ORIGINAL ARTICLE

Conversations about health—Sharing the personal experiences of women with intellectual disabilities

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Abstract

Background: The text presents the opinions of women with intellectual disabilities about their lives and experiences in Polish society. The key recurring issue in the participants' statements was health in the light of their disability and femininity.

Methods: For the purpose of this study, focus group interviews were conducted with 20 women with intellectual disabilities. The collected interviews were analysed with the use of constructivist grounded theory.

Results: During the analysis, five general thematic areas were distinguished: appearance and beauty, health and sickness, intimate relationships, friends and acquaintances, and self-determination.

Conclusions: The results of this research suggest that neither womanhood nor disability, as such, are perceived by the study's participants as a burden or health problem in any of the aforementioned areas. Moreover, the participants identified sources of oppression, as well as the means of opposing them, for example cooperation, and claiming the right to self-determination.

KEYWORDS
focus group interviews, gender (femininity), health, Poland, women with intellectual disabilities

1 | INTRODUCTION

Women with intellectual disabilities suffer discrimination—mostly because of their disability but also because of their gender.[1] This discrimination manifests itself in the form of stereotypical and primarily negative social feedback when others learn about the diagnosis of a lower-than-average IQ score or notice physical traits characteristic of certain genetic mutations that are often accompanied by a lower-than-average intelligence quotient, and adaptive deficits in the areas of conceptualization, socialization and practical skills (DSM-V, 2013).

In Poland, people with intellectual disabilities are still regarded as a "less deserving" part of the population, which experiences numerous problems and is potentially vulnerable; they therefore often require continuous care, support and, most often, "protective" control (cf. Gajdzica, 2012; Koperski, 2012; Kosiorek, 2010; Ploch, 2018). In addition, the last few years have seen a transition towards a traditional approach to the disabled in state policies that is contrary to regulations that strongly protect the constitutional rights of people with intellectual disabilities under the Convention on the Rights of Persons with Disabilities (Gąciarz, 2017; Nowak, 2015; Szreniawska, 2012).

The expectations that others hold regarding the capability of people with intellectual disabilities to perform more challenging tasks are very low; it is a priori assumed that any person with an intellectual disability will fail regardless of the circumstances. Over the course of their lives, people with intellectual disabilities receive unequivocal signals from non-disabled members of society (relatives,

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[1]The multiple-discrimination phenomenon with reference to the population of women with disabilities was discussed at a European Conference held in Madrid in 2007 (CERMI Recognising the Right of Girls and Women with Disabilities, 2008). During this event, it was asserted that the multifaceted nature of discrimination is a result of interwoven elements of identity being assigned to an individual, rather than the sum of exclusions due to sex, disability, race and religion (Cieślikowska & Sarata 2012).

close acquaintances and those they meet on the streets) about their (inferior) role and (very low) social position—a situation that heavily influences people with intellectual disabilities and the way in which they define the boundaries of their subjectivity (Głodkowska, 2014). In subject matter literature, this process is known as adopting the identity of a disabled person (Beart, Hardy, & Buchan, 2005; Brzezińska, Kaczan, Piotrowski, & Rękosiewicz, 2011; Putnam, 2005; Zakrzewska-Manterys, 2010; Żółkowska, 2013).

Adopting the identity of a disabled woman can be perceived as an extension of this phenomenon. Women with either intellectual or physical disabilities experience gender discrimination even more acutely and suffer from mental illness more often than non-disabled women (Taggart, McMillan, & Lawson, 2008; Zaorska, 2013). Parents and people from their close network typically think of women with intellectual disabilities as "eternal children," thus allowing for a broad dismissal of any notion of self-driven fulfilment of biological, psychological and social needs to be acted upon by women with intellectual disabilities (especially achieving intimacy, engaging in sexual intercourse, being solely responsible for the decisions made in their lives, creating a lasting network of acquaintances, entering civil partnerships, etc.). Close contacts also exert tighter control over their lives (Mahony & Richardson, 2018; Pinto, 2015; Suwalska-Barancewicz & Malina, 2013). The femininity of women with intellectual disabilities is regarded as "defective" (cf. Coleman, Brunell & Haugen,2015): they are too inept to hold down any professional occupation, they cannot be boasted about by their husbands or serve as an adornment to their house, they are too irresponsible to be entrusted with taking care of a child, etc. (cf. Kijak, 2016; Kumaniecka-Wiśniewska, 2006; Malacrida, 2007).

Various aspects of the stereotypes and prejudices faced by women with intellectual disabilities may encourage research into different areas of their lives. Topics connected with their experiences of their own adulthood and femininity in a contemporary Polish society full of contradictory attitudes towards people with disabilities are of particular interest. On the one hand, most Poles perceive themselves as tolerant and accepting towards others (60% of the respondents in a national survey; cf. Omyła-Rudzka, 2017) but, at the same time, they quite often deny the right of people with disabilities to equally participate in social, educational and vocational activities (Niedbalski, 2019; Zakrzewska-Manterys, 2010, 2015) or simply reveal their more authentic beliefs (Kazanowski, 2019). The illusion of being good while doing wrong is encouraged among Poles by current social policy and by governmental ideas on how to "manage" the disabled. Nonetheless, people with disabilities are not as helpless as others might think. In our research project, we wanted to get to know the opinions of women with intellectual disabilities on their life in contemporary Polish society and on being adult, gendered persons. We assumed that talking about oneself and one's life would be a great opportunity to experience empowerment as well as solidarity with others (Stefánsdóttir & Traustadóttir, 2015). In general, women in Poland still encounter the expectation that they should stay silent and invisible, that is not to fight against gender discrimination

or not to assert their rights. Among these disadvantaged women are women with intellectual disabilities whose informed opinions on the perception of gender identity had not been investigated until 2015.

