

**Exploring barriers to seeking help after abuse:
health outcomes in people with developmental disabilities**

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Master's Thesis

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Abstract

Background: Interpersonal violence (IPV) is increased for men and women with disabilities and it has been associated with negative health outcomes in the general population. People with disabilities may experience barriers to seeking help after abuse due to social stigma and inadequacy of resources. **Objective:** To examine barriers to seeking help after abuse in people with developmental disabilities and identify associations between barriers and health outcomes. **Methods:** We surveyed 350 men and women with developmental disabilities about their health, disability and history of abuse. This analysis was limited to the 223 (64%) participants who reported abuse experiences as an adult. We compared the characteristics of people who reported barriers to those who did not. We used linear regression to examine the association between barriers to seeking help and adapted CESD-10 (depression) scores, PHQ-15 (physical health) scores, and PCL-C (PTSD) scores. **Results:** Participants who reported barriers to seeking help (56%) were more likely to be employed, utilize personal assistance, and have a history of child abuse (all $p < 0.05$). Participants with at least one barrier had a mean depression score 1.67 points higher than those without any barriers, after adjusting for demographic characteristics and child abuse history ($p = 0.045$). This association was attenuated after adjustment for functional limitation and abuse severity. **Conclusions:** The association between barriers to seeking help and depression following abuse in people with developmental disabilities is complex and will require more focus in future research efforts. We must address the social conditions that could be disincentives to help-seeking following abuse in this population.

Introduction

There is strong evidence to suggest that the risk of interpersonal violence (IPV) is increased for men and women with disabilities (Hughes, 2011; Curry, 2011; Nosek, 2001; Nosek 2006; Powers, 2008; Marchetti et al, 1990). Population-based data from over 200,000 women, 50,000 of whom had a disability, found that the risk of physical abuse, threatened violence and unwanted sex was doubled for women with disabilities compared to those without a disability (Smith, 2008). Data from the National Crime Victimization Survey found that the rate of violent victimization directed towards men with disabilities is twice that of men without disabilities (42/1000 versus 21.6/1000; Harrell, 2012). While people with disabilities are at risk for physical and sexual violence, the presence of a disability introduces additional types of perpetrators and unique forms of IPV (such as refusal to provide assistance with essential activities of daily life, medication manipulation, financial abuse, and withholding or destruction of an assistive device) (Oschwald, 2008; Copel, 2006; Gilson, DePoy, & Cramer, 2001; Oktay & Tompkins, 2004; Powers et al., 2009; Saxton et al., 2001).

IPV in the general population is associated with negative psychological and physical health consequences: not only do survivors of IPV have higher rates of depression, anxiety and post-traumatic stress disorder (PTSD) (Kendler, 2000, Goldings, 1999, and Kendall-Tackett, 1993), but the stress of abuse and multiple forms of violence compound symptoms of depression and chronic physical complaints (Nicolaidis, 2004, Thomas, Joshi, Wittenberg, & McCloskey, 2008). Given the high prevalence of abuse towards people with disabilities, it is important to address the adverse psychological and physical symptoms associated with abuse or abuse related issues.

This study focused on one potential access point to address the health consequences of abuse: barriers to seeking help for people with disabilities. Prior research supports the presence of barriers to seeking help experienced by our population; one of which is difficulty identifying disability-related abuse (Saxton et al., 2001 and Plummer, 2012). In this regard, Curry et al. found that women with cognitive disabilities reported barriers to seeking help and reporting abuse (Curry, 2011). The most endorsed item leading to less reporting of an abusive experience was: “[I] don’t want to report until I am sure it is abuse” (Curry, 2011). Another possible barrier to seeking help is confusion about what constitutes abuse on an institutional level. Cramer et al. (2003) showed that some legislative and social service agencies differ in how they define abuse (Cramer et al, 2003). Cultural and societal barriers can limit one’s ability to find assistance or function as disincentives for people with disabilities to name abuse and reach out for assistance (Gilson et al., 2001; Hassouneh-Phillips & Curry, 2002; Nosek et al., 2001; Oswald et al., 2009; Swedlund & Nosek, 2000). Several researchers have reported that barriers to care exist because of a lack of accessible resources for people with disabilities following violence, insensitive behavior by service providers, and internalized societal discrimination leading to self-devaluation and feelings of self-blame (Plummer, 2012, Hassouneh- Phillips & McNeff, 2005; Milberger et al., 2003; Oswald et al., 2009; Swedlund & Nosek, 2000).

