed the group process. The goal of the first session was creating a safe and open environment for the students. The consent form was discussed, and house rules were established to ensure that all students felt comfortable enough to talk about their online experiences. The three following sessions involved substantive subjects like online sexuality, aggression, and consumer behavior. The students were promised a small gift for their participation. Every session started with rereading the consent form and checking whether the students still wanted to participate or had any uncertainties regarding their consent.

The second focus group was larger and comprised of 14 students of a special education school. As there were no extra classrooms available to divide the group, the first three sessions were held with all 14 students together. In this case, the teacher chose not to be present in the classroom to avoid social desirable discussions between students. During every session, the consent form was discussed. As part of the sessions, "Kahoot" was introduced, a game-based online learning platform that creates multiple-choice questions that students can answer on their own smartphone. Many students were already familiar with Kahoot, which eased use. Their answers formed the input for the group discussions on topics like online consuming and aggression. For the fourth and final session, an extra classroom was available, which gave more time for all students to participate. The participants were consequently divided into two smaller groups based on gender (eight boys and six girls).

# Pilot Study 3: Participatory Observations

In the third pilot study, the researcher initially considered monitoring the online activities of two adolescents by systematically looking at their browsing history, mapping the places they went online. Boyd (2014), however, stresses that just following the online trail of what teenagers do online is not enough to capture their online experiences. Interviewing, observing, and spending time in their own environment is crucial in how teenagers use online technology. Therefore, using ethnographical research techniques seemed logical as ethnographers emerge themselves in this context to develop a deep understanding of the people and their behavior (Morse & Field, 1996).

To find out whether an ethnographical approach could generate data on lived online experiences, deep hanging out was

used as the primary research technique. Deep hanging out is a form of participatory observation in which the researcher is present in a group for extended periods of time or for long informal sessions. Coined by Clifford in 1997 and rehabilitated by Geertz in 1998, the term "deep hanging out" describes how immersing oneself in a cultural group on an informal level can generate real stories of real people (Walmsley, 2018). Although poorly documented and described in literature, there are some studies where deep hanging out was used (e.g., Boyd, 2015; Wogan, 2010; Woodward, 2008). Walmsley (2018) gives a detailed account of the advantages and disadvantages of deep hanging out. He reports that deep hanging out potentially increases confirmation bias, raises questions about power and control, and is not for everyone due to the highly unstructured nature of the process. However, he also states that:

[t]he potential impact of these issues do not reduce the impact nor question the authenticity of the personal narratives presented and analyzed in this and similar audience research. Indeed one of the advantages of deep hanging out over shorter-term qualitative methods such as depth interviews and focus groups is that it allows for a multiplicity of modes and moments of communication, and encourages the development of a longer-term, more honest relationship between co-researchers, which is likely to reduce any confirmation bias. (Walmsley, 2018, p. 284)

Two adolescents with MID/BIF were contacted through the professional network of the researcher: a 14-year-old girl living in foster care and a 14-year-old boy living with his parents. Both adolescents were asked whether they wanted to meet with the researcher regularly. In order to reaffirm suitability for this study (relying on information the families gave), the respondents completed the SCIL (Screener voor intelligentie en licht verstandelijke beperking): a validated screening instrument for adolescents with MID/BIF aged between 14 and 17 (Kaal, Nijman, & Moonen, 2016)

Both respondents and their caregivers had a week to read the consent form and were invited to ask questions or express concerns during the first meeting. To ensure ongoing informed consent was given freely, the consent form was reexamined in subsequent meetings. Also, when new or important events occurred during conversations, the consent form was reread and discussed together (see also Carlson, 2013; Coons & Watson, 2013). Both respondents seemed receptive to this approach and showed a good understanding of the consent form. The adolescents and their caregivers agreed that for the study's purpose, visits would take place twice a week and additional contact could take place through the online messenger service WhatsApp. If anyone wanted to withdraw from the study, or when data collection saturated, data collection would end. As a reward for their time and effort, respondents were promised €25, which is considered to be an acceptable level of payment and minimizes the potentially coercive effect that incentives can have on adolescents (Crane & Broome, 2017).