All the issues mentioned above are, in our view, unacknowledged social and cultural failures that should be studied in scientific research projects. This was also the reason we asked women with intellectual disabilities whether they are interested in sharing with us their opinions about living their adult lives. The aim of our research project was to learn how women with intellectual disabilities experience life in contemporary Polish society as gendered persons and participants of rehabilitation centres.

2 | METHOD

2.1 | Data collection

The focus interview method was used in the research. The subject matter literature mentions how social, psychological and educational aspects of the focus group interviews manifest themselves throughout the research participants' interactions (cf. Nyumba, Wilson, Derrick, & Mukherjee, 2018; Rabiee, 2004). There are several advantages of carrying out focus group interviews: such interviews can help obtain valuable data, they are conducive to group integration, they create a safe space for mutual learning, and they can lead to spontaneous "auto-therapy" (cf. Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007; Kamberelis & Dimitriadis, 2009).

A single focus group consisted of four to six participants and two moderators. There were four groups in total; one interview was conducted with each. Interviews lasted from 1h 20m to 2h, the average duration being 1 hr 40 min.

The study was carried out in 2015 in a facility located in Wroclaw (Poland) where well-established occupational therapy workshops (OTW) and a therapeutic rehabilitation centre (T-RC)[2] have been operating for a number of years. Both places were used to recruit research participants and obtain their consent to conduct the study.

It is important to pay attention to the threats that may appear while conducting group interviews: group conformism mechanism, a dominant leader in the group and failure to maintain anonymity among respondents (Kamberelis & Dimitriadis, 2009; see also Cyr, 2019).

2.2 | Participants

Twenty women with mild-to-moderate intellectual disabilities, aged between 19 and 34 (with an average age of 25), took part in the

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[2]OTW make up organizationally and financially distinct entities within the Polish help industry landscape. They are tasked with enabling persons with disabilities, who are otherwise incapable of finding and keeping paid employment, to acquire a job and/or hone the skills expected by prospective employers. T-RC is one of the forms of support offered to people with disabilities by non-governmental organizations.

study. All the participants lived with their parents, were unmarried and had no children. Only 5 were employed: 3 in the open labour market (OLM) and 2 through a Vocational Activity Centre (protected workplaces) (Table 1).

2.3 | Ethical issues

The study was approved by the main managers of the two centres where the research project took place. The ethical principles of the conducted research have derived from Helsinki Declaration and its subsequent amendments.[3]

In accordance with the method's assumptions, the activity of participants during the interviews was not forced, and each participant joined in when it was convenient and interesting for them. The respondents agreed to participate in the focus groups, signing the written consent.

The women were assured about the complete anonymity of research (in a written research report); it was also suggested that all conversations be treated as confidential by all the participants as they come from the same environment and know each other. All the respondents agreed to these conditions, which meet the minimum ethical requirements for this kind of research (see Lisek-Michalska, 2013). The research procedure was carefully prepared in order not to cause any discomfort to research participants.

A few rules regarding the course of focus interview were agreed on: each person had the right to speak, and participants agreed not to interrupt one another, criticize each other's statements or use unpleasant or vulgar words.

The moderators, after introducing themselves, initiated the interviews, presented the topic of the research project and asked the participants to share their experiences from their everyday life. The opening questions referred to femininity and adulthood (What is femininity for you? What do you associate it with? What does it mean for you to be an adult woman?). Subsequent questions were formulated during the course of the interview and related to issues that appeared spontaneously.

2.4 | Data analysis

The research we conducted was qualitative in nature and was guided by the interpretative paradigm and, more precisely, by constructivist grounded theory. For the researcher to interpret the collected data, he or she needs to immerse him- or herself in the experience of the research participant. That personal experience is only accessible through the participants' words and can be understood and explicated only when the wider individual and socio-cultural contexts are taken into account (Charmaz, 2009b, cf. Żuchowska-Skiba, 2018).

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[3]In Poland, there is still no obligatory principle concerning approval gaining from Ethical Committee (see Surmiak, 2019).

According to the assumptions adopted for the purpose of this research, the world is subjectively experienced by an individual. This assumption does not mean, however, that any effort at deriving meaningful insight from personal experience is futile. Conducting focus group interviews allowed participants of the study to explore two key categories, which are at the centre of this study: perceiving one's own disability and "performing" one's own gender (femininity). Researchers take it upon themselves to understand research participants' enunciations in their "raw" form, that is imbued with multifarious impressions. Every study entails the analysis of collected materials (which include recorded interviews and filed notes), followed by interpretation and, in the final stage, formulating (through induction) meaningful conclusions (expressed in the form of a report that constitutes anything but an objective account of reality). Preparing accurate and well-founded research reports relies upon adequate methodological and content-related preparation on the part of the researcher, his or her general knowledge of the participants' daily realities, cognizance of the socio-cultural contexts of participants' lives and being conscious of one's own role in the research process (Denzin & Lincoln, 2009).

The interviews were recorded and transcribed in Polish. The resulting text has been analysed in accordance with the constructivist grounded theory methodology (Charmaz, 2009b), which is especially suitable to research projects which concern with issues of social injustice (see also Charmaz, 2009c). It is, therefore, useful for giving a voice to those who are usually marginalized by a dominant group in society. Learning about experiences and opinions of women with intellectual disabilities can reveal how power structures work to reify social hierarchy by producing "others" and then placing them in unprivileged positions. Constructivist grounded theory methods enable participants to (co)construct and re-construct meanings of their experiences and, in such a way, support the processes of becoming self-aware agents in their own lives. Most of the time people act routinely, without reflecting on the processes and situations they participate in, and without being aware of just how much they know (Charmaz, 2009c, p. 733–735). The research process is also an exploratory challenge for researchers, since it requires them to uncover their own assumptions and "look at liminal, tacit meanings" from research participants who "draw on socially constructed discourses" (Charmaz, 2009a, p. 142). They must also confront internalized discourses on the perceived inferiority of socially disadvantaged participants.

