

Key Take Aways – Adolescence

84% of respondents indicated they were not encouraged to explore their body, sexuality, and boundaries.

Only 70% of women and 1/3rd of men reported being taught about puberty. Only 55% of women and no men recalled being taught about periods.

56% of respondents reported not being taught how to prevent pregnancy, and less than 1/3rd of those in the 46-65 age range reported being taught how to prevent pregnancy.

Only 39% of respondents reported being taught how to prevent STI transmission and only 31% were taught how to actually use barrier method contraceptives – but these proportions were much lower for men compared to women.

70% of respondents overall reported that they did not receive sex education that prepared them for intimate relationships.

3/4th of respondents reported that adults did not help them practice communicating their desires and boundaries (generally) during adolescence.

Half of the respondents reported adults did help them practice listening to and respecting others' desires and boundaries, but 2/3rd of all respondents indicated that they were not taught to find out what other people did or didn't want in a relationship.

40% of respondents reported having at least one intimate relationship that "felt really good" in adolescence (55% did not).

Over half of respondents reported having an intimate relationship in adolescence that "hurt me more often than not".

63% of respondents reported that someone touched them "in a private area" during adolescence in a way that made them uncomfortable or upset, but 20% of men reported being unsure if they experienced this.

48% of all respondents (31% strongly agree) that they were convinced to have sex with someone when they did not want to during adolescence.

Key Take Aways – Adulthood/General

Only 65% of respondents indicated they usually received accurate information about how their body works and 17% of men reported fearing retaliation for seeking out this information.

50% of those aged 56-65 reported “rarely” received accurate information regarding how to take care of their body.

Less than 60% of respondents reported usually receiving accurate information about practicing safer sex.

2/3rd of respondents reported they usually have someone they trust who can help them make decisions about their sexual health.

Less than 2/3rd of respondents reported that they could usually decline services they didn’t want and could usually inform a service provider if they were uncomfortable with the services they received.

59% of respondents indicated they usually felt able to inform a service provider of another service provider who is abusing them, and another 10% indicated they would fear retaliation for doing so.

57% of respondents experienced at least once incident in which service provider ignored their input.

27% of respondents reported having the experience of services being withheld until they complied with an expectation, even if compliance made them uncomfortable, including 1/3rd of men and 50% of respondents aged 56-65.

30% of respondents indicated that at least once someone has prevented them from engaging in sexual activity with a partner.

Half of the respondents reported that someone had instructed (“told”, not “requested”) to touch that person’s genitals despite the respondent not wanting to do so, including 40-50% of all respondents across ages 18-55.

This report asked respondents to share their decisions regarding reporting 7 kinds of sexual violence, including sexual assault and coerced service provision. Only 15-36% of respondents affected by each of the experiences reported the experience.

Introduction

Background

There is a severe shortage of information about self-reported experiences of bodily autonomy, hygiene, sexuality, safer sex education, sexual autonomy, affirming relationships, and sexual harm among people with disabilities, especially information that is specific to Indiana. To begin to address this information gap, Indiana Disability Justice (IDJ) has developed and continued to improve upon a community strengths, needs, and desires assessment (CSNDA) for people with disabilities in Indiana.

The pilot survey was designed in the 2018-2019 grant year and was distributed in the 2019-2020 grant year. Embedded in the pilot survey were opportunities for feedback on the survey itself in terms of content and accessibility. Based on this feedback, IDJ updated and redesigned the survey to be more comprehensive, robust, and accessible for survey respondents. These changes included adding more questions about rape and sexual assault (most of the original questions were about harassment), faith background, sexual identities of respondents, and additional questions about protective factors against sexual violence (SV). The updated survey also added “desire” or “goal” related questions about how respondents’ environments could better prevent SV. The sections were more clearly organized to distinguish questions regarding adolescence vs. adulthood. The supplemental resources IDJ developed for the survey (definitions, disability support organizations list, and violence prevention agency list) were again used to provide resources to survey respondents. IDJ’s goal was to organize in-person and virtual townhalls for people with disabilities to have an opportunity to respond to the survey in a verbal and interactive format as an alternative to a written survey. However, the leadership team did not have the capacity to do so in 2021-2022, especially given restrictions imposed by Covid19.

Survey Purpose:

This purpose of this survey was to collect feedback from people with disabilities (PWD) in Indiana to assess community priorities regarding bodily & sexual autonomy, wellness, and independence, and to better understand their experiences reporting harm. The survey also collected feedback about survey questions from PWD to enhance the clarity and efficacy of others’ assessment tools.

Data Collection Topics:

1. Bodily autonomy and wellness (body function, hygiene education, safer sex): Questions 1, 4, 5, 6, 7, 8, 21, 22, 23, 30
2. Sexual autonomy and wellness (education about consent & healthy sexuality & relationships, supported decision making): Questions 2, 3, 9, 13, 14, 15, 16, 17, 18, 19, 20, 28
3. Access to affirming service provision: Questions 24, 25, 26, 27, 34, 35
4. Experiences with sexual violence: Questions 10, 11, 12, 29, 31, 32, 33
5. Experiences reporting sexual violence: 36, 37, 38, 39, 40, 41, 42

Some Notes on Reading the Data Analysis in this Report

- The results are compiled by area of study (the data collection topics listed above) rather than chronologically in the survey. This allows us to explore the overall experiences of people with disabilities in Indiana in each general area of experiences.
- As this survey includes questions about adolescent and adulthood experiences, all questions and charts will include (<18) if the question was specifically about adolescence. Questions 1-20 were all asking respondents about adolescence and not adulthood.
- Every question and chart is labeled with the number of the question in the survey for clarity and cross-referencing ease.
- The survey includes 4 types of closed question responses. Each kind of question has a different set of colors within charts (indicated in the legend) to help readers more easily identify the question types. For example, all likert scale charts use one set of colors consistently throughout the report; the yes/no questions also use one set of colors throughout, but these are different than the colors used in the likert scale charts. “Likert scale” questions refer to questions with word choice response options that make up a range of negative to positive intensity. The types of questions include:
 - Likert Scale: Strongly Disagree to Strongly Agree
 - Life experiences: Rarely - It depends - I’m unsure - Yes, but I may get in trouble – Yes, usually
 - Yes/No
 - Reporting experiences
- There were enough respondents in the demographics of age and gender to analyze the relationships of each response against the age and gender of the respondents. Note that although we did have non-binary respondents, there were too few to include in the gender analysis.
- Data that cross references gender identity with question responses are weighted. Data that cross references age with question responses is not weighted.

Some Notes on Area Results Summaries & Conclusions

In areas of summaries where results are broken down across age and gender, responses from the 66-75 age range will not be included since there were only 2 respondents in this group, and non-binary/genderqueer respondents will not be included as there were only 2 respondents in this group as well.

For the questions that used likert scale responses ranging from “strongly disagree” to “strongly agree”

- “strongly disagree” and “disagree” will be referred to collectively as “disagree” responses’
- “strongly agree” and “agree” responses will be collectively referred to as “agree” responses.

Some questions had response options: “yes, usually”, “yes, but I may get in trouble”, “I’m unsure”, “it depends”, and “rarely”. For purposes of this summary:

- “I’m unsure” and “it depends” will be referred to as “circumstantial” responses “yes, but I may get in trouble” will be referred to as “retaliatory” responses.

Survey Demographics Summary

While the pilot survey collected 26 responses from respondents residing across 9 (out of 92) counties in Indiana (in 2020), this updated survey received 41 responses with respondents residing across 17 counties in Indiana and representing 9 out of 10 INSILC (Indiana Statewide Independent Living Council) districts. While women made up nearly 3/4ths of survey respondents, this is in alignment with data indicating women are disproportionately impacted by sexual violence. A couple of non-binary individuals responded to the survey. Given the very high rates of sexual violence against trans and gender non-conforming people, this means non-binary people are underrepresented in this survey. This is compounded by the fact that some preliminary data suggests there are higher rates of disabilities among trans people compared to the general population. Respondents included a wide range of sexual identities, ages, faith backgrounds, and current faith orientations. While the survey received responses from various racial groups, people of color were generally underrepresented.

Area 1 Conclusions

The majority of respondents were not encouraged to explore their body and sexuality. This has significant ramifications for people with disabilities as they age. Not being encouraged to better understand one's body could impact a disabled person's ability to understand and identify body changes and self-advocate for adequate support services. This may also negatively impact their skills in developing and maintaining boundaries in any kind of relationship. There may also be social impacts resulting lack of understanding how to care of one's body. For example, if someone does not know how practice certain kinds of hygiene they may smell strongly, causing others to limit their interactions with the disabled person.

Compared to women, a larger proportion of men did not receive education regarding puberty and periods, and how to prevent pregnancy and STI transmission. Men also reported lower rates of consistently in accessing accurate safer sex education. While there may be many contributing factors to this, one possibility could be related to the way children's sexual development is socially gendered in the context of disabilities. There is a general cultural belief (largely rooted in white, Christian norms) that boys have a "natural" sex drive, while girls and women do not have a strong natural sex drive. People with disabilities are often assumed to be asexual or "incapable" of intimate relationships, and disabilities are often seen as socially "feminizing". For example, many neurodivergent people use more exaggerated movements, such as wrist flopping, "raptor arms", or swaying (to assist with proprioception and balance), all of which are largely coded as women-specific expressions in American society. Men are often expected to be more stiff, stoic, and less expressive in movements in the context of American cis het white dominant social norms. This dynamic may lead people to treat boys as asexual if seen as more feminine. Additionally, since girls and women are often expected to be aware of and inhibit boys' and men's sexuality, there may be added pressure to education girls about their bodies to "prevent" sexual assault or male advancements.

While access to these areas of education varied among age groups, there was a larger proportion of those in older age groups who reported experiencing inconsistency in their access to body and sexual care information, and experiencing a fear of retaliation for seeking this information.

Area 1 Results: Bodily Autonomy and Wellness

Adolescence Results Summary

Body empowerment (Adolescence): Respondents conveyed overwhelmingly that they experienced profoundly inadequate education about their body, sexuality, safer sex, and were often even actively discouraged from exploring these areas of their lives. For example, 84% of respondents indicated they were not encouraged to explore their body, sexuality, and boundaries during adolescence (Q1). While the proportion of both men and women who *agreed* and *strongly agreed* that they received this encouragement were both about 84%, only women *strongly disagree* that they were encouraged in these areas. While 15% of women indicated they were encouraged to do to explore their bodies, sexuality, and boundaries, no men reported this experience. When reviewing the age distribution, at least 65% of respondents in each age group reported not being encouraged to explore their body, sexuality, and boundaries during adolescence.

Puberty Education (Adolescence): Slightly over 1/3rd of respondents reported not being taught about puberty (Q5) or periods (Q4) at all during adolescence. While 70% of women reported being taught about puberty during adolescence, only 55% reported being taught about periods. Astoundingly, only 1/3rd of men reported being taught about puberty at all and no men recalled being taught about periods (60% said they were not taught while 40% said they were unsure if they had been). At least 60% of respondents across all age groups reported being taught about puberty while 20% reported definitely not being taught about puberty. At least 1/3rd of respondents across all age groups reported being taught about periods.

Safer Sex Education (Adolescence): 56% of respondents indicated they were not taught how to prevent pregnancy (only 41% agree) during adolescence (Q6). Half of both women and men reported they were taught how to prevent pregnancy during adolescence. 60-66% of those in age groups 18-45 reported being taught how to prevent pregnancy while less than 1/3rd of respondents in age groups 46-65 reported the same. Although 39% of respondents agreed they were taught how to prevent transmission of STI's (2/3rd of women, 1/3rd of men) (Q7), only 31% of respondents (50% of women, 17% of men) indicated they were taught how to use barrier method contraceptives (Q8). 55% of respondents reported not being taught how to prevent transmission of STI's, but 69% reported not being taught how to use barrier method contraceptives. The proportion of respondents in age groups that were taught about barrier method contraceptives varied widely with at most, 2/3rds of those aged 56-65 reporting being taught this compared to only 12% of those aged 46-55.

Adulthood Results Summary: Receiving Accurate Body Information

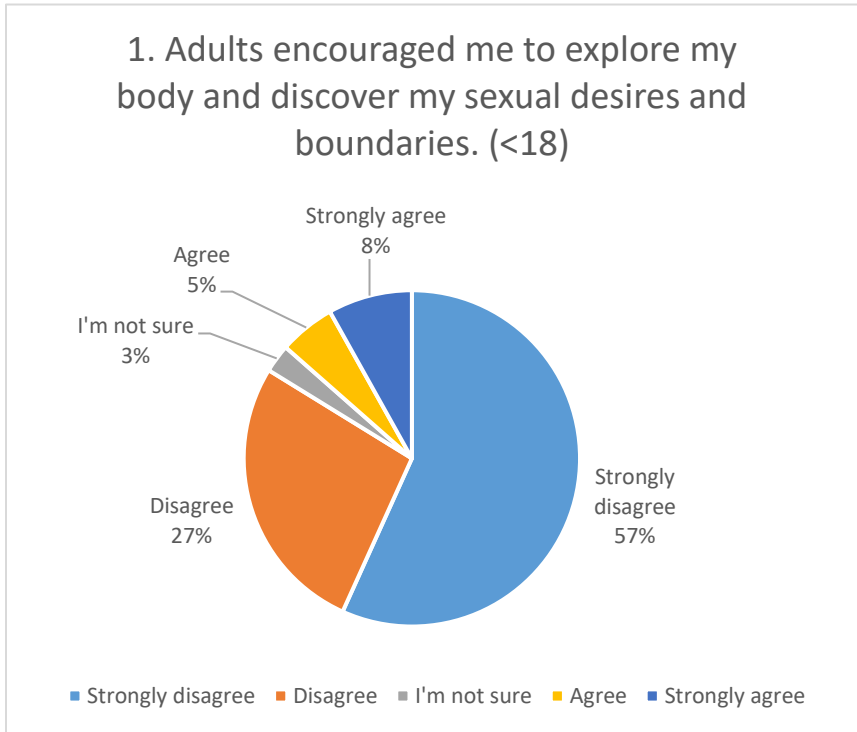
65% of respondents reported usually receiving accurate information about how their body works (Q21) and 73% reported usually receiving accurate information about how to take care of their body (Q22). However, there were significant age and gender differences. While 70% of women reported usually receiving accurate information about their body while only 50% of men did (17% of men also reported a fear of retaliation for acquiring this information). 100% of men reported usually receiving accurate information about how to take care of their body, while 73% of women reported the same. While responses varied greatly across age groups, it is notable that 50% of those aged 56-65 reported “rarely” receiving accurate information about how to take care of their body. There were also large proportions of respondents who indicated their ability to access these kinds of information was circumstantial and not consistent.

Despite the access most respondents had to information about their body function and hygiene, 2/3rds of respondents (same proportions of men and women) overall reported being given inaccurate information about their body at least once (Q30). 75-100% of those aged 18-35 reported experiencing someone giving them inaccurate information about their body (Q30), while 40-66% of those aged 36-65 reported the same. This disparity across age may, in part, be a result of the significant advances society has made in terms of making medical information more accessible. This shift in technology and education increase access to education about the body among younger people and enhance young people’s knowledge in differentiating accurate and inaccurate medical information.