In the first few meetings, the researcher worried that the differences in age, culture (both adolescents had a Hindu

background), and cognition could hinder conversations between him and his participants. Research suggests that adult researchers who work with young people often have fears about patronizing respondents, not behaving appropriately, and not finding common ground (Harden, Scott, Backett-Milburn, & Jackson, 2000). To address this, no data collection occurred during the first month. The teenagers were only asked to hang out with the researcher after school. Subsequently, both teenagers were invited for dinner at a restaurant of choice. Although the teenagers expressed some surprise with this approach, it positively contributed to building rapport. At first, they said it felt odd to play video games, eat a burger, or browse for clothes together, but it also made them more comfortable during the research, resulting in a relationship built on confidence rather than having someone around who studies them. This addressed a need in line with Dickson-Swift, James, Kippen, and Liamputtong (2007) who state that many respondents do not have enough people or opportunity to talk about their lives. Respondents also appreciated the high level of selfdisclosure: Both parties, researcher and teenagers, felt more comfortable by "leveling the field" during the meetings.

To reduce the potential disadvantages of deep hanging out, four measures were taken. First, a research diary was kept. All impressions of meetings were recorded onto a voice recorder directly after the meetings and transcribed and analyzed afterward. Besides generating data and providing more scientific rigor, this procedure contributed to the reflexivity of the study, making the researcher more aware of the role played in the research. The second measure entailed adopting a basic nonjudgmental attitude by the researcher, in which the teenagers were considered experts in their own lives. For example, the researcher asked the teenagers frequently whether they could explain how certain applications worked or whether they had tips for the researcher or other teenagers on Internet safety. The third measure included aiding and assisting the respondents in things not directly tied to the research, like fixing a computer problem, giving advice on how to communicate with a parent, or recommending a good movie. Both teenagers expressed their appreciation for the time the researcher spent on their personal lives. In return, the teenagers gave the researcher tips on music, video games, and certain smartphone applications. Dorozenko, Bishop, and Roberts (2016) also mention this approach to address the power imbalance between researcher and respondents with IDs. The fourth measure entailed incorporating two additional research techniques into the framework of deep hanging out, creating better structured meetings and providing better scientific rigor: conversational interviewing and photovideo voice.

Conversational interviewing is a research technique that supports the methodology of deep hanging out. This interview technique is a recursive process by which the agenda for the interview is established interactively by both participant and researcher (Burgess-Limerick & Burgess-Limerick, 1998). In conversational interviewing, research participants and researchers are considered co-constructors of knowledge. The researcher takes an active role by answering questions of

respondents, self-disclosing information, or even establishing friendships with respondents (Ribbens, 1989). Conversational interviewing was deemed helpful in strengthening the rapport that was built with the respondents, enabling the possibility to move beyond initial explanations of certain online behavior and provide better opportunities to check whether respondents understand questions and explore their (online) versions of reality (Burgess-Limerick & Burgess-Limerick, 1998).

Photo-video voice (Wang & Burris, 1994, 1997) was incorporated into the research strategy as it aims to shift the power of creating knowledge from the researcher to the respondent and thus reduces the influence of knowledge, status, and cultural background of the researcher (Kearney & Hyle, 2004) and acknowledges respondents as experts in their own lives. In between meetings, the respondents were asked to share screenshots of social media conversations, photos, and movie clips. Both respondents received an updated consent that included giving consent to media sharing.

### **Research Ethics**

Although methodological exploration may yield interesting insights into the possibilities of knowledge construction, it raises ethical concerns that point to the need of reflexivity. Reflexivity has several definitions; nevertheless, it revolves around the idea that researchers need to be aware of their influence on research and research participants (Charmaz, 2006). Although reflexivity is usually not seen in connection to ethics, several studies confirm the importance of reflexivity in doing ethically sound research. Guillemin and Gillam (2004) and McGraw, Zvonkovic, and Walker (2000) all state there is a useful connection between reflexivity and ethics in research because they see reflexivity as a process that not only revolves around the critical reflection of knowledge creation but also acknowledges ethical dilemmas that can arise before, during, and after fieldwork. Therefore, a research and ethical guideline was written, which gives detailed descriptions of the fieldwork and ethical approach. The guideline was intended to be a living document that can be updated when needed and gives respondents, organizations, and fellow researchers an idea of the methodological, practical, ethical, and legal implications of the research. It also serves as a mental reminder of the ethical challenges that can arise during the process of fieldwork and how to deal with them without harming respondents. The guideline contains three ethical topics important for all three methodological experiments: responsibility, informed consent, and confidentiality.