Constructivist grounded theory methodology necessitates coding on three levels—initial, focused and theoretical. Initial coding consisted of reading the transcribed interviews and coding them line-by-line, as well as incident-by-incident. These codes, labelled with gerunds (e.g. *applying makeup*, *visiting a gynecologist for the first time*, *breaking up with boyfriend*), were constantly compared within one interview and between interviews in order to establish "a strong fit between data and codes. Because codes initially come very fast, recognize that these codes need to be constantly compared with new data" (Thornberg & Charmaz, 2012, p. 46). Focused coding enables us to "discover" the most important

TABLE 1 Data of focus interview participants

No.	Age	Intellectual disabilities severity level	Recruited at	Focus group number	Employment status
1	24	Moderate and physical disability	OTW	I	Not working
2	26	Moderate	T-RC	I	Not working
3	28	Moderate	OTW	I	Not working
4	26	Moderate	OTW	I	Not working
5	27	Mild	T-RC	I	Working OLM
6	30	Mild	T-RC	I	Not working
7	26	Moderate	OTW	I	Not working
8	29	Moderate	OTW	II	Not working
9	31	Moderate	OTW	II	Not working
10	34	Moderate	OTW	II	Not working
11	27	Moderate	OTW	II	Not working
12	30	Moderate	T-RC	II	Not working
13	32	Moderate	T-RC	III	Working OLM
14	30	Moderate	T-RC	III	Working VAC
15	29	Moderate	T-RC	III	Working OLM
16	32	Mild	T-RC	III	Working VAC
17	19	Moderate and physical disability	T-RC	IV	Not working
18	22	Mild	T-RC	IV	Not working
19	26	Moderate	T-RC	IV	Not working
20	32	Mild	T-RC	IV	Not working

or frequently used codes in the initial step (e.g. in our analysis, the core category named *one's sense of health and disease* derived from the concentration of the following codes: *valuing health as the most important issue, feeling sick, suffering from..., visiting the doctor*). The next step of the analysis was the verification of these emerged codes in terms of adequacy and analytical significance for an in-depth and comprehensive data categorization. Theoretical codes define relationships that may occur between categories constructed during focused coding. These codes are integrative in nature, and help to form complex and sensitive units (e.g. *An exchange of experiences related to illness and health*). The constant comparative method is the analytical core of grounded theory; it allows us to capture similarities and differences in the actions taken, in the ongoing processes, in the views and in the beliefs (e.g. *in feeling of health and feeling the disease*) of the research participants (Charmaz, 2009b, p. 76–110).

The categories that emerged in the process of constant comparison—"data with data, and data with categories, and categories with categories" (Charmaz, 2009c, p. 726)—pertained to experiences, actions, situations and events, as well as to attendant explanations, assigned meanings and personal interpretations. According to the principles of grounded theory, comparing codes with varying levels of saturation, and focusing on them afterwards allowed for the emergence of certain theoretical categories that indicated issues that were important for the participants of this study. These issues

represent five general thematic areas: appearance and beauty, health and sickness, intimate relationships, friends and acquaintances, and self-determination. Both moderators coded individual interviews separately, and then, the discrepancies were discussed, particularly in terms of each moderator's own approaches and convictions, and with regard to the proper use of data and quotes from the interviews. The confidentiality and safety of the examined data was also cross-checked.

3 | RESULTS

The following chart has been drawn up to facilitate the analysis of the collected material, as well as to present a complete view of the areas and emergent codes (see Figure 1).

We were mostly interested in the everyday life experiences and opinions of women with intellectual disability. The issue of health appeared in the interviews in each group and, seeing the interest and following the participants' needs, we have continued these talks. The research participants were eager to discuss health, pointing out diverse ways in which health can be perceived (somatic, psycho-emotional, psychosexual, psychosocial, psycho-political) and various meanings that can be assigned to it. These meanings also revealed individual and collective understandings of femininity.
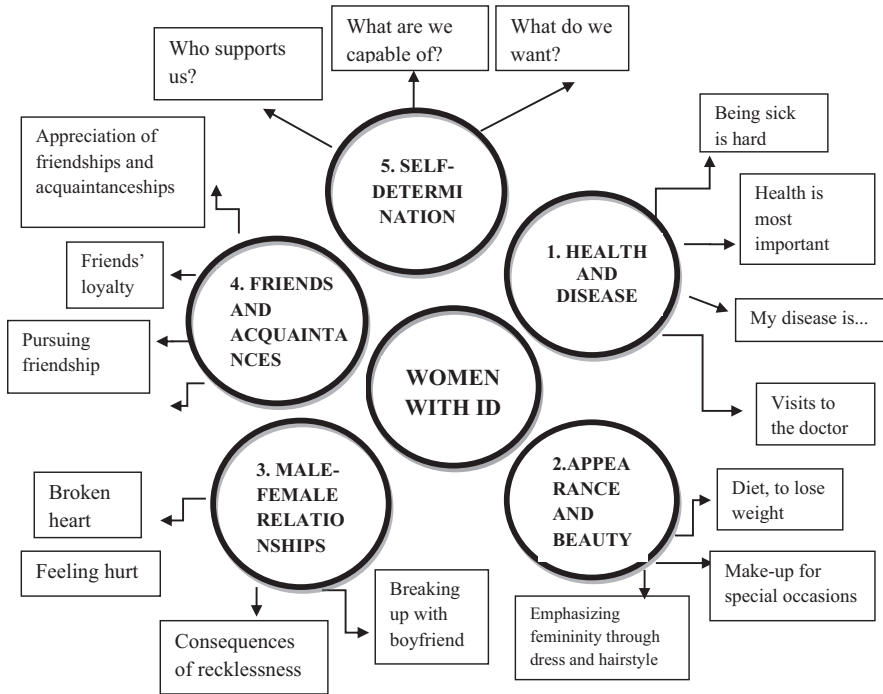
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FIGURE 1 Areas and codes extracted from focus interviews with women with intellectual disabilities