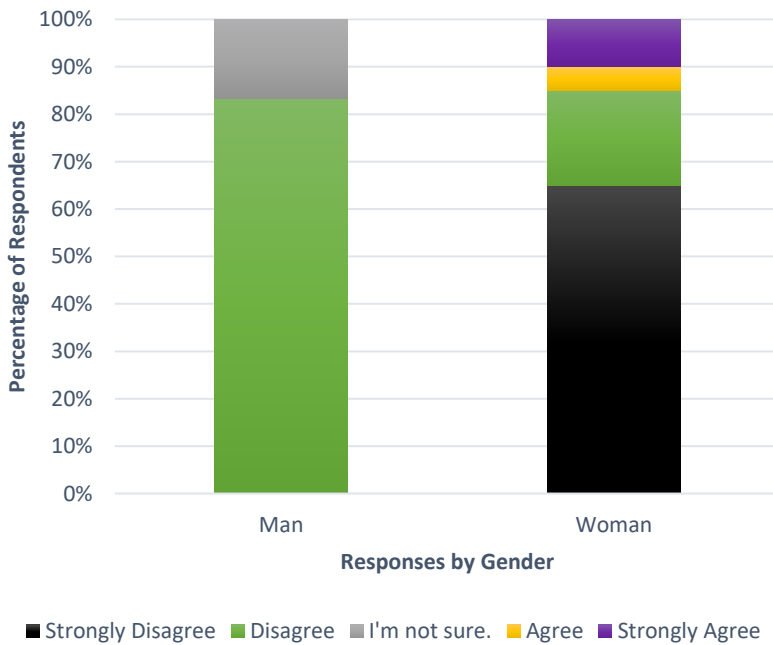
Less than 60% of respondents overall reported usually receiving accurate information about practicing safer sex while over 1/4th of respondents state they rarely receive the this information accurately (Q23). 60% of women and 50% of men reported usually receiving accurate safer sex education, but 16% of women and 14% of men reported rarely receiving accurate safer sex education. Proportions of age groups with access to this information varied, but 66% of those aged 56-65 and 40% of those aged 36-45 reported rarely having access to accurate safer sex information.

1. Adults encouraged me to explore my body and discover my sexual desires and boundaries. (<18)

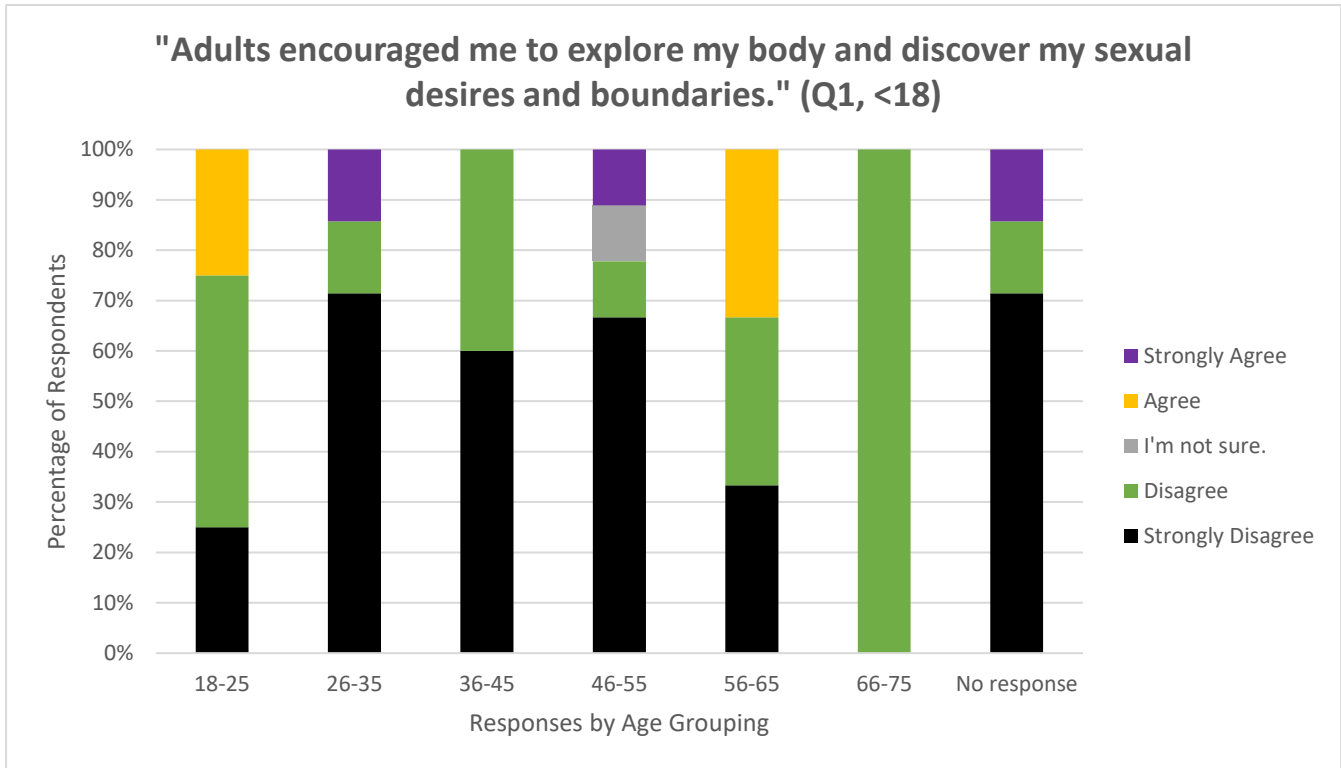
Out of 37 respondents, 21 respondents (57%) strongly disagreed and 10 respondents (27%) disagreed that they were encouraged to explore their body and discover their sexual desires and boundaries as an adolescent. Only 3 (8%) strongly agreed and 2 (5%) agreed that they were encouraged to explore their body and discover their sexual desires and boundaries as an adolescent. 1 respondent (3%) was unsure and 4 individuals (10% of all respondents) did not respond.



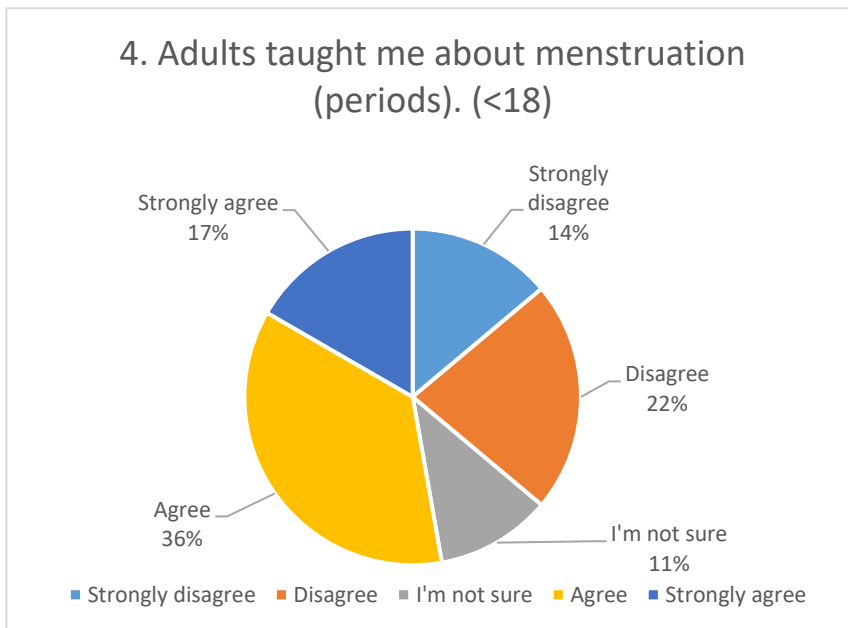
"Adults encouraged me to explore my body and discover my sexual desires and boundaries." (Q1, <18)



Gender: While over 80% of women and men responded that adults did not encourage them to explore their body and sexuality in adolescence, women had a much stronger reaction to the question. Over 60% of female respondents indicating they strongly disagree with this statement. This suggests girls with disabilities may be more inundated with messages about bodies and sexuality being taboo, experience more active discouragement from family members and caretakers, or possibly even experience some punishment around these areas. Additionally, no men indicated any encouragement whatsoever while about 15% of the female respondents did experience encouragement from adults in body and sexuality exploration.



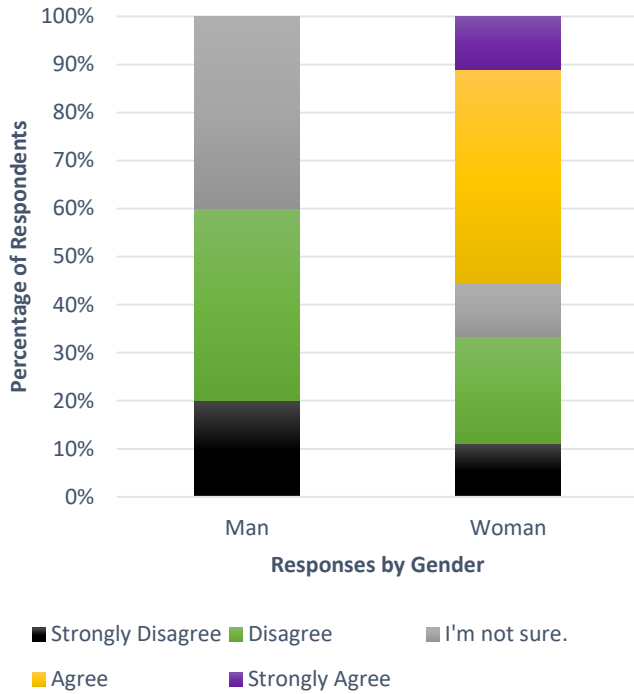
Age: While all at least 65% of all age groups indicated adults did not encourage them to explore their bodies and sexuality, age groups 36-45 and 66-67 unanimously reported not experiencing any encouragement from adults in exploring their body and sexuality. 33% of those aged 56-65, 25% of those aged 18-25, 15% of those aged 26-35, and about 11% of those aged 46-55 indicated they did experience encouragement from adults to explore their body and sexuality during adolescence.



4. Adults taught me about menstruation (periods) (<18).

Out of 36 respondents, 13 (36%) agreed and 5 (17%) strongly agreed that adults taught them about menstruation as an adolescent. 8 respondents (22%) disagreed and 5 respondents (14%) strongly disagreed that adults helped them practice listening to and respecting others' desires and boundaries as an adolescent. 4 (11%) were unsure. 5 respondents (12% of all respondents) did not respond.

"Adults taught me about menstruation (periods)." (Q4, <18)

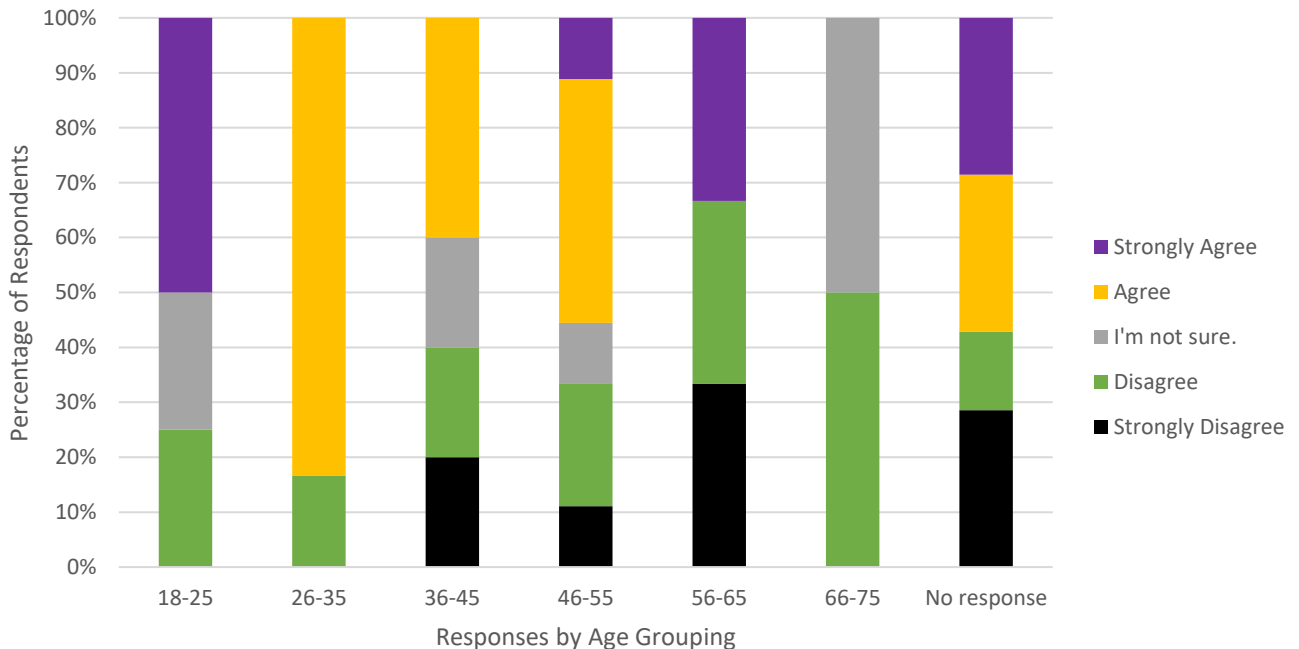


Gender: A third of all female respondents indicated adults did not teach them about periods during adolescence. None of the male respondents were taught about periods or recalled that they were taught about them. While the “I’m not sure” responses could partly be impacted by the age of the person, qualities of their memory, and cognitive time processing differences, the lack of recollection among men with disabilities is important as the information may not have been presented in an accessible way or it was not retained, making the information largely unusable for boys at the time.

Age: While responses varied among age groups, there is a general increase in the proportion of respondents who were not taught about periods as age increases. The age group with the largest proportion of respondents who were taught about periods within their group was ages 26-35 (83%) followed by 46-55 (55%), 18-25 (50%). Only 40% of those aged 36-45 and 34% of those aged 56-65 reported being taught about periods during adolescence.

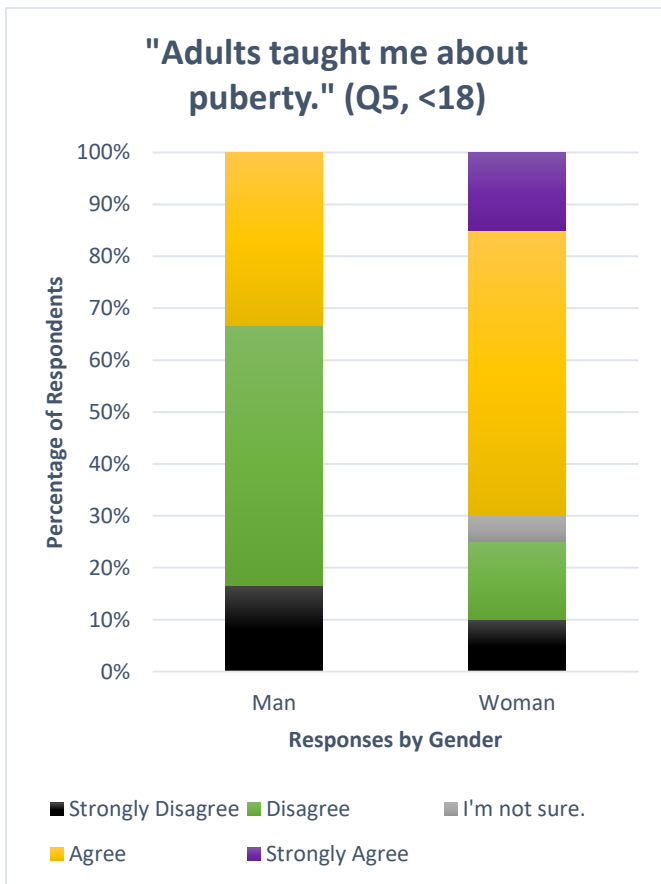
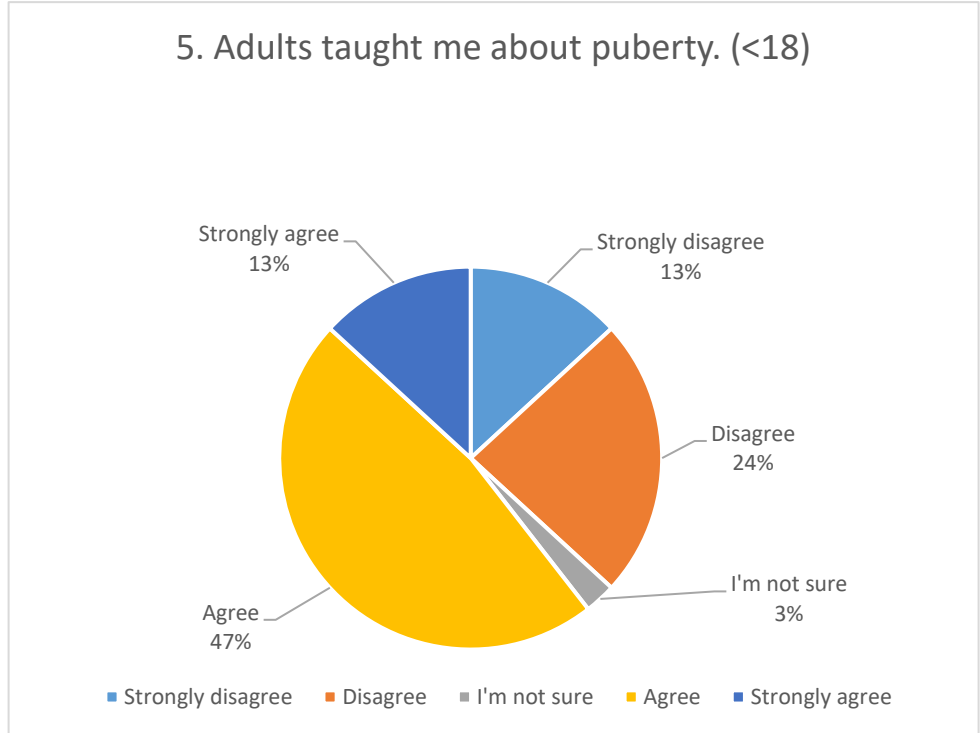
those aged 36-45 and 34% of those aged 56-65 reported being taught about periods during adolescence.

