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Access and utilization of intimate partner violence-related services: The multiple-level barriers encountered by women with disabilities

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Abstract

Background: Current data suggests a high prevalence of intimate partner violence (IPV) among women with disabilities (WWDs), yet there is still scanty research on the experiences of this population regarding access and utilization of IPV services.

Methods: Using qualitative in-depth data obtained from WWDs, our current study sought to identify factors that hinder WWDs from accessing and utilizing IPV services.

Results: This study showed that WWDs exposed to IPV encountered multilevel barriers nested at different societal levels as they attempted to access violence-rated services. At the individual level, the identity category of disability, not knowing about certain forms of violence, and being better off silent were the main explanations for not using IPV services. The role of personal connections was the main factor that influenced the utilization of IPV services, at the interpersonal level while at the organizational level, a lack of effective communication, power imbalances, inadequate resources, and failures to follow response standards were identified as the major barriers to using IPV services. Societal incompetence, as exemplified by treating violence as a taboo and the lack of regulations criminalizing psychological violence, was the main barrier at the societal level.

Conclusions: Our findings suggest that regarding WWDs, improving their access and utilization of IPV services requires interventions that address barriers at societal multiple levels including the individual, interpersonal, organizational, and societal levels. This should include early interventions and programs that not only target WWDs but also include other key players such as service providers on violence recognition and improve the quality of services. There is a need to also review laws and regulations regarding psychological violence and the nature of interventions in place for this type of violence.

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34 services, at the interpersonal level while at the organizational level, a lack of effective
35 communication, power imbalances, inadequate resources, and failures to follow response
36 standards were identified as the major barriers to using IPV services. Societal incompetence,
37 as exemplified by treating violence as a taboo and the lack of regulations criminalizing
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39 **Conclusions:** Our findings suggest that regarding WWDs, improving their access and
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41 levels including the individual, interpersonal, organizational, and societal levels. This should
42 include early interventions and programs that not only target WWDs but also include other
43 key players such as service providers on violence recognition and improve the quality of
44 services. There is a need to also review laws and regulations regarding psychological violence
45 and the nature of interventions in place for this type of violence.

46

47 **Key words:** abuse, Bronfenbrenner, socio-ecological theory, intimate partner violence, close
48 relationship, disabled, women with disabilities, service providers, qualitative.

49 **Background**

50 There is strong evidence that intimate partner violence (IPV) is the most
51 common form of gender-based violence that occurs in most cultures and at all societal levels
52 [1]. IPV can manifest in physical, sexual, psychological, and financial natures [2]. WWDs are
53 particularly more vulnerable to IPV due to other intersecting factors, such as having limited
54 material resources [3], dependence on others for long-term support [4-6], or a constraining
55 social environment [7]. IPV is considered a major public health threat that contributes to
56 increased physical and mental health problems [1, 8, 9]. The devastating consequences of
57 violence tend to linger on, even long after an abusive relationship has ended.

58 Receiving adequate support following exposure to violence plays a critical role
59 in minimizing its negative social and health impacts [10, 11]. It is of utmost importance to
60 build accessible domestic and family violence services to meet the additional needs of
61 WWDs[3]. Robinson et al. (2021) refer to Levesque et al.'s (2013) framework that discusses
62 the importance of access and accessibility in responding to women with disabilities in need of
63 domestic and family violence services [3]. Levesque's framework involves five dimensions of
64 accessibility, i.e., that the services must be approachable, acceptable, appropriate, affordable,
65 and available. Another key factor for successful access to violence-related services is the
66 competence to facilitate trust, choice, and agency [3]. In another study, IPV service providers
67 in Sweden indicated that coordination and collaboration were key aspects of providing
68 adequate services to women with disabilities [12].

69 Data from several contexts suggest that women with disabilities encounter
70 difficulties in accessing IPV services due to infrastructural barriers [3, 13], a lack of
71 confidence in providers, and services that are not adapted to the needs of people with
72 disabilities [10]. Obstacles in accessing IPV services often result in an increased risk of not

73 having one's experience acknowledged, being denied information, or missing out on
74 establishing contact with other women in similar positions [1, 8, 9, 14].

75 The devastating effects of non-adequate support were shown in a recent study in
76 Sweden where Skoog (2022) interviewed women (without acknowledged disabilities) who
77 had experienced IPV in a previous relationship [14]. Violence had repeatedly been focused on
78 restraining and controlling their social relations [14], which increased their isolation and
79 loneliness. This loneliness lingered on and increased long after the relationship ended. An
80 example mentioned was how women with children were forced to facilitate contact between
81 the child and their father (the violent partner), resulting in continued exposure to violence and
82 maintaining the abusive power structure [14]. However, little is known about the experiences
83 of women with disabilities in accessing IPV services.

84 This paper uses the term "IPV services" as an umbrella term referring to various
85 services, support, and care offered to individuals exposed to IPV [12]. We specifically focus
86 on experiences of accessing services offered by professional service providers working in
87 healthcare, social services, police, women's shelters, and centrum mot våld (the Centre
88 Against Violence). Even though IPV was the focus of our study, women described shared
89 experiences beyond IPV to encompass other perpetrators including family members and
90 caretakers.

91

92 **Theoretical framework**

93 Historically, people with disabilities (PWDs) have been regarded as "the other"
94 and have been separated from the "normative" society because of their "otherness" [15]. The
95 process of "othering" results in discrimination and the systemic exclusion of PWDs [16],
96 which affects their level of social participation and their access services, including IPV
97 services for women with disabilities. Discrimination against PWDs is so recurring and

98 pervasive that even those assuming a progressive posture (un)consciously support ableism
99 [17]. Ableism is the social prejudice towards PWDs constructed around a norm of the able
100 body, a body without physical or cognitive disability, impairment, or chronic illness. People
101 of able body/mind construct the world, language, culture, and belief systems to maintain their
102 norm as superior [17]. Ableist views support discrimination, creating and sustaining other
103 oppressive systems. Structures created to uphold ableist attitudes interfere with the full and
104 equitable participation of PWDs, eventually excluding them from accessing available
105 services. The oppression resulting from ableism can occur not only at an institutional level,
106 such as through laws and policies but also through social norms, even coloring personal
107 narratives among PWDs [7]. “Othering” creates access barriers, for example, people that have
108 negative experiences in accessing healthcare systems are less likely to reenter a health system
109 and seek appropriate healthcare [18].