3.1 | Analysis and interpretation of emerging categories

3.1.1 | An exchange of experiences related to illness and health (somatic category of health)

The women participating in the study did not focus on trivial, transient problems. They understood illness as a situation that changed their lives and as a daily hindrance which they actively try to overcome with the help of professionals and family members. Notably, these women did not consider their intellectual disability an illness; they only spoke of themselves as being sick when they referred to the troubling consequences of disability or more severe illnesses independent of it. *My problem is that I have sick legs, and I can't always get everywhere, which is maybe why I don't have a group of friends*? (Participant/P 1). This observation may come as a surprise since, in Polish society, disability is still popularly seen (also by many medical professionals) as a disease-related to incapacity of the organism.[4] Sometimes, even people with disabilities (or their parents) tend to equate their condition with being ill (Zakrzewska-Manterys, 2018, p. 136). Clearly, this rule was not entrenched in the women with intellectual disabilities participating in our study. Notably, however, at least some of the participants presented disability as the reason behind the lack of success in their life in general, particularly related to their personal relationships (as presented in the above quote).

As the initial tensions subsided, the atmosphere became relaxed, and the participants started to feel safe around each other,

stories about severe physical illnesses became a major talking point:

> *I have a mental disability, but it can't be seen.*
>
> *(P 3)*

> *I have had psoriasis for years. Since the 6th grade, I have this disease. I don't know if you know what it's about? Psoriasis means that when I ate crisps, a small pack, it was immediately worse. [...] When I stopped eating crisps and started eating rice bread, the psoriasis just decreased. When there's, for example, sun, in the summer, you wear a bathing suit and psoriasis dries out. However, it reappears.*
>
> *(P 2)*

The research participants were clearly moved by what they heard from their peers and, even though they could not give any advice on the issues raised, they attempted to support each other by referring to other cases they knew of personally, for example *I am sick and my dad's brother also can't see—he had surgery on both eyes* (P 4); *My colleague has epilepsy, I found on the internet how to help him when he has a seizure* (P 5). Sharing one's own experience appeared to be related to the need to express acceptance of others and of the health difficulties that sometimes have to be dealt with in one's life. The ensuing communication exchange allowed everyone to brush the burden of unfulfilled social expectations off their shoulders and paved the way for the feeling of not being stigmatized because of one's disability. There was a sense of belonging to a group of like-minded people with whom one can safely share shameful or stress-inducing topics. It is typical for social

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[4]For example, Down syndrome and autism are still often called diseases, a misinformed statement that can also sometimes be seen in the media (e.g. Kochman & Stawicka 2012; Płatos, 2018).

comparisons to serve as a means for boosting one's safe-esteem (because others can be worse off), achieving acceptance of experienced difficulties (because everyone has to struggle with something) and, in general, improving one's day-to-day performance (because I am doing better than others in similar circumstances). Even when it became apparent that the results of the social comparison were not favourable to any of the research participants, for example *You have epilepsy, I'm worse off because I have schizophrenia... I've been taking medication for 10 years now and have become obese* (P 4). Those who had greater obstacles to overcome than others were not denigrated. In contrast, other women tried to buttress their self-esteem. The research participants also tried to comfort each other by expressing "universal truths" about life, such as *Everyone has some health issues* (P 3). Care and empathy took hold when it became clear that everyone was open-minded and willingly sharing their stories about personal health struggles.

All the women regarded taking care of intimate parts of one's body as an interesting topic, even if they already knew a great deal about it. All the women conceded that regular health check-ups are necessary. They described visits to a gynaecologist as something ordinary, even self-evident. They did not feel ashamed or disgruntled about this form of medical care. Some of the women, however, did complain about the attitudes of physicians towards them as patients: *As soon as I came to the doctor, he asked "Where's mom"? Without my mom, he didn't want to examine me* (P 12). A few others also complained of such unpleasant, infantilizing behaviour revealed by the specialists they had encountered. The perception of such situations varied between the participants of all four focus groups; it was the women with mild intellectual disabilities who expressed their discontent most clearly, probably because they were more accustomed to relative independence in their daily lives and expected others to respect their right to self-determination. Women experiencing more constraints on their daily functioning (in this case, participants of OTWs) regarded the necessity of someone without a disability being present during a check-up as obvious, perhaps even desirable: *No, not without mom because I might forget about something and won't know what to say* (P 13). Recollections of a visit to a gynaecologist shared by one of the women in one of the focus groups (all its members were in their 30s or older, and held jobs from the TR-C) were met by barely concealed, and pleasant, surprise: *The doctor asked me if I wanted my mom to be present during the check-up or if she should come in after it was over* (P 14). Open respect for the dignity of the patient was not deemed prevalent. Typically, the women observed that doctors of all specializations do not ask them about their opinions, arbitrarily assuming instead that they cannot or should not be responsible for their own treatment or that they are incapable of remembering its important aspects. In fact, almost all of the women voiced their opinion on this topic and, in the end, they agreed that having their carers' support during medical visits is something they are content with. Having their mothers or sisters by their side decreases the chances of misunderstanding doctors' prescriptions or making incorrect medical decisions and boosts the general sense of security. What the group discussion revealed, however, was that women with intellectual disabilities appreciate when doctors act towards them as they would towards any other adult woman, for example showing respect for their opinions and intimacy. This kind of "supervised" independence appears to meet their expectations and augments their sense of self-worth and dignity. Interestingly, most of the participants agreed that the proclivity of physicians to objectify them is outrageous and annoying.

3.1.2 | Giving advice, derived from personal experience, about taking care of one's physical appearance (psycho-emotional category of health)

It is still believed, or rather promoted by traditional and social media, that beauty care (which includes diet and focusing on body appearance) is the realm of women (e.g. Czernecka, 2018; Izydorczyk & Rybnicka-Klimczyk, 2009; Powierska, 2013). In the course of the research, it became clear that women with intellectual disabilities are fascinated by this topic. The most common themes that emerged from the research discussions were dissatisfaction with one's own physical appearance (reinforced by the critique from significant others by way of open comments about being, e.g. "too curvy"), losing weight (and feeling social pressure to become slim) and physical attractiveness (e.g. attained via the use of cosmetics).