"Adults taught me about menstruation (periods)." (Q4, <18)



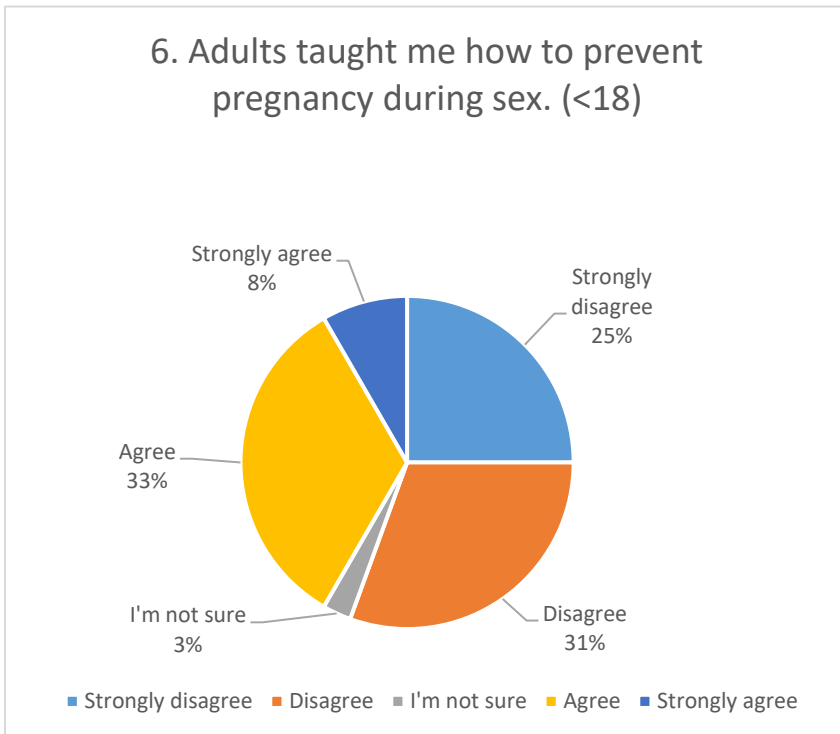
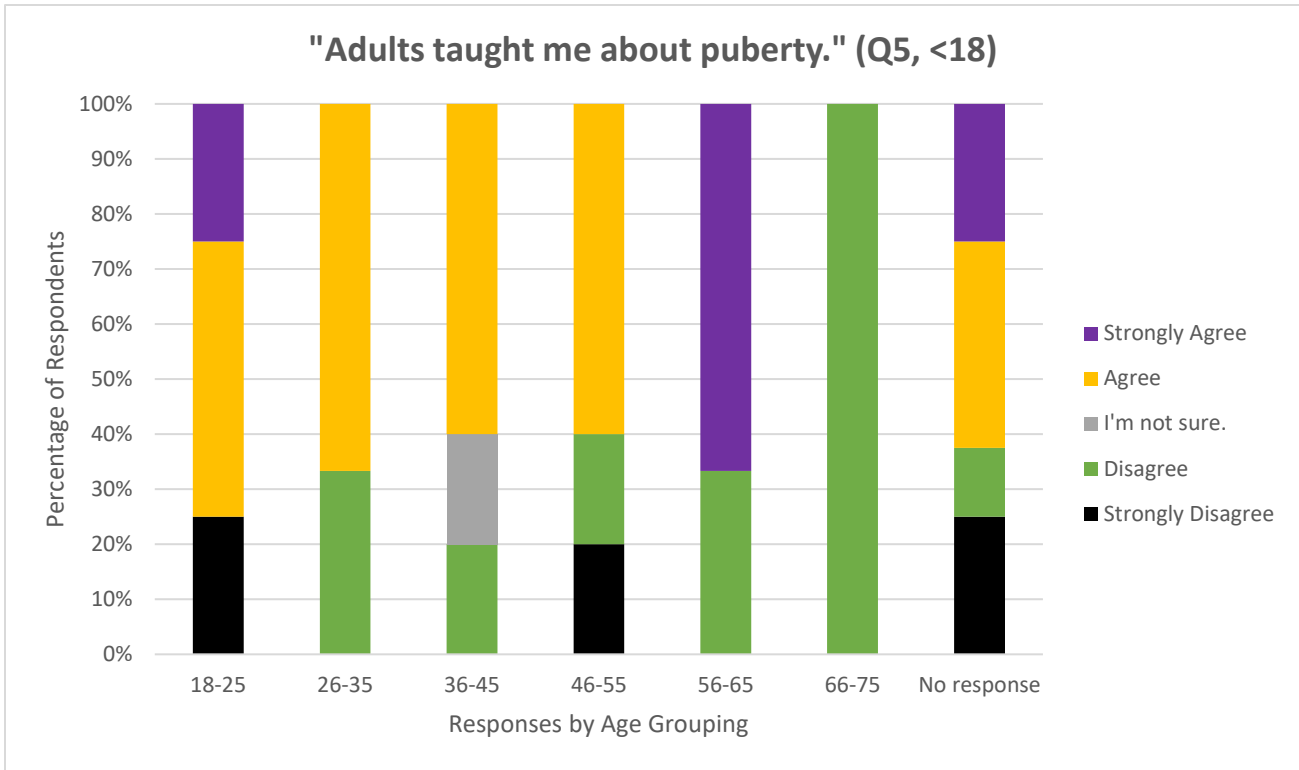
5. Adults taught me about puberty.

Out of 38 respondents, 35 (47%) agreed and 6 (13%) strongly agreed that adults taught them about puberty as an adolescent. 8 respondents (24%) disagreed and 5 respondents (13%) strongly disagreed adults taught them about puberty as an adolescent. 1 (3%) was unsure. 3 respondents (7% of all respondents) did not respond.



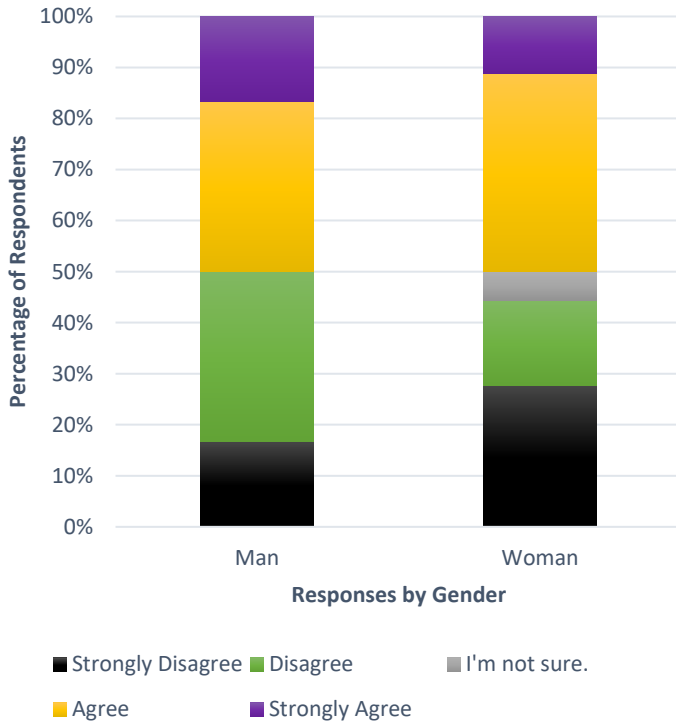
Gender: The proportions of men and women who were taught about puberty is almost inverted. About 2/3rd of men report not being taught about puberty while less than 1/3rd of women were not taught about puberty or were unsure if they were taught about puberty. While this dynamic is similar to responses regarding education about periods, both men and women received more education about puberty than periods. Additionally, the proportion of men who were taught about puberty was much larger than those who were taught about periods.

Age: Similar to the comparisons around gender, respondents in all age groups indicated receiving education about puberty to a greater degree than about periods specifically. However, the proportion of people not given education regarding puberty was still 20-40%, which can have significant impacts among people with disabilities in terms of understanding their body, how to care for their body, and how to be sexually safe and avoid unintended pregnancy.



6. Adults taught me how to prevent pregnancy during sex.
 Out of 36 respondents, 11 (31%) disagreed and 9 (25%) strongly disagreed that adults taught them how to prevent pregnancy as an adolescent. 12 respondents (33%) agreed and 3 respondents (8%) strongly agreed adults taught them about how to prevent pregnancy as an adolescent. 1 (3%) was unsure. 5 respondents (12% of all respondents) did not respond.

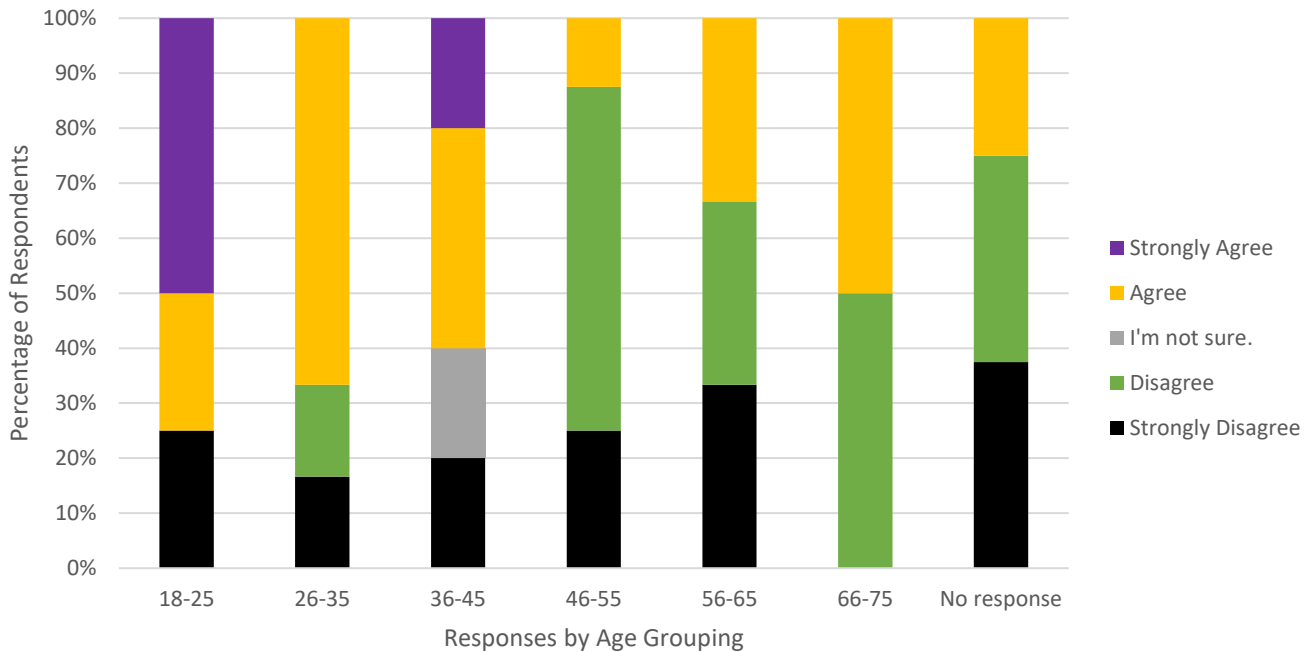
"Adults taught me how to prevent pregnancy during sex." (Q6, <18)



Gender: About half of both men and women were taught about pregnancy prevention in adolescence. Given how people with disabilities, especially children with disabilities, are often seen as “asexual” or being “incapable” of having romantic relationships, it is surprising that half of both men and women indicated being taught how to prevent pregnancy. However, that also suggests that an enormous proportion of people with disabilities are not receiving this kind of education during adolescence.

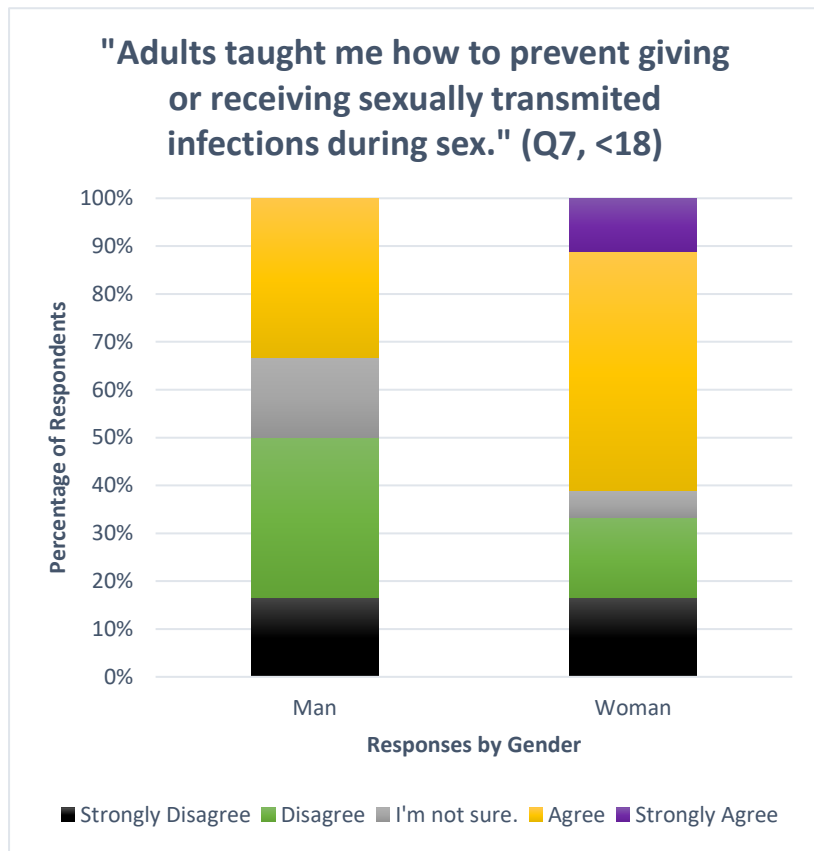
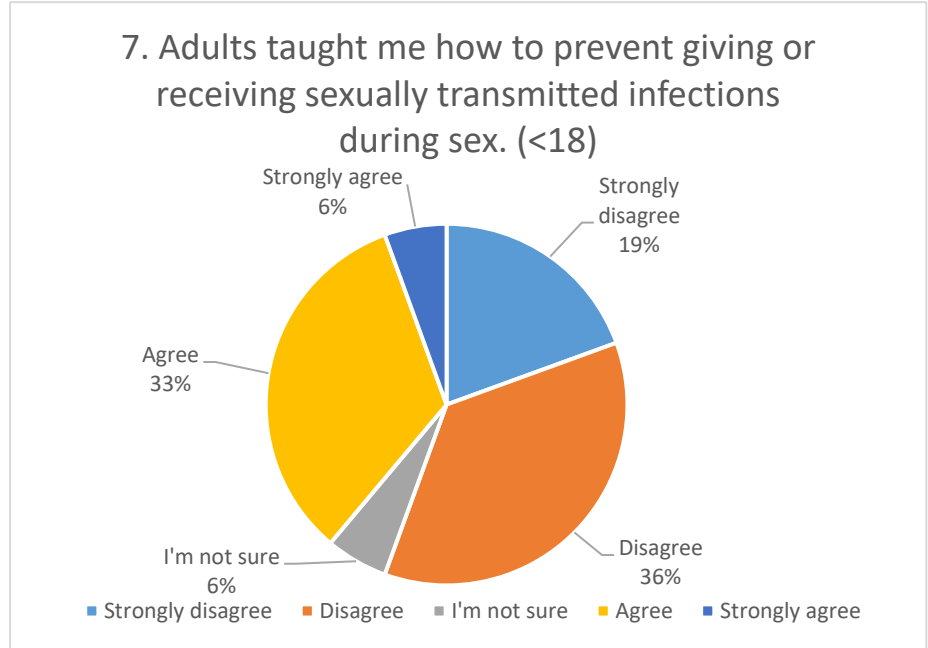
Age: Similar to other aspects of adolescence sex education, those under 46 seem to have significantly greater access to pregnancy prevention education than those over 45. 60-75% of those aged 18-45 reported being taught how to prevent pregnancy in adolescence, while only 33% of those aged 56-65 and 12% of those aged 46-55 reported being taught how to prevent pregnancy during adolescence.