The foremost ethical rule in human sciences is the researcher's responsibility to prevent harm to participants. Respondents with MID/BIF are considered to be at extra risk of being strained or misinformed, especially if researchers ignore disabilities or are unaware of them. It has been reported that obtaining informed consent can be a challenge (e.g., Carlson, 2013; Goldsmith & Skirton, 2015) due to a greater desire to please adults and professionals, a tendency to give socially desirable answers, and difficulty or inability in overseeing and

assessing the consequences of choices. Dye, Hare, and Hendy (2007) even challenge the possibility of people with IDs to give consent. In their study on the capacities of people with IDs to give consent in research studies, they found that of the 85 research participants with mild or moderate IDs, only 5 participants were deemed able to give their consent to a study. Moreover, many adolescents with MID/BIF experience complex mental health issues, which makes it more difficult to assess set standards concerning capabilities of giving full consent.

Being aware of these challenges, the researcher took several measures to make the consent process as understandable and accessible as possible. Accessibility of the consent form in this study was generated by language use involving clear, short sentences structured by nine different bullet points. At the first research session, each bullet point was verbally explained and discussed. Respondents encircled a happy or angry emoticon to give visual clues whether they understood what was written or to what extent they consented. As described earlier, to ensure understandability of the consent form throughout the whole research process, the consent form was reread and rediscussed in several research sessions.

In a research context, confidentiality refers to which information can or cannot be discussed with or presented to others. Because of the sensitive nature of the research topics and the vulnerability of the respondents, it was crucial that respondents knew what confidentiality meant and what implications it might have. The consent form, therefore, contained a threestep process: (1) everything respondents shared with the researcher was confidential; (2) if respondents had a negative (online) experience, the researcher could decide to discuss this with a confidant anonymously, voicing concerns to respondents first, and always letting them know what the next step would be; (3) if this experience crossed the researcher's ethical or certain legal lines, breaking confidentiality was allowed. There is a legal duty to report knowledge of specific serious crimes, such as murder, rape, or arson, to a criminal investigator.

In sum, the guideline provided more rigor to the research methodology and sensitized the researcher to possible research bias, the relationship with his respondents, and the impact these factors could have on respondents' lives and research outcomes.

# Findings With Regard to Methodology From the Pilot Studies

Pilot Study 1: Online Questionnaire

All 16 adolescents who took part in the questionnaire pilot study first attempted to fill out the questionnaire without help. However, not one respondent felt able to answer all questions. Therefore, respondents were assisted in answering items they found most difficult. They were asked how they felt about the questionnaire and why they thought it was unsuitable for adolescents with MID/BIF. Most respondents explained they

experienced difficulty in understanding concepts and words used in the questionnaire. Most inaccessible items involved interpretation of certain concepts such as online abuse, theft, fraud, and deception or how to distinguish between making nude pictures and sexy pictures. Additionally, using a 5-point Likert-type scale in some questions proved difficult: Terms such as often, sometimes, and almost never were hard to interpret. Combined with the number of questions that used the Likert-type scale, most respondents explained that the task felt overwhelming. Another related problem was the absence of vivid, real-life examples that could support their understanding of the questions: Providing examples made it easier for respondents to understand the different concepts in the questionnaire. However, because of additional explanations and examples, completing all questions took more time. Rather than the reported 10 min, it required at least 20 min for most respondents. This counteracted the advantages of this data collection method as the prolonged time investment put too great a strain on attention and concentration. Furthermore, questions that made an appeal to recollections of past behavior were strenuous for all respondents; some reported difficulties in providing specific examples of certain online experiences and others experienced difficulties remembering the time frame in which their experiences took place. Participants also expressed concerns about their answers not meeting the expectations of the researcher: Several respondents mentioned they gave answers they thought the researcher would prefer based on his introduction of the research.

### Pilot Study 2: Focus Group Interviewing

As two different focus group interviews were held, these will be reflected on separately.

Group 1. Filling out the consent form proved difficult. Not all students had read and discussed the consent form with their parents, resulting in time-consuming discussions with some students at the start of each session. Even after giving consent, the researcher was not completely convinced that informed consent was given because some students lost concentration during the explanation.

Over the course of the four sessions, several meaningful discussions emerged. The sessions were led by the researcher or by one of the applied psychology students. The assisting students seemed to connect with the students with MID/BIF by presenting information in accessible, clear language supported by visual material (pictures and video). They checked whether the respondents understood the questions and topics regularly and asked them whether they could explain it in their own words. This led to positive results on less sensitive topics like their favorite websites and applications or their consumer behavior.