As noted earlier, the age range of the women taking part in this study was between 19 and 34. Perhaps the age factor was the main contributor to their increased focus on looks and critical perception of what they saw in the mirror.

Based on the abovementioned information, all issues related to nutrition, body care and beauty unsurprisingly made up the bulk of topics raised by the participants of our focus groups; all the conversations, to a greater or lesser extent, were centred around these subjects. When one of the participants meekly admitted to her excessive body weight, *I can avoid eating in the morning, even at noon, but in the evening, I could eat the whole fridge* (P 4), the rest of the participants at once began listing all the ways in which she could overcome her predicament, for example *I have an idea! I heard that yoghurts or fruit... So, for example, white cheese* (P 5). Another participant revealed her own secret for becoming slim: *For dinner, instead of nothing, I eat "Mleczny start" ["Milky beginning"], a porridge that they say is for children. I only eat the porridge with water for dinner* (P 6).

Unfortunately, all the well-meaning advice given to this woman did not bring about a change in her dietary habits. She admitted trying everything and even noticed small progress in her endeavours, but her weakened willpower prevents her—as her mother does—from maintaining a habit of eating *only salad leaves* (P 4). This time, instead of giving advice, other participants showed compassionate understanding. One of the participants described facing incessant criticism from her grandmother for *growing too big of a belly* (P 5) and being constantly urged to do something about it. She herself conceded to feeling dissatisfied with her appearance (even though she could hardly be classified

as obese) because a person important to her kept noticing only her shortcomings. What the grandmother seemingly did was say circuitously that she needs to take care of herself, and then, she will have one less problem to deal with; she cannot change her mind's abilities, but she can change her body; a "normal" body can avert attention from an "abnormal" intellect.

Beauty care is perceived through the dominant cultural framework. At the same time, this perspective means pursuing an ideal of beauty as well as conceiving of "beauty self-discipline" such as hygiene, and perhaps even pleasure. Therefore, the participants spoke about "beauty regimes":

> ...for pleasure, for health. I think that for myself as well. And probably to look nice for others;
>
> (P 7)

> I learned to put on makeup when one lady came here and taught us;
>
> (P 11)

> I put on makeup only before going out; I don't normally like it;
>
> (P 8)

> I like to go [to the hairdresser] to have good hair and also because, unfortunately, I have grey hair and have to dye it.
>
> (P 16)

Conversations about improving one's appearance—even if they focused on the reasons behind the failure to adhere to a diet or feeling despondent about the difficulties and obstacles to achieving societal goals set out for women in general—facilitated the establishment of a safe, feminine space within the parameters of which the participants could learn from one another about new strategies for beauty self-discipline and about new trends and social expectations for (non-disabled) women. The group discussions on health (here, with regard to the psycho-emotional category of health) involved the traditional/stereotypical ideal of femininity, which is unattainable for many women, not only those with intellectual disabilities.

3.1.3 | An exchange of experiences resulting from relationships with men (psychosexual category of health)

Another issue that attracteda lot of attention from all the focus group participants was the problem of relationships with men.[5] Some of the women claimed to be in stable relationships, but most of them did not feel satisfied with the quality of these relationships. Additionally, none

of the participants seemed to maintain an intimate relationship with another woman; those who had become disappointed with their male partners exhibited greater appreciation for their relations with female friends and close acquaintances.

Sharing insights in public about one's partner (regardless of whether he is real or fantastical) and about the challenges experienced in a relationship (or a disappointment of not being in one) can be embarrassing and disconcerting to many. Our research shows that, initially, the participants felt uneasy about divulging any personal information. It was, however, sufficient for one person to break the silence, and then, other women followed suit. Openness gave rise to empathy and helped establish a safe space for all the participants to share their thoughts. As a result, the women themselves initiated conversations on topics that were especially painful or relevant to them. *I need some sort of help, advice... Because I just broke up with my boyfriend, my ex, and a new one caught my eye, and I don't know where I'm standing at the moment* (P 1)—one of them said. *Talk with him, ask if he truly wants you* (P 4)—other women spontaneously replied.

Sharing information about changing one's partner provoked conversations about the reasons behind a break-up, for example infidelity or betrayal of trust:

> I'm not lucky when it comes to boys. I can see nice boys here, but feelings hurt; I don't want to impose myself on anyone. When I trust someone, everything is okay. But when someone hurts you... I have a colleague whom I dated... I really liked him. We became close to each other, but not quite. I felt something, but not quite. And it ended... Yes, he hurt me. He talked, he smiled, he said that I'm his girlfriend... And in the evening, I received a text message: "I don't love you. I love someone else". And this has just... It was clear... because he didn't tell me he's meeting someone behind my back.
>
> (P 19)

Other research participants attentively listened their peer's statements and shared similar stories in response: about men's infidelities, about feeling abandoned by a partner and even about a terminated pregnancy or pregnancy and single parenting: *I had a boyfriend, because now I don't have one, and we spoke about him leaving me if I got pregnant. He told me that directly* (P 18). Another one added: *Often, boys just think "You're nice, let's make out"! There are boys like that, right?* (P 19).