110 In regard to access barriers, there is a tendency to attribute this to the problem of
111 cultural beliefs and practices of underserved groups rather than to discriminatory attitudes and
112 practices of care practitioners [19]. Such tendencies may be more common but hard to notice
113 which can result in microaggression, occurring as intangible discriminating and prejudiced
114 interactions, whether intentional or unintentional [20]. People who experience
115 microaggression question their perception of it through microinvalidation, leading to self-
116 blame and to the internalization of ableism [20]. This study serves to expand our
117 understanding of the experiences and perceptions of women with disabilities concerning
118 available IPV services.

119

120 **The socio-ecological systems theory**

121 In addition to the ableism theory, the socio-ecological systems theory was used
122 as an analysis framework in reviewing the women’s perspectives on factors that influence

123 access and utilization of IPV services. The socio-ecological systems theory was first proposed
124 by Bronfenbrenner (1979) to explain how social environments impact development [21]. This
125 theory provides an understanding of the way in which individual behavior can be influenced
126 by social and environmental factors and the interactions between them [21]. The socio-
127 ecological framework is used in violence research, policy, and practice to illustrate the
128 complex range of factors at the individual, relationship, community, and society levels that
129 protect people from or put people at risk of, experiencing or perpetrating violence [22-24].
130 We apply the socio-ecological systems approach to consider the complexity in the utilization
131 of IPV services among WWD.

132

133 **Methods**

134

135 **Aim**

136 The aim of our study was to explore and analyze barriers to access and utilization of IPV
137 services among women with disabilities. This knowledge might contribute to strengthening
138 the support of women with disabilities exposed to intimate relationships.

139

140 **Study design and setting**

141 This is a qualitative study based on eleven in-depth interviews with WWDs who
142 have, at any point in time, experienced IPV and subsequently sought IPV services. The
143 recruiting process lasted 10 months. It included advertising through disability organizations,
144 membership magazines, social media, national radio, and contacting shelters. The original
145 plan was to include both men and women in this study and as such both men and women were
146 invited to participate. However, of the 15 participants who showed interest to participate,
147 there was only 1 man who later declined to participate due to time constraints. Of the 14

148 women, 11 were interviewed, among the 3 participants who were not interviewed, one woman
149 reported time constraints, while the remaining two could not find a competent interpreter to
150 manage a digital interview. The participants' ages ranged from 25 to 55 years of age, and their
151 gender and disability were self-identified.

152 Semi-structured interviews themed around WWDs' experiences with different
153 IPV service providers were conducted by VL. While no participants were asked about their
154 specific type of disability or impairment, 10 of the 11 participants reflected on the disabilities,
155 which included: mobility impairment, hearing impairment, attention deficit hyperactivity
156 disorder (ADHD), personality disorder, stress-related disorders, eating disorder,
157 schizophrenia, depression, anxiety disorders, and post-traumatic stress disorder. Most women
158 spoke of having multiple disabilities.

159

160 **Analysis**

161 Data collected from the interviews was analyzed using thematic analysis. The transcripts were
162 read several times to identify themes and categories. All the transcripts were read by FN and a
163 subsample was read by VL and KW. Following several discussions between the authors, the
164 transcripts were coded by FN. Data coding and analysis were performed using the MAXQDA
165 software. The analysis process involved identifying and coding common words and phrases
166 that were subsequently grouped into subthemes and themes. Key themes were generated with
167 regards to barriers to access and utilization of IPV services by WWDs. Quotes from the
168 participants were anonymized and used to illustrate the themes identified in the study. The
169 study is reported in accordance with the consolidated criteria for reporting qualitative research
170 (COREQ guidelines).

171

172 Measures to ensure trustworthiness

173 Attention was paid, during the interview, to power relationships, and emphasis
174 was placed on developing security and trust in interactions, feeling shared comfort and safety,
175 which helped to minimize the distance between the participants and the researcher. To ensure
176 trustworthiness, we applied the four principles of credibility, transferability, dependability,
177 and confirmability [25, 26]. The interviewing researcher ensured credibility through
178 interacting and engaging with participants during the process of recruitment and data
179 collection. At the analysis stage, confirmability was established using an audit trail, checking
180 that the research team brought different perspectives to the interpretations, conclusions, and
181 recommendations of the results. Dependability was ensured at the writing stage through
182 elaborately providing details of the applied methodology. Using MAXQDA made audit
183 trailing simple and efficient, as each code could be easily traced to the person who said it. To
184 ensure transferability, we used verbatim transcripts and detailed descriptions of the data to
185 provide the readers with adequate information to make judgments as to whether the findings
186 of our study are applicable to other settings.

187

188 Ethics approval and consent to participate.

189 Ethical approval for the DIS-IPV project was obtained from the Swedish Ethical
190 Review Authority [J. Reg no. 2019–05249]. All interviews were conducted after appropriate
191 verbal and written consent from the participants. Identifiable information was removed to
192 prevent the results from being traceable.

193

194 Results

195 We identified eight themes described by the participants to have influenced their
 196 access and utilization of IPV services. The identified barriers occurred at multiple levels, i.e.,
 197 (1) the individual, (2) the interpersonal, (3) the organizational, and (4) the societal level,
 198 bearing a strong resemblance to the dimensions proposed in Bronfenbrenner’s ecological
 199 systems theory [21]. Results are presented according to these levels.

200

201 **Individual-level barriers**

202 Barriers that were identified at the individual level included the identity category
 203 of disability, not knowing what certain forms of violence were, and being better off silent.