There has not been research investigating whether barriers to seeking help are associated with worse health outcomes among people with disabilities. The aim of this study was to examine the barriers to seeking help after abuse experienced by people with developmental disabilities and their potential association with depression, PTSD, and

physical health. If an association exists between barriers to seeking help and psychological or physical symptoms, the barriers may offer a target for public health efforts to minimize the consequences of abuse towards people with developmental disabilities, a staggeringly pervasive problem. For this purpose, the objectives for this analysis were:

- 1) To describe the prevalence of experiencing barriers to seeking help among adult victims of violence and how socio-demographic, abuse, and disability factors differ between those who report barriers from those who do not report barriers.
- 2) To examine the association between reporting barriers to seeking help for interpersonal violence and physical and mental health outcomes in adults with developmental disabilities after adjusting for potential confounding variables.
- 3) To expand the model examined in objective 2 by considering important variables in the complex relationship between barriers to seeking help and health outcomes: severity of functional limitation and severity of abuse.

Methods

Study Design

Project overview. We conducted this research as one portion of a large cross-sectional study aimed to answer many questions to advance our understanding of the associations between interpersonal violence, health, and disability. The project was guided by the principles of Community Based Participatory Research (CBPR) in order to maximize the applicability of the process and end result. CBPR is an approach that engages both researchers and community members to generate knowledge accessible and

relevant to marginalized communities (Minkler, 2005 and Hassouneh, 2011). Our community-academic partnership selected a number of instruments to measure violence and health and adapted them to be accessible to people with developmental disabilities (Nicolaidis, under review). We then developed and implemented a novel Audio-Computer Assisted Self-Interview (ACASI) to ethically and effectively collect data from individuals with a variety of functional limitations (Oschwald, in press). The Health and Safety Survey was administered using the ACASI to collect detailed information from men and women with developmental disabilities.

Participants. We recruited 350 male and female adults with developmental disabilities from rural Montana and Portland, Oregon. We recruited participants through direct mailings to state disability service recipients as well as through outreach in local community networks by CAB members (Oschwald, in press). Participants had to meet the following inclusion criteria:

- 1) be at least 18 years of age;
- 2) demonstrate the ability to give informed consent with appropriate accommodations;
- 3) be able to communicate at a level needed to answer questions with accommodations provided;
- 4) understand English;
- 5) have a developmental disability defined either as receiving developmental disability services from the state or:
 - a. having a disability that began before age 22 and is likely to continue through one's lifetime;

- b. have three out of nine areas of functioning limited by their disability (self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency; processing and socialization impairments).

These criteria were based on the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). We added two areas of functioning (processing and socialization impairments) that represented individuals on the autism spectrum as well as one item addressing visual impairments that were not included in the DD Act (Oswald, in press).

Data Collection. The Health and Safety Survey was administered on a laptop audio-computer assisted self-interview (ACASI) at a scheduled location that was safe, accessible, and convenient for the participant after a brief orientation with staff on how to use the program. Detailed information about the processes for obtaining informed consent, providing technical support, and ensuring safety and privacy for our participants is provided elsewhere (Oswald, in press). At survey completion, a wallet card with local and national abuse information was offered to all participants.

Survey Items

Abuse. The Health and Safety Survey contained 13 dichotomous (Yes/No) items to determine if an individual experienced a range of abuse or violence during adulthood. These items included disability-specific abuse experiences (i.e. breaking or keeping the participant from using assistive devices, misusing medications or bank accounts), physical abuse and sexual abuse experiences. The items were derived from Curry et al. (2009), who evaluated the factor structure and internal consistency of an abuse measure

for women with disabilities, which integrated items from previous measures developed by McFarlane et al. (2001) and Curry et al. (2003), and incorporated enhancements suggested by women with disabilities and a language specialist. A positive response to any of the 13 abuse variables was used to determine eligibility for this analysis. We also created scores to characterize the abuse for each individual participant. We used factor analysis to examine all of the adult abuse items in the survey. We examined the adult abuse items together with our goal being to condense and summarize the data in a way that could be used as variables in future analyses. When we examined the adult abuse items, we found two factors ("sexual abuse," and "mixed abuse" which included emotional, physical, and disability abuse). A higher score represents experiencing more severe abuse. We used the sexual abuse score and the mixed abuse score as covariates in our analysis. The survey also contained items about past history of child abuse. The presence or absence of child abuse was used as a covariate in this analysis.