The tenor of the interview (Focus Group no. III) conducted with four women in their 30s who were independent to a significant degree and held professional positions was markedly different from the other three groups that participated in the focus interviews. What they had to say about relationships with men provided further proof of their social and psycho-emotional maturity. No one in this group gave advice about how to deal with men. All of the participants gingerly listened to each other and shared their own life experiences, both good and bad. The latter were framed as cautionary tales for

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[5]The topic of intimate relationships arouses interest in the majority of people with intellectual disabilities (this has been proven in studies by, *inter alia*, e.g. Nowak-Lipińska, 2003; Janiszewska-Nieścioruk, 2013; Żyta, 2013; Kijak, 2016).

the rest, but they did not contain any explicitly voiced advice. For example, one of the women spoke about the dangers associated with online encounters:

> I met a certain man on the internet. He gave me his phone number and said "Call me". I wrote him back that I am a person with a disability and said something about myself. He replied "Call me, we can meet". I called him, introduced myself, told him where I live and that he should come visit me. To that, he said, "No, you come to my place, I want to see".
>
> (P 14)

All the other participants immediately replied with comments, such as *you can't do that, meeting someone online can be dangerous* (P 16), that were directed more towards themselves than to the person who just spoke. Cautioning one another about engaging in risky contacts with unacquainted men suggests that the study participants not only had internalized social sanctions directed towards women in general but also found these sanctions legitimate in their particular circumstances. These exhortations, along with making references to one's own experience, giving advice or encouraging more intimate communication with men, are considered typical of conversations between women.

3.1.4 | Underscoring the importance of friendships and acquaintanceships (psychosocial category of health)

The categories that underpin the framework for understanding female–male relationships have been noted earlier. Along with this analysis, relations with other women have been observed to play an important role in the research participants' lives; almost everyone emphasized how important the bonds are between themselves and their colleagues and friends. Boys only *smile, when I prefer drinking coffee with a friend, but with girls you can talk about everything: life, TV shows, boys—not only about football and sports* (P 18). One of the women described the importance of her same-sex friendship in the following way:

> I have a friend I have known since the first grade of primary school, so quite some time now. She has already started a family, gotten married, and has a daughter, but we still contact each other from time to time. We always remember each other during holidays or on birthdays for visiting. And I can see that she cares for me because she always wants me to be with her when something important happens. Like when she got married, I attended the wedding. I was also present during her daughter's christening... One, but true. I wish everyone a friend like that, at least one.
>
> (P 5)

Not everyone, however, is content with the acquaintanceships they have established. One of the women voiced her disappointment about the difficulties in finding friends:

> I don't really have friends... I sometimes come home utterly desolate because I also want to have some friends in the sense that I also want to meet with them after class, get to know each other. (...) And I would want to just turn up knowing that they're going to be nice to me, that they're going to talk to me. (...) I would want to meet with a few people, a crew as I call it, for example, during the weekend... And I don't know if they like me or what's going on here? (...) It's when I come to the centre, I want it to be cool; I would like to meet with them, speak to them. Only a few people visit me at home...
>
> (P 1)

A number of researchers have written about the social lives of adults with intellectual disabilities, particularly about the ways in which members of this group spend their leisure time (e.g. Cytowska, 2012; Krause, Żyta, & Nosarzewska, 2010; Żuraw, 2008). Conclusions drawn from this research are similar: women and men with intellectual disabilities who typically do not move beyond their homogenous environment (schools, centres, OTW), do not carry over their acquaintanceships from these environments into their homes. Those with greater autonomy and exposure to more diverse milieus more often meet outside of homes, institutions or workplaces—in what are more commonly known as places for social get-togethers. This tendency is reflected in the words of one of our research participants: *at work, I have a super group of friends with whom it's fun to talk, and we sometimes meet outside of work* (P 5).

A different issue pertaining to friendships/acquaintanceships (and to social support) that was eagerly discussed during the focus group interviews centred around loyalty or, more accurately, the distress caused by the lack thereof. It is for this reason that all the women taking part in the study realized the importance of this quality in building successful interpersonal contacts and called upon each other to keep all the conversations they took part in confidential: *Just don't be like, here we talk to each other, and when we leave you'll just turn on your heel, as if you didn't know me or didn't want to speak to me* (P 8).

From this and other enunciations, it can be safely concluded that, at least according to the research participants, focus group interviews could be the beginning of successful friendships with intimacy, openness, trust and loyalty as their cornerstones. The participants admonished each other to refrain from sharing opinions learned during the research with anyone outside of the group. The request for confidentiality opened a Pandora's box of problems encountered on a daily basis by these women when they participate in OTWs or T-RCs:

> A day won't pass by without scandals, gossips, it's just...;
>
> (P 9)

They pretend to be someone else during workshops, and before the class, you know what they do? Don't even ask...;

(P 10)

Every day, I come home fed up because they called me names, that I'm... Can I say that? (...) and when I had a boyfriend, they were mean as well;

(P 1)

What happens here is dreadful! I come home in tears, maybe not in tears but fed up...

(P 13)

The research participants were brought together by similar experiences of interpersonal difficulties, rejection by their peers and/or harassment (causing constant fear), and a longing for social encounters. Ambivalence towards social connectedness (on the one hand, the desire to become part of the, so-called, gang; on the other hand, feelings of anger and dislike towards their peers for their oppressive behaviours) is normal and common during adolescence and in early adulthood when the main developmental task of an "emerging adult" is to establish one's position in a group and find fulfilment of related needs: affiliation and affirmation (cf. Arnett, 2015).

3.1.5 | Mutual self-assurance about the ability to decide for oneself (psycho-political category of health)

The greatest challenge facing every adult is achieving self-determination.[6] People with intellectual disabilities in Poland are not only most often prevented from trying to attain this goal but are also precluded from even thinking about any personal needs that might be associated with it (cf. Gawlik & Pawlik, 2018; Krause, 2016; Kumaniecka-Wiśniewska, 2017; Marciniak-Madejska, 2013; Nowak, 2019). Normally, no one in the surrounding environment of people with intellectual disabilities believes that they are capable of taking care of themselves or being responsible for the consequences of their actions (e.g. Myśliwczyk, 2017; Żuraw, 2018; Żyta, 2018). Their yearning for independence is dismissed by others as whimsical, an unrealistic pursuit, a child's dream, etc.