"Adults taught me how to prevent pregnancy during sex." (Q6, <18)



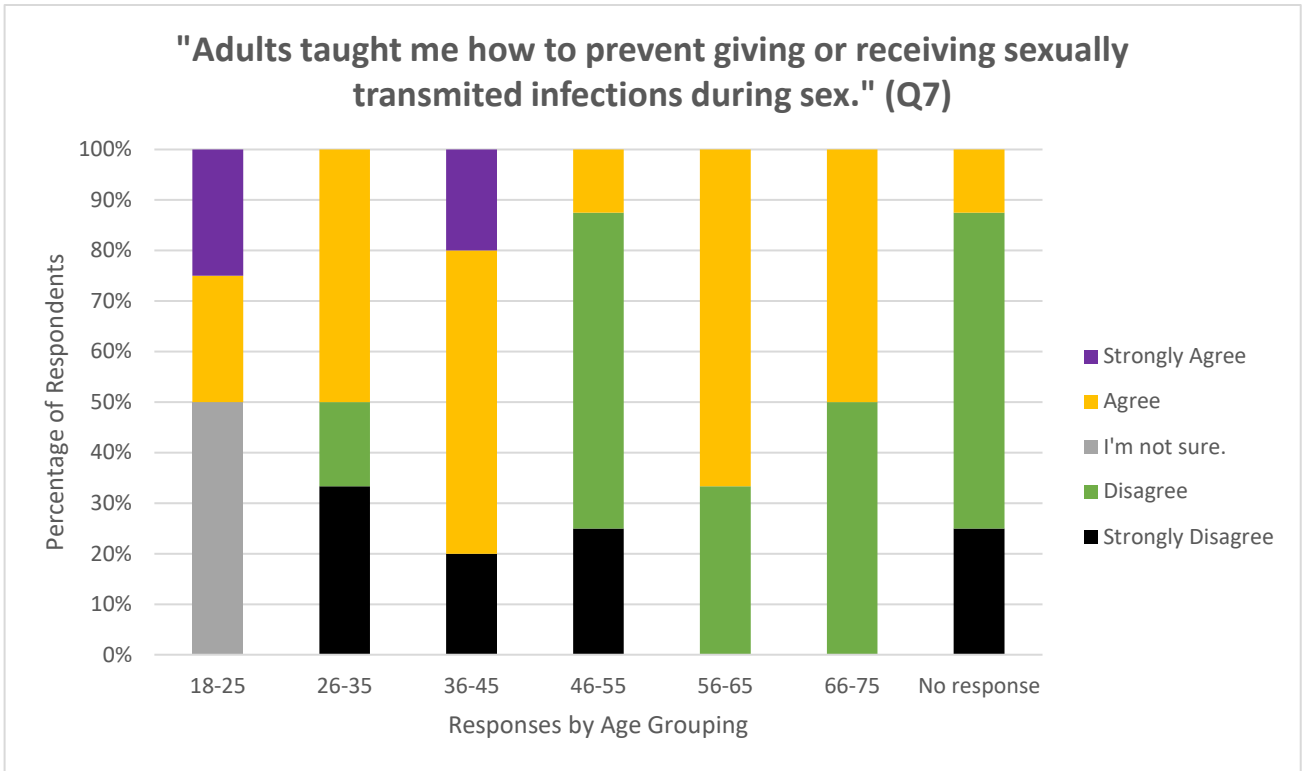
7. Adults taught me how to prevent giving or receiving sexually transmitted infections during sex.

Out of 36 respondents, 13 (36%) disagreed and 7 (19%) strongly disagreed that adults taught them about STI prevention as an adolescent. 12 respondents (33%) agreed and 2 respondents (6%) strongly agreed that adults taught them about STI prevention as an adolescent. 2 (6%) were unsure. 5 respondents (12% of all respondents) did not respond.

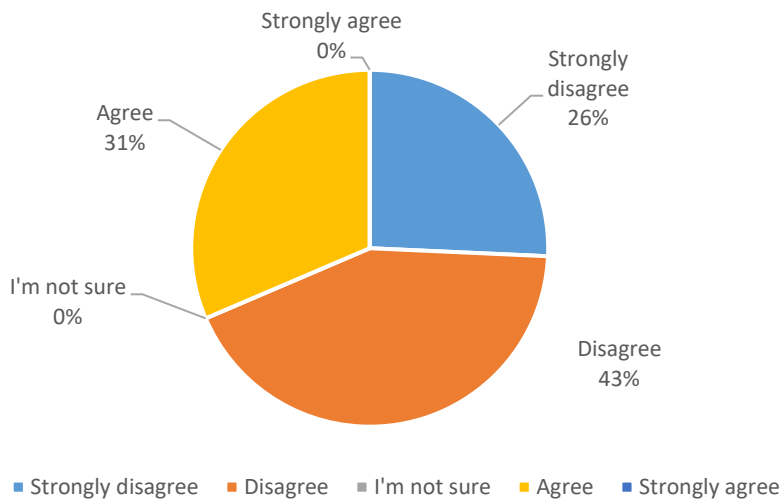


Gender: While 2/3rd of male respondents indicated they did not receive (or are unsure if they received) education to prevent STI's, about 2/3rd of female respondents indicated they did receive this education in adolescence.

Age: While those ages 36-45 (80%) and 56-65 (66%) had the highest proportions of people who were taught how to prevent the spread of STI's, those in the 46-55 age range had the lowest proportion (only about 12%) of respondents who received this kind of sex education during adolescence.



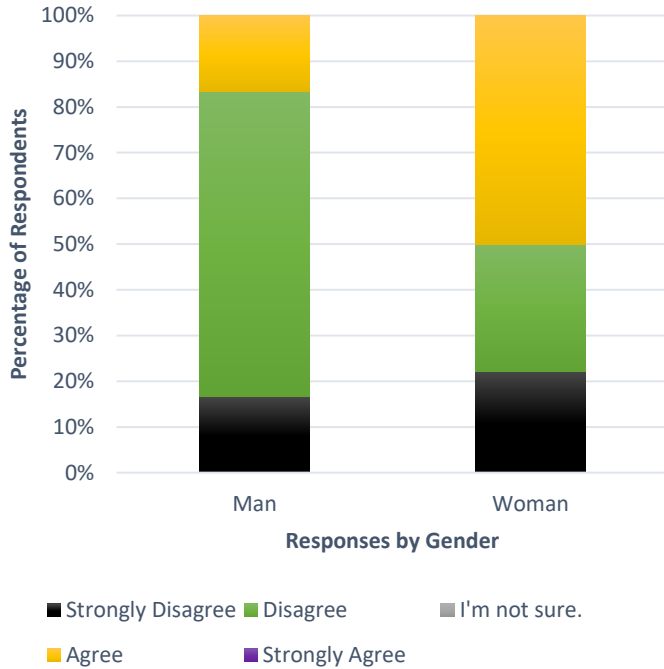
8. Adults taught me how to use barrier method contraceptives such as condoms, dental dams, and gloves. (<18)



8. Adults taught me how to use barrier method contraceptives such as condoms, dental dams, and gloves.

Out of 35 respondents, 15 (43%) disagreed and 9 (26%) strongly disagreed that adults taught them about barrier method contraceptives as an adolescent. 11 respondents (31%) agreed that adults taught them about barrier method contraception during adolescence. No respondents strongly agreed that adults taught them about barrier method contraception as an adolescent. 6 respondents (15% of all respondents) did not respond.

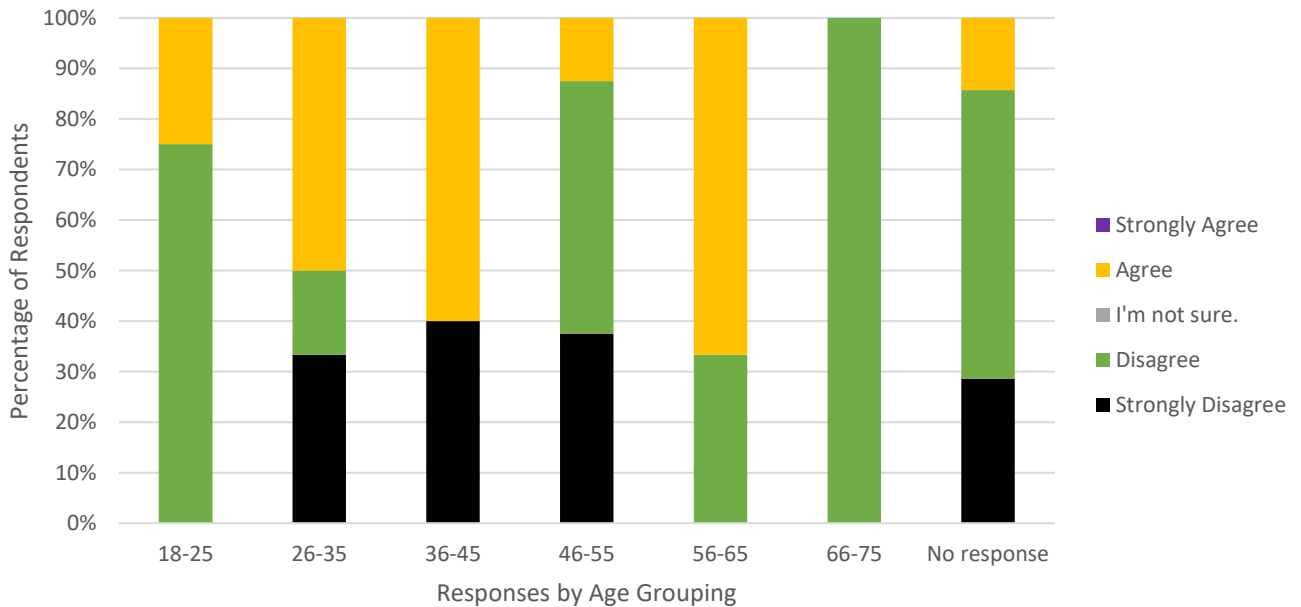
"Adults taught me how to use barrier method contraceptives, such as condoms, dental dams, and gloves." (Q8, <18)



Gender: While half of female respondents indicated they were taught about barrier method contraceptives, only about 16% of men were. The lack of “strongly agree” responses also suggests that while some people were given this education, it may not have been a priority or emphasized in their sex education as children.

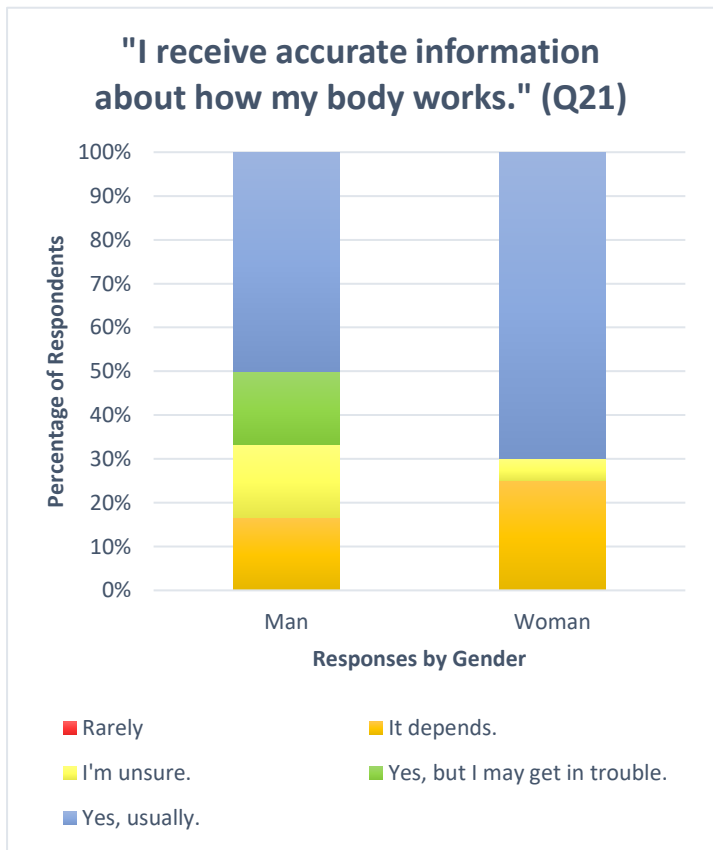
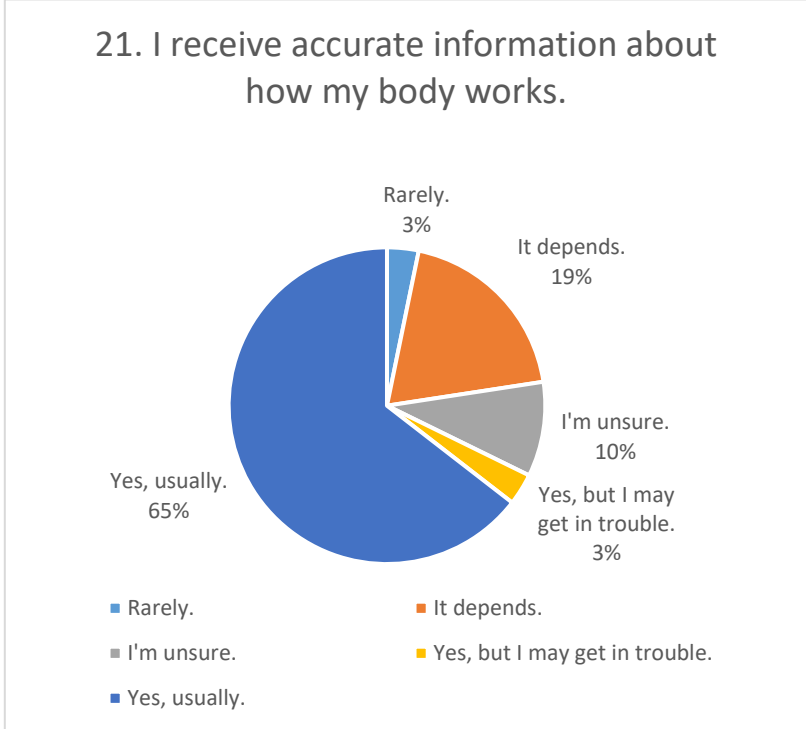
Age: Access to education regarding barrier method contraceptives during adolescence varies greatly across age groups. Those in the 56-65 range (66%) having the largest proportion of respondents indicating they had access followed by those in the 36-45 age range (60%). Those in the 46-55 age range had the lowest proportion of respondents who were taught about barrier method contraceptives at about 12%. This chart also elucidates that access to this education seemed to be divisive as significant proportions of respondents responded that they “strongly disagreed” with the statement.