Demographics. The Health and Safety Survey explored the social and community context of the respondents. These items included details about age, sex, race and ethnicity as well as if the individuals lived in an urban or rural context, which state they lived in (Montana or Oregon), their living circumstances, and if they were employed, in a relationship, or eligible for state disability services. We simplified the categories for responses to the items concerning race, rural/urban status, living circumstances, employment, relationship status, and education. See Table 1 for details on the original items and the categories used for analysis.

Table 1. Groupings of demographic variables used in analysis compared with original response options.

Variable and options listed on Health and Safety Survey	Groupings used for analysis
Race American Indian/Alaskan Native Asian Black or African American White Native Hawaiian/Other Pac. Islander Bi-racial/Multi-racial Other Do Not Want to Say	Black or African-American White Other
Rural or Urban A city or large town Suburb, just outside city or large town A small town In the country or a long way from town On a reservation	City or Suburb Small town/country/reservation
Living circumstances My own home or apartment Family/someone else’s home or apt Group home, assisted living, or other group care setting College dorm Homeless shelter/domestic violence shelter Other	Own home or apartment Family/someone else’s home or apartment Group home, assisted living, or other group care setting Homeless shelter /domestic viol shelter Other
Level of education I never attended school Attended school but didn’t complete HS High school diploma or GE Attended college but did not get degree Associate or bachelor degree Graduate degree, like a Masters or PhD	Less than high school High school Some post-high school
Employment Status Full-time Part-time Unemployed	Full-time or Part-time Unemployed
Relationship Status Single Married (marriage-like relationship) Boyfriend/girlfriend Divorced Widowed Separated Do not want to say	Married or Marriage-Like Not married

Functional limitation. We asked participants to characterize their functional limitation. The different categories of functional limitations included: difficulty taking care of daily personal needs, not being able to speak and be understood clearly, being

deaf or blind, having difficulty learning or remembering things, having difficulty understanding or processing what is happening around them, having difficulty moving or walking around, having difficulty making decisions and plans, having difficulty socializing, having difficulty living independently in the community, having difficulty working independently in a paid job, and having difficulty taking care of money.

Participants were given a score between 0 – 12 to describe the number of functional limitations. We also asked individuals if they required personal assistance or the use of assistive devices to further characterize the functional limitation of each participant. We used these items as covariates in our analyses.

Barriers to seeking help. The Health and Safety Survey contained five items concerning whether participants perceived they would face barriers to seeking help if they were abused. We constructed these items based on previous work detailing barriers commonly experienced by people with disabilities (Curry, 2011 and Plummer, 2012). The items included: 1) not having a way to tell someone, 2) feeling too ashamed to tell someone, 3) perceived inaccessibility of services such as domestic violence shelters or crisis lines to help, 4) not feeling that they would be believed if they told someone of their abuse, and 5) believing that they could lose independence or support if they told of their abuse experience. We considered one positive answer to any of these items as the presence of a barrier. This was used as our predictor variable for our linear regression.

Health outcomes. The Health and Safety Survey included items concerning the physical and mental health status of the participants. We based our analysis on three instruments that were adapted for people with developmental disabilities through the CBPR approach (Nicolaidis, under review). We explored depression symptoms with an

adapted version of the Center for Epidemiologic Studies Short Depression Scale (CES-D 10; range of scores 0 – 30; Cronbach’s alpha 0.81) (Nicolaidis, under review). The adapted CES-D 10 contained ten questions addressing the presence of symptoms of depression within the past week. We used the adapted Personal Health Questionnaire (PHQ-15; range of scores 0 – 45; Cronbach’s alpha 0.94) (Nicolaidis, under review) to assess health symptoms experienced over the past four weeks. Lastly, we used the adapted 17-question PTSD Checklist – Civilian (PCL-C; range of scores 0 – 85; Cronbach’s alpha 0.81) (Nicolaidis, under review) to inquire about symptoms of PTSD experienced over the past month. We used scores from these three adapted surveys as the outcome variables for our linear regression.