204

205 ***The identity category of disability***

206 Women who had less visibly obvious disabilities were hesitant to seek IPV services.
 207 Hesitance and ambivalence in seeking IPV services arose from fear of disclosing their
 208 disability as this would allow others to view and treat them as disabled, for example, WWDs
 209 11 said that,

210 “You just become synonymous with your diagnosis or your history. It very
 211 much becomes pity. I have a hard time talking to people, e.g., curators...
 212 doctors, people who have not worked with people who have gone through
 213 things... I met a psychologist and a counselor who started crying. I sat there
 214 thinking "yeah" this is my life, my everyday life, this is what I live with
 215 every day. That you sit and cry does not help me. I was very pissed when I
 216 got there... I was angry at everything and everyone”, (WWD 11).

217 In the example above, this woman resented her experience of being met with pity, she
 218 considered such professionals to lack experience. Women wanted providers to treat them in a
 219 similar way as they treated other women without disabilities. Revealing one’s disability led to
 220 the loss of their own identity, as service providers were described as viewing them as identical
 221 to their diagnosis. This form of treatment was often described as service providers’ lack of
 222 experience. In some other instances, women felt it was a way of service providers’ attitudes

223 toward the disability itself that led to not taking them seriously, not being visible, and not
 224 being listened to as illustrated in the examples below. In this first text, this woman reflected,
 225 “It does not seem to be that they always take your words seriously”, (WWD 5). Another
 226 woman viewed this ongoing negative treatment to bear resemblances to how PWD have been
 227 treated in the past,

228 “We who have disabilities, we are not there yet, I can say because we are not
 229 visible, we are not heard as much as all other people... Considering the old view of
 230 people we had several years ago, you saw us as disabled, so people are still hooked
 231 on those ideas... We were locked up in institutions... I think it is a shame that this...
 232 is still allowed to exist as it does now in Sweden and in our society”, (WWD 7).

233

234 ***Not knowing about certain forms of violence***

235 Some participants were aware of physical and sexual violence, however, the vast
 236 majority of interviewed WWD were uncertain of what constituted economic and
 237 psychological violence. Many admitted that they had never sought professional help due to
 238 these latter two types of violence because they did not consider them violence. WWD 10
 239 described getting shocked the first time someone referred to her experiences as being
 240 subjected to psychological violence “they told me that I had been subjected to psychological,
 241 physical, and financial violence. At first, I did not know what mental abuse was. I was so
 242 shocked”, (WWD 10). In another example, the woman did not consider her partner abusive
 243 because he had never hit her, she had never considered naming her partner’s angry outbursts
 244 as a form of abuse, “He never hits, so what’s the problem? He just got a little angry. Yes, he
 245 broke the wall next to my head, but he did not hit me”, (WWD 9). Failure to recognize the
 246 partner’s behavior as abusive hindered some women from viewing it as a problem worth
 247 seeking care and support for.

248 In some cases, women describe a lack of awareness of what constituted a
 249 healthy, or a non-healthy relationship. Failure to label a relationship as healthy or not made it

250 difficult for WWD to differentiate between acts of love and acts of violence. Some women
251 described a scarcity of role models in their own environment exemplifying how healthy
252 relationships should look like. They also discussed the fact that the most common source of
253 information available mostly focused on unhealthy relationships. “You rarely talk about what
254 is healthy, you only talk about what is bad and you do not talk about the consequences either,
255 so there are two, there are three different balls, but you only talk about one ball all the time”,
256 (WWD 1).

257

258 ***Better off silent***

259 WWD expressed a heightened level of mistrust in the providers and the system’s
260 effectiveness to provide good quality IPV services. Many women questioned the importance
261 of seeking IPV services if systems could not be trusted and if reporting did not result in
262 getting the support needed. In the example below, even though WWD 9 was encouraged by
263 her mother to report her abuser to the police, she chose to remain silent fearing the possible
264 consequences and presumed inaction.

265 Yeah, the only one I told at the beginning was my mom. She wanted me to
266 report, and I could not. I could not bear the consequences that would be
267 directed at me. I know how it works...I know how many cases are closed. It
268 felt unnecessary. I was just going to stick my head in the sand, (WWD 9).

269 Some women who had sought support from IPV services narrated encountering breaches of
270 trust and confidentiality prompting them to discontinue the services. WWD 1 was
271 disappointed by the breach of trust when her confidential information was revealed without
272 her consent.

273 I felt great disappointment because I felt that I was opening up to the last
274 person now and throwing a stone in the hope that it would not sink as far as
275 it could. So, it turns out that he has leaked some things ... and she used it
276 against me, (WWD1)

277 In addition, participants talked about feeling discouraged from reporting violence to
278 the police because they were required to provide their full names at the registration stage.
279 Women were hesitant to provide such personal details due to fear of further violence if these
280 details were passed on to their abuser. The women were aware that, in Sweden, government
281 officials are obliged to provide such details upon request. Women who had escaped abusive
282 relationships were worried that providing full names increased the chances of being located
283 by their abuser. Below, WWD1 recalls her conversation with a police officer.

284 I talked a lot about being able to give my first name and avoid my whole
285 last name because it would give more personal data from me, like how you
286 can find me on hitta.se [a site for finding addresses of people living in
287 Sweden]. I do not want to be contacted by this person...how should I
288 proceed; it was frustrating, (WWD 1).

289 Some chose silence as a way of maintaining family stability and preventing further
290 harm. Even in instances where help was available, some did not seek IPV services, fearing it
291 would lead to instability in their relationships. Despite the abuse, some women still
292 appreciated certain aspects of their relationships and were willing to make trade-offs. In the
293 quotation below, this woman chose not to report abuse in order to please her partner, “just
294 because I know that he will at least be kind and happy about this. You choose your battles”.
295 Women with children expressed fear of relationship dissolution and this discouraged them
296 from seeking IPV services. Ending a relationship implied that one had to find a new home and
297 change children’s schools, forcing them to move away from a familiar environment and lose
298 friends. Additionally, women also dreaded custody battles as expressed by this respondent.