Despite these results, the students felt reluctant to talk with each other and with the researcher about sensitive and personal topics like their online identities, sexuality, and aggression. Group dynamics, trust issues, peer pressure, and social desirability prevented in-depth conversations. An example was when the transgender student opened up about his frequent visits to pro-ana (pro-anorexia nervosa) sites, the other students laughed and made hurtful comments that may have compromised his personal safety, but the safety of the group as well. The researcher addressed this by talking to the transgender student after the group session. The researcher asked her whether she felt uncomfortable or unsafe during the session and whether she wanted to talk about what happened. She told the researcher that she did not care and that she was used to being treated differently. Another example came from a student who talked about his online encounters with sex workers and clearly stated that he felt reluctant to go into details, partly because of the presence of other students, partly because he did not know the researcher.

Group 2. In the second special education school, the consent form posed a problem as well. Not only was discussing the form time-consuming with 14 students but some students showed what was considered noncooperative behavior by, for example, pleading they had a right to remain silent, that they did not want to snitch, or by shaming classmates for watching online porn. The chaotic nature of discussions that followed was attributed to described behavior, the large size of the group, and heterogeneity with regard to age, religious and cultural background, and language skills. Despite these issues, there were several discussions that the researcher deemed meaningful. Working with Kahoot in combination with personal examples of the topic at hand helped bring focus into the discussions and aided in breaking the ice between the researcher and the students. Students gave their opinions on topics like online gaming, identity fraud, illegal downloading, online stalking, online threats, and buying online without paying.

With the division of the group for the fourth session (see methods), a change was observed in the behavior of the students: Although some participants still dominated the conversation, the groups seemed more in balance. This may in part be due to the result of the smaller groups divided by gender and familiarity with the researcher and research goals. Most students seemed more relaxed and did not express the need to provoke the researcher like they did in previous sessions. There was more room for conversation on sensitive topics like sexting, grooming, and online pornography. One of the female participants expressed to attribute this mainly to the lack of peer pressure of the male students.

Concluding reflections on focus group interviewing. Although the focus groups in both schools showed potential for studying online behavior, several methodological problems emerged from these experiments. Key issues were the comprehension of the research questions, the risk of collecting socially desirable answers, the influence of group dynamics, and a lack of rapport between the researcher and the respondent. Because of these issues, it was difficult to capture the complexities and varieties of online experiences of adolescents with MID/BIF.

# Pilot Study 3: Participant Observations and Visual Elicitation

The respondents in the third pilot study were followed for approximately 6 months. After the first month of building rapport, a deep investment in the lives of the teenagers and their families began. There were meetings twice a week and listening to their favorite music, playing video games, and talking about their lives became the norm. The conversations became personal, intimate, and authentic. At first, neither respondents talked much about their online experiences or how these impacted on their lives. Although initially there was a fear on behalf of the researcher that starting a conversation on their online behavior would generate an unequal power and control dynamic, it brought more balance because of a mutual understanding of each other's motives and motivations for participating in the research. As a researcher, being transparent and open about the research and private (online) life seemed to resonate with both adolescents who opened up about their own online lives as well.

By hanging out with both teenagers and treating them as experts in their own lives, the playing field was leveled. Actual discussions on sensitive topics that went beyond the adolescents' online behavior started and showed how their online and off-line behavior are intertwined. As a result, both researcher and adolescents shared a deeper understanding of this connection. For example, when one respondent was asked why she forwarded movie clips through WhatsApp depicting teenagers being beaten or filmed in secret while engaging in sexual activities, initially she argued that the movie clips were funny and exciting. She did not see any harm in forwarding a video she had not shot herself and did not seem to realize the consequences of her actions. After a long discussion about the video content and the (potential) impact on the teenagers in these videos, she changed her perspective. When reflecting on the situation openly, it became clear that things had happened to her in the past for which she blamed herself. Concerning the girls in the videos, she thought they were, like herself, to blame for being in the video. She explained that her own experiences forced her to act like this toward others, both off-line and online. Watching and sharing these movie clips may have been a way for her to cope with her own negative experiences in the

Although trust seemed to be gained from the adolescents and deep, meaningful discussions on their online experiences arose, there still were some methodological issues. First, recollecting experiences that happened two or more days ago and, subsequently, linking them to a website or application often proved difficult for the respondents. This made tracking and discussing their recent digital activities problematic. Also, the regular removal of browsing history, photos, or text messages due to limited storage capacity on their smartphones (which were their primary device to go online) complicated the data collection process even further. Because of these two problems, the researcher sometimes took a more directive approach and

asked the respondents whether they would show him specific online content like WhatsApp conversations or websites.