"Adults taught me how to use barrier method contraceptives, such as condoms, dental dams, and gloves." (Q8, <18)



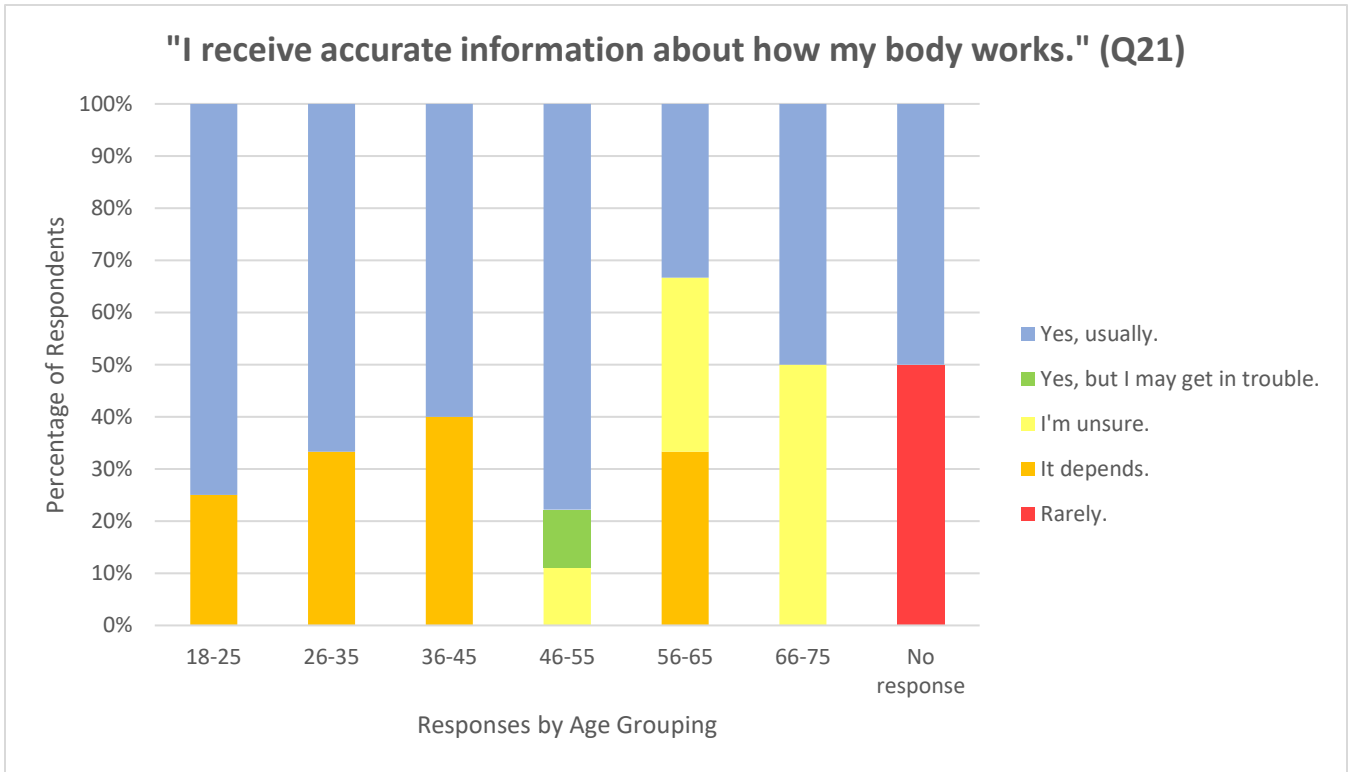
21. I receive accurate information about how my body works.

Out of 31 respondents, 20 respondents (65%) indicated that they usually receive accurate information about how their body. 6 respondents (19%) only sometimes (“It depends”) receive accurate information about how their body works while 1 respondent (3%) rarely received accurate information about how their body works. 1 respondent (3%) indicated they worried about retaliation for trying to receive accurate information about how their body works while 3 (10%) were unsure whether they received accurate information about how their body works. 10 respondents (24% of all respondents) did not respond.

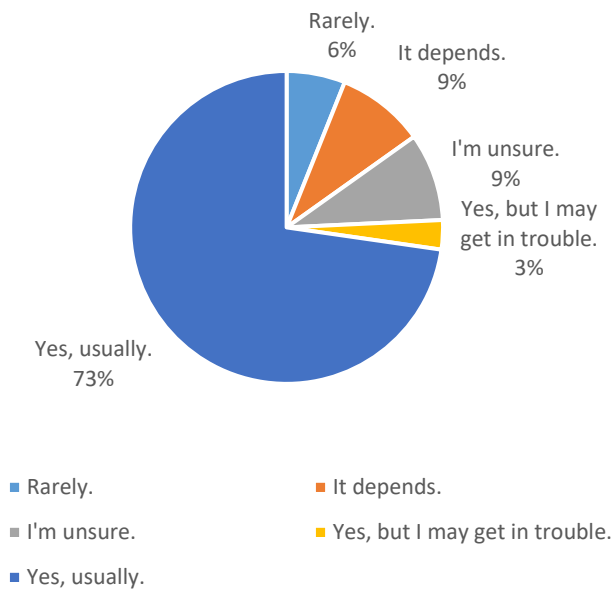


Gender: While 70% of women indicated they consistently receive accurate information about how their body works, only 50% of men did. About 15% of men also indicated that receiving accurate information about their body may be dangerous for them. About 16% of men and 25% of women who responded indicated that receiving accurate information about their body may depend on the situation or person involved.

Age: Those in the age range of 46-55 (77%) had the greatest proportion of respondents indicating they consistently receive accurate information about their body. Otherwise, the proportion of respondents stating they have consistent access (all other groups had a minimum of 50% indicating they usually have access) to this information decreased with increasing ages. With increasing age, there was also increased uncertainty about whether they were receiving accurate information.



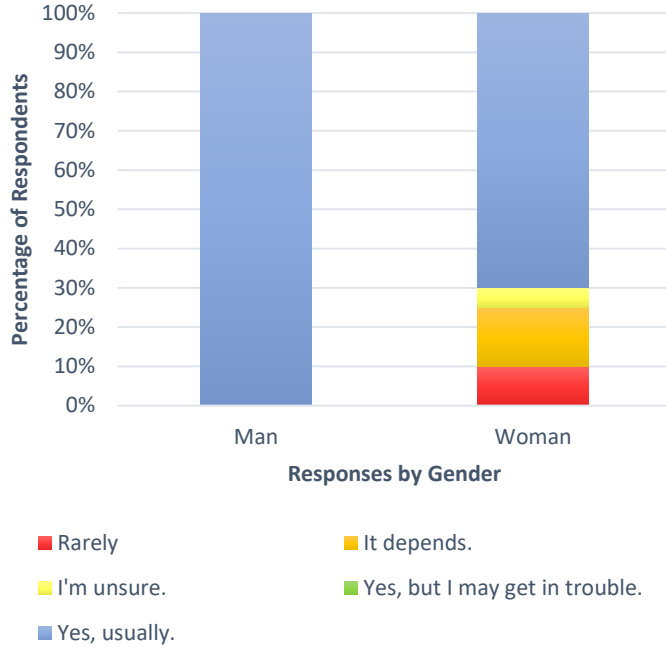
22. I receive accurate information about how to take care of my body.



22. I receive accurate information about how to take care of my body.

Out of 33 respondents, 24 respondents (73%) indicated that they usually receive accurate information about how to take care of their body. 3 respondents (9%) only sometimes ("It depends.") receive accurate information about to take care of their body while 2 respondents (6%) rarely received accurate information about how to take care of their body. 1 respondent (3%) indicated they worried about retaliation for trying to receive accurate information about how to take care of their body while 3 (9%) were unsure whether they received accurate information about how to take care of their body. 8 respondents (20% of all respondents) did not respond.

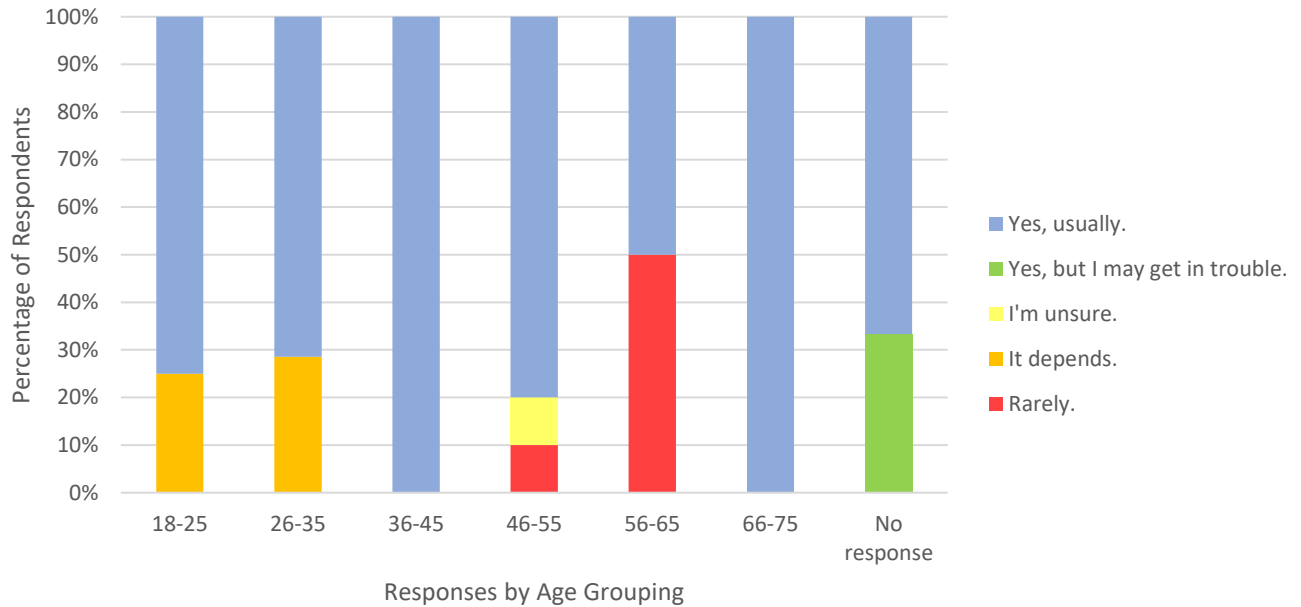
**"I receive accurate information about how to care for my body."
(Q22)**



Gender: Male respondents unanimously felt that they receive accurate information about how to care for their body. 10% of women indicated they rarely received accurate information about how to care for their body and another 15% indicated it depends on the circumstances whether they receive accurate information about how to care for their body.

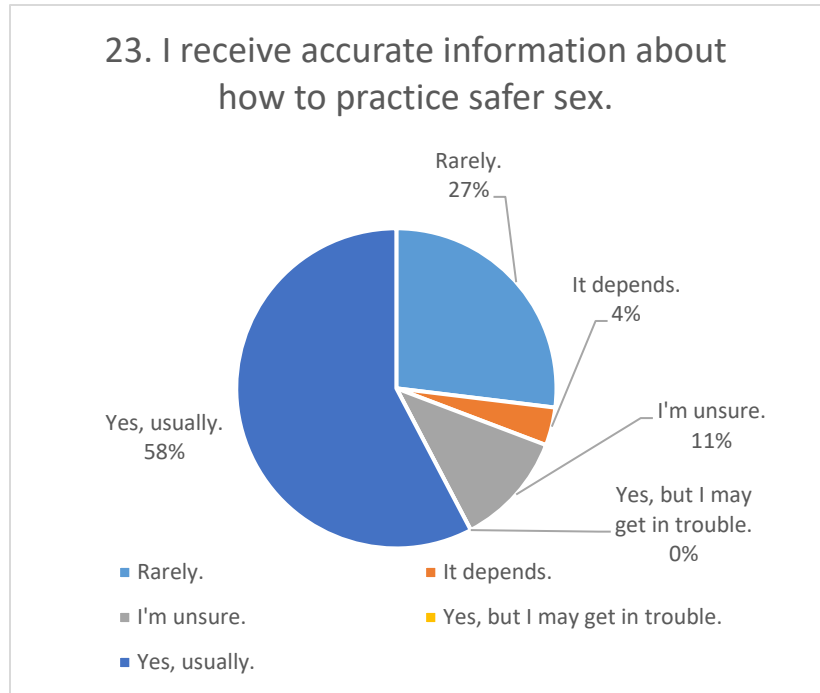
Age: 100% of those aged 36-45 and 80% of those aged 46-55 reported usually having access to accurate information about how to care for their body. About 3/4th of those aged 18-35 and 50% of those aged 56-60 reported usually having access to accurate information about how to care for their body. 10% of those aged 46-55 and the other 50% of those aged 56-65 reported rarely having access to accurate information about how to care for their body.

**"I receive accurate information about how to care for my body."
(Q22)**

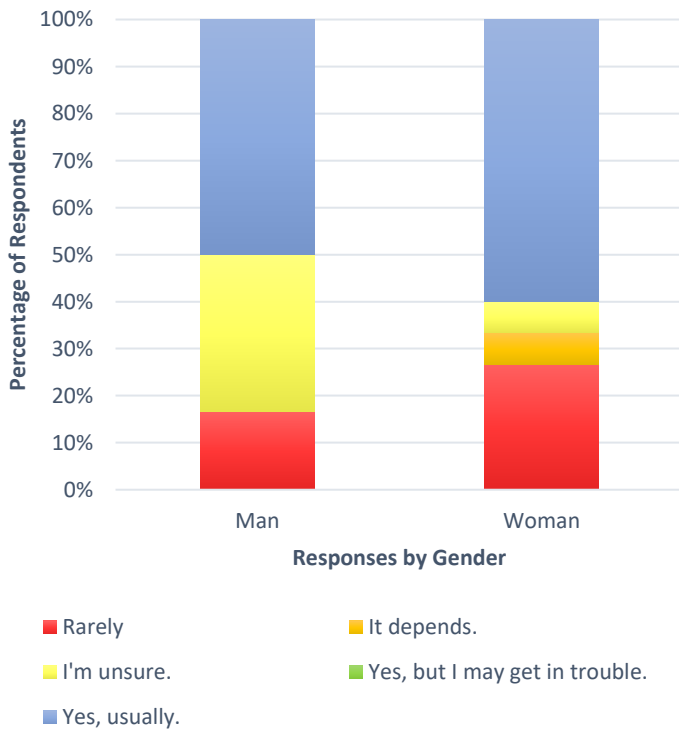


23. I receive accurate information about how to practice safer sex.

Out of 26 respondents, 15 respondents (58%) indicated that they usually receive accurate information about how to practice safer sex. 1 respondent (4%) only sometimes ("It depends.") receives accurate information about to practice safer sex while 7 respondents (27%) rarely received accurate information about how to practice safer sex. No respondents indicated they worried about retaliation for trying to receive accurate information about how to practice safer sex while 3 (11%) were unsure whether they receive accurate information about how to practice safer sex. 15 respondents (37% of all respondents) did not respond.

