A Community-Engaged Project Discovering the Sexuality Questions of Adults with Intellectual and Developmental Disabilities

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Abstract

This study used a community-based participatory research approach to examine what adults with intellectual and developmental disabilities (IDD) view as important topics in sexuality education. A thematic analysis was conducted on questions written by adults with IDD regarding sexuality after attending a sexuality education group. Results were checked for accuracy using a community focus group. Findings provide direct implications for community-based sexuality education programs for adults with IDD, demonstrating the need for mentoring regarding authentic relationship experiences as well as developmentally appropriate sexual health information. Programs need to focus on helping adults navigate these interpersonal experiences. This study also demonstrates the importance of including the voices of adults with IDD in research in order to ensure its applicability and acceptability.

Keywords: community-engaged, sexuality, intellectual and developmental disabilities

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Socialization and sexuality play a unique and fundamental role in adult experiences and are important to well-being and quality of life for all people (Diamond & Huebner, 2012; Knox & Hickson, 2001). However, for adults with intellectual and developmental disabilities (IDD), sexuality and romantic relationships are often overlooked or actively avoided topics (Fulford & Cobigo, 2018). Service providers, parents, and other caregivers of adults with IDD frequently avoid discussions about relationships and sexuality (Evans et al., 2009), and discourage these adults from engaging in sexual relationships (Author, 2013; Author, 2019; Fitzgerald & Withers, 2011). Additionally, education on these topics is frequently disregarded in favor of educational programs such as daily living skills or employment, despite the essential role relationships play in adult independent living (Chrastina & Vecerova, 2018).

Despite the benefits that social and sexual health education has on both individual health and future interpersonal relationships of all persons (Klein, 2015), proper sexuality education is lacking even among the general school-age population (Barr et al., 2014). In special education curricula specifically, sexuality education is often skipped or minimally covered (Brown & McCann, 2018). Barnard-Brak et al. (2014) found that 56% of students with mild IDD and 84% of students with moderate to profound IDD had not received sexuality education. Sometimes this is due to the stigmatization and fear of normative sexual behaviors within this population. Barnard-Brak and colleagues (2014) also found that 60% of teachers believed that those with mild IDD could benefit from sexuality education, but only 25% of teachers believed those with moderate to profound IDD would benefit. Ballan (2012) found that specifically regarding adults with IDD, parents and professionals perceived sexuality education as potentially dangerous due

to the myth that individuals with IDD are either asexual, or oversexed and lacking control. They

expressed concern that many young people with IDD have difficulty with discernment, may not

fully comprehend sexuality education information, may overgeneralize the information, and may

struggle with understanding the reality of sexuality experiences. Parents also expressed concerns

that misunderstandings could lead to increased vulnerability. While they felt comfortable talking

about hygiene, grooming, and abuse prevention, they did not feel comfortable talking to their

child with IDD about dating, relationship development, intercourse, or birth control. Similarly,

Stein and colleagues (2018) found that most parents approved of some form of sexuality

education for their children but felt more comfortable with biology-based education.

Parents play a critical and influential role in the sexuality education and socialization of

all children (Shtarkshall et al., 2007). Parent beliefs regarding sexuality education for their child

with IDD translate into sexuality knowledge and experiences. Research has found in tests of

sexual knowledge that participants with IDD scored well on questions about anatomy and

puberty, but had limited knowledge on safe sex practices, contraception, sexually transmitted

infections, and legal issues regarding rights and behaviors (Galea et al., 2004; Jahoda & Pownell,

2014). Frawley and Wilson (2016) also found that young people with IDD were more aware of

facts regarding sexuality and health, but distinctly lacked applicable knowledge on relationships

and sexual interactions. Gil-Llario and colleagues (2018) questioned 360 adults with IDD and

found that 89.4% of participants were unhappy with their previous sexuality education and

desired further conversation around sexuality and general sexual health knowledge.

Despite an increase in sexual health education resources and curricula, many students

with IDD still leave high school without receiving any type of sexuality education due to lack of

access to these resources (Treacy et al., 2018) as well as being excluded from this component of

general education (Curtiss, 2018). This is alarming considering sexuality education has been

found in typically developing populations to have significant positive impacts on sexual health

behaviors (Kirby et al., 2005), as well as cultivating positive attitudes towards multiple aspects

of personal health and romantic relationships (Yankah, 2015). This has extended ramifications

for individuals with IDD as they transition into adulthood, as it can lead to isolation, loneliness,

and increases in negative mental health symptoms (Fulford & Cobigo, 2018; Prohn et al., 2019).

It also may be a contributing factor to recent findings based on U.S. Department of Justice data

that people with IDD are sexually assaulted at a rate more than seven times that for people

without disabilities (Shapiro, 2018). The young person with IDD typically has not had dating or

intimate relationship experiences, or their experiences have been abusive or dependent.