Statistical Analysis

We determined the proportions of participants who experienced any type of barrier as well as each of the five specific types of barriers. We summarized demographic variables, functional limitation, disability types and health outcome variables (adapted CESD 10, PHQ 15, and PCL-C scores) by group with and without barriers. Differences between the groups with and without barriers were determined using two-sample t-tests, Pearson’s chi-square, and Fisher’s Exact Tests when appropriate. .

We used linear regression to determine if a statistically significant association exists between the predictor (any barrier to seeking help) and each outcome (adapted CES-D 10, PHQ-15, and PCL-C). We evaluated the associations between the predictor and each outcome variable in a stepwise fashion. We conducted two levels of adjustment for Objective 2. The first level of adjustment included demographic variables. The

demographic variables considered included age, sex, race, ethnicity, living circumstances, rural or urban status, social security eligibility, relationship status, employment status, and education level. To build our models, we assessed the univariate associations between all covariates and each outcome variable. Any covariates with an association with the outcome variable where $p < 0.20$ were included in variable selection. We then performed variable selection by constructing the backward stepwise parsimonious model, using $p = 0.2$ for adding a variable to the model and $p = 0.1$ for removing a variable in order to include each important variable. The second level of adjustment added a history of child abuse and the backward parsimonious model was built again, using the same p -value thresholds. We conducted two additional levels of adjustment for Objective 3, building on the model that was adjusted for demographics and presence of child abuse. First, we included the functional limitation score, use of a personal assistant, and use of assistive devices. After more backward stepwise variable selection, we included the sexual and mixed abuse scores obtained from the factor analysis. The final model was constructed through one more step of backward stepwise variable selection and was tested for the assumptions of normality and homoscedasticity. For all analyses, we used the conventional 0.05 significance level as our cut off for statistical significance. STATA data analysis and statistical software was used for all analyses.

Results

Sample characteristics. Out of 350 total participants, 223 individuals (64%) reported some form of abuse experience as an adult, be it disability-related, physical or

sexual abuse. Mean age was 38 years with an age range of 18 – 78. Among adults who had experienced abuse, 48% (n=107) were male and 52% (n=116) were female. The majority of our sample was White and not Hispanic (73% and 90% respectively). 70% (n=157) lived in a city or suburb; 58% (n=130) lived in their own home or apartment, and 15% (n=33) lived in a group home, assisted living or other group care setting. Almost 80% (n=177) of our sample was receiving money from social security; only 25% (n=55) had received any education beyond high school. Thirty-eight percent (n=84) of our sample was employed and 15% (n=34) was married or in a marriage-like relationship.

The mean number of functional limitations experienced by our sample was 6, with over half of our sample reporting difficulty learning or remembering things, understanding or processing what’s happening, working independently in a paid job, making decisions or plans, living independently, taking care of money and socializing. 30% (n=66) utilized assistive devices and 63% (n=141) utilized personal assistance. Three-fourths of our sample reported a history of child abuse. Demographic and disability characteristics are summarized in Table 2.

Table 2. Sample characteristics

Variable	Summary measure
Median Age	38 (Range 18-78)
Sex	
Male	48.0% (n=107)
Female	52% (n=116)
Race	
Black or African-American	8.6% (n=19)
White	73.4% (n=164)
Other	14.9% (n=33)
Hispanic	
Yes	6.3% (n=14)
No	89.7% (n=200)
Rural or Urban	
City or Suburb	70.4% (n=157)
Small town/country/reservation	29.6% (n=66)