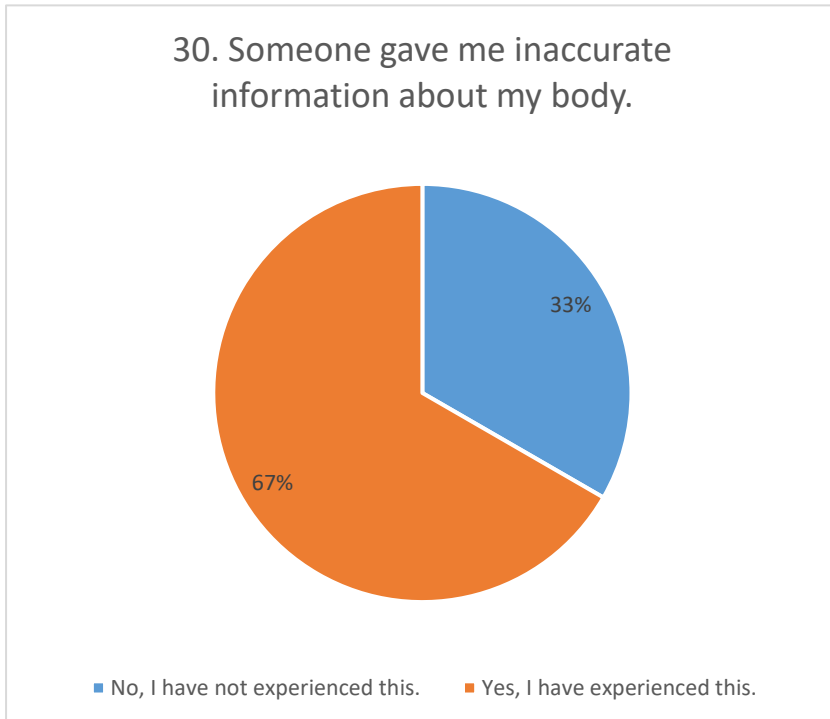
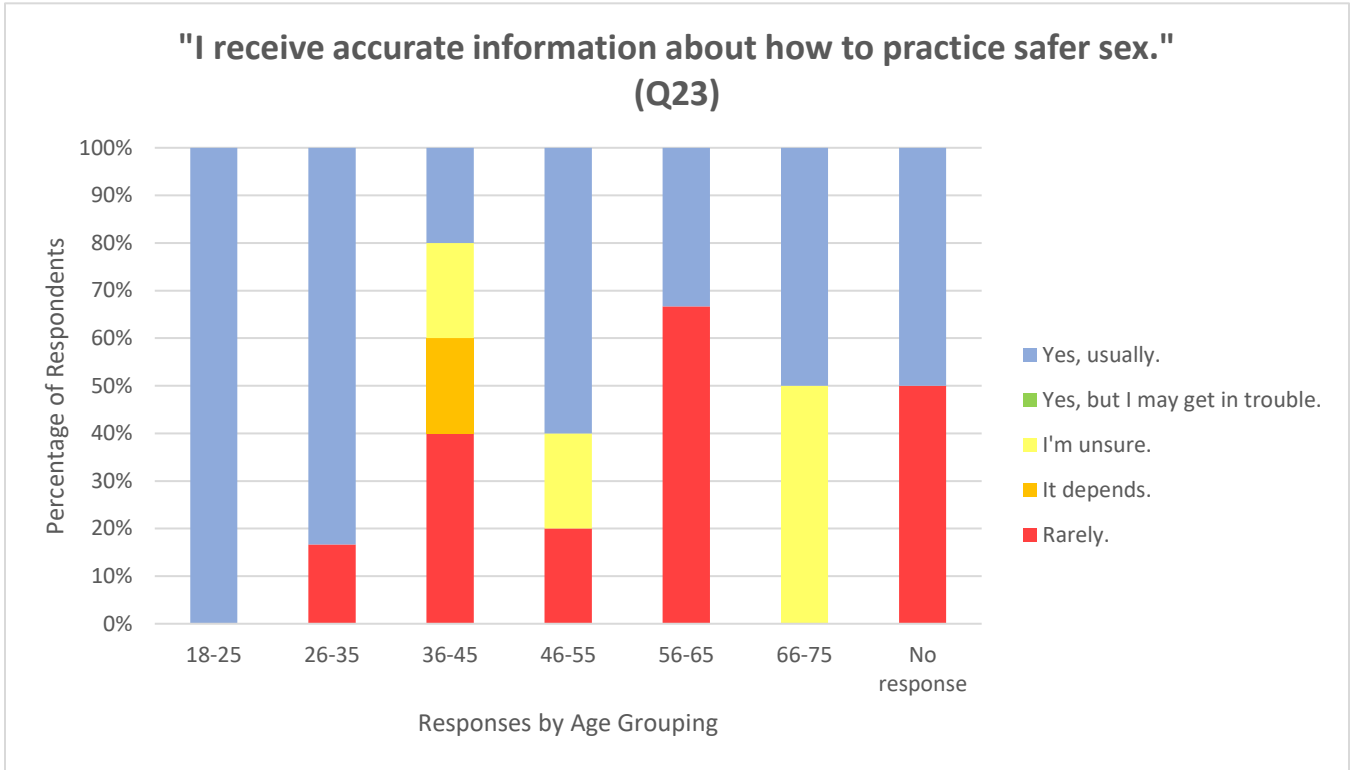


"I receive accurate information about how to practice safer sex." (Q23)



Gender: Only 40% of men and 60% of women indicate having access to consistently accurate information about practicing safer sex. About 26% of women and about 17% of men reported rarely having access to safer sex education.

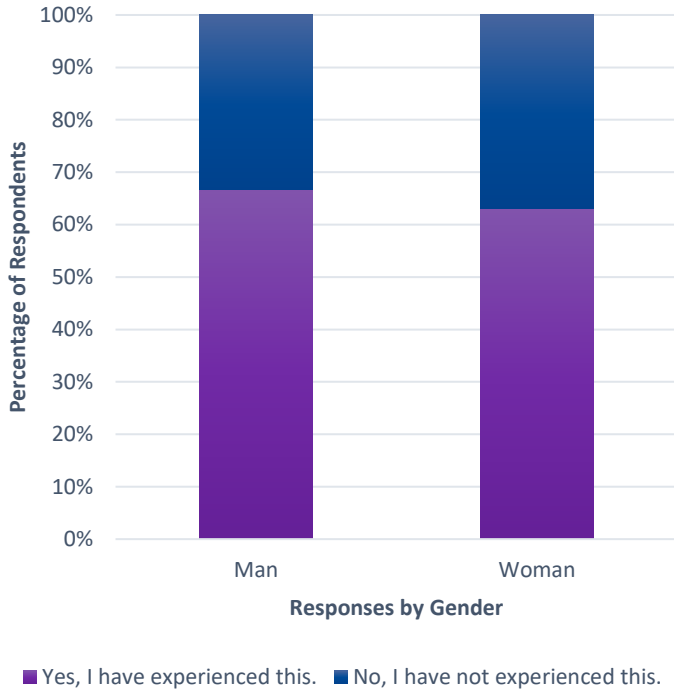
Age: Although those ages 18-25 reported unanimously having access to safer sex education, those in all other ages groups did not. Among the age groups that indicated rarely having access to safer sex education, about 2/3rd of those aged 55-65 rarely received safer sex education. Among the age groups that indicated rarely having access to safer sex education, those ages 26-35 reported the lowest relative proportion of people rarely having access at about 15%. Only 20% of those ages 36-45 reported having consistent access to safer sex education - the lowest proportion of respondents in any age group.



30. Someone gave me inaccurate information about my body.

Among the 30 respondents, 20 (67%) experienced someone giving them inaccurate information about their body while 10 (33%) had not. 11 respondents gave non-response answers.

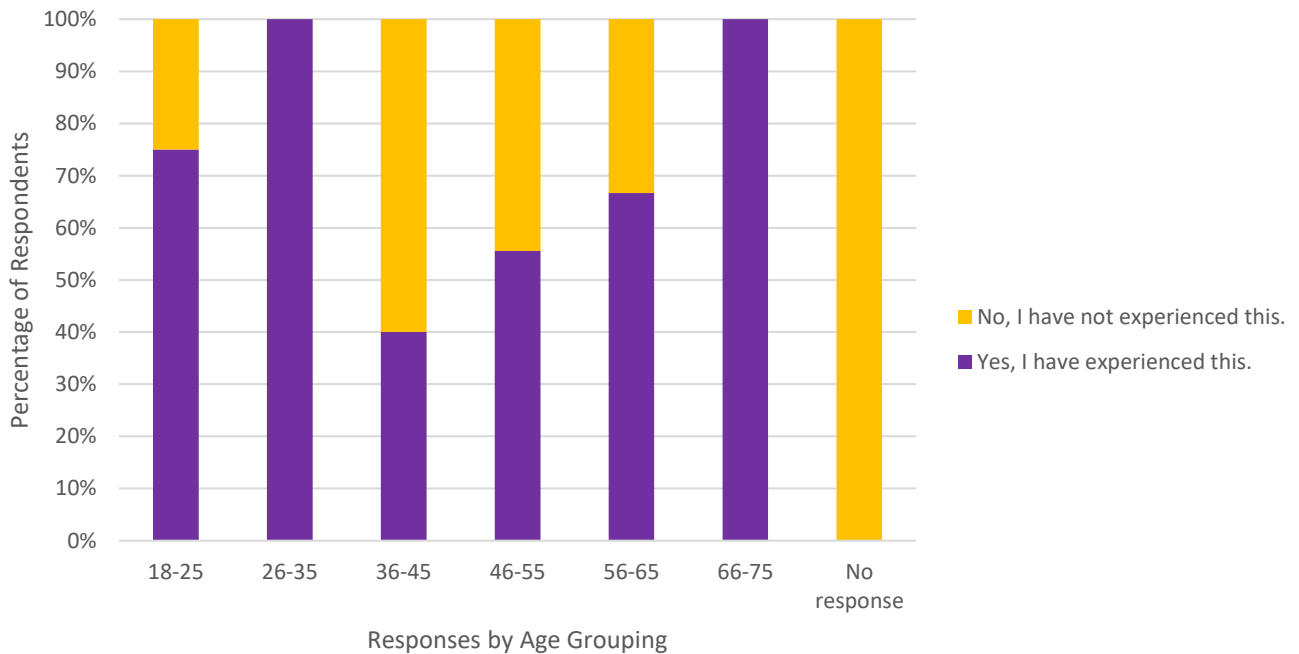
"Someone gave me inaccurate information about my body." (Q30)



Gender: About 2/3rd of both men and women report being given inaccurate information about their body at some point.

Age: Ages 26-35 and 66-67 unaniously reported being given inaccurate information about their body at some point. About 3/4th of the 18-25 year old respondents and about 2/3rd of the 56-65 year old respondents indicated being given inaccurate information about their body at some point. Given that overall 2/3rd of respondents experienced being given inaccurate information about their body, only those ages 36-55 reported a lower proportion of respondent experiences, and even then the at least 40% experienced being given inaccurate information about their body.

"Someone gave me inaccurate information about my body." (Q30)



Area 2 Conclusions

Sex Ed Results Summary: 70% of all respondents indicated not having access to adequate (or any) sexuality education during adolescence that would prepare them for affirming intimate relationships or family planning. During adolescence, only 10% felt able to ask questions about masturbation, and only 5% were taught about kinks and fetishes. While it is unusual for people with disabilities to be asked about their experiences with kinky sexuality in most surveys, this is a vital component of sexuality for disabled people. Most sex education provides a very narrow view of sex that is primarily focused heterosexual, allosexual, non-disabled, cisgender, middle class couples. Many disabled people require access to kinky sex education to learn how to experience pleasure, reduce pain or discomfort, adjust for muscle tone and flexibility. This kind of expansive sex education can also support people in learning how to create sexual boundaries (which may look different for different bodies and minds) and how to request help from personal care attendants in preparing for a sexual experience.

While greater proportions of men had access to education regarding masturbation and sex education that would prepare them for intimate relationships, there was a significantly larger proportion of women who received education regarding family planning during adolescence.. There were much higher proportions of respondents in age groups 18-35 who had access to information regarding masturbation, sex education, and family planning. The greatest disparities in sex education and family planning education during adolescence showed up among those aged 46-55.

Communicating Boundaries Results Summary: At least 2/3rd of respondents indicated they did not receive adequate, if any, education regarding communication in relationships generally and 3/4th reported they had no support from adults in communicating their desires and boundaries during adolescence. This paints a devastating portrait of the intimate social lives of disabled people because many people with disabilities naturally have differences in information processing and communication. It is unsurprising that even as disabled people become more integrated into society, the rates of isolation and loneliness are extreme for disabled people. People with disabilities are already socially disadvantaged by the inaccessibility of non-disabled and neurotypical dominated spaces. This includes the ways non-disabled and neurotypical people avoid slowing down to meet the needs of disabled people and the lack of effort of non-disabled people to bridge differences in body and mind function. Without being supported in building communication skills, disabled people are set up to have difficulty identifying and communicating boundaries, understanding others' boundaries, and building safe, stable, and affirming relationships.

Understanding Other's Boundaries Results Summary: 50-66% of respondents did not receive adequate, if any, education regarding listening for and understanding others' boundaries during adolescence. A much higher proportion of men reported accessing this education compared to women. There are many peer reviewed publications attempting to address the instances of adults with disabilities unintentionally physically or sexually harming others, particularly adolescents. This data suggests that adults with disabilities are being failed beginning in childhood by adults, who are not supporting disabled youth in developing these skills.

Sexual Decision Making Results Summary: While 3/4th of respondents reported not having adults who would help them make sexual activity decisions during adolescence, this experience disproportionately affected women and those in age ranges 26-35 and 56-65. Most respondents indicated that they did not have an intimate relationship during adolescence that felt “really good”. Over 1/5th of respondents said they “strongly disagreed” they had an affirming intimate relationship during adolescence, suggesting a large number of respondents may have experienced abusive, coercive, and/or unsafe intimate relationships during adolescence. As childhood and adolescent relationships help form the foundation and framework for adults to understand and build intimate relationships, the large proportion of respondents who did not receive support for sexual decision-making and the proportion of respondents who reported not experiencing an intimate relationship during adolescence are very troubling.

In adulthood, most respondents indicated that they have at least one person in their lives that they trust who can help them make decisions about their sexual health. Those who reported the least access to this kind of support were in age ranges 46-55 (50%) and 18-25 (25%).

Area 2 Results: Sexual Autonomy and Wellness

Sexuality Education Results Summary

84% of respondents disagreed and only 10% of respondents agreed that they felt allowed to ask questions about masturbation during adolescence (Q17). Only 18% of men and 5% of women agreed that they were allowed to ask questions about masturbation. All age groups unanimously disagreed that they were allowed to ask questions about masturbation during adolescence except for 25% of those aged 18-25 (all the “strongly agree” responses were here) and 15% of those aged 26-35 (all the “agree” responses were here).

92% of respondents disagreed (over 70% strongly disagreed) that they were taught about kinks or fetishes during adolescence (Q15). While men and women had similar proportions of responses, women had more “strongly disagree” responses. The only age group that had any “agree” responses was the 26-35 age group.

70% of respondents overall reported that they did not receive sex education during adolescence that prepared them for intimate relationships (Q19). Only 1/3rd of men and 1/4th of women reported receiving this kind of education in adolescence. Responses varied by age group with 84% of those aged 26-35 indicating they did receive this education, down to only 13% reporting the same among those aged 46-55. All those who responded that they strongly agreed that they received this education were in the 18-25 age group. Similarly, 70% of respondents reported they were not taught about family planning and fertility during adolescence (Q20). There were great differences by gender with 64% of women indicating they were taught about family planning compared to only 16% of men. 50-66% of each age group reported receiving family planning education except those aged 46-55 of which only 13% reported the same.

