



**In the Daily Life of Adolescent Girls and Young Women
(AGYW) with Disabilities –**
evidence gathering for AGYW policy and advocacy

**A Her Voice Fund sponsored project conducted by Afrique Rehabilitation and
Research Consultants (ARRC) NPC, South Africa.**

Report prepared by Prof Julie Phillips and Jacqui Kaschula

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The facilitators are young women with disabilities themselves, providing support and engagement from a peer support perspective whereby people with disabilities are engaging with and receiving support from people with disabilities.

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For more information contact Jacqui Kaschula (Project Lead) at:

Email: jacqui1997@gmail.com

Tel: +27 76 145 5926

Afrique Rehabilitation and Research Consultants NPC on:

WhatsApp: +27 67 005 7868

Call: +27 72 713 4649

Email: Vernon.openshaw@gmail.com

Website: <https://arcc-npc.org.za/>

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Introduction

Globally adolescent girls and young women (AGYW) aged 10 to 24 years have emerged as a priority group in desperate need of targeted interventions and aid, especially in the realm of sexual and reproductive health and rights (SRHR) (Holmes et al, 2020). Exacerbated by gender inequalities and restrictive gender norms, AGYW face stigma and discrimination that compounds their vulnerability to a number of SRHR-related health issues, one of which being Human Immunodeficiency Virus (HIV) (UNAIDS, 2019; Karim & Baxter, 2019). For AGYW in South Africa, HIV is the second leading cause of death and it has been shown that young women and girls are 2 to 4 times more likely to have HIV and more likely to acquire HIV (with rates as high as 64%) as compared to their male counterparts (Davids et al, 2020). Moreover, data has shown that HIV prevalence among young women ages 15 to 19 years increases by 5.6% and at ages 20 to 24 years increases by 17.4%, for men of the same age groups the increases in HIV prevalence's are 0.7% and 5.1% respectively (Harrison et al, 2015). Unfortunately, among this group, AGYW with disabilities oftentimes are excluded and overlooked when it comes to the SRHR needs of AGYW as a whole, being largely underrepresented and invisible in policies, programmes, and services (Jones et al, 2018; UNAIDS, 2019). Meanwhile, numerous research has shown that AGYW with disabilities have significantly poorer sexual health outcomes alongside poorer access to SRHR-related services as compared to their peers without disabilities (Jones et al, 2018). Moreover, it has been shown that AGYW belonging to marginalized groups, such as those with disabilities, face increased risks of violence, stigma and discrimination, compounding their risk to HIV infection (UNAIDS, 2019). Factors such as disability-related stigma (i.e. the misperception that people with disabilities are non-sexual and thus do not need to practice their sexual rights), physical inaccessibility, and cost have been shown to lag, and in oftentimes prevent, AGYW with disabilities from accessing SRHR-related services and education (Jones et al, 2018). In South Africa, AGYW with disabilities have been shown to face greater vulnerability and marginalisation as compared to their peers without disabilities, placing them at a greater disproportionate risk for HIV infection and sexual violence (Cockburn et al, 2019). Despite this, AGYW with disabilities still lack access to SRHR-related services and comprehensive sexuality education (CSE) in South Africa; in turn further increasing their vulnerability and risk to HIV infection and sexual violence (Hanass-Hancock et al, 2018).

The vulnerability of AGYW to HIV infection has been shown to be largely affected by societal norms contributory of masculine dominance and sexual entitlement, and stigma and discrimination (Sokhela et al, 2018). Incidentally, this leads to gender inequalities and power imbalances resulting in young females being unable to negotiate safer sex and thereby engaging in risky sexual behaviours (Holmes et al, 2020; Goga et al, 2020). High risk behaviours that are linked to HIV infection include minimal condom use, intimate partner violence (IPV) and sexual violence (Sokhela et al, 2018). Violence or the fear of violence can prevent AGYW from negotiating safer sex, accessing SRHR-related services and communicating about their HIV status with family, healthcare providers and partners (UNAIDS, 2019). Incidentally, violence creates a vicious cycle, increasing AGYW's vulnerability to HIV infection while those who are HIV positive subsequently face increased discrimination and violence (Goga et al, 2020). According to the World Health Organisation (WHO), South Africa has one of the highest rates of gender-based violence (GBV) globally (13). A July 2020 survey conducted across all South African provinces indicated a 54%