299 I wanted the children to be close to the school so that they would have their
300 friends left, I don’t want to move away. I know how difficult it is to get sole
301 custody. It is almost impossible to get sole custody today, despite intimate-
302 partner violence, (WWD 10).

303

304 Another barrier to not seeking IPV services some WWDs talked about was fear
305 of stigmatization. Being abused created an internalized sense of stigma, which manifested in
306 feelings of shame, embarrassment, and fear of being viewed as failures, which hindered
307 women from talking about their violent experiences. “Yeah, I did not say it until later, I hardly
308 dared to say it”, (WWD 3). Aside from the internalized stigma, some women also described
309 experiencing external stigma, which manifested in the lack of a supportive environment to
310 talk about their violent experiences. The respondent below described difficulties in disclosing
311 abuse to her own mom because her mother belonged to a generation that was not open to
312 talking about such a topic, “She is of the generation that is a bit hush-hush, things should look
313 good on the outside. But she is aware of what is happening”, (WWD 11).

314

315 **Interpersonal level**

316 ***The role of personal connections***

317 Lack of personal connections to offer support while seeking formal services was
318 a major barrier. However, supportive family and friends were described as major facilitators
319 in accessing IPV services. Women mostly relied on informal support from family and friends
320 and often described formal IPV services as dysfunctional and unreliable. Some women who
321 had sought IPV services with the help of a family member or a friend had positive
322 experiences. “I remembered that my mother and the legal representative worked a lot... mom
323 had to call and report him (the abuser) to the police” (WWD 3).

324 In the example above, WWD 3 viewed the legal process as cumbersome, she felt
325 overwhelmed taking on such a task on her own. Even with the help of her mother (who wasn't
326 disabled), the process was tedious. Women who did not have anyone supporting them
327 described encountering difficulties and often giving up. Mothers in particular played a
328 significant role in encouraging women to seek help and offering support during this process.

329 The supportive role of mothers manifested in their efforts to initiate contact with the providers
330 and to link women to the different providers.

331 WWD frequently addressed the role of friends as essential, friends helped in
332 talking things through, reflecting on circumstances, and at times provided a safe space where
333 one could hide if they decided to leave the abuser. “I talked a lot with both my mother and my
334 best girlfriend who then lived in the USA. She said on several occasions that she was
335 genuinely worried about me”, (WWD 9). Therefore, a lack of supportive personal connections
336 was a major barrier to using IPV services among women with disabilities.

337

338 **Organizational level**

339 Overall, WWDs viewed the IPV services provision system as complex and inadequately
340 equipped to identify and respond to violence. The primary organizational challenges were
341 characterized by an imbalance in power relationships, inadequate resources, and failure to
342 follow the set response standards.

343

344 ***Imbalance in power relationships***

345 Women describe situations of power imbalances that frustrated their efforts to
346 communicate with service providers. IPV service providers used their privileged position to
347 act as gatekeepers. In some cases, the power imbalances manifested in the ways they
348 described the communication between them and the service providers. In the example below,
349 this respondent felt excluded from deciding on the course of action regarding her situation:

350 I want to be treated like a human being. It sounds so heavenly, basic...No
351 one has talked to me, they have talked about me over my head...I have been
352 told that the reason why we are here is me, but no one is talking to me”,
353 (WWD 11).

354 Another participant viewed the way people with disabilities were treated to be rooted in the
355 history characterized by institutionalization and exclusion of people with disabilities from

356 mainstream society. The interviewed women generally felt that such prejudices still exist even
 357 today and considered them shameful. In the example below, this interviewee likens the history
 358 of institutionalization to how society handles intimate partner violence.

359 “We who have disabilities... we are not visible, we are not heard as much
 360 as all other people, which I think is very shameful actually. That should not
 361 really be the case. Considering the older view of people we had several
 362 years ago, you saw us as disabled, so people are still hooked on those
 363 ideas... We were locked up in institutions ... It was a bit like ... violence in
 364 close relationships ... it is a shame that this...is still allowed to exist as it
 365 does now in Sweden and in our society”, (WWD 7).

366

367 ***Inadequate resources***

368 Lack of resources was another overarching theme that women described. Most
 369 IPV service agencies lacked financial and human resources. In instances where resources
 370 were available, they were not easily accessible. Lack of resources was exhibited in terms of
 371 long waiting times, frequent turnover of service providers, short time allocation to sessions,
 372 and inadequate communication systems. WWD 2 talked about the fact that agencies have a
 373 specific amount of time allocated per client and providers could not exceed this limit. “Each
 374 authority has a certain amount of time to receive, either for free or for payment. Then they can
 375 do no more. Prosecutors shut down. The district court closes its eyes”, (WWD 2). Some
 376 women felt that the time allocated to meet with professionals was often very short. Some felt
 377 that their disabilities constrained communication, therefore they needed more time to talk
 378 about their concerns, which was never offered. Moreover, women felt that providers often got
 379 impatient and were eager to get rid of them through referral “We did not have time to talk at
 380 all. He just asked if he could send me on to a colleague”, (WWD 9).

381 Another challenge identified was regarding high turnover. Most of these
 382 institutions frequently changed service providers. This was problematic because women felt

383 that they needed to constantly introduce their problems to the new staff, which limited
384 progress in getting the needed support.

385 “You get sick between doctors; it is quite unusual to have a regular doctor.
386 Every time you come to psychiatry, you meet a new doctor, which means
387 that you have to tell your whole life story again at every meeting. You never
388 get anywhere”, (WWD 11)

389 Several women felt that the process of referral led to what was described as
390 “falling between the chairs” (meaning to be neglected or overlooked), which resulted in not
391 receiving IPV services.

392 There were many factors there that were problematic. But just that I wasn’t
393 heard by the municipality... It becomes a very difficult thing... You have a
394 support effort that is supposed to support you in such situations, but that
395 does not happen...So there are many that fall between the chairs”, (WWD 8)

396

397 WWD also talked about getting discouraged from seeking IPV services due to the
398 long wait duration. Excessive delay in providing services led women not only to question the
399 effectiveness of the service provision sector but also made them skeptical of the government’s
400 ability to address the societal needs of those with disabilities.