Table 2 continued. Sample characteristics

Variable	Summary measure
Living circumstances	
Own home or apartment	58.3% (n= 130)
Family/someone else’s home or apartment	24.7% (n=55)
Group home, assisted living, or other group care setting	14.8% (n=33)
Homeless shelter /domestic viol shelter	0.90% (n=2)
Other	1.4% (n=3)
Receiving money from social security	
Yes	79.4% (n=177)
No	18.8% (n=42)
Level of education	
Less than high school	23.8% (n=53)
High school	51.6% (n=115)
Some post-high school	24.7% (n=55)
Employment Status	
Full-time or Part-time	37.7% (n=84)
Unemployed	62.3% (n=139)
Relationship Status	
Married or Marriage-Like	15.2% (n=34)
Not married	82.1% (n=183)
Functional Impairment	
Median number of functional limitations	6 (range 0 – 12)
Difficulty learning or remembering things.	77%
Difficulty understanding or processing what’s happening.	77%
Difficulty working independently in a paid job.	68%
Difficulty making decisions or plans.	61%
Difficulty living independently in the community.	57%
Difficulty taking care of money.	57%
Difficulty socializing.	55%
Not being able to speak and be understood clearly.	50%
Difficulty moving or walking around.	32%
Difficulty with daily personal needs.	30%
Being deaf.	22%
Being blind.	27%
Needs assistive devices	29.6% (n=66)
Needs personal assistance	63.2% (n=141)
Disability Type*	
Cognitive	64.6% (n = 144)
Autism Spectrum	14.4% (n=32)
Deaf	13.5% (n=30)
Mobility	22.9% (n=51)
Blind	12.6% (n=28)
Speech	21.5% (n=48)
Mental Health	52.9% (n=118)
Health	38.6% (n=86)
Any child abuse	
Yes	74.9% (n=167)
No	25.2% (n=56)

* Participants could report more than one disability type.

Barriers to seeking help. The proportion of our sample that experienced any form of barrier to seeking help after abuse was 56% (n = 124). Twenty-nine percent (n=64) answered, “Yes” to feeling too ashamed to tell someone that they were being hurt or mistreated. Twenty-four percent (n=54) thought that they could lose their independence or support if they told someone. Twenty-three percent (n=51) reported that they would not be believed if they told someone. Eighteen percent (n=40) did not think there would be services such as domestic violence shelters or crisis lines to help them and 9% (n=19) reported that they wouldn’t have a way to tell someone of their abuse experience.

Compared to those who did not report any barrier to seeking help, individuals who reported barriers were more likely to be employed (44.4% vs. 28.1%, $p = 0.0135$), need personal assistance (70.2% vs. 54.2%, $p = 0.0147$), and be a victim of child abuse (82.3% vs. 64.6%, $p = 0.0028$). Other demographic characteristics were not significantly different between groups (Table 3).

Table 3. Comparison of demographics and outcome variables between participants with or without barriers.

Variable	Barriers (n=124)	No barriers (n=96)	p-value*
Median Age	38.5 (Range 18-78)	39 (Range 18-71)	0.6472
Sex			
Male	52.4% (n=65)	43.7% (n=42)	0.2020
Female	47.6% (n=59)	56.3% (n=54)	
Race			
Black or African-American	9.8% (n=12)	7.3% (n=7)	0.461
White	74.8% (n=92)	71.9% (n=69)	
Other	13.8% (n=17)	15.6% (n=15)	
Hispanic			
Yes	8.9% (n=11)	3.1% (n=3)	0.173
No	87.9% (n=109)	92.0% (n=88)	
Rural or Urban			
City or Suburb	67.7% (n=84)	75.0% (n=72)	0.2398
Small town/country/reservation	32.3% (n=40)	25.0% (n=24)	

Table 3 continued. Comparison of demographics and outcome variables between participants with or without barriers.

Variable	Barriers (n=124)	No barriers (n=96)	p-value*
Living circumstances			
Own home or apartment	57.3% (n=71)	59.4% (n=57)	0.069
Family/someone else's home or apartment	21.0% (n=26)	29.2% (n=28)	
Group home, assisted living, or other group care setting	20.2% (n=25)	8.3% (n=8)	
Homeless shelter /domestic viol shelter	0.8% (n=1)	1.0% (n=1)	
Other	0.8% (n=1)	2.0% (n=2)	
Receiving money from social security			
Yes	80.7% (n=100)	78.1% (n=75)	0.7285
No	17.7% (n=22)	20.8% (n=20)	
Level of education			
Less than high school	24.2% (n=30)	24.0% (n=23)	0.794
High school	49.2% (n=61)	53.1% (n=51)	
Some post-high school	26.6% (n=33)	22.9% (n=22)	
Employment Status			
Full-time or Part-time	44.4% (n=55)	28.1% (n=27)	0.0135
Unemployed	55.7% (n=69)	71.9% (n=69)	
Relationship Status			
Married or Marriage-Like	12.9% (n=16)	18.8% (n=18)	0.224
Not married	85.5% (n=106)	77.1% (n=74)	
Functional Disability Status:			
Mean number of functional limitations	6.31 (SD 2.95)	5.88 (SD 2.68)	0.2648
Needs assistive devices	32.3% (n=40) 70.2% (n=87)	27.1% (n=26)	0.4062
Needs personal assistance		54.2% (n=52)	0.0147
Any child abuse			
Yes	82.3% (n=102)	64.6% (n=62)	0.0028
No	17.7% (n=22)	35.4% (n=34)	
CES-D 10 score	12.59 (SD 0.586)	10.63 (SD 0.577)	0.0199
PHQ-15 score	9.53 (SD 0.488)	9.13 (SD 0.545)	0.5890
PCL-C score	40.65 (SD 1.39)	37.60 (SD 1.37)	0.1284