The common perception of persons with intellectual disabilities as "eternal children" becomes a self-replicating "social practice," a self-fulfilling prophecy. This perception results in people with intellectual

disabilities playing their role according to subconsciously accepted social scripts. This focus group research has revealed how efficacious the process of the internalization of those expectations is. Most of our research participants, especially those already less autonomous in their daily lives, considered parental control, dependence on care and submitting to the decisions made by "significant others" as obvious. This was not so much because of the importance of any particular bonds or emotions but because the authority of non-disabled adults was simply deemed legitimate (this rationale was revealed by statements about their carers being "wiser"). Some of the participants' enunciations on this subject are presented below:

Mom buys me shoes, she knows which ones. When I'm at home, she brings them to me; [she says] she bought them for me and that they're my size; my mom always buys them. She chooses things that I look good in, and I'm fine with that;

(P 15)

I've yet to start looking for a job, and miss A. (teacher) says that she'll call my mom and tell her what kind of job she would want to give me; for example, placing items on store shelves;

(P 17)

I go to the store with dad. I don't use public transport alone because I have sick legs; as I've already said, I wouldn't make it alone on those buses;

(P 1)

I make decisions myself; I tell mom that I'm going here and here, and then, mom tells me that yes, I can go. I am independent.

(P 7)

Those participants who were active on the job market were more thoughtful of their personal situation, as well as their functioning at home and at work. When one of the women began to share her observations, emotions, ways in which she has been treated by others, etc., other participants joined the conversation and reflected on their own independence, overall competences and the need for developing a sense of agency. What the participants said were mostly slogans, but the dignity and sense of righteousness that underpinned them, and the tone in which they were uttered, suggested that these women were aware of their (limited) capabilities to "fight" for themselves and their autonomy: *We are right* (P 4); *It's about what you want! We're adults so we can decide for ourselves* (P 3); *We have the strength to be who we really are* (P 12); *I do it because I feel good about it, and you?* (P 9) (in the latter statement, one of the participants referred to staying up late at night to use the Internet, despite the bans and admonitions of her parents).

The study participants also raised potential obstacles to their plans; they thought about the difficulties they may face and advised each other about how to behave in various circumstances, for example:

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[6]The idea of a "psycho-political category of health" was construed for the purpose of this research to emphasize the necessity of addressing the issue of health even more broadly than only in relation to the somatic (body), psychological (emotions and psychological states), cognitive (thinking) and social (relations) spheres of human life. Similarly, important is the systemic aspect of health that encompasses: oppression and power relations, political processes of marginalization, deprivation of rights, injustice and discrimination, which all weigh heavily on personal well-being, daily capability to effectively function as a member of a given society, self-identification and maintaining healthy relationships with others and, even more importantly in the context of this research, developing a sense of agency, being capable of resisting or openly challenging injustices and fighting for one's rights (e.g. to self-determination), etc. (cf. Prilleltensky, 2003).

Yes, because they sometimes scam me in stores. That's a learning experience for me because I have to check if everything is okay;

(P 6)

Now I'm an adult, and people accept me the way I am, and you can see it; but sometimes, they make fun of me... I admit that's how it was, and sometimes, I just feel like I want to go somewhere, run. It's tempting, but I hold myself back from such things.

(P 19)

Those women who found employment on the open job market and in vocational training centres (who attended TR-Cs) attached greater importance to the possibility of working and receiving remuneration because it gave them: *a sense of security, self-realisation and motivation to live in general; I feel appreciated* (P 20). One of the women said:

I became more open towards people than I once was. I feel satisfied and, overall, I don't stay idly at home. I can buy myself cosmetics or go somewhere. (...) I'm most happy about exactly that, working.

(P 14)

Beyond work and deciding for oneself, another important topic raised during the focus group interviews was the necessity to hold one's own political views and to be cognizant of what happens around the globe. One of the women—a self-described feminist—admitted to watching news and information programmes whenever she had spare time. Because the idea of feminism was new to all the other study participants, she described in broad terms what it entails and why she advocates such views. After this short speech, all the women stated that achieving equal partnership is a goal they intend to attain.

4 | DISCUSSION

Health is a topic of paramount importance to every person. At the same time, it is subject to constant and intensive medical, social and political surveillance (especially with regard to women, e.g. Gromkowska-Melosik, 2013). Health can be analysed from various perspectives. Research on various aspects of the health of adults with intellectual disabilities has been conducted in different countries (e.g. Byrne, Lennox, & Ware, 2016; Cocks, Thomson, Thoresen, Parsons, & Rosenwax, 2016; Mach, 2017).[7]

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[7]In certain studies, we encounter women's health issues; for example, Noonan-Walsh & Heller (2002) dedicated her publication to various health contexts concerning women with intellectual disabilities and disease prevention; Kyrkou (2005) examined the experience of menstrual pain by women with IDs but through a survey addressed to their parents; Greenwood & Wilkinson (2013) reviewed research on the six aspects of sexual health care of women with intellectual disabilities, including barriers to sexual health care, sex education, sexual abuse and consensual sexuality, contraception, screening for sexually transmitted infections and cervical cancer, and pregnancy and parenting.

Considering the abovementioned information, it seems warranted to raise the "problem" of the individual experience of health among women with intellectual disabilities, especially the issue of health inequalities (cf. Bollard, Mcleod, & Dolan, 2018). This kind of approach makes it possible to notice problems that are acutely felt by women with intellectual disabilities, hear about the issues that bother them and learn about the neglect they often face, while simultaneously discovering the opportunities and chances they create for themselves, as well as their signs of resistance against not only the pressures of the dominant political and cultural discourse but also the strains experienced in day-to-day interpersonal relationships. Health both "invites" medical gaze (i.e. professional scrutiny) and, more recently, facilitates opposition to it (i.e. becoming a self-advocate on any crucial issue) (cf. Pinto, 2015).

The analysis of the data collected during this study was meant to discern the extent to which this research enabled its participants to share their personal experiences of being women and of being disabled individuals, that is persons who face numerous problems and often experience contradictory pressures from a patriarchal society and from overly protective relatives. Health, the issue at the centre of the research participants' discussions, influences every aspect of any individual's life.