Additionally, perpetrators of this abuse have typically been peers (other individuals with IDD) or

caregivers (Gill, 2015). Most abuse goes unreported, as individuals with IDD often do not have

the words to express what has happened or they are not believed when they do report. Sexuality

education can give them words to articulate their experience and concerns (Ward et al., 2010).

Identifying a healthy, as opposed to abusive, relationship is difficult for any young adult

but is even more difficult for a person with IDD (Coyle, 2016). A lack of sexuality and

relationship education coupled with impoverished social networks contributes to this lack of

discernment (Brown & McCann, 2018). These adults lack peers with whom they can discuss

common relationship concerns such as boundaries and respect, which is how typically

developing young adults frequently gain information (Sun et al., 2018). Young adults with IDD

rely on parents and educators for sexuality and intimate relationship information, and these

individuals often avoid the topic assuming someone else will take on the responsibility

(Chrastina & Vecerova, 2018). A compounding factor is that many people with IDD are lonely

or isolated (Callus, 2017). Isolation, loneliness, and overprotection all can lead to vulnerability

for abuse (Coyle, 2016), and one of the best ways to stop sexual assault is to teach individuals

how to identify abuse and recognize healthy relationships (Shapiro, 2018). Despite increased

vocational programs aimed at expanding previously unmastered skills, there is still a distinct lack

of appropriate and applicable sexual health education for adults with IDD (Richards et al., 2006).

The purpose of this study was to directly engage community partners who were invested

in this topic to examine the actual sexuality education needs of adults with IDD. This included

gaining insight into sexuality education experiences and questions from adults with IDD

themselves as well as those who work with them in their community. The goal of this study was

to interact directly with community members, gain their perspectives, and include them in all

aspects of the research process. A participatory and emancipatory framework guided the study

(Chappell, 2000). Such a framework has at its core that research should (a) be a tool for

improving the lives of people with disabilities, (b) provide more opportunities for those with

disabilities to participate in all phases of the research, and (c) serve to form alliances between

people with disabilities, researchers, and other experts (Chappell, 2000).

Method

A community-based participatory research (CBPR) approach was selected for this study

(Doberneck et al., 2010; Israel et al., 1998). CBPR methodologies provides a direct reciprocal

partnership between academic researchers and community stakeholders that effectively builds a

stronger capacity for change within the community, while providing implications from research

that are directly applicable to wider audiences (Israel et al., 2010; Powell & Takayoshi, 2003).

CPBR allows for further empowerment of people and groups, enhancing their voices and power

in society, and facilitating further social change (Tremblay et al., 2017). Through this design,

community partners are involved in all aspects of research. This includes determining research

questions, as well as collecting and analyzing data (Israel et al., 1998). Data collection and

analyses are completed in methods most aligned with the community partners' values and

functioning of the community. This gives the community ownership over the research and allows

results to be community-situated, collaborative, and action-oriented (Doberneck et al., 2010;

Israel et al., 2006; Ochocka et al., 2010). This is especially important when discussing

intervention-related research (Wallerstein & Duran, 2010).

      CBPR engages community and academic partners in a common knowledge production

process aimed at improving the well-being of community partners (Tremblay et al., 2017). In this

study, CBPR was used to amplify the voices of adults with IDD and those who work closely with

them to allow for a deeper exploration of lived experiences (Schmidt, 1993). This study

progressed in three distinct phases that included integrated community collaborations on research

that guided their teaching and learning while also generating scholarship for wider audiences

(Jameson et al., 2011). The first phase included connecting and collaborating with the

community partners to discuss presenting concerns and create the research questions. Following

Institutional Review Board approval, in the second phase data were gathered and a team of

researchers analyzed the data to determine themes and initial results. In the final phase, a panel

of community members reviewed the initial results and provided feedback to further describe

and finalize the results. Figure 1 provides an overview of the three phases of the study.

Phase 1: Community Collaboration and Research Questions

      During the first CBPR phase, the research team connected with a local non-profit

organization to discuss their concerns and issues regarding sexuality education for adults with

IDD. Through meetings, members of this organization were able to specify their concerns and

begin to identify potential areas in which action needed to be taken (Powell & Takayoshi, 2003).

During this phase, the research team learned more about the organization, specifically their

sexuality education program, and they discussed areas in which they could collaborate.

Community Partners

A main component of CBPR is the inclusion of the community partners in all aspects of

the research. The community partners were all associated with a non-profit organization in a

midwestern state that provides services for adults with IDD in the areas of sexuality education,

social skill acquisition, and employment soft skills training. They work with approximately 250

adults (over the age of 18) each year. This partner organization structures their services around

the belief that education and enrichment are lifelong needs and their goals are to promote

personal independence and encourage work within the community.

The SHARE Program

The Sexual Health And Relationship Education (SHARE) curriculum that was developed

by one of the founders of the non-profit organization was used to provide sexuality education to

the adults with IDD that they serve. Participants met in small groups once a week for 12 weeks.