*p-values determined through two-group two-sample t-tests, Pearson's chi-square, and Fisher's Exact Tests.

Note: if percentages do not add to 100%, missing responses were "Do not want to say".

Association between barriers to seeking help and physical or mental health

outcomes. Univariately, the mean adapted CES-D 10 score for those participants who experienced barriers to seeking help was 12.59, significantly higher than the mean of those without barriers to seeking help (10.63, $p = 0.0199$). There was no significant difference in the mean PHQ 15 scores ($p = 0.5890$) and PCL-C score ($p = 0.1284$) between the two groups (Table 3).

After adjusting for demographics, the association between barriers to seeking help and depression persists, and the participants with a barrier have a mean score 2.23 points higher than those without ($p = 0.007$). When child abuse was added to the model the participants with a barrier have a mean score 1.67 points higher than those without ($p = 0.045$).

After expanding the model to include severity of functional limitation the association between barriers to seeking help and depression scores is attenuated and no longer statistically significant (adjusted mean difference 1.53; $p = 0.056$), and further attenuated after adjustment for the severity of abuse (adjusted mean difference = 1.34; $p = 0.083$).

The model that adjusts only for demographics explains 11.03% of the variation in depression scores; when child abuse is added and adjusted for the model explains 14.76% of the variation. After adding functional limitation, the explained proportion of variation in depression scores increased to 24.34% ($p < 0.0001$ for the change in R^2 compared to the model adjusted for demographics and child abuse only). With further inclusion of severity of abuse, the model explains 27.94% ($p = 0.0057$ for the change in R^2 compared to the model adjusted for demographics, child abuse, and functional limitation) of the variation in depression scores. The assumptions of normality and homoscedasticity were satisfied for the final model. Results of the stepwise model building for the association between barriers to seeking help after abuse and depression scores are summarized in Table 4.

Table 4. Stepwise Multiple Linear Regression Models to assess association between Barriers and CESD.

Variable	Model with Demographics (R ² = 0.1103)		Model with Demographics & Child Abuse (R ² = 0.1476)		Model with Demographics, Child Abuse & Disability (R ² = 0.2434)		Model with Demographics, Child Abuse, Disability and Abuse Severity (R ² = 0.2795)		Final Model (R ² = 0.2793)	
	B coefficient (95%CI)	P- value	B coefficient (95%CI)	P- value	B coefficient (95%CI)	P- value	B coefficient (95%CI)	P-value	B coefficient (95%CI)	P- value
Any barrier	2.23 (0.60, 3.85)	0.01	1.67 (0.04, 3.30)	0.05	1.53 (-0.04, 3.09)	0.06	1.34 (-0.18, 2.9)	0.08	1.35 (-0.17, 2.86)	0.08
<u>Step One:</u> *										
Rural/Urban	-1.49 (-3.42, 0.45)	0.13	-1.52 (-3.41, 0.38)	0.12	-1.47 (-3.27, 0.33)	0.11	1.44 (-3.20, 0.32)	0.11	-1.46 (-3.21, 0.30)	0.10
SSI	1.82 (-.08, 3.72)	0.06	1.75 (-0.12, 3.62)	0.07	1.43 (-0.36, 3.22)	0.12	1.26 (-0.48, 3.00)	0.16	1.25 (-0.48, 2.98)	0.16
Level of education										
Less than HS	Reference		Reference		Reference		Reference		Reference	
High school	-0.82 (-2.78, 1.14)	0.41	-0.67 (-2.60, 1.26)	0.49	-0.48 (-2.32, 1.36)	0.61	-0.21 (-2.00, 1.60)	0.82	-0.20 (-1.99, 1.59)	0.83
Post-HS	1.33 (-1.04, 3.70)	0.27	1.79 (-0.55, 4.13)	0.13	1.78 (-0.44, 4.01)	0.12	1.63 (-0.54, 3.80)	0.14	1.63 (-0.53, 3.80)	0.14
Employment	1.23 (-0.60, 3.05)	0.19	0.98 (-0.82, 2.77)	0.29	1.10 (-0.62, 2.81)	0.21	1.14 (-0.53, 2.81)	0.18	1.13 (-0.53, 2.80)	0.18
<u>Step Two:</u>										
Child Abuse			2.84 (1.00, 4.68)	<0.01	2.36 (0.60, 4.12)	<0.01	1.69 (-0.08, 3.45)	0.06	1.69 (-0.07, 3.45)	0.06
<u>Step Three:</u>										
Impairment					0.71 (0.42, 1.00)	<0.01	0.60 (0.34, 0.86)	<0.01	0.60 (0.34, 0.86)	<0.01
Asst Device					0.06 (-1.64, 1.75)	0.70	~	~	~	~
Pers. Asst					0.33 (-1.37, 2.04)	0.95	~	~	~	~
<u>Step Four:</u>										
Abuse –Mix							0.17 (0.05, 0.29)	0.01	0.16 (0.06, 0.26)	<0.01
Abuse - Sex							-0.01 (-0.11, 0.86)	0.84	~	~