By implementing photo-video voice in the conversations, these issues were partly addressed. Especially with the male respondent, this yielded some promising results. Before using photo-video voice, he was often quiet and unresponsive to questions. By discussing screenshots he made of WhatsApp conversations and browsing through his phone and computer during conversations, he opened up and started talking about things he liked and disliked and how this affected his life. There seemed to be a growing sense of ownership after he used his online activities as an anchor for the conversations. He also gave the impression that he was more confident to talk about himself and his issues, both off-line and online. One example of this was when he felt confident enough to show the researcher a WhatsApp conversation with someone who tried to persuade him to sell his dad's scooter. He said he felt pressured to sell the scooter, although he knew that his dad would be furious if he would tell him this. The way he took initiative by showing the WhatsApp conversation, and spoke about his fears and his relationship with his parents, was something he had not done prior to using his social media as input for the conversations.

The above shows the added value of using photo-video voice. Using visual examples of (past) online activities of the respondents as a trigger for conversations about their online experiences seemed to make them feel more comfortable and in control of the situation. There were, however, two issues that arose during the research sessions. First, structurally gathering photos or videos of online activities appeals heavily on executive functioning skills and proved difficult for both respondents. In most sessions, the researcher asked the respondents whether they would browse through their social media together. This somewhat diminished the control respondents had over the content that was discussed and possibly weakened their sense of ownership. Second, some examples the respondents shared contained explicit sexual and violent content. Some of these examples may be labeled as sexting or even assault. Legally and ethically, as a researcher, watching this content presents a dilemma. After a dialogue with the respondents, the researcher did not involve others and it was agreed to delete the video files from their phones, as the respondents did not create the content but were encouraged to share these examples.

#### **Discussion**

The aim of this article was to discuss and reflect upon different research techniques that can help understand the online experiences and behavior of adolescents with MID/BIF and does justice to their lived experiences. This is a necessary and important step, as this online behavior remains largely unexplored (Chadwick et al., 2016; Chadwick et al., 2013). Because looking after safety and development of preventive measures geared to their specific situation are often important parts of the support provided to these adolescents, this lack of knowledge provides a problem. The perceived vulnerability of this group,

the sensitivity of the research topics, and the concealed nature of the behavior under study make describing online behavior complex and difficult. Therefore, an explorative research approach was adopted to find research techniques that enable adolescents with MID/BIF to voice their insights and perspectives on their own online lives.

There is evidence that both questionnaires (Didden et al., 2009; Douma et al., 2012) and focus groups (Moonen, 2006) can be applied in MID/BIF research. However, the first two pilot studies suggest that both techniques do not generate indepth knowledge on the online behavior of adolescents with MID/BIF. Key issues that arose during these pilot studies were the comprehension of research questions, the tendency to give socially desirable answers, the influence of group dynamics, and a lack of rapport between researcher and respondent.

To address these issues, the third pilot study took an ethnographical approach, combining participatory observation in the form of deep hanging out, conversational interviewing, and visual elicitation. The most important finding is that these research techniques strengthen each other in generating rich and detailed accounts of (problematic) online behavior of adolescents with MID/BIF. Deep hanging out combined with conversational interviewing and photo-video voice helped create an authentic research environment, build real relationships, level the playing field between researcher and respondents, and invited respondents to voice their opinions and feelings about their online experiences. It also inspired the use of different communicational means with the adolescents to increase the understanding of their virtual world (e.g., talking and sharing photos and videos through WhatsApp and playing video games together) and the problems that they (may) encounter.

There are limitations that warrant discussion. First, the informal and reciprocal relationship between researcher and respondents created two ethical issues that had to be addressed. Both respondents shared private information on their off-line and online activities that could potentially harm them. This presented a dilemma between respecting the privacy and well-being of the respondents and completing the study. For example, the female adolescent confided in the researcher about chatting online with a male teenager, while both her foster parents and professional care workers forbade her to do so. The information she gave was important to better understand what she did online and what her motives were, but on the other hand, she was not allowed to talk to strangers online due to her perceived vulnerability. Acting on these dilemmas required careful balancing. Breaking trust in the interest of the respondents' well-being or keeping a secret that benefits the research both could have negative consequences for either party. The second ethical issue was that the developed bond between respondents and researchers could be classified as more informal than professional. Therefore, managing expectations was critical. In this light, both respondents were asked whether they wanted to stay in touch after completing the research, explaining that although they could always seek contact, visits could not be as regular as during the research. Although both respondents said to like the idea of having the

opportunity to stay in contact, only the female respondent occasionally did.