401 “I have waited an extremely long time, and it shouldn’t really be the case
402 that you have to wait 7-8 months to have psychological help...that’s why I’m
403 critical and skeptical of our government, why they are doing what they do...
404 you should not fall chairs (being in an unsatisfactory position) because you
405 do not get the help and support and care that you have actually asked for”,
406 (WWD 7).

407 Lack of effective communication, including a lack of adequate equipment and poor
408 communication skills, was also identified as a major barrier to both access and utilization of
409 IPV services. WWD 10 had a hearing impairment and narrated the agony she endured while
410 she attempted to contact service providers by phone:

411 “I had a very hard time from the beginning contacting the women's shelter
412 because I have a hearing impairment, I find it difficult to talk on the phone...
413 I've been crying so much because I cannot hear. Even the Swedish Social
414 Insurance Agency, which works with disability issues, speaks quietly. I had
415 to call another insurance company and I asked, can you call this person
416 because I do not hear what she says? Then he did and he said he could
417 hardly hear what she was saying”, (WWD10).

418 WWDs also talked about providers who could not communicate effectively because they
419 lacked empathy and merely went through routines without showing actual care. In this
420 example, this woman described getting upset by what she characterized as “psychologist
421 sound”.

422 “I can meet a new psychologist and if the first thing they do is make a
423 psychologist sound, then it doesn't work. You want a conversation. I have
424 not met a person who has been in contact with psychiatry who has not been
425 disturbed by these fucking sounds”, (WWD 11).

426

427 ***Failure to follow set response standards***

428 Failure to follow set institutional policies, guidelines, and protocols was mainly
429 encountered while seeking services from health care institutions and social services. Women
430 narrated encounters with providers who made assessments based on their own opinions rather
431 than the set guidelines. Some respondents observed instances where set standards were not
432 adequately followed and that providers were not using proper methods in making assessments
433 which the respondents attributed to a lack of knowledge as expressed by the respondent
434 below.

435 “Despite the social services' guidelines, no one follows the guidelines. Investigations
436 are not investigated according to investigation methodology or adequate facts, but
437 opinions and thinking. ...they do not take in knowledge from those who are
438 knowledgeable”, (WWD 2).

439 Some WWD felt that the providers failed to inform them of the procedures that
440 were to be taken, which left them feeling anxious, further escalating their worries, and
441 confirming that the providers were not following the accepted procedures of care.

442

443 **Society level**444 ***Societal incompetence***

445 There was a consensus among the respondents that psychological violence was
446 the most neglected form of violence at a broader societal level. Society treated psychological
447 violence as a taboo, a subject completely forbidden to talk about. WWD 1 reflected upon this
448 as she exemplified by a case of bullying; “Society is not so competent when it comes to
449 bullying and such... it is also a kind of abuse that is quite taboo here in Sweden and you
450 almost never talk about it”, (WWD 1).

451 Aside from silence, the lack of societal competence was further reinforced by
452 the absence of rules and regulations criminalizing psychological violence as the same
453 respondent mentioned “We lack laws and rules that punish mental abuse. Now people talk a
454 lot about the physical, but you forget to talk about the mental, which is quite taboo”, (WWD
455 1). The general lack of laws outlawing psychological abuse was perceived as a sign that
456 society still viewed this type of violence as taboo and this attitude is a testimony to why fewer
457 resources are invested in addressing it.

458 Societal incompetence was further reinforced by the lack of knowledge about
459 disability. In some cases, service providers were knowledgeable on how to handle IPV but
460 lacked knowledge of different forms of disability, which frustrated the process of seeking IPV
461 services. “They know their subject but do not know the social aspect, not the least about
462 disability”, (WWD 10). Lack of knowledge regarding certain types of disability resulted in
463 misjudgment and poor assessment of needs hindering women from accessing adequate IPV
464 responses. In the quotation below, the respondent shares her personal experience where her
465 disability was poorly assessed, eventually leading to a denial of psychiatric services and the
466 loss of her children;

467 “They have said that you cannot receive therapy because of your
 468 disability...In addition, I have lost my two children due to my diagnosis... if
 469 a person has children and is involved in LSS and also lives in housing...
 470 you can be considered a very dysfunctional person in society, or in your
 471 private life...it looks like you cannot manage yourself ... and your children
 472 are exposed because you are considered dysfunctional.... for a person who
 473 does not have knowledge about it, who does not have all the facts on the
 474 table”, (WWD 8)

475

476 **Discussion**

477 Our finding highlights a range of multilevel barriers that are often entangled in each other in
 478 given situations. At the individual level, we identified three themes, identity category of
 479 disability, not knowing about certain forms of violence, and being better off silent. At the
 480 interpersonal level, lack of personal connection was the major barrier identified while the
 481 organizational level barriers included power imbalances, inadequate resources, and failures to
 482 follow set response standards. At the societal level, societal incompetence was the main
 483 barrier described by the respondents, this manifested in the form of treating violence as a
 484 taboo never talked about, and the lack of laws condemning psychological violence.

485 Women with invisible disabilities were reluctant to seek IPV services for fear of
 486 exposing their disabilities, as this would lead to being treated as disabled, which they
 487 considered devaluing to their identity. To a greater extent health care providers are socialized
 488 to view disability from a biomedical perspective. The biomedical perspective puts the focus
 489 on treating disability as an individual tragedy which might lead to societal devaluation of
 490 people with disabilities [27, 28], and to pervasive stereotypes, and the “othering” [29]. To
 491 avoid societal devaluation, those with imperceptible disabilities choose to hide their
 492 disabilities to evade discrimination and systemic preclusion [30].