Communicating Boundaries Results Summary

While 65% of respondents indicated they were not taught how to let others know what they did and didn't want in a relationship generally, 73% of women and 50% of men responded the same (with most “strongly disagree” responses being submitted by women) (Q13). 50-60% of those aged 18-25 and 36-45 reported that they were taught how to let others know what they needed during adolescence, in contrast to only 13% of those aged 26-35 and 46-55. No respondents aged 56-65 reported receiving this kind of education.

About 3/4th of respondents reported that adults did not help them practice communicating their desires and boundaries during adolescence (Q2). While 83% of men reported that they did not receive this support during adolescence, 75% of women reported the same and women also had all of the “strongly disagree responses” (which made up over half of their “disagree” responses), suggesting this topic may have been especially stigmatized and gendered for girls.

Understanding Others' Boundaries Results Summary

2/3rd of all respondents indicated that they were not taught how to find out what other people did or didn't want in a relationship during adolescence (14). While half of men reported they were taught how to find out what people did or didn't want in a relationship, only 18% of women reported the same. At least 40% of respondents in every age group reported not being taught this information. At most, 60% of respondents aged 36-45 indicated they were taught how to find out what others' did and didn't want in relationships.

About half of respondents indicated that adults did help them practice listening to and respecting others' desires and boundaries, and these proportions held for both men and women (Q3). At best, 80% of those aged 36-45 received this kind of education, while at worst, 1/4th of those aged 46-55 reported the same. Over 40% of respondents reported that they were not taught how to respect others' boundaries during adolescence. 84% of men and 53% of women indicated they did receive this kind of education and at least 30% of each age group reported having had access to this education during adolescence.

Sexual Decision Making Results Summary

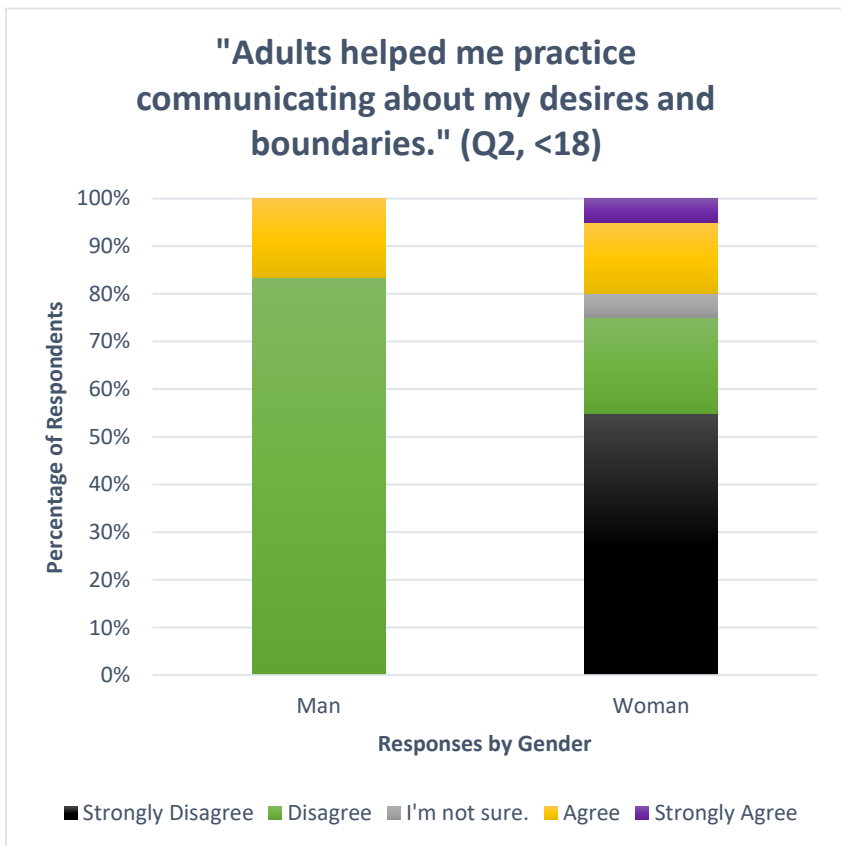
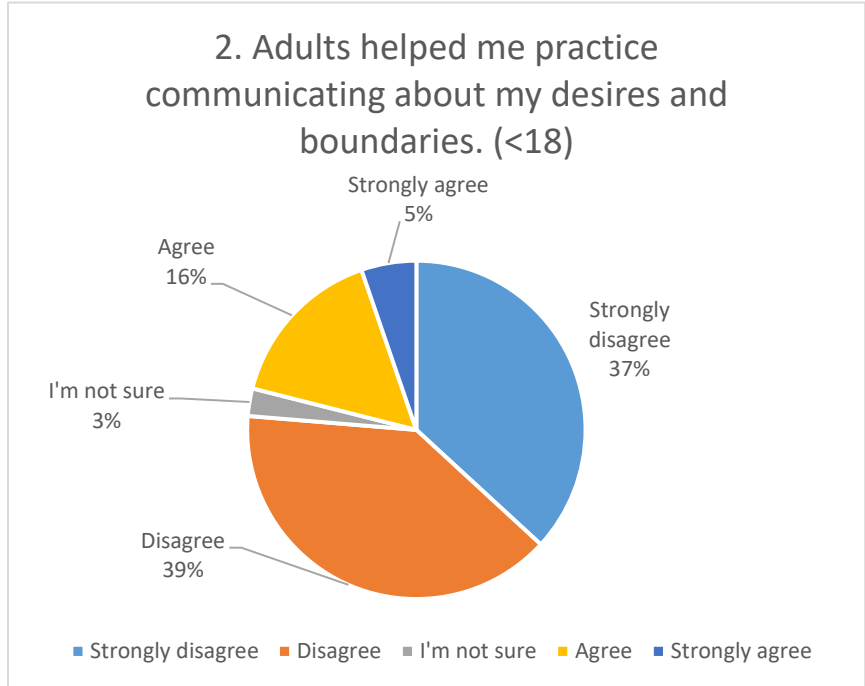
3/4th of respondents indicated that adults did not help them with sexual activity decision making during adolescence (Q9). 33% of men reported they did receive this support while 50% reported they did not. In contrast, only 17% of women reported sexual decision making support from adults while 83% reported they did not. At least half of the respondents in every age group reported that adults did not help them with sexual decision making during adolescence, but all respondents in age groups 26-35 and 56-65 reported the same. At best, half of respondents in age group 18-25 indicated adults did help them in this way.

Question 18 asks survey participants whether they experienced an intimate relationship during adolescence that felt "really good" (Q18), and it is informative to include the detailed response breakdowns. Only 15% of respondents strongly agreed, 25% agreed (40% total agree), 33% disagreed, and 22% strongly disagreed (55% total disagree) that they had an intimate relationship that felt really good during adolescence. Among men 34% of agreed, 50% disagreed (17% strongly disagreed), and 16% were unsure about whether they experienced a relationship that made them feel really good. Among women, 41% agreed, 59% disagreed (24% strongly disagreed) that they experienced an intimate relationship during adolescence that made them feel really good.

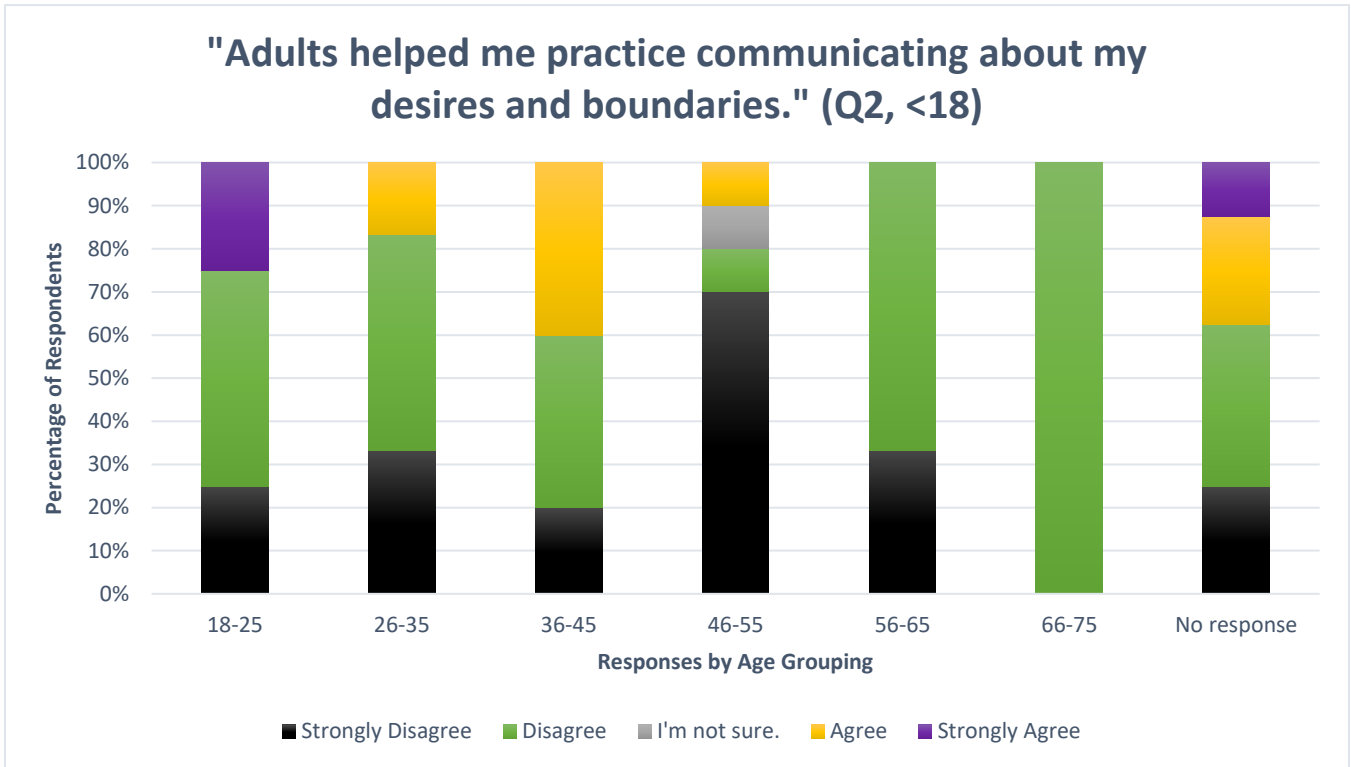
66% of respondents indicated that (currently, in adulthood) they usually have someone they trust who can help them make decisions about their sexual health, 17% reported rarely having someone they trust, and 17% said this support was inconsistent or circumstantial (Q28). 50% of those aged 46-55 and 25% of those aged 18-25 reported rarely having someone they trust to help them make sexual health decisions. 66% of those aged 56-65 indicated that having someone they trust who can help them with these decisions was inconsistent or circumstantial. At least 1/3rd of respondents in each age group reported they usually have someone they can trust to help them make decisions about their sexual health.

2. Adults helped me practice communicating about my desires and boundaries.

Out of 38 respondents, 15 respondents (39%) disagreed and 14 respondents (37%) strongly disagreed that they were helped in practicing communicating about their desires and boundaries as an adolescent. Only 6 (16%) agreed and 2 (5%) strongly agreed that they were helped in practicing communicating about their desires and boundaries as an adolescent. 1 respondent (3%) was unsure. 3 individuals (7% of all respondents) did not respond.



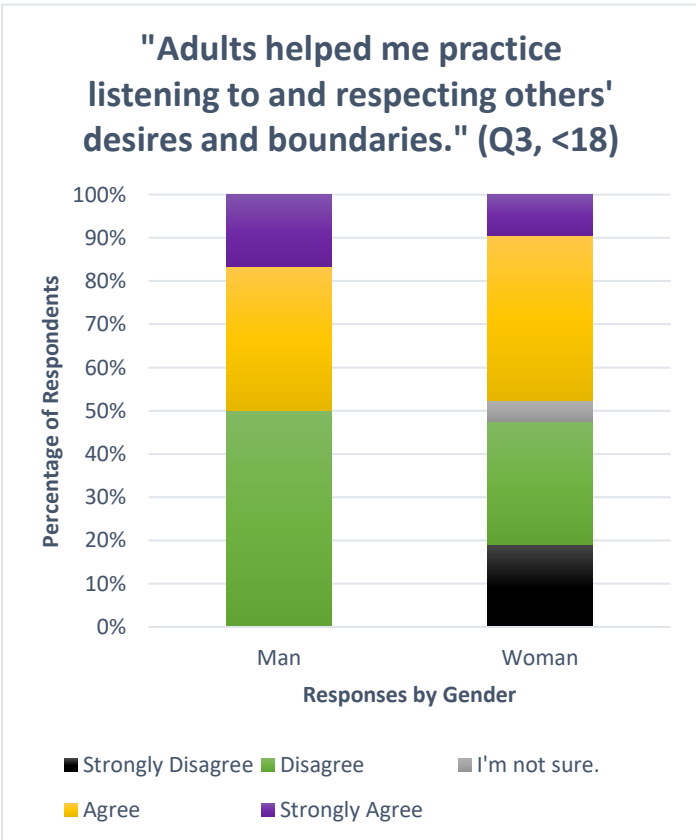
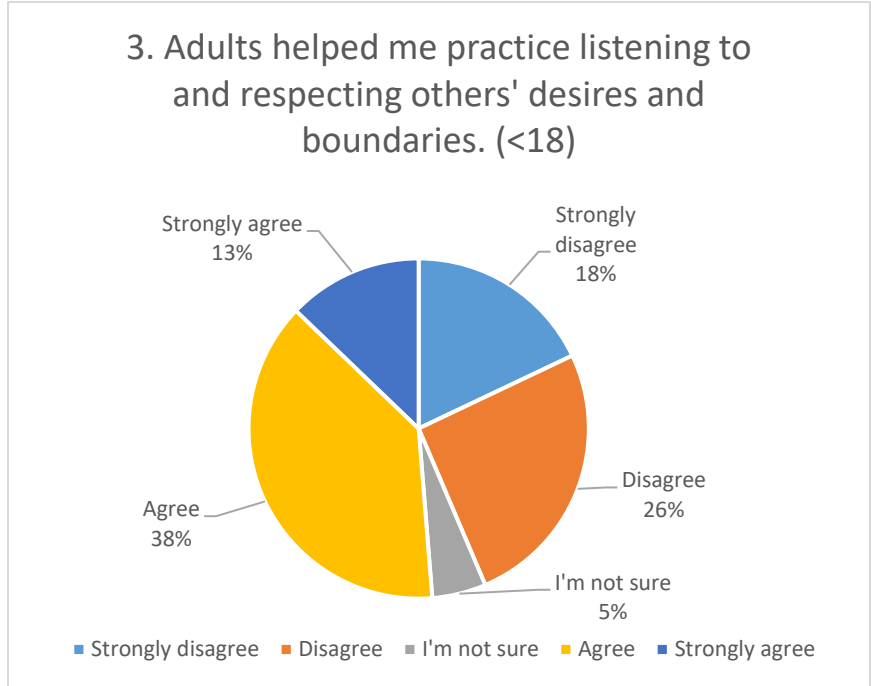
Gender: While both women and men overwhelmingly reported that adults did not help them communicate their desires and boundaries, there’s a stark difference in the extent to which respondents may have been affected. While about 83% men reported adults did not help them and about 75% of women reported adults did not help them with these communication skills as children, 55% of the women who responded “strongly disagreed” with this statement. This suggests some environmental factors rooted in sexism or gender norms that shaped how people with disabilities are raised to relate to their bodies and communicate about them.