increase in GBV cases and a similar study revealed that 1 in 5 South African women reported experiences of IPV (13). Moreover, the South African Police Service (SAPS) Crime Statistics reported in 2019/2020 over 53,000 sexual offenses and over 42,000 rape cases (both an increase from the previous reporting year 2018/2019) (13). AGYW who are survivors of rape and violence have been shown to suffer a myriad of other health issues, including poor sexual and reproductive health outcomes, increased alcohol use, and mental illness such as anxiety, post-traumatic stress disorder (PTSD) and depression (UNAIDS, 2019; Davids et al, 2020). Compared to their counterparts, AGYW with disabilities are 3 to 4 times more likely to experience physical and/or sexual violence, and in particular are more vulnerable to sexual violence and abuse as they are perceived as being ‘easy targets’ and the ‘unlikeliest’ to report violence or be believed to have been sexually abused (Jones et al, 2018). Research shows that AGYW with intellectual disabilities are most vulnerable to sexual violence (Jones et al, 2018). On the other hand, AGYW with disabilities often find difficulties and barriers (i.e. societal and physical) in accessing protection mechanisms and healthcare services, reporting cases, seeking justice, and receiving support services (Jones et al, 2018). Incidentally, they are faced with increased vulnerability to violence while also having no to limited access in services that provide SRHR support, education and assistance, thereby increasing their vulnerability and risk of poor sexual and reproductive health outcomes further.

Other factors that have been associated with the risk of HIV infection among AGYW are socio-demographic factors such as age, employment status, area of residence, and education level (Sokhela et al, 2018). Factors such as unemployment and area of residence increase AGYW’s vulnerabilities to exploitation and abuse. In Sub-Saharan Africa data has shown that 7 in 10 young women do not have comprehensive knowledge on HIV, and 29.8% have basic knowledge on how to protect themselves from HIV (UNAIDS, 2019). Numerous data has indicated that level of education plays a major role in the associated risk of HIV infection among youth (Jones et al, 2018; Sokhela et al, 2018). Findings from population-based surveys in Southern Africa indicated that poorer or less educated AGYW are less able to negotiate male condom use (i.e. negotiate safer sex) and have less control over sexual decision making as compared to their more educated peers (Goga et al, 2020). The education gap between AGYW with and without disabilities is extensive, and only increasing (Jones et al, 2018). AGYW with disabilities are often not provided or have limited access to CSE (Maart & Jelsma, 2010; Cockburn et al, 2019). There are also misperceptions carried by society and healthcare providers that youth with disabilities do not require CSE as they are viewed as non-sexual/asexual and thus do not engage in sexual behaviours. On the contrary, youth with disabilities are engaging in risky sexual behaviours just as much as their peers without disabilities (Maart & Jelsma, 2010).

Incidentally, while we know that AGYW with disabilities have a greater risk and vulnerability to HIV infection and sexual and physical violence, and have limited to no access to SRHR-related services and CSE, there is still minimal research and awareness on the priority areas and needs of AGYW with disabilities in South Africa. In addition, AGYW with disabilities are afforded minimal opportunities to voice their stories and concerns (Jones et al, 2018). For these reasons, it was identified that the vicious cycle of GBV, HIV infection and gender inequalities must be broken and AGYW with disabilities empowered and their voices amplified.

As such, the current project looked to gather evidence on the priority areas/needs, issues and stories of AGYW with disabilities in South Africa as a means of providing evidenced-based information that can be used to beneficially inform and potentially change AGYW advocacy and policy, with a clear focus on AGYW with disabilities and within the disability sector. Moreover, as a means to amplify AGYW with disabilities voices by having their stories heard. By doing so the hope is to bring more attention to the topic and create much needed change within the SRHR needs of AGYW with disabilities. The project thereby focused on conducting facilitation in two provinces, namely Gauteng and the Eastern Cape, and utilising facilitators who are young women with disabilities themselves. The facilitators engaged with participants and asked them a number of questions related to their disability, demographics, knowledge of HIV, sexual behaviour and violence. Facilitators also shared their own experiences and stories with participants as part of peer support, providing a safe and comfortable space for information sharing and storytelling. Facilitation was entirely voluntary, and information was provided anonymously. Participants could also choose to have a guardian or parent present during the facilitation. The project ran from December 2020 to February 2021.

Results

Demographic characteristics of the group

Data for this project was collected from 13-29 January 2021 by the two facilitators. The participant group was chosen to be comprised of adolescent girls and young women aged 15 to 24 years and having a disability.

The group comprised of 148 adolescent girls and young women with an average age of 20.5 years. However, to provide a description of the group, data for 8 participants had to be excluded because crucial information was missing, i.e. age, ethnicity, and variables such as sexual activity and knowledge.