*Age, sex, race, ethnicity and living circumstances were assessed but not included in the model after variable selection.

~ not included in model after variable selection.

SE = standard error

CI = 95% confidence interval

For personal health, there was no statistically significant association between barriers to seeking help and adapted PHQ 15 scores (unadjusted $p = 0.589$; adjusted for demographics, severity of functional impairment and severity of abuse $p = 0.870$). There was also no statistically significant association between barriers to seeking help and PTSD scores (unadjusted $p = 0.128$; adjusted for demographics, severity of functional impairment and severity of abuse $p = 0.833$).

Discussion

The prevalence of interpersonal violence towards people with disabilities has been found to be more than fifty percent in both men and women (Curry, 2011; Nosek, 2001; Nosek 2006; Powers, 2008; Marchetti et al, 1990; Powers et al, 2008; Harrell, 2012). IPV results in significant mental and physical symptoms in the general population (Kendler, 2000 and Kendall-Tackett, 1993; Nicolaidis, 2004, Thomas, Joshi, Wittenberg, & McCloskey, 2008). Research focused on violence towards people with disabilities is vitally important to understand how best to help people with disabilities in circumstances that are compromising their independence, health, and wellbeing. This research study explored a relationship that, as of yet, has been unaddressed in the literature: the relationship between barriers to seeking help and psychological or physical symptoms after abuse in people with developmental disabilities. The barriers to seeking help that the Health and Safety Survey addressed relate to both stigma and lack of access to resources for help. This work revealed that social conditions are important factors in the depression that occurs following an abuse experience.

Our demographic analysis comparing people who experienced barriers and those who did not shows an interesting statistical difference in employment. Those with barriers to seeking help were more likely to be employed than those without barriers. Our Community Advisory Board (CAB) speculated that individuals with a job have more to lose if they share their abuse experiences, or abuse may be occurring at the participant's place of employment. This was an unexpected and important finding in this work.

An individual requiring personal assistance was more likely to experience barriers to seeking help after abuse. It is possible that people who use personal assistance could experience more barriers to seeking help after abuse related to factors such as increased functional limitation, more social isolation, and more difficulty finding and accessing help. That being said, there is another circumstance that may explain this difference between the groups: caregivers as the perpetrators of abuse. Caregivers play a vital role in the lives some people with disabilities – they provide opportunity, support, and social connection. Unfortunately, it has been shown that caregivers can also be the perpetrators of abuse (Saxton, 2006, Oktay, 2004, and Powers, 2002, 2008). For example, 30 percent of adults with disabilities reported some form of abuse by their primary caregiver in a cross-sectional study done a decade ago (Oktay, 2004). This has been supported by other research (Curry, Powers, Oschwald, & Saxton, 2004; Saxton, 2001; Powers et al., 2002; Saxton et al., 2006, and Powers, 2008). This is one of the complexities presented to people with disabilities: how to report abuse when your caregiver is the perpetrator. It follows logically that these individuals could experience the possibility of losing support if the abuse had been reported, one of the barriers considered in this study.