Age: While the proportions differ between age groups, some respondents in nearly every age range indicated that they “strongly disagreed” or “disagreed” with the statement that adults helped them practice communication about desires and boundaries (exception being the 66-75 age range). Ages 18-55 included some respondents who either “agreed” or “strongly agreed” with the statement. The age range 36-45 had the highest proportion of respondents (40%) who agreed or strongly agreed that adults helped them practice, but those in ages 56-75 unanimously reported having no help from adults in communicating their desires and boundaries.

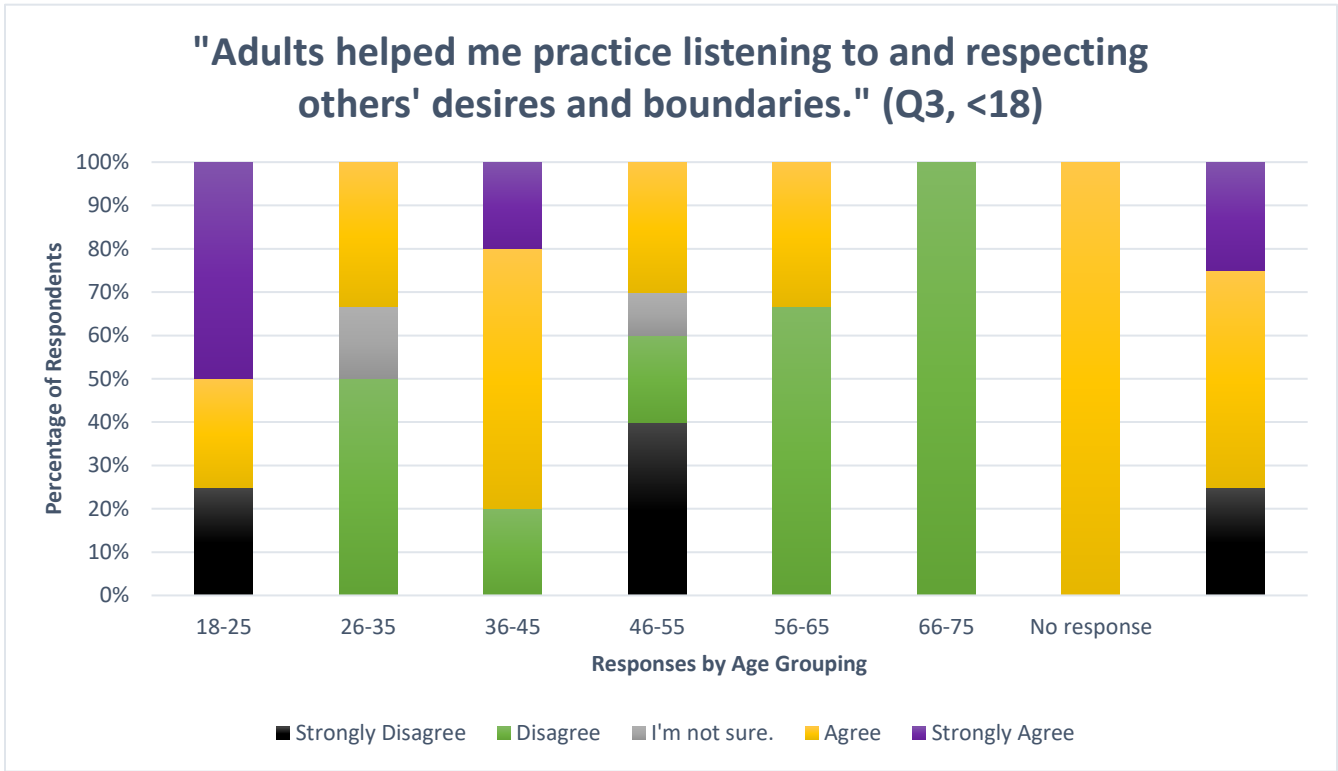
3. Adults helped me practice listening to and respecting others' desires and boundaries.

Out of 39 respondents, 15 (38%) agreed and 5 (13%) strongly agreed that adults helped them practice listening to and respecting others' desires and boundaries as an adolescent. 10 respondents (26%) disagreed and 7 respondents (18%) strongly disagreed that adults helped them practice listening to and respecting others' desires and boundaries as an adolescent. 2 (5%) were unsure. 2 respondents (5% of all respondents) did not respond.



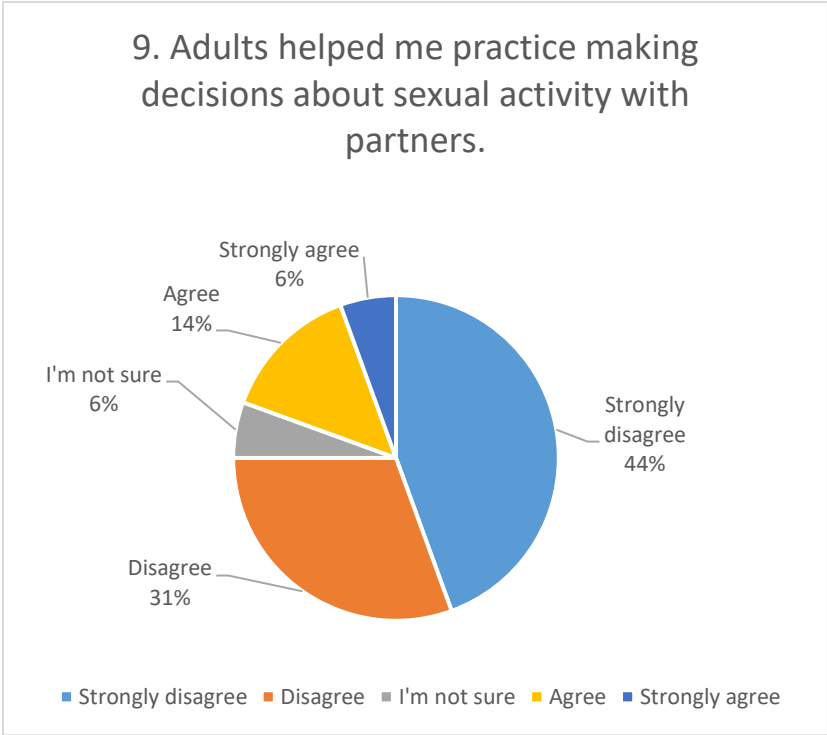
Gender: While proportions of respondents who selected each response option was fairly even between men and woman, 20% of women reported “strongly disagreeing” with the statement (men didn’t report “strongly disagree” at all). Additionally, about 17% of men – compared to 10% of women – strongly agreed that adults helped them practice listening to and respecting others’ desires and boundaries.

Age: While about 2/3rd of those aged 56-65, and 50% of those aged 26-35 reported adults not helping them practice listening to and respecting others’ desires and boundaries, 40% of those aged 46-55 and 15% of those aged 18-25 strongly disagreed with the same. The age group with the highest proportion of respondents who indicated they did receive support from parents in this area were aged 36-45 (80%). The largest proportion of respondents in an age group who strongly agreed that adults helped them practice listening to and respecting others’ desires and boundaries during adolescence were 18-25. The 18-25 group also showed the greatest polarization of responses.



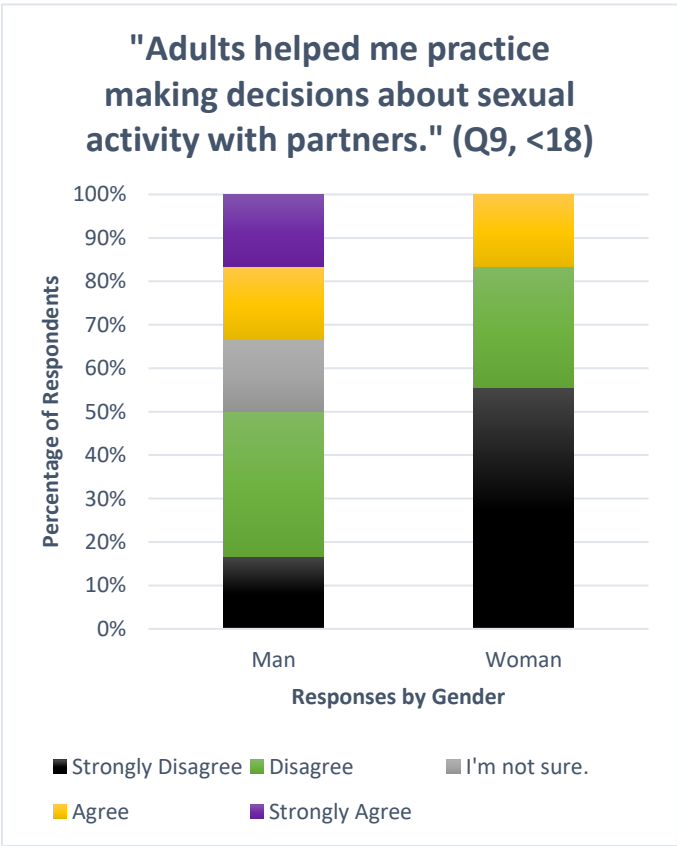
9. Adults helped me practice making decisions about sexual activity with partners.

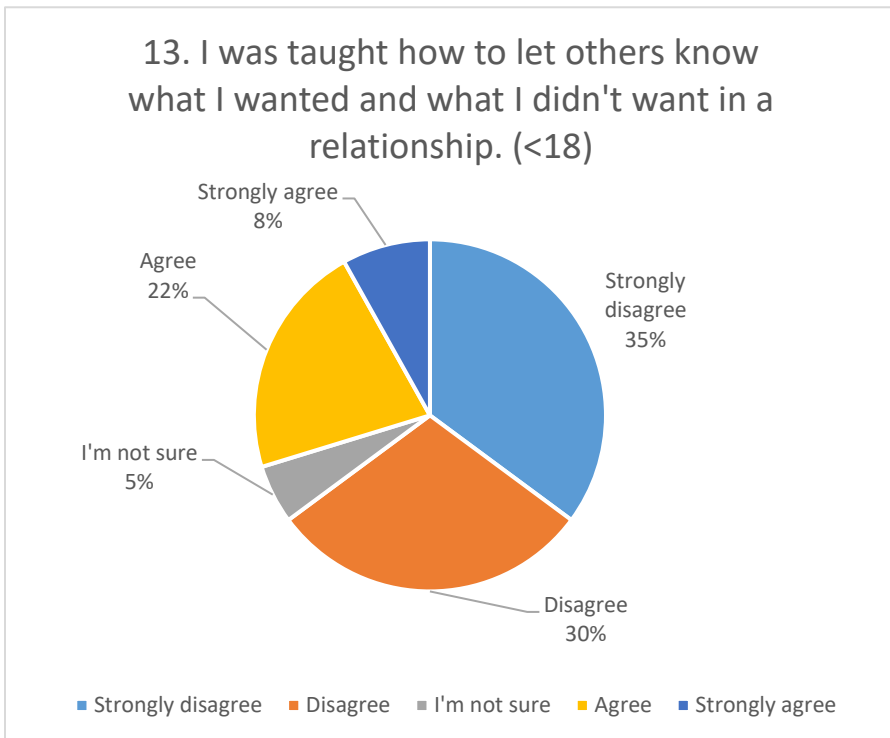
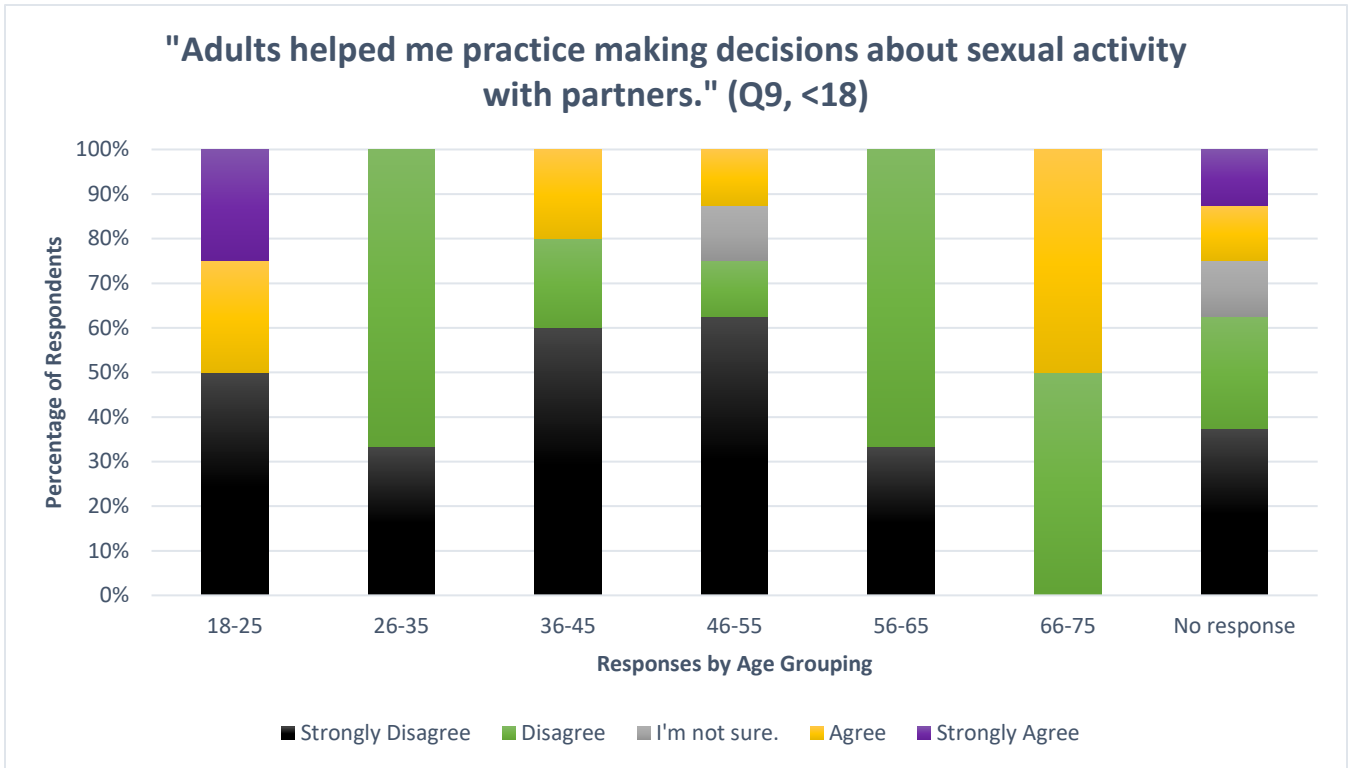
Out of 36 respondents, 16 (43%) strongly disagreed and 11 (26%) disagreed that adults helped them practice making decisions about sexual activity as an adolescent. 5 respondents (14%) agreed and 2 respondents (6%) respondents strongly agreed that helped them practice making decisions about sexual activity as an adolescent. 2 individuals (6%) were unsure. 6 respondents (15% of all respondents) did not respond.



Gender: While over 80% of women disagreed that adults helped them practice making decisions about sexual activity with partners (about 55% strongly disagreed), about 50% of men reported the same. About 66% of men reported having adults who helped them practice making decisions about sexual activity (about 17% strongly agreed). This contrasts starkly to women of which only 17% indicate having adults help them practice making decisions about sexual activity (without any “strongly agree” responses).

Age: Given that 44% of respondents overall “strongly disagree” that adults helped them practice making decisions about sexual activity, it is not surprising that “strongly disagree” responses present in all age groups other than 66-75. Overall 33% to 60% of respondents in all age groups strongly disagreed that adults helped them make decisions about sexual activity. Half of those in age ranges 18-25 and 66-76 reported agreeing that adults helped them make decisions regarding sexual activity. However, no respondents in age groups 26-35 and 56-65 reporting have any adults who helped them make decisions regarding sexual activity.