Second, asking respondents to gather visual examples of online experiences may create ethical and legal difficulties for both researchers and respondents. Future research needs to address how to deal with respondents who, for example, share photos or videos of cyberbullying, online threats, or sexual representations of themselves or others.

Third, although all three field experiments were carefully planned and executed, several biases should be taken into account. In addition to already discussed recollection and confirmation bias, selection bias may influence the validity of reported experiments. Also, research samples were small and the participants may not be representative of the research population.

Finally, the complexity of the research meant it often appealed to research skills, reflexivity, and ethical responsibilities due to, for example, the unstructured nature of data collection, power balance issues, the informal relationship with both respondents, and the sensitive nature of their narratives and visual materials. These difficulties are in line with Walmsley's (2018) observation that deep hanging out is not for everyone. During data collection, improvisations had to be made while entering an unfamiliar research territory. In combination with long, unstructured, and sometimes difficult conversations, the research process is considered to be time-consuming and mentally challenging and may need more rigor. Because of these complexities, caution is recommended before generalizing the usability of these research techniques to other studies. More field-testing in different contexts is recommendable.

Nonetheless, the insights gained by using the combination of these techniques show potential on how to study the online behavior of adolescents with MID/BIF and empower them at the same time.

#### Conclusion

There is no extensive knowledge about the online behavior of adolescents with MID/BIF, which is a problem for their social environment (e.g., parent, caretakers, teachers) to support their online safety. One of the important aspects of this knowledge gap is the lack of focus on the lived experiences of these adolescents and the reliance on proxies and experts as sources of data. This study explored several research techniques that could help gain more insight into the online behavior of adolescents with MID/BIF and their lived experiences. After conducting three field experiments, the results show that qualitative research techniques can facilitate a deeper understanding of the online behavior of adolescents with MID/BIF. Especially, the combination of participatory observation in the form of deep hanging out, conversational interviewing, and visual elicitation yield promising results. This study also highlighted several methodological and ethical challenges that need to be addressed in future research.

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#### Note

1. In the Netherlands, MID/BIF is defined by having an IQ between 50 and 70 or between 70 and 85, with additional problems with social adaptive behavior.

#### References

- Anderson, E. L., Steen, E., & Stavropoulos, V. (2017). Internet use and problematic Internet use: A systematic review of longitudinal research trends in adolescence and emergent adulthood. *Interna*tional Journal of Adolescence and Youth, 22, 430–454.
- Boertjes, M., & Lever, M. (2007). *LVG en jeugdcriminaliteit*. Diemen, the Netherlands: Expertisecentrum Jeugdzorg-Gehandicaptenzorg William Schrikker.
- Boxall, K., & Ralph, S. (2009). Research ethics and the use of visual images in research with people with intellectual disability. *Journal* of *Intellectual and Developmental Disability*, 34, 45–54.
- Boyd, D. (2014). *It's complicated: The social lives of networked teens*. New Haven, CT: Yale University Press.
- Boyd, D. (2015). Making sense of teen life: Strategies for capturing ethnographic data in a networked era. In E. Hargittai & C. Sandvig (Eds.), *Digital research confidential: The secrets of studying behavior online* (pp. 79–102). Cambridge: MIT Press.
- Burgess-Limerick, T., & Burgess-Limerick, R. (1998). Conversational interviews and multiple-case research in psychology. *Australian Journal of Psychology*, 50, 63–70.
- Carlson, L. (2013). Research ethics and intellectual disability: Broadening the debates. *Yale Journal of Biology and Medicine*, 86, 303–314.
- Caton, S., & Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual & Developmental Disability*, 41, 125–139.
- Chadwick, D., Quinn, S., & Fullwood, C. (2016). Perceptions of the risks and benefits of Internet access and use by people with intellectual disabilities. *British Journal of Learning Disabilities*, 11, 21–31.
- Chadwick, D., Wesson, C., & Fullwood, C. (2013). Internet access by people with intellectual disabilities: Inequalities and opportunities. *Future Internet*, *5*, 376–397.

Charmaz, K. (2006). Constructing grounded theory: A practical guide through qualitative analysis. London, England: Sage.