The majority of the participants classified themselves as African Black (90.0%) and small percentages as Coloured (5.7%), White (2.9%) and Ethiopian (0.7%). The majority was never married (94.3%) while a small minority was either divorced, separated or married. Almost a quarter (23.5%) completed secondary schooling, 41.4% completed some secondary schooling and 15.7% some tertiary education. A very small minority (1.4%) had no schooling. The largest percentage (81.4%) stayed in their own family home/flat, 13.6% with a family member and the rest stayed in a hostel or school residence.

As far as employment is concerned, 68.6% were unemployed and 9.9% were employed on either a full-time or part-time basis, while 19.3% were studying.

Disability

Participants were asked to describe their disability. The majority described their disability as physical (75.0%) and 10% as a sensory disability such as vision or hearing impairments. The types of disabilities the participants have are summarized in the figure below (next page).

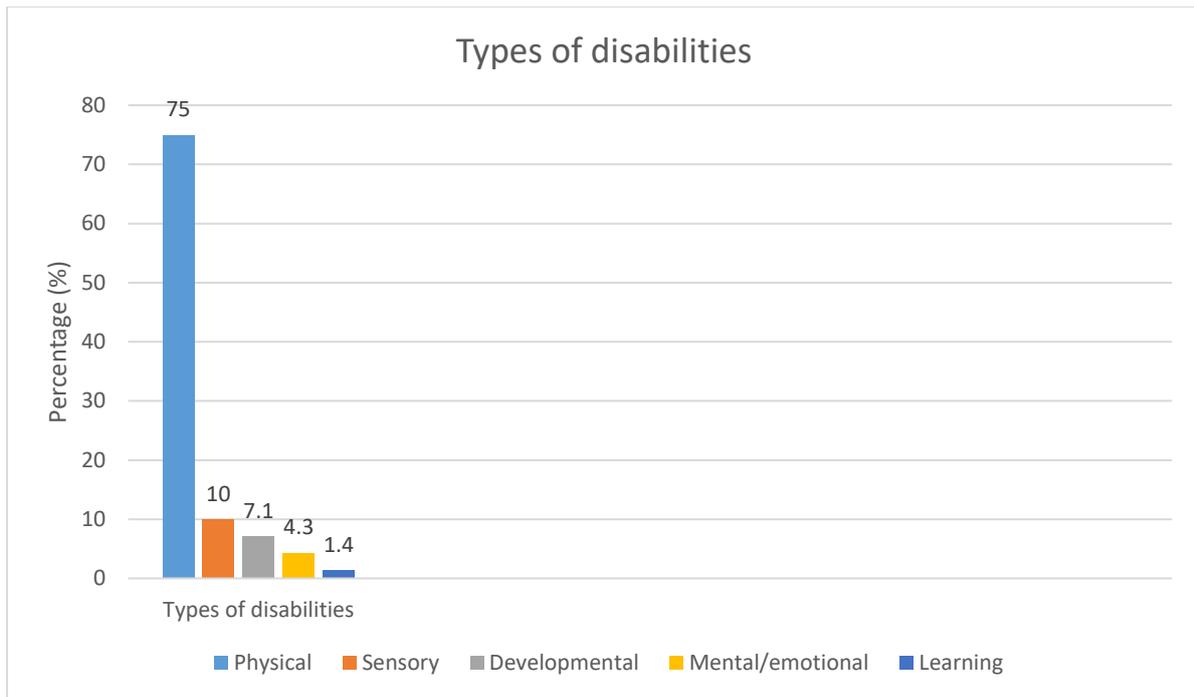


Figure 1 Percentage indicating the different types of disabilities among the participant group.

Participants were asked to describe how their disabilities impacted them, with participants indicating that their disability impacted them differently. The biggest percentage of the group reported that their disability contributes to a lack of confidence (32.4%) followed by 21.6% who reported that they feel different from others. The participants feelings about the impact of their disability are all summarized in the figure below.