493 In this current research, most women were able to recognize and name physical
 494 and sexual violence as such, but some found it hard to recognize psychological violence on
 495 their own.. The idea that certain types of violence are not easily recognized is not a new one,

496 research conducted on women, in general, has documented similar observations, where
497 women report difficulties in recognizing and naming psychological abuse in the absence of
498 physical abuse [31]. Most women in this study were only able to recognize and name
499 psychological violence as such with the help of family, friends, and professionals. In
500 literature, being able to clearly label psychological abuse has not only been problematic
501 among women but also among professionals [32]. For example, some research report a lack of
502 consensus on which particular behaviors constitute psychological abuse in adult intimate
503 relationships [33]. Parallel to naming violence, women also described a lack of role models in
504 their society exemplifying healthy relationships. Most of the women's views on relationships
505 were often shaped by what they saw in the media and other forms of popular culture, a finding
506 similar to earlier studies [34], where violence is often characterized by explosive, isolated
507 events [35].

508 In as much as some women recognized the dangers of staying in a violent
509 relationship, they still opted to remain silent and to avoid seeking IPV services. Seeking IPV
510 services often led to the undesired outcome of dissolution of their intimate relationships. To
511 these women, separation or divorce implied loss of companionship, isolation, disorganization
512 of children's environment, and custody battles. Research shows that PWD are less likely to
513 cohabit or to get married [36]. According to Chenoweth (1996), having a boyfriend or
514 husband is highly desired among women and girls with disabilities, this could partly explain
515 why some women did not want to get help if this implied dissolving their intimate
516 relationships [37]. This phenomenon of hesitance to leave an abusive relationship is well-
517 known even among women without disabilities [13, 14]. Despite these challenges, there is a
518 need to encourage women to seek help, to provide information on violence disclosure and to
519 empower women to act against abuse [38].

520 Furthermore, the choice to remain silent was exacerbated by the perception that
521 institutions could not listen to WWDs because they were considered less worthy and less
522 trusted according to the ableism norms. This idea reinforces the notion that the disabled and
523 their voices are deftly silenced, ignored, and rendered unintelligible [37]. The experiences
524 described in this study are not at all divorced from the current literature, Sobsey (1994) used
525 the term silent acceptance to describe violence and abuse in the lives of people with
526 disabilities [39]. This silence practiced by the women themselves and promoted by their social
527 networks such as family members and overall, by society, reflects the culture of silence that
528 surrounds the covering up of abuse of people with disabilities [37]. Being treated as invisible
529 and not being heard creates frustration. It is also possible that PWDs experienced such
530 treatment early in their lives. Penchansky and Thomas (1981), assert that such treatment leads
531 to a decrease in utilization of services, dissatisfaction with the services and care received, and
532 subsequently inequality in service provision [40].

533 At the interpersonal level, our study found that personal connections
534 significantly encouraged women to recognize abuse and seek IPV services. This finding is in
535 line with previous research that highlights the importance of informal support networks in the
536 long process that women go through when attempting to create safe and independent lives
537 [12]. The way family and friends react to women wanting to leave a violent relationship, by
538 either supporting or discouraging them, shapes the meanings women give to their experiences
539 of violence, subsequently influencing their decision-making process [14]. The involvement of
540 social connections plays an essential role in shaping women's views of their coping options,
541 which may encourage them to seek help [41]. Support from the family and social context is
542 especially important because barriers to IPV services occur in a hierarchical structural context
543 as shown in this study. Thus, changes implemented at the different hierarchical structures are
544 bound to yield better results.

545 At the organizational level, women were confronted by a power imbalance.
546 There seems to be a battle of communicative silence in which providers make no effort to
547 hear and understand what women communicate. A similar observation was made by
548 Chenoweth (1996) when describing the structured silence around women with disabilities as
549 deeply embedded in social practices where women are confronted with marginalization,
550 rejection, and extensive control over all aspects of their lives[37]. The silence surrounding
551 violence can also be reflected in the way women describe the absence of laws that condemn
552 psychological violence. In the absence of laws criminalizing psychological violence, women
553 choose to remain silent, the willingness to report violence diminishes as women question its
554 severity, which encourages cultural stigma. Cultural stigma legitimizes violence and devalues
555 survivors by culturally constructing the reality of the event in ways that minimize its severity
556 [42].

557 Our findings show that providers' failure to follow set response standards
558 discouraged WWDs from seeking IPV services. In recent years, the Swedish government
559 through the National Board of Health and Welfare and several professional associations have
560 issued guidelines to aid professionals working in institutions and associations on how to
561 assess risk and identify violence. Subsequently, institutions have also created training
562 programs and service protocols to guide responses to women who are experiencing abuse
563 [43]. In our recent study, service providers clearly indicated that the described processes were
564 instrumental in providing IPV services to WWDs exposed to violence [12]. Nevertheless,
565 there is a need for a more concerted effort on IPV service response to WWDs, accompanied
566 by structural changes in sectors to support the implementation of such guidelines.

567 At the societal level, women pointed at a glaring need for strengthening societal
568 competence. The societal silence around psychological violence, lack of knowledge on
569 disability, and the absence of laws criminalizing psychological violence create favorable

570 grounds for violence to occur while at the same time discouraging WWDs from doing
571 anything about it. To build community trust in IPV services, the system needs to implement
572 proper management of reported cases and allocate resources to programs to support WWDs. It
573 is also important that in early years young people gain knowledge about boundary setting,
574 communication, and respect for privacy. Community-level research has appealed to the
575 concept of social capital, which is embodied in the social ties among persons and positions
576 [27]. Social capital is built on mutual obligations, opportunities to exchange information,
577 shared norms, and the ability to enforce standards and administer sanctions. These models
578 also provide an opportunity for the community to be actively engaged in the implementation
579 and promotion of social control, in which community residents take an active role in the
580 sanctioning of offenders, and emphasize accountability [44].