A history of child abuse was also statistically more prevalent in people with barriers to seeking help than those without barriers. It is possible that childhood abuse experiences carry over into an individual's perception of the possible reactions to their disclosure of abuse as an adult. Some of the barriers that were included in the Health and Safety Survey (i.e. feeling too ashamed to report abuse and not feeling that they would be believed) could be related to the history of child abuse.

We chose to do a step-wise adjustment for our multiple linear regression examining the association between barriers to seeking help and depression symptoms. The first step was intended to explore the association between barriers to seeking help and depression, adjusted for demographics which acted as confounders. The second step adjusted for child abuse, which was a particularly important confounder. The third and fourth adjustments were intended to address our last objective: to expand the model by considering important variables in the complex relationship between barriers to seeking help and health outcomes: severity of functional limitation and severity of abuse. The explained proportion of the variation in depression scores increased dramatically after adding the functional limitation items and the abuse scores to the model (from 15% to 27%). It is clear that these are very important variables to consider when describing the relationship between barriers and depression, but they should not be considered confounders as they may be in the causal pathway. For example, the items concerning functional limitation and those asking about barriers to seeking help may address the same concept: how easily the participant interacts with the world around them. In a similar regard, having a barrier to seeking help may increase an individual's risk of more severe abuse. This could subsequently lead to higher depression scores. The findings of

the final two steps in our analysis should not diminish the importance of the independent association identified in the analyses for Objective 2.

We found a statistically significant association between barriers to seeking help after abuse in people with developmental disabilities and depression symptoms, after adjustment for demographic characteristics and history of child abuse. With every statistical association, the clinical context is vital to address. A score of 10 or higher indicates depression clinically, and both groups (barriers and no barriers) were above this cut off. The participants who reported barriers had a score 1-2 points higher than those who did not report barriers. While it may appear small, a 1- or 2-point increase on a 30-point scale may mean the difference between experiencing hopelessness occasionally and all of the time. For an individual this may have large significance in their daily life and functioning.

The magnitude of the association between barriers and depression was attenuated after adjustment for the number of functional limitations, and further attenuated when adjusted for the abuse score. The third and fourth steps of our model building showed that the high depression scores among participants with barriers relative to those without barriers are partially mediated by functional limitation and severity of abuse.

One of the most important strengths of PPWD is its inclusion of people with disabilities throughout the study process. The CBPR approach used in Partnering resulted in the ethical inclusion of the perspectives of people with disabilities in both process and outcome. The ACASI developed was a unique method of including people with disabilities in the research process, because it accommodated a myriad of functional disability types.

An important limitation present in this work is related to reverse causation. It is possible that our outcome variable, depression and its symptoms, could *increase* barriers to seeking help (i.e. one's perception that they would not be believed or that resources are not available to them), which may explain the association we observed. We were also limited in our minority representation and our sample size was moderate: when analyzing subsets of our sample (i.e. participants who reported abuse, or who reported barriers to seeking help) caution must be taken when generalizing our results. Also, recall bias in abuse items is challenging to minimize. That being said, a cross-sectional study was the most feasible design for a study of this size with a sample from a population that has difficulty with transportation and accessibility. Despite these limitations we were able to study a population that rarely has an opportunity to share their health experiences in the context of research.

This study revealed possible predictors of experiencing barriers to seeking help (employment, need for personal assistance, and child abuse history) and an association between barriers to seeking help and higher depression scores in adults with developmental disabilities. The step-wise adjustment supported that the association between barriers to seeking help and depression in people with developmental disabilities is complex and will require more focus in future research efforts. This should be based on the inclusion of people with developmental disabilities in the research process through utilization of tools like the ACASI and the principles of CBPR. We also need more exploration into the roots of the societal discrimination against people with disabilities leading to barriers both inherent to the individual and inherent to our culture and society. We must address the social conditions that could be disincentives to seeking help

following abuse in this population from a policy standpoint by addressing the social stigma that leads to feelings of shame and misunderstanding and making shelters and crisis lines more accessible, comfortable, and available to people with disabilities. The medical community must create a safe environment for the disclosure of abuse which may mean a greater focus on consistent training in mechanisms for assessing for the presence of abuse and abuse trends for people with disabilities: types of perpetrators and unique forms of IPV.

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