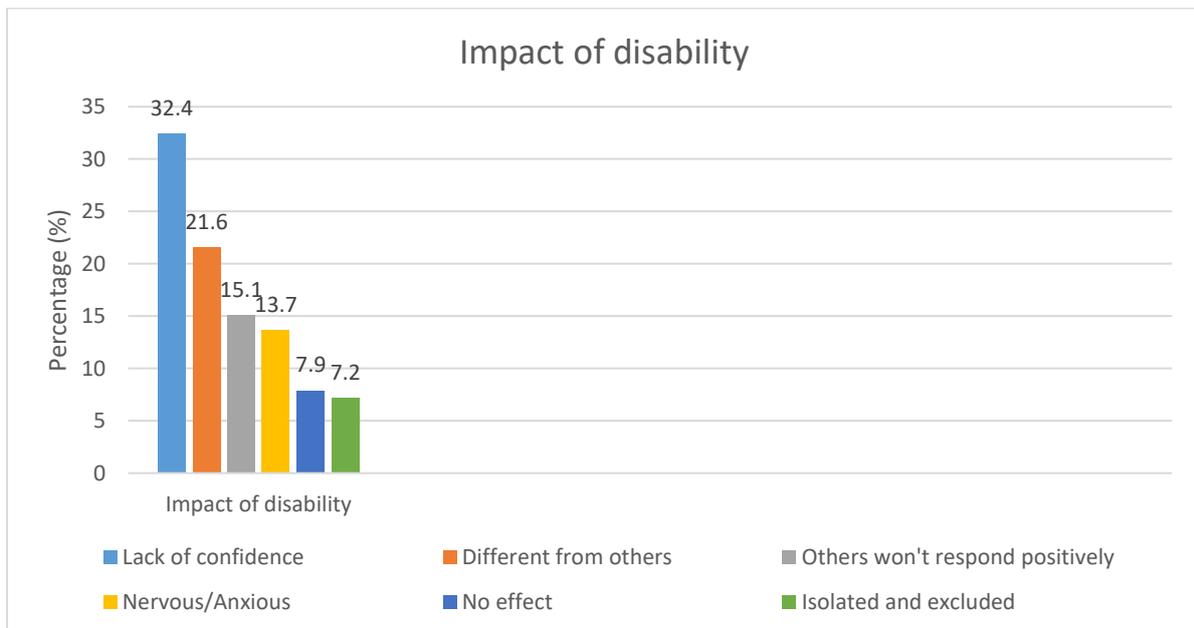


Figure 2 Percentages indicating the different impacts participants disabilities had on them as an individual.

The participant group was also asked if they made use of any disability-related services, networks, or organizations. The majority of the group did not make use of disability services (86.4%) while the rest made use of services such as support groups, social groups, and sports groups. When asked about their opinion regarding the importance of having specific activities and events for people with disabilities, majority (59%) of the participants reported that some activities or events should be specific to people with disabilities. Others reported that they need activities only for them (28.8%) (i.e. tailored only for people with disabilities) while a small percentage (6.5%) reported that they should just join in with existing activities and the rest did not know.

Sexual behaviour

The sexual behaviours of the group are illustrated in the figure below. Those who reported ever having had sexual intercourse in their lifetime amounted to 57.6%, with those indicating ‘no’ to ever having had sexual intercourse in their lifetime at 42.4%. More than one-third (37.9%) have a current partner and 54.8% of those that reported having had sex, used a condom at their most recent sexual encounter. The average age of first sexual intercourse was 17.3 years of age among the participant group.