581

582 **Conclusion**

583 Our findings indicated that WWDs encounter several barriers at different
584 societal levels that hinder their utilization of IPV services. These findings suggest that
585 improving access and utilization of IPV services for WWDs requires multilevel changes in the
586 form of policies and programs directed at the individual, interpersonal, organizational, and
587 societal levels. The themes identified at the individual level included the identity category of
588 disability, not knowing what violence looks like, and a feeling of being better off silent. A
589 lack of personal connection was the major barrier identified at the interpersonal level; at the
590 organizational level, power imbalances, inadequate resources, and failure to follow set
591 response standards were the themes identified while at the societal level, societal
592 incompetence was the main theme identified. It is important that women with disabilities get
593 the opportunity to speak for themselves about their IPV experiences and that they feel that
594 service providers listen to them when seeking IPV services as this will improve their trust in

595 the IPV service providers and subsequently encourage access and utilization of IPV services.
596 This study provides a robust set of findings that stand in their own right while inviting other
597 researchers to contribute to future research aimed at strengthening IPV service provision for
598 people with disabilities across diverse populations and methodologies.

599

600 **List of abbreviations**

601 IPV – Intimate partner violence

602 WWD- Women with disabilities

603 PWD- People with disabilities

604

605 **Declarations**

606 ***Ethics approval and consent to participate***

607 Ethical approval for the DIS-IPV project was obtained from the Swedish Ethical Review
608 Authority [J. Reg no. 2019–05249]. All interviews were conducted after appropriate verbal
609 and written informed consent was obtained from the study participants. The authors confirm
610 that all study procedures were performed in accordance with the 1964 Helsinki declaration
611 and in accordance with relevant institutional and national research committee guidelines and
612 regulations.

613

614 **Consent for publication:** Not applicable

615 **Availability of data and materials:** Due to the requirements of the ethical review board, we
616 are not able to share this research data publicly, as this would compromise individual privacy.
617 However, data can be made available to individual researchers after they obtain ethical
618 permission from the Swedish Ethical Review Authority.

619

620 **Competing interests:** No known potential conflict of interest by the authors

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 625 interpretation, or writing of the report.

626

627 **Authors' contributions**

628 **FN:** Secured project funding, supervised the research project, wrote the first draft of the
 629 manuscript, and performed the analysis. **VL** conducted all the interviews and contributed to
 630 data analysis. **KW** participated in data analysis. All authors participated in developing the
 631 research idea, interpreting the research findings, and revision of the subsequent manuscripts.
 632 All authors have read and approved the final draft of the manuscript.

633

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635

636 **References**

- 637 1. Garcia-Moreno C, Jansen HA, Ellsberg M, Heise L, Watts CH, Health, WHO Multi-
 638 country Study on Women's Health and Domestic Violence against Women Study
 639 Team. **Prevalence of intimate partner violence: findings from the WHO multi-
 640 country study on women's health and domestic violence.** *Lancet* 2006,
 641 **368**(9543):1260-1269.
- 642 2. World Health Organization: **Responding to intimate partner violence and sexual
 643 violence against women: WHO clinical and policy guidelines.** [Responding to
 644 intimate partner violence and sexual violence against women \(who.int\)](https://www.who.int/publications/m/item/responding-to-intimate-partner-violence-and-sexual-violence-against-women).
- 645 3. Robinson, Frawley, Dyson: **Access and Accessibility in Domestic and Family
 646 Violence Services for Women With Disabilities: Widening the Lens.** *Violence
 647 against women* 2021, **27**(6-7):918-936.
- 648 4. Brownridge DA: **Partner Violence Against Women With Disabilities: Prevalence,
 649 Risk, and Explanations.** *Violence against women* 2006, **12**(9):805-822.
- 650 5. Nosek MA, Foley CC, Hughes RB, Howland CA: **Vulnerabilities for Abuse Among
 651 Women with Disabilities.** *Sexuality and Disability* 2001, **19**(3):177-189.
- 652 6. Shah S, Tsitsou L, Woodin S: **Hidden Voices: Disabled Women's Experiences of
 653 Violence and Support Over the Life Course.** *Violence against women* 2016,
 654 **22**(10):1189-1210.