- Claes, L. (2016). In de Kijker: Disability Studies en interpretatieve, creatieve onderzoeksmethoden. In G. Van Hove, A. Schippers, M. Cardol, & E. De Schauwer (Eds.), *Disability studies in de Lage Landen* (pp. 32–48). Garant, Europe: Antwerpen-Apeldoorn.
- Coons, K., & Watson, S. (2013). Conducting research with individuals who have intellectual disabilities: Ethical and practical implications for qualitative research. *Journal on Developmental Disabil*ities, 19, 14–24.
- Crane, S., & Broome, M. E. (2017). Understanding ethical issues of research participation from the perspective of participating children and adolescents: A systematic review. *Worldviews on Evidence-based Nursing*, 14, 200–209.
- Decker, S., Naugle, A. E., Carter-Visscher, R., Bell, C., & Seifert, A. (2011). Ethical issues in research on sensitive topics: Participants' experiences of distress and benefit. *Journal of empirical Research on Human Research Ethics: An International Journal*, 6, 55–64.
- Dedding, C. (2009). Delen in macht en onmacht. Kindparticipatie in de (alledaagse) diabeteszorg [Sharing in power and powerlessness. Child participation in the (everyday) diabetes care practice]. Amsterdam, the Netherlands: Universiteit van Amsterdam.
- de Cocq, M., & Boot, L. (2014). LVB-jeugd en sociale media: Rapport over jongeren met een licht verstandelijke beperking (LVB) en de risico's van sociale media [Adolescents with Mild Intellectual Disabilities and social media: Report on adolescents with a mild intellectual disability (MID) and the risks of social media]. Stichting Kennisnet. Zoetermeer, the Netherlands: Stichting Kennisnet.
- Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2007). Doing sensitive research: What challenges do qualitative researchers face? *Qualitative Research*, 7, 327–353.
- Didden, R., Scholte, R. H., Korzilius, H., De Moor, J. M., Vermeulen, A., O'Reilly, M., . . . Lancioni, G. E. (2009). Cyberbullying among students with intellectual and developmental disability in special education settings. *Developmental Neurorehabilitation*, 12, 146–151.
- Dorozenko, K. P., Bishop, B. J., & Roberts, L. D. (2016). Fumblings and faux pas: Reflections on attempting to engage in participatory research with people with an intellectual disability. *Journal of Intellectual and Developmental Disability*, 41, 197–208.
- Douma, J., Moonen, X., Noordhof, L., & Ponsioen, A. (2012). Richtlijn Diagnostisch Onderzoek LVB: aanbevelingen voor het ontwikkelen, aanpassen en afnemen van diagnostische intstrumentenbij mensen met een licht verstandelijk beperking [Guideline diagnostic research mild intellectual disability: recommendations to develop, adjust and assess diagnostic instruments by people withmild intellectual disability]. Utrecht, Netherlands: Landelijk Kenniscentrum LVB.
- Dye, L., Hare, D., & Hendy, S. (2007). Capacity of people with intellectual disabilities to consent to take part in a research study. Journal of Applied Research in Intellectual Disabilities, 20, 168–174.
- Gabel, S. (2005). Disability studies in education: Readings in theory and method. New York, NY: Peter Lang.