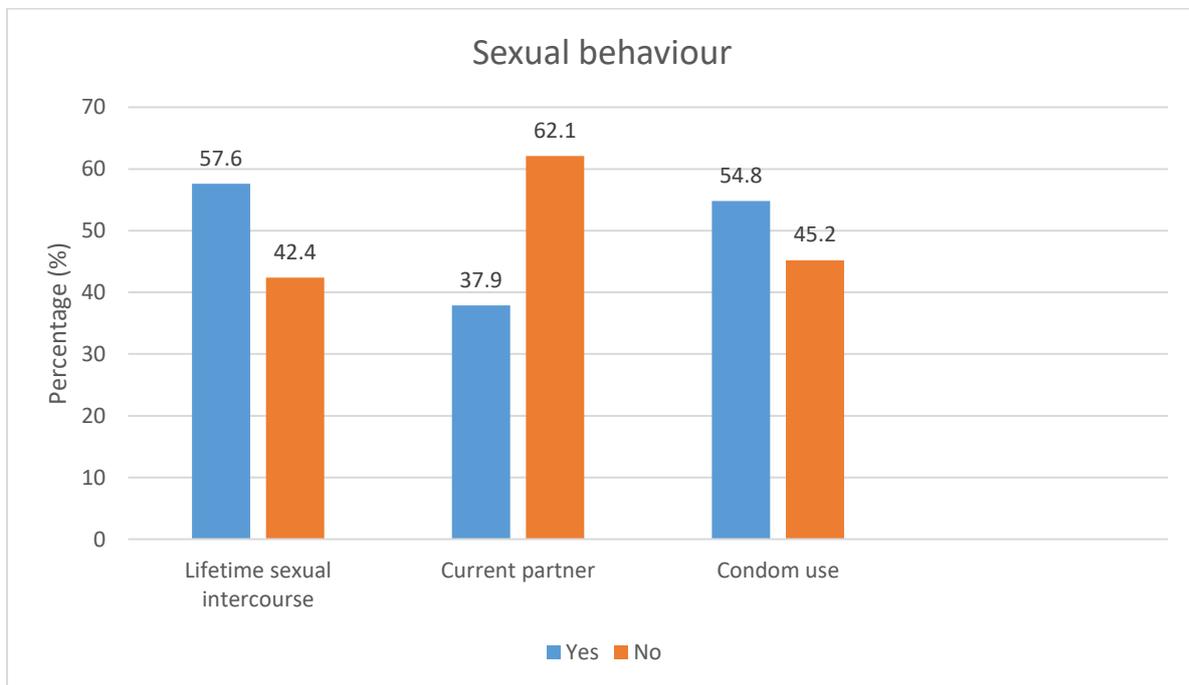


Figure 3 Sexual behaviour of the participant group – the figure indicates the percentage of participants every having had sexual intercourse in their lifetime, the percentage of participants who have a current sexual/romantic partner, and the percentage of participants who have used a condom during their most recent sexual encounter.

Violence-related experiences

Of the total group, 15.7% reported having been physically forced to have sexual intercourse when they did not want to.

One-fifth (19.3%) of the group reported that they were forced to do sexual things such as kissing, touching, or being physically forced to have sexual intercourse during the last 12 months from when facilitation commenced (i.e. when the questions were posed to the participants). In addition, 20.7% also reported being physically hurt on purpose, such as being hit, slammed into something or injured with an object or weapon during the last 12 months. The figure below indicates the percentages of participants who have experienced intimate partner violence in terms of sexual violence (including non-consensual kissing, touching or being forced to have sexual intercourse) and physical violence (which includes being hit, slammed into something or being injured with an object or weapon). An indication for participants who do not have a sexual/romantic partner was also given.

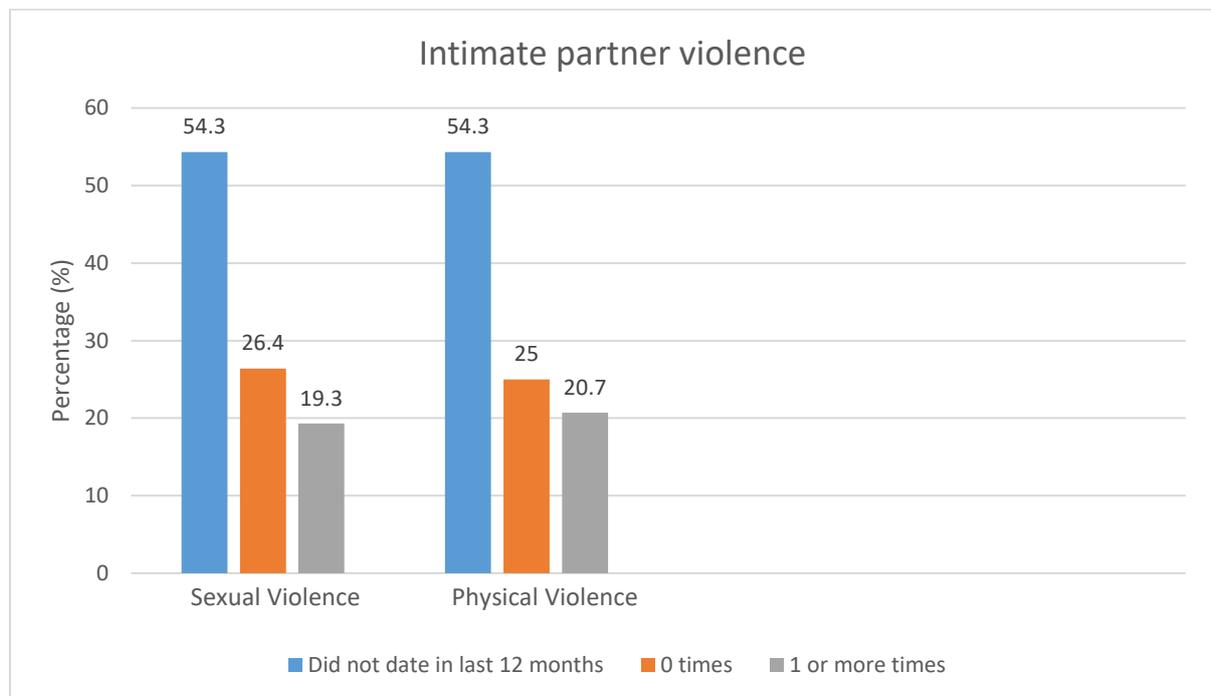


Figure 4 Percentage of participants who have experienced IPV 0 times or 1 or more times and those who do not have a current romantic/sexual partner.