The average group size was seven adults with IDD and two facilitators. In order to be flexible to

the different needs of different groups of participants, the curriculum covered one topic each

week, and included a collection of resources for facilitators to use depending on the

developmental level and previous sexuality education level of the participants in the group. See

Table 1 for session topics and examples of content covered. All the topics in the curriculum were

covered throughout the program, but the depth that each topic is taught for each group is

determined based on the facilitators' determination of the appropriateness of the material. The

SHARE program has been run with nine different cohorts.

For the most recent seven cohorts, the same two SHARE facilitators implemented a teaching tool they called "question cards". After each session, participants were provided with index cards to ask any further questions they had. Participants were able to write these questions themselves, or they could verbally relay them to facilitators who would write a question card for them. Facilitators would attempt to answer these questions during the next session, but indicated they often ran out of time and were unable to do so. If unable to cover it in session, they would follow-up with participants individually. Question cards from these seven different SHARE groups were collected and saved by facilitators. Through collaborative discussion these question cards were determined to be a potential avenue for resources and data (Gust & Jordan, 2006).

Research Questions

Three research questions were developed in direct collaboration with and driven by the community partners (Sandmann, 2006). These were designed specifically regarding adults with IDD who have taken a sexuality education course developed for adults: 1) in what sexuality education topics do adults still have gaps in knowledge?; 2) what types of questions do adults continue to have unanswered?; and 3) what are the areas of sexuality education for adults with IDD specifically that need to be covered more thoroughly or in different ways?

Phase 2: Analysis of the Question Cards

During the second CBPR phase, the research team analyzed the question cards that facilitators had collected. All questions cards used in the analyses had been collected prior to beginning Phase 1 of the study, therefore not influencing what participants wrote on their cards. The research team consisted of an expert in the field of sexuality education for adults with IDD, and educational and therapeutic group instruction with eight years of experience in the field. The second research team member was an expert in the field of sexuality and special education with

20 years conducting research and delivering interventions related to sexuality. The third member

of the research team was a doctoral student in the area of rehabilitation counseling. No member

of the research team was involved in the creation or implementation of the SHARE program.

SHARE Participants

Thirty-three adults with IDD (28 males, 5 females) participated across the seven SHARE

groups. Participants were aged 20-52 (M = 29.12, SD = 8.87). Most participants (21; 64%) had a

diagnosis of ASD and mild IDD. Five participants (15%) had a diagnosis of emotional

impairment and mild IDD, and seven participants (21%) had a diagnosis of mild IDD or

cognitive impairment. Most participants lived at home with a caregiver (70%), some lived in

community supported living arrangements (15%), and some lived independently in the

community (15%). Many of the participants were employed (36%) or going to school (27%).

Twelve of the participants (36%) were currently not employed or attending any school or

vocational program. We do not have information on race/ethnicity and current relationship status

because the organization did not collect that information from participants of their services.

Data Analysis

All collected question cards (87 total) were gathered and given to the research team for

analysis. Participants did not write any identifying information on the cards; therefore, their

identities were kept confidential. The cards were also collected and grouped by cohort, but to

which cohort each group of cards belonged was not identified. The research team was also given

demographic information for SHARE participants as a group with no identifiable information

provided. The research team analyzed the question cards using a constructionist thematic

analysis approach (Braun & Clarke, 2006). Analyses were conducted across two levels of

coding. The first level of coding consisted of a semantic categorial analysis. The second level of

coding consisted of a latent analysis to examine underlying ideas and conceptualizations.

During the first coding level, the research team coded all question cards semantically

using a categorical coding system based on Blanchett and Wolfe's (2002) review of sexuality

education curricula for individuals with intellectual disabilities. Their list of curriculum concepts

was used to categorically code the question cards. Table 2 provides a comprehensive list of these

codes. All members of the research team independently coded all question cards. All applicable

codes were applied to each question card, as some cards fell into multiple categories. After the

initial independent round of coding, the research team met and discussed coding disagreements

until consensus was reached. These codes were then tallied to provide information regarding

what sexuality education curriculum topics were asked about.

During the second level of coding, the research team analyzed all question cards at the

latent level for underlying ideas and concepts. All three researchers had previously become

familiar with the data through the first level of categorical coding. They then read through all the

question cards independently and generated codes and themes they felt were omitted through the

first level of coding. The research team then met to discuss and agree upon the thematic codes.

The team then returned to the data independently and coded all question cards based on the

finalized codes. Finally, the team met again and discussed any coding disagreements until

consensus was reached. These codes were then tallied, and the results were merged with the

results of the categorical analysis to provide a more thorough understanding of the data.

Phase 3: Gathering Community Partner Feedback

During the final CBPR phase, the research team met with a panel of individuals from the

community partners to discuss the results of the question card analyses. The community panel

was given the results and asked to provide feedback to add a deeper explanation and ensure the

results were realistic and applicable to the community, as well as working to negate any potential

inherent biases the research team may have (Chambers, 2006; Schmidt, 1993). The community

panel was only given access to the results of the analyses to provide experience/opinion-based

feedback and did not conduct any analyses themselves. The feedback from the panel was then

integrated to provide the finalized results of the study.