The study participants spoke succinctly about health and emphasized its moral character: *it's most important* (P 10); *it's primarily connected with life* (P 14). Most likely, the women were not entirely aware of the influence exerted by the widespread culture of health and sickness on their way of thinking about life; they repeated the socially sanctioned message about the need to be mindful of health and to avoid illness (Byrne et al., 2016; Cocks et al., 2016; Mach, 2017).

Through the mass media (many of the participants regularly watch TV shows like soap operas and surf the Internet), a great number of women with intellectual disabilities are consciously or subconsciously exposed to such messages, even if they are not the target audience. While the women are deft at noticing information and cultural exhortations directed towards (non-disabled) women for the purpose of encouraging them to "produce" (or adequately enact/perform) gender stereotypes and to strive to achieve traditionally feminine goals (in this context, marriage and giving birth to a child), they face both overt and covert pressures to attain those goals/desires; the majority of them quickly learn about these pressures or become aware of their existence early in life (Wolf, 2014). The ubiquitous nature and persuasiveness of socialization-oriented messages greatly affect women with intellectual disabilities who experience an unfathomable and vague tension arising from the conflict between cultural precepts and familial prohibitions (cf. Friedan, 2012; Ramik-Mażewska, 2018).

A change in the attitudes of women with intellectual disabilities, especially those with moderate disabilities, towards their own lives and health, leading to greater openness and self-determination, is a function of an increase in the quality of their lives and of the people in their closest environment showing respect for their rights (Bollard et al., 2018; Kyrkou, 2005). This research has corroborated

what other studies have already shown (see, e.g. Strnadova & Evans, 2012; Arias, Ovejero, & Morentin, 2009), namely that the degree of control over one's life and the sense of self-determination are not determined by intellectual disability; other factors appear to be more relevant, such as health (which includes mental well-being) and environment—in this context, the harmful/infantilizing impact of family interventions, the negative impact of overly protective and supportive actions taken by people closest to them, the limited possibilities of finding employment and being able to plan one's future. Interestingly, the authors of the studies mentioned above also noted that the women participating in their research tended to develop certain strategies that allowed them to regain control over their lives and make decisions for themselves. These strategies included having discussions with relatives, openly expressing one's needs, becoming independent (therefore, proving that this in itself is not a pipe dream) and, on the other side of the spectrum, being passive and yielding to the requests of others. In the research presented here, it was possible to discern similar aspirations and behaviours. In addition, the focus group discussion itself was conducive to raising emancipatory strategies (cf. Beart et al., 2005; Cytowska, 2012; Głodkowska, 2014).

The need to respect the rights of women with intellectual disabilities is not only grounded in the Convention on the Rights of Persons with Disabilities (2012) but also in the Manifesto by Disabled Women in Europe passed during the European Disability Forum (2011), as well as in the agreements reached during the European Conference Recognising the Rights of Girls and Women with Disabilities. This issue has also been raised on several other occasions, for example in the document published by CERNI in 2008 and in the Standard Interpretation of the UN Convention on the Rights of Persons with Disabilities (CRPD) from a Female Perspective put forward by the German Disability Council in 2011. Ultimately, it seems vitally important to empower this population, to secure the inalienable rights of these women, to raise not only their own awareness but also the awareness of others in their immediate environment, and to make it possible for women with intellectual disabilities (to the greatest possible extent) to assume various day-to-day responsibilities.

4.1 | Implications for future research and for social practice

Recently, more Polish research projects in social sciences, and in special pedagogy in particular, have been shaped by the rather critical perspective on the social, political, educational and cultural problems and barriers faced by people with disabilities (e.g. Antosz, 2018; Kumaniecka-Wiśniewska, 2017). These researchers also prove how important it is to invite people with intellectual disabilities to participate in projects exploring their views on their lives, needs, activities, dreams and so forth. Some of these projects concern self-advocacy of people with intellectual disabilities as the most desirable way of gaining self-fulfilment, as well as

respect from other social actors. Our research findings also contribute to developing public discussion on this important subject. Unfortunately, there is a huge gap between social research derived from the assumptions on social justice and everyday social injustice and discrimination faced by people with intellectual disabilities, especially by women.

In 2018, the Committee on the Rights of Persons with Disabilities of the United Nations organization examined how Poland has been implementing the UN Convention on the Rights of Persons with Disabilities (ratified in 2012). The report, prepared by the Committee with cooperation with Polish Commissioner for Human Rights, identified a lot of instances of violations of rights of the citizens with disabilities (see Committee on the Rights of Persons with Disabilities, 2018). In the same year, 2018, in Polish Parliament experienced a second strike of parents of adult persons with disabilities, which lasted for 40 days and ended without any reasonable solution (cf. Kubicki, Bakalarczyk, & Mackiewicz-Ziccardi, 2019).

Taking the issues mentioned here in account, we should emphasize that research projects like ours may inform the public perception of people with intellectual disabilities, as well as public knowledge about their views and demands for respect and their human and citizens' rights. Although we can perceive some small changes in public and scientific discourses about people with intellectual disabilities, there are a lot of difficulties in accepting them by society as whole, as well as by officials responsible for social policy. We believe, however, that this could be transformed when people with intellectual disabilities become respected social agents whose opinions are heard.

4.2 | Limitations of the research

The research presented in the article was of qualitative in-depth character but, for this reason, the conclusions drawn refer to a small number of respondents from two Polish therapeutic–vocational institutions. Our interviewees participated in various workshops, vocational trainings and social activities; however, they were never asked before about the meaning they attributed to their femininity and how they experienced it in their adult lives. Thus, they were initially shy and lost in the research situation. The limitations of our study are also related to the difficultly of eliminating the tendency to seek social approval, that is agreeing of opinions held by the participants within a group setting.

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