Knowledge of HIV

The HIV-K-Q was used to measure the knowledge of the participant group with regards to HIV. The total possible score is 18. The overall average score of the group was 13.5. The figure below summarizes the knowledge scores. Of the total group, 41.7% scored 25% or less of the total score, 16.5% scored 50% and 40.4% scored 75% or more.

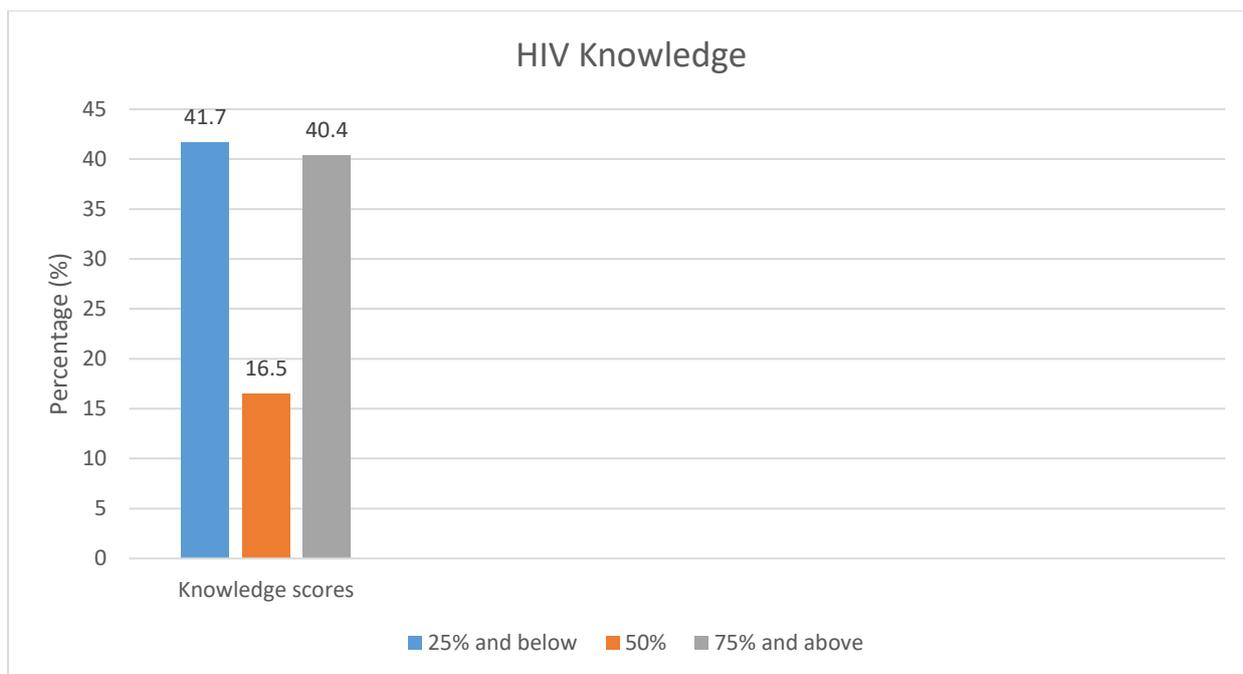


Figure 5 Percentage of participant scores on HIV knowledge.

Stories

A part of the facilitation and engagement with AGYW with disabilities was hearing their stories and concerns as young women and girls and as people with disabilities. As such, our facilitators got to hear numerous stories and important information from AGYW with disabilities regarding their life struggles, things they have overcome, challenges they have faced as females and as people with disabilities, and what they would like for the future. Some examples of these stories are listed below.

Stories from our facilitators:

“There was a participant who shared her rape story and fell pregnant. She was raped by a family member and was told by her own mother not to report the case to the police. I was able to advise the participant to seek for professional help from social services. The participant is now attending counselling sessions but has not yet reported the matter to the police.”

“One of the participants with a mental disability, as told by her mother, would not open up or talk to anyone since her disability. However, the day I called, introduced myself and mentioned I am also a paraplegic and should there be anything she is not comfortable with answering she can skip it, the participant responded to every question willingly. The mother expressed her shock towards me being able to get her daughter to speak and open up for the first time. Ultimately, the participant needed someone to listen and let her be, knowing that we all have different abilities and there is nothing wrong with having a disability.”