- 655 7. Mueller CO, Forber-Pratt AJ, Sriken J: **Disability: Missing from the Conversation**
656 **of Violence.** *J Soc Issues* 2019, **75**(3):707-725.
- 657 8. Ellsberg M, Jansen HAFM, Heise L, Watts CH, Garcia-Moreno C: **Intimate partner**
658 **violence and women's physical and mental health in the WHO multi-country**
659 **study on women's health and domestic violence: an observational study.** *The*
660 *Lancet* 2008, **371**(9619):1165-1172.
- 661 9. Thomas KA, Joshi M, Wittenberg E, McCloskey LA: **Intersections of Harm and**
662 **Health: A Qualitative Study of Intimate Partner Violence in Women's Lives.**
663 *Violence against women* 2008, **14**(11):1252-1273.
- 664 10. Evans MA, Feder GS: **Help-seeking amongst women survivors of domestic**
665 **violence: a qualitative study of pathways towards formal and informal support.**
666 *Health Expect* 2016, **19**(1):62-73.
- 667 11. Rose LE, Campbell J, Kub J: **The role of social support and family relationships in**
668 **women's responses to battering.** *Health Care Women Int* 2000, **21**(1):27-39.
- 669 12. Namatovu F, Ineland J, Lövgren V: **Exploring the perspectives of professionals on**
670 **providing intimate-partner violence services to women with disabilities.** *Violence*
671 *against women* 2022, 0(0). <https://doi.org/10.1177/10778012221137916>
- 672 13. Feder GS, Hutson M, Ramsay J, Taket AR: **Women exposed to intimate partner**
673 **violence: expectations and experiences when they encounter health care**
674 **professionals: a meta-analysis of qualitative studies.** *Arch Intern Med* 2006,
675 **166**(1):22-37.
- 676 14. Skoog Waller S: **Utan mig är du helt ensam : kvinnors levda erfarenheter av**
677 **omgivningens och samhällets ensamgörande i spåren av mäns våld och eftervåld.**
678 In. Gävle: Högskolan i Gävle; 2022: 52.
- 679 15. Kudlick CJ: **Disability History, Power, and Rethinking the Idea of “the Other”.**
680 *PMLA/Publications of the Modern Language Association of America* 2005,
681 **120**(2):557-561.
- 682 16. Bogart KR, Dunn DS: **Ableism Special Issue Introduction.** *J Soc Issues* 2019,
683 **75**(3):650-664.
- 684 17. McRuer R: **Crip Theory. Cultural Signs of Queerness and Disability.** *Scandinavian*
685 *Journal of Disability Research* 2008, **10**(1):67-69.
- 686 18. Bowes AM, Domokos TM: **South Asian women and health services: A study in**
687 **Glasgow.** *New Community* 1993, **19**(4):611-626.
- 688 19. Johnson JL, Bottorff JL, Browne AJ, Grewal S, Hilton BA, Clarke H: **Othering and**
689 **Being Othered in the Context of Health Care Services.** *Health Communication*
690 2004, **16**(2):255-271.
- 691 20. Garland-Thomson R: **Extraordinary Bodies: Figuring Physical Disability in**
692 **American Culture and Literature:** Columbia University Press; 1997.
- 693 21. Bronfenbrenner U: **The Ecology of Human Development**
694 **Experiments by Nature and Design:** Harvard University Press; 1979.
- 695 22. Krug EG, Mercy JA, Dahlberg LL, Zwi AB: **The world report on violence and**
696 **health.** *Lancet* 2002, **360**(9339):1083-1088.
- 697 23. Sabri B, Hong JS, Campbell JC, Cho H: **Understanding Children and Adolescents'**
698 **Victimizations at Multiple Levels: An Ecological Review of the Literature.** *J Soc*
699 *Serv Res* 2013, **39**(3):322-334.
- 700 24. El-Murr A: **Problem sexual behaviors and sexually abusive behaviors in**
701 **Australian children and young people. A review of available literature.** In.; 2017.
- 702 25. Guba EG, Lincoln YS: **Epistemological and Methodological Bases of Naturalistic**
703 **Inquiry.** *Educational Communication and Technology* 1982, **30**(4):233-252.

- 704 26. Guba EG: **Criteria for assessing the trustworthiness of naturalistic inquiries.**
 705 *ECTJ* 1981, **29**(2):75.
- 706 27. Coleman JS: **Foundations of social theory.** Cambridge, MA: Harvard University
 707 Press; 1990.
- 708 28. Coleman L: **Stigma: An enigma demystified.** New York: Routledge; 1997.
- 709 29. Thomas C: **Female forms : experiencing and understanding disability.**
 710 Philadelphia, Pa: Open University Press; 1999.
- 711 30. Cureton A: **Hiding a Disability and Passing as Non-Disabled.** In: *Disability in*
 712 *Practice: Attitudes, Policies and Relationships.* edn. Edited by Cureton A, Hill JTE:
 713 Oxford University Press; 2018: 18-32.
- 714 31. Stark E: **Coercive control: How men entrap women in personal life.** New York,
 715 NY, US: Oxford University Press; 2007.
- 716 32. Seff LR, Beaulaurier RL, Newman FL: **Nonphysical Abuse: Findings in Domestic**
 717 **Violence Against Older Women Study.** *Journal of emotional abuse* 2008, **8**(3):355-
 718 374.
- 719 33. Follingstad DR, DeHart DD: **Defining Psychological Abuse of Husbands Toward**
 720 **Wives: Contexts, Behaviors, and Typologies.** *Journal of interpersonal violence*
 721 2000, **15**(9):891-920.
- 722 34. Canfield A: **Stephen King's Dolores Claiborne and Rose Madder: A Literary**
 723 **Backlash against Domestic Violence.** *Journal of American culture (Malden, Mass)*
 724 2007, **30**(4):391-400.
- 725 35. Berns N: **Degendering the Problem and Gendering the Blame: Political Discourse**
 726 **on Women and Violence.** *Gender & society* 2001, **15**(2):262-281.
- 727 36. Namatovu F, Häggström Lundevaller E, Vikström L: **The impact of disability on**
 728 **partnership formation in Sweden during 1990-2009.** *The History of the Family*
 729 2020, **25**(2):230-245.
- 730 37. Chenoweth L: **Violence and Women With Disabilities: Silence and Paradox.**
 731 *Violence against women* 1996, **2**(4):391-411.
- 732 38. McFarlane J, Symes L, Maddoux J, Gilroy H, Koci A: **Is length of shelter stay and**
 733 **receipt of a protection order associated with less violence and better functioning**
 734 **for abused women? Outcome data 4 months after receiving services.** *J Interpers*
 735 *Violence* 2014, **29**(15):2748-2774.
- 736 39. Sobsey R: **Violence and abuse in the lives of people with disabilities: The end of**
 737 **silent acceptance?** Baltimore, MD, US: Paul H Brookes Publishing; 1994.
- 738 40. Penchansky R, Thomas JW: **The Concept of Access: Definition and Relationship to**
 739 **Consumer Satisfaction.** *Medical care* 1981, **19**(2):127-140.
- 740 41. Haj-Yahia MM, Uysal A: **Beliefs about Wife Beating among Medical Students**
 741 **from Turkey.** *Journal of family violence* 2008, **23**(2):119-133.
- 742 42. Overstreet NM, Quinn DM: **The Intimate Partner Violence Stigmatization Model**
 743 **and Barriers to Help Seeking.** *Basic and applied social psychology* 2013, **35**(1):109-
 744 122.
- 745 43. Garcia-Moreno C: **Dilemmas and opportunities for an appropriate health-service**
 746 **response to violence against women.** *Lancet* 2002, **359**(9316):1509-1514.
- 747 44. Bazemore G: **The "Community" in Community Justice: Issues, Themes, and**
 748 **Questions for the New Neighborhood Sanctioning Models.** *The Justice system*
 749 *journal* 1997, **19**(2):193-227.
- 750