Community Panel Participants

The community panel consisted of seven individuals. The first panelist was the executive

director of the organization which runs the SHARE program. The second panelist was the creator

of the SHARE program and the original facilitator. The third panelist was a female SHARE

facilitator with a background working as a direct service personnel for adults with IDD. The

fourth panelist was the second female SHARE facilitator who was currently a master's student in

rehabilitation counseling. The fifth panelist was an adult female with ASD who had previously

participated in the SHARE program. The sixth panelist was an adult female with a mild IDD

who had previously participated in the SHARE program. The final panelist was an adult male

with ASD who had not taken the SHARE program but had received a sexuality education course

in high school. Using a CBPR framework (Doberneck et al., 2010) it was important to include

those directly connected to the SHARE program in the focus groups as their experiences would

provide the research team with the most applicable feedback to ensure accurate results. It was

also important to include adults with IDD in the panel to ensure the inclusion of all community

partners (Bigby et al., 2014). Demographic information (e.g. age, race, education level) were not

collected for the panel.

Community Panel Feedback

The panel was sent only the summarized results of the question card analysis, no examples of cards were given to ensure the deidentification of the data throughout the study. The panel was asked to gather their initial thoughts along with answers to three specific reflection prompts: 1) could the timing of when the question cards were collected have impacted the results of the study?; 2) please provide specific feedback on the new themes of social norms, sexual behaviors outside of intercourse, and communication within relationships; and 3) what are potential concerns with the format of how SHARE presents these topics?

Two focus groups were then conducted to gather feedback (Krueger & Casey, 2015). During each focus group, the participants were asked the three reflection prompts, and then were asked to provide any additional open-ended feedback regarding the results. The first focus group consisted of the executive director of the organization, the creator of the SHARE program, and the two SHARE facilitators. This focus group lasted 1.5 hours. The second focus group consisted of the executive director and the three adults with IDD. The executive director did not participate in the feedback portion of this group and was only there to make the other participants feel comfortable and to help them clarify their feedback as needed. This focus group lasted 2 hours.

The strong relationships established between the research team and all the community partners during Phase 1 of the study enabled those who participated in the focus group to feel more comfortable. Feedback from all groups was audio recorded. Two members of the research team listened to the audio and summarized the feedback. They met to discuss and finalize the feedback. This information was then merged with the results of initial question card analysis for finalized results. A member check of the finalized results (Lincoln & Guba, 1985) was conducted by the panelists. The panelists did not add or change anything, and all agreed with the results.

Results

The results of the study provided two overarching themes. The first theme includes the desire to further their knowledge about authentic relationship experiences. This theme also contains three subthemes. The second theme includes the need for continuing discussion of general individual sexual health knowledge.

Theme 1: Authentic Relationship Experiences

The first theme is that of participants desiring further knowledge and information on authentic, real-world relationship experiences. During the first round of coding, the majority (93%) of participant questions were coded as belonging in either the *relationships* or *self-protection/self-advocacy* categories of the sexuality education curriculum topics review (Blanchett & Wolfe, 2002). This indicated a desire from participants to understand how the information they received in the sexuality education course translated to real-world experiences. An example of a relationship-focused question was, "does sex need to be central to a relationship?" Another example was, "how to know when you are ready to get into bed with your girlfriend for the first time?" An example of a question regarding the self-protection/ self-advocacy category was, "how do you handle peer pressure?" Another example was, "why are females more often victims of sexual assault than males?" The results from the community panel indicated that although these topics were covered as part of the curriculum, facilitators recognized that they did not cover the topics in depth like they did other topics (e.g. sexual hygiene, safe-sex practices, sexual anatomy). They specified that the topic of relationships is difficult to cover. This is because it requires discussions of personal values, gray areas, and individual desires that are difficult for facilitators to discuss in a group setting. One panelist stated, "it's the issue of participants needing more 'black and white' answers, but these aren't

really that way, so that's why the adults have so many questions about them." Because of these

concerns, more emphasis is placed on other sexuality topics within the curriculum.

Social Norms

The subtheme of social norms refers to questions regarding general societal expectations

about relationships. In these questions, participants expressed concern regarding what they

should be expecting as they date or enter a long-term relationship, as well as concern with

whether they would be able to meet the expectations of others. One example of this type of

question was, "what are the rules of texting?" A second example was, "is it right to date someone

at least 10 years older/younger than you?" Some of these questions were disability-specific, for

example one participant with ASD questioned, "is it possible that I might get a rejection from

other people, because of the fact that I have autism?"

Questions in this category also showed a concern for integrating information they have

heard from siblings, peers, and the media, and being able to discern between phrases that are

social clichés compared to real expectations. As these participants enter adulthood, they find

themselves either in these situations, or have friends and siblings who are in these situations, and

so their awareness and questions become more focused on these types of understanding. For

example, one participant asked, "the joke is a man will last a minute. So actual sex is not like a

porn video. Will my partner understand that?" Another participant echoed this sentiment asking,

"what is actually the average length of intercourse?"

Sexual Behaviors Outside of Intercourse

This subtheme related to specific questions regarding a wider range of sexual behaviors

outside of the biological act of intercourse. This included issues such as oral sex, self-

stimulation, and foreplay behaviors. One participant asked, "is it ok to masturbate while in a

relationship?" Another participant questioned, "can you have oral sex with condoms?" Another

example of this type of question was, "can you hold off on an orgasm? How?" These questions

were sometimes also related to social norms and what is to be expected in authentic relationship

experiences, such as the question "is sex addiction real?" Sexual intercourse is covered in the

SHARE curriculum, but other sexual behaviors are often not discussed. The community panel

indicated this as a very difficult area to teach, specifically because of the impact that personal

values have on potential answers to these questions. They also indicated worry about potential

issues if caregivers with guardianship of participants have concerns with what they are teaching.

Facilitators recognize that this is a topic area that could be a divisive issue for many caregivers,

and they avoid the topic in order to avoid those concerns.

Communication Within Relationship

This subtheme refers to specific questions regarding communication expectations within

relationships. This includes how to talk with dating partners about sexual preferences, previous

experiences, and sexual expectations. Related to this category one participant asked, "when do

you know when it is the right time in a relationship to start having sex?" Another participant

questioned, "I remember hearing a phrase 'I would never date someone who has had more sexual

partners than me.' How do I know?" A third example of this subtheme was, "how do you handle

dating around when you have trust issues?" Some of these questions were also regarding how to

determine explicit compared to implicit communication and rules within the relationship. One

participant listed "consent v. non-consent with drinking and how to know" as a topic they wanted

to know more about.

Theme 2: Individual Sexual Health Knowledge

The second theme is that of participant questions related to their own sexual health that are not specifically asked within a relationship context. During the first round of coding, only 49% of participant questions were coded as belonging in either the *biology and reproductive* or *health and hygiene* categories of the sexuality education curriculum topics review (Blanchett & Wolfe, 2002). This indicated that although participants still had questions regarding these topics, they were fewer in comparison to questions regarding authentic relationship experiences.

Overall the category of *health and hygiene* had the fewest questions (12%). An example of a health and hygiene question was, "what is toxic shock?" Another participant asked, "what lubricant is healthy to use for sex?" A final example of the health and hygiene category is the question, "should women wear a bra when they sleep at night?" The community panel provided insight into this. One panelist stated, "hygiene seems to be more addressed actually in session and it also might be easier for participants to ask about it in person so that is why they don't have as many cards." Another panelist and SHARE facilitator noted, "the SHARE program always teaches these topics first, so there is probably more energy around this because of that. Plus, it's not as embarrassing since the same information basically applies to everyone."

The *biology and reproductive* category had more questions than *health and hygiene*, but still fewer than those related to authentic relationship experiences (33%). One participant asked, "does the mother get scratches when giving birth to the baby?" Another participant questioned, "during ovulation how much does the women's temp go up?" A final example of a biology and reproductive question was, "what exactly does the prostate do?" Feedback from the panel indicated that there may be more questions regarding this topic due to the tangible nature of the information. One panelist noted, "these topics overall are more tangible and concrete, so they're

probably easier to ask about." The information may be easier for participants to integrate the knowledge and have specific questions. A panelist who was also an adult with IDD noted "this is the only thing they really taught me in school. So, it's nice to hear it again because now I know what questions to ask. But I don't have many because I've learned more over the years."

Discussion

This study resulted in two themes regarding sexuality education for adults with IDD. The first theme was authentic relationship experience knowledge and information, and the second theme was content related to individual sexual health knowledge. Adults with IDD expressed a desire for information regarding authentic relationship experiences. They wanted to further understand how to integrate this information into their own personal experiences, and what types of experiences they should be expecting. The community panel helped explain that this information was difficult to cover because of the ambiguous nature of the topic. This indicates that this topic may be more suited to a coaching and mentoring style of teaching, as opposed to the dyadic instruction that is common in most sexuality education groups. Adults with IDD demonstrated a desire to engage in relationship experiences but need further guidance and explicit instruction in putting this information into practice (Galea et al., 2004). Safety and self-protection related to these experiences should be integrated into education in a manner related to healthy relationships as opposed to simply avoiding abuse (Ward et al., 2013). This study indicated that adults with IDD know what types of questions to ask and understand the types of information they desire, and sexuality education should be implemented accordingly.

The results of this study also indicated that adults with IDD still have questions related to general individual sexual health knowledge. This is consistent with the findings of Schaafsma and colleagues (2015) that repetition, rehearsal and practice over time are the most effective

methods for teaching sexuality education to individuals with IDD. This study indicates that

adults feel they need a review of this information specifically as it relates to their developing

adult bodies. This may be difficult to do as groups are often comprised of adults with many

different levels of previous experience in sexual health education, so it would be important to

assess the knowledge of the group before beginning to determine what topic areas need to be

covered. These topics are often easy to cover in a didactic training model and can most likely be

easily implemented in any adult sexuality education course.

Limitations of the Study

One limitation of this study is that the SHARE program did not follow a specific

evidence-based curriculum. Because of this, no treatment fidelity checks were conducted and

therefore we cannot determine the exact content each group of participants received. However,

for the purposes of this study the researchers had access to all curriculum materials, and it was

determined that the program covered the same components as most sexuality education curricula

described in the research literature (Blanchett & Wolfe, 2002). While this may have had an

impact on the study results related to content covered in the SHARE program, this is also a

common reality for many non-profit adult programs who are unable to purchase and access most

sexuality education curricula. And while many free curricula do exist, most of them are aimed

towards adolescents and young adults and materials often need to be supplemented for adults.

In relation to the use of an organization-specific curriculum, it should be noted that the

community panel did consist mainly of people who were directly aligned with the use of this

curriculum. Due to this factor, they were not included in the analysis of the question cards.

However, this may have influenced their interpretations of the results during the focus groups.

Another limitation of the study is that most adults with IDD who participated in the SHARE program were males. This is potentially connected to a high rate of ASD among participants, and that males are more commonly diagnosed with ASD than females (Adamou et al., 2018). This could potentially impact the results of the study in relation to questions asked, as male and female adults may have different areas of interest in sexuality, as well as potentially receiving different levels of sexuality education previously (e.g. females often receive more abuse avoidance information socially than males: Radin, 2017; Scriver & Kennedy, 2016).

Regarding the question cards themselves, a limitation of their use is in the deidentification process that was used. We were unable to tell who wrote the cards or even which cohort the cards came from. Due to this, we are unable to tell if cards were evenly distributed across participants or if there were some who disproportionally asked more questions.

A final limitation is the number of participants. The small group of adults with IDD who participated in these groups also limits the generalizability of the study. This study is meant to be an introductory CBPR study to begin elevating the voices of adults with IDD in their own sexuality education and offering innovative ways to collect research data from these adults.

Implications for Practice

Results of this study provide direct implications for community-based sexuality education programs for adults with IDD regarding what topics are important to these adults, and the most common knowledge gaps. In order to support further inclusion within society, these programs need to be learner-centered and place more of an emphasis on helping adults integrate and apply knowledge regarding everyday relationship experiences. Sexuality education for adults with IDD should be conducted within a healthy relationship context. Groups specifically designed for adults with IDD should be focused on advocating for the adult's need for information that is

essential to more authentic and impactful personal experiences and directly applicable to their

lives. This would include information that considers different living situations, the potential

inability to marry, as well as multiple other barriers these adults experience in having

relationships (Author, 2019). Including components of coaching and mentoring will also help

adults with IDD directly apply the knowledge to their own experiences (Gilson & Carter, 2016;

Walker et al., 2016). For adults, sexuality education is more than the instruction of anatomy and

sex. It needs to include an understanding of the inner-self within the context of the outer-world.

This initiative would be aided with the inclusion of further materials regarding sexual identity

and sexual orientation (Bedard et al., 2010; Löfgren-Mårtenson, 2009; Noonan & Taylor Gomez,

2011). It is important to note that objective sexuality education topics (i.e. health and hygiene,

anatomy and physiology) continually and progressively need to be covered at a developmentally

appropriate level with multiple examples for individuals with IDD (Schaafsma et al., 2015).

Adults with IDD benefit most from direct and literal examples and information. The type and

need for information develop as individuals age.

        Often adults of varying disability levels are placed into the same groups due to lack of

funding for multiple groups. These groups are impacted by facilitators lack of knowledge on the

difficulties of having different ability levels in one group, and overall lack of adult community-

based programming for these adults (Ward et al., 2013). This has negative impacts on the ability

of the adult to improve overall, as well as on their ability to apply self-determination (Brown &

McCann, 2018; Glen, 2015). It is important to provide adults with IDD with "real-world" advice

and examples, especially related to social norms, their own sexual behaviors, and communication

within interpersonal relationships.

Sexuality is personal, and the social nature of relationships are difficult topics to discuss. The more conversations in which adults with IDD can engage on the topics of sexuality and relationships, the less anxiety and uncertainty they will likely experience. Sexuality education providers should deliver reliable emotional support and guidance to foster a supportive open environment to discuss any topic a participant may inquire about. It is important to feel that discussions will not be judged by those in a position of power as an educator. It is crucial that the staff is comfortable discussing sexuality and relationships. Staff need training in how to explain the complexity of sexuality within the context of relationships. It is also important to consider the gender of the facilitator in comparison to participants for these groups, as participants may be more comfortable discussing sexuality with an individual who they relate to in regard to gender (Harrison & Ollis, 2015; Mannix et al., 2010).

Due to the directly applicable nature of the CBPR study design (Powell & Takayoshi, 2003), the SHARE program has already used the results to create a sequential model for their program. In this model, adults must first take SHARE 1, which focuses on individual sexual health using didactic instruction and group education practices. After the completion of SHARE 1, participants are eligible to take SHARE 2 which focuses on healthy sexuality within a relationship context using didactic instruction, group therapy techniques, and personal coaching.

Policy Implications

The results of this study indicate the need for policy change in how sexuality education is embedded into transition programs. It would be helpful to embed sexuality education first within transition programs prior to exiting compulsory schooling, and then in community-based vocational and adult day programs. Sexuality is a large component of adult life and experiences and integrating this information within other programming would help adults with IDD to

examine the systemic nature of these issues and understand relationships within a broader cultural and experiential context.

The CBPR methodology used in this study also underscores the importance of continuing to conduct research on the topic of sexuality with the population of adults with IDD. There currently exists limited available grant funding for this type of research. The results of this study show the importance of conducting this type of research to ensure practices are applicable and acceptable to the individuals they are meant to be servicing. Funding CBPR projects would allow adults with IDD more opportunity to engage in supported decision-making that could also impact policy and programming.

This study also has implications for altering policy to require schools to incorporate inclusive and meaningful sexuality education for individuals with IDD in grades K-12. It is a disservice to individuals with IDD to wait until adulthood to receive appropriate sexuality education, especially if basic concepts such as anatomy and physiology are not being covered in the manner necessary for these individuals. There is a direct need for policy change regarding sexuality education in K-12 schools, especially in regard to the inclusion of individuals with IDD and incorporating this information into special education classrooms as well.

Future Research with Adults with IDD

This study amplifies the importance of including the voices of adults with IDD in research in order to ensure its applicability and acceptability (Beail & Williams, 2014; Caldwell, 2014). The CBPR process specifically could further promote the inclusion of adults with IDD, as the use of CBPR methods provides a more inclusive way to address health disparities among underrepresented communities (Sandoval et al., 2011). Having adults with IDD engage in the research process beyond simply as participants provides them with more ownership in addressing

issues that are of concern to them directly (Shogren & Wehmeyer, 2015). This is especially true for the topic of sexuality and with recent advances in initiatives for adults with disabilities to engage in sexual self-advocacy (English et al., 2018; Fulford & Cobigo, 2018; Whittle & Butler, 2018). Sexuality in general is a difficult topic to discuss, and researchers need to continue to find different ways to help participants discuss these issues and concerns.

This study also points to the need for continued research into evaluating sexuality education programs to ensure they are meeting the needs of the individuals they are intended to serve. The community panel in this study indicated difficulties in finding a sexuality intervention that was applicable to the population of aging adults with IDD. These programs may already exist, and researchers need to continue to evaluate them and make them available to the public.

Conclusion

This study used CBPR methods to discover what types of questions adults with IDD have regarding sexuality education and what topic areas continue to be of concern in adulthood. It was discovered that participants wanted more information regarding authentic relationship experiences, as well as the need for more developmentally appropriate information regarding ageing. Adults with IDD also need access to information and mentorship regarding relationship experiences that facilitate safe community integration. This should include helping them understand what to expect and guiding them through current experiences. Future research and practice should continue to examine appropriate methods for implementing sexuality education and ensure the inclusion of the voices of adults with IDD in both research and practice.

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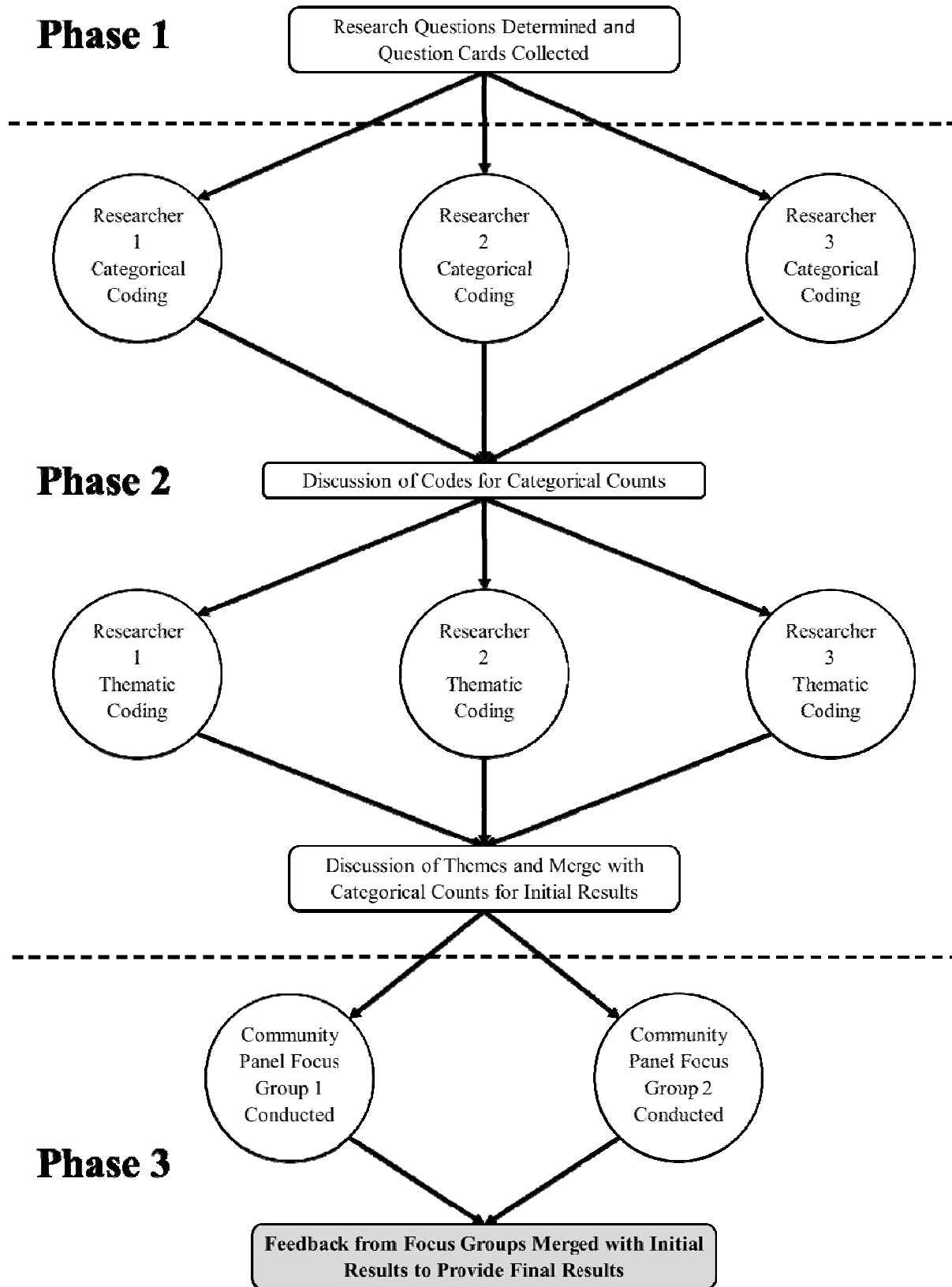
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Phase 1

Research Questions Determined and
Question Cards Collected

Researcher
1
Categorical
Coding

Researcher
2
Categorical
Coding

Researcher
3
Categorical
Coding

Phase 2

Discussion of Codes for Categorical Counts

Researcher
1
Thematic
Coding

Researcher
2
Thematic
Coding

Researcher
3
Thematic
Coding

Discussion of Themes and Merge with
Categorical Counts for Initial Results

Community
Panel Focus
Group 1
Conducted

Community
Panel Focus
Group 2
Conducted

Phase 3

**Feedback from Focus Groups Merged with Initial
Results to Provide Final Results**

Figure 1. CBPR Study Phases: Data Collection, Analyses, and Interpretation Procedures

Table 1

SHARE Session Topic and Example of Content Covered

Session Topic	Example of Content Covered
1. Introduction to the Group	Ice breakers and personal introductions
2. Anatomy & Reproductive Systems	Male vs. female reproductive systems
3. Puberty, Sexual Health & Hygiene	Secondary sex characteristics, menstruation
4. Puberty, Sexual Health & Hygiene Part II	Bathing, shaving
5. Sex	Vaginal and anal intercourse
6. Contraception, Birth Control & Pregnancy	Condoms, birthing process
7. Sexual Abuse, Exploitation, & Law Enforcement	Consent and abuse/exploitation definitions
8. Sexual Abuse, Exploitation, & Law Enforcement Part II	Local laws regarding perpetrator behaviors
9. Types of Relationships	Dating vs. long-term relationships
10. Stress & Anxiety in Relationships	Recognizing anxiety & depression symptoms
11. Making Friends & Dating	Acquaintance vs. friendship vs. dating relationships
12. End of Group Party	Knowledge game and celebration

Table 2

Sexuality Education Curriculum Topics Coding Categories

1. Biological & Reproductive
    - Anatomy and physiology
    - Gender differences
    - Pregnancy
    - Birth control
2. Healthy & Hygiene
    - Hygiene
    - Health and wellness
    - Alcohol and drug use
    - STD/HIV prevention
    - STD epidemiology
    - Body and disease
3. Relationships
    - Relationships/social skills
    - Responsibility to partner
    - Family types and roles
    - Feelings and expressions
    - Dating and marriage
    - Parenting
    - Sexual orientation
4. Self-Protection/Self-Advocacy
    - Protection against abuse
    - Sexual feelings
    - Sexuality as positive aspect of self
    - Sexual behavior other than intercourse
    - Appropriate and inappropriate touching
    - Decision making
    - Use of condoms
    - Reduction of fear and myths
    - Personal rights
    - Sexual discrimination
    - Saying "no" to sex
    - Saying "no" to drugs
    - Saying "no" to alcohol
    - Saying "no" to tobacco

Note. Coding categories taken from Blanchett & Wolfe (2002)