“One of the participants shared her life story of how she sustained injuries from a car accident at the age of 13 years and how she struggled emotionally with her disability. She was married but following emotional abuse from her husband, got divorced. She had numerous incidents

where people would stare because of her disability, and she didn't feel accepted by members in her community. However, despite all of this she completed her schooling, got her degree, has full-time employment, went to therapy, and has now become a motivational speaker. She is now confident enough to wear shorts (something she couldn't previously do) and accepts her differences and motivates others. She spoke about the importance of motivating other women and girls with disabilities and letting them know anything is possible."

A lot of the participants expressed concerns about dating and being sexually active as they are concerned about how others will perceive them (i.e. no longer being attractive since their disability or not being 'able' to be sexually active and have romantic relationships). Others brought up the issues of fitting in socially and at school as well as difficulty in accessing education following their disability. Lastly, a few participants expressed their parents' concerns for the future of their child/children with a disability. In these situations, our facilitator shared her own life story and success (being a motivational speaker, Paralympic athlete, and mother) with the participants and their parents thereby letting them know that they themselves (and their kids) could be successful, be married/date, can start a family, and can finish school. Sharing her life story and success really helped highlight to the participants and their families that anything is possible and having a disability does not mean 'the end of the road'.

Discussion

Research has shown that social, demographic and behavioural factors interact in a myriad of ways to increase the risk of HIV infection among AGYW (Sokhela et al, 2018). Research has also shown that there is a significantly greater risk of HIV infection among AGYW with disabilities, as compared to AGYW without disabilities. This is due, in part, to their increased vulnerability to sexual and physical violence as well as to the increased difficulties and barriers they face in accessing SRHR-related services and CSE. Regarding demographic factors that have been shown to have an impact on HIV infection, unemployment and level of education was recorded by the project with findings indicating majority of the participant group being unemployed (68.6%) and most only completing some of their secondary schooling (41.1%). In terms of unemployment, limited economic options have been shown to strongly influence AGYW's decisions to engage in risky behaviours, including risky sexual behaviour, and increases their risk of being exploited (i.e. sexual exploitation) (Sokhela et al, 2018). These inevitably further increase their risk of HIV infection. As previously highlighted, AGYW with poor or no education have been shown to have poorer sexual and reproductive health outcomes due to their decreased ability to negotiate safer sex and decreased power in decision making regarding sexual encounters (Goga et al, 2020; Sokhela et al, 2018). In contrast, greater gains in HIV prevention and decreased rates of new HIV infections among AGYW has been recorded in countries with higher rates of secondary school completion (Goga et al, 2020). Incidentally, research has indicated that this may be due to increased female empowerment that comes with education and to behavioural interventions that may be offered such as CSE and counselling (Goga et al, 2020). As highlighted, AGYW with disabilities in South Africa lack access to CSE and when compared to their peers without disabilities the education gap is noticeably larger (Hanass-Hancock et al, 2018; Jones et al, 2018). When looking at the participants knowledge of HIV-related

topics and health information using the HIV-K-Q, there was a large discrepancy between participants scoring low (25% or below) on HIV knowledge and those scoring high (75% and above), with both percentages being 41.7% and 40.4%, respectively. Incidentally, there is a 1.3% difference in favour of those scoring low. The participants limited HIV knowledge could be a representation of their lack in inclusion to and access of CSE and/or be reflective of the groups limited basic secondary education. Either way, both would indicate that more needs to be done in providing AGYW with disabilities access to SRHR-related education and information.

When observing the sexual behaviour of the participant group, more than half had indicated having had sexual intercourse in their lifetime (being 57.6% respectively) with the average age of first sexual intercourse at an age of 17.3 years. With the high numbers of participants indicating they engage in sexual intercourse and starting from a relatively young age, it can be argued that AGYW with disabilities do in fact require access to SRHR-related services and that they should be given the same attention and focus as their peers without disabilities in policies, programmes and services targeted at AGYW and HIV prevention. Our findings debunk the misperceptions and assumptions that AGYW with disabilities are non-sexual/asexual and thus do not require access to SRHR-related services (Cockburn et al, 2019). In fact, our findings indicate that AGYW with disabilities should be included in and provided access to integrated sexual and reproductive health information, services and counselling that includes the prevention of sexually transmitted diseases (STDs) such as HIV (Jones et al, 2018). Regarding condom use at their most recent sexual encounter, for the participants who were or had engaged in sexual intercourse, majority (54.8%) had indicated using a condom. However, considering the percentages, this means that a little under half had engaged in risky sexual behaviour (i.e. not using a condom) during their most recent sexual encounter. As previously mentioned, AGYW with disabilities in South Africa still lack access to vital SRHR-related services (Sokhela et al, 2018). With the findings indicating a little under half of the participant group not practicing safe sex, the prospect of limited to no access for their SRHR-related health needs is cause for concern.