- Goldsmith, L., & Skirton, H. (2015). Research involving people with a learning disability—Methodological challenges and ethical considerations. *Journal of Research and Nursing*, 20, 435–446.
- Guillemin, M., & Gilliam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative Inquiry*, 10, 261–280.
- Gutiérrez, P., & Martorell, A. (2011). People with intellectual disability and ICTs. Rev. Comun, 36, 173–180.
- Harden, J., Scott, S., Backett-Milburn, K., & Jackson, S. (2000). Can't talk, won't talk? Methodological issues in researching children. Sociological Research Online, 5, 1–12.
- Hasebrink, U., Livingstone, S., & Haddon, L. (2008). Comparing children's online opportunities and risks across Europe: Crossnational comparisons for EU Kids Online. London, England: EU Kids Online.
- Hoppe, M. J., Wells, E. A., Morrison, D. M., Gilmore, M. R., & Wilsdon, A. (1995). Using focus groups to discuss sensitive topics with children. *Evaluation Review*, 19, 102–114.
- Jacobs, N. C., Goossens, L., Dehue, F., Völlink, T., & Lechner, L. (2015). Dutch cyberbullying victims' experiences, perceptions, attitudes and motivations related to (coping with) cyberbullying: focus group interviews. *Societies*, 5, 43–64.
- Jurkowski, J. M. (2008). Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities*, 46, 1–11.
- Kaal, H. L., Nijman, H. I., & Moonen, X. M. (2016). SCIL. Screener voor intelligentie en licht verstandelijke beperking. Voor volwassenen (SCIL 18+) & voor jongeren van veertien tot en met zeventien jaar (SCIL 14-17) [Screener for intelligence and learning disabilities. For adults (SCIL 18+) & for adolescents in the age between fourteen and seventeen (SCIL 14-17)]. Amsterdam, the Netherlands: Hogrefe Uitgevers B.V.
- Kaehne, A., & O'Connell, C. (2010). Focus groups with people with learning disabilities. *Journal of Intellectual Disabilities*, 14, 133–145.
- Kearney, K. S., & Hyle, A. E. (2004). Drawing out emotions: The use of participant-produced drawings in qualitative inquiry. *Qualitative Research*, 4, 361–382.
- Kerstens, J. (2015). Youth and cybersafety: Youth being at risk and being a risk on the Internet (Doctoral dissertation). Open University, Heerlen, the Netherlands.
- Kroll, T., Barbour, R., & Harris, J. (2007). Using focus groups in disability research. *Qualitative Health Research*, 17, 690–698.
- Livingstone, S., Görzig, A., & Ólafsson, K. (2011). *Disadvantaged children and online risk*. London, England: EU Kids Online Network.
- Löfgren-Mårtenson, L. (2008). Love in cyberspace: Swedish young people with intellectual disabilities and the internet. *Scandinavian Journal of Disability Research*, 10, 125–138.
- McGraw, L. A., Zvonkovic, A. M., & Walker, A. J. (2000). Studying postmodern families: A feminist analysis of ethical tensions in work and family research. *Journal of Marriage and Family*, 62, 68–77.

- Moonen, X. (2006). Residential treatment, perceptions and experiences of young people admitted to a remedial treatment centre for young people with mild intellectual disabilities (Doctoral dissertation). University of Utrecht, Utrecht, the Netherlands.
- Morse, J. M., & Field, P. A. (1996). *Nursing research: The application of qualitative approaches*. London, England: Chapman & Hall.
- Nikken, P., Berns, J., & Beekhoven, E. (2018). *Mediawijsheid bij kinderen met een lvb: Een verkenning naar ervaringen in de praktijk*. Utrecht, the Nederlands: Nederlands Jeugdinstituut.
- Norris, A. E., Aroian, K. E., & Warren, S. (2012). Interactive performance and focus groups with adolescents: The power of play. Research in Nursing and Health, 35, 671–679.
- Nunkoosing, K. (2000). Constructing learning disability. *British Journal of Learning Disabilities*, 4, 49–62.
- Povee, K., Bishop, B. J., & Roberts, L. D. (2014). The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities. *Disability and Society*, 29, 893–907.
- Ribbens, J. (1989). Interviewing—An "unnatural situation"? *Women's Studies International Forum*, 12, 579–592.
- Salafranque-St-louis, F., & Normand, C. L. (2017). From solitude to solicitation: How people with intellectual disability or autism spectrum disorder use the Internet. Cyberpsychology: Journal of Psychosocial Research on Cyberspace, 11, Article 7.
- Schuurman, M., Speet, M., & Kersten, M. (2004). Onderzoek met mensen met een verstandelijke beperking: Handreikingen voor de praktijk. Utrecht, the Nederlands: LKNG.
- Seale, J. (2007). Strategies for supporting the online publishing activities of adults with learning disabilities. *Disability & Society*, 22, 173–186.
- Seale, J., & Chadwick, D. (2017). How does risk mediate the ability of adolescents and adults with intellectual and developmental disabilities to live a normal life by using the Internet? Cyberpsychology: Journal of Psychosocial Research on Cyberspace, 11, Article 2.
- Walmsley, B. (2018). Deep hanging out in the arts: An anthropological approach to capturing cultural value. *International Journal of Cultural Policy*, 24, 272–291.
- Wang, C., & Burris, M. A. (1994). Empowerment through photo novella: portraits of participation. *Health Education & Behavior*, 21, 171–186.
- Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, 24, 369–387.
- Wogan, P. (2010). Deep hanging out: Reflections on fieldwork and multisited Andean ethnography. *Identities: Global Studies in Culture and Power*, 11, 129–139.
- Woodward, K. (2008). Hanging out and hanging about: Insider/outsider research in the sport of boxing. *Ethnography*, 9, 536–560.