Numerous research has shown that AGYW with disabilities, in particular and at higher rates than their counterparts without disabilities, experience increased vulnerability to both physical and sexual violence; with sexual violence being the most prominent (Jones et al, 2018). Among our participants, 15.7% reported an experience of being physically forced to have sexual intercourse, 19.3% reported IPV regarding sexual violence (including kissing, touching and/or being forced to have sexual intercourse) in the last 12 months, while 20.7% reported IPV regarding physical violence (including being hit, forced/slammed against something, or being injured by an object or weapon) in the last 12 months. Although the percentages for IPV are lower compared to those who indicated never having experienced IPV of a sexual or physical nature, having a few participants indicate that they have experienced IPV in the last 12 months is alarming. More so, when taking into consideration the research indicating their limited access to justice and legal support services and protection mechanisms.

Lastly, regarding the participants use of disability-related services (including support, counselling, etc.) majority (86.4%) indicated never having made use of such services. These findings relate well to those in the literature, highlighting the large numbers of AGYW with disabilities who do not access services. The question here would then be why AGYW with

disabilities do not access these services? Research has indicated stigma (and fear of stigma) and discrimination as a reason for people with disabilities' and AGYW's low rates in accessing services (Jones et al, 2018; Ayton, Pavlicova & Karim, 2020). Incidentally, our findings indicated high percentages of the participant group feeling a lack in confidence (32.4%), different from others (21.6%), and feelings that other people would not respond positively to them (15.1%) when asked to comment on the impact their disability has had on them. These findings could be indicative of how the participants not only feels about themselves, but how they may perceive others feel about them. Gender norms and societal taboos about sexuality have been shown to negatively impact the ability of AGYW from seeking help and accessing SRHR-related services and information (UNAIDS, 2019). Other studies highlighted the lack of youth friendly services, particularly sexual and reproductive health services, as a reason for youth not accessing these vital services (Davids et al, 2020). These kinds of negative views, stigma and feelings of stigma and discrimination could be the reason AGYW with disabilities do not access SRHR services. On the other hand, other studies have indicated that services and programmes often underrepresent and underserve people with disabilities, subsequently maybe the reasoning lies in AGYW with disabilities needs and priority areas not being met by these services (UNAIDS, 2019; Jones et al, 2018). Our findings highlighting that majority (59%) of the participants agreed that activities and services should be tailored to people with disabilities could be indicative of such reasoning. Lastly, research has also highlighted physical inaccessibility and cost as a reason for AGYW with disabilities not accessing services (Jones et al, 2018). At a glance, the reasoning for our participant group having such high numbers that do not access services, could be suggestive of one, a few or all reasons; further research into this topic would have to be conducted.

Conclusion

When looking at the project's findings in totality, one can take away the message that SRHR-related services should be largely focused on including AGYW with disabilities if the country seeks to reduce HIV transmission and infection. Increased and improved understanding of the determinants of HIV among AGYW with disabilities needs to be conducted in order to provide for new and targeted interventions seeking to address the sexual behaviours, vulnerabilities, SRHR and HIV knowledge and sexual and reproductive health outcomes of AGYW with disabilities. It would be recommended that the country, and relevant organisations, look at designing a combination of prevention/intervention initiatives targeted at the social, demographic and economic determinants of HIV infection among AGYW with disabilities. Moreover, that focus be given to promoting the increased inclusion of AGYW with disabilities in CSE and completion of secondary schooling and in SRHR-related services and programmes. Lastly, provisions and targeted attention should be given to the rates of violence amongst AGYW with disabilities. Interventions should be provided to both AGYW and men on GBV-related health topics in order to combat the rates of IPV and violence experienced among AGYW with disabilities. Only through a combination of interventions, targeted focus and integrated assistance can a difference in the rates of HIV infection among AGYW with disabilities be achieved.

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For more information contact Jacqui Kaschula (Project Lead) at:

Email: jacqui1997@gmail.com

Tel: +27 76 145 5926

Afrique Rehabilitation and Research Consultants NPC on:

WhatsApp: +27 67 005 7868

Call: +27 72 713 4649

Email: Vernon.openshaw@gmail.com

Website: <https://arcc-npc.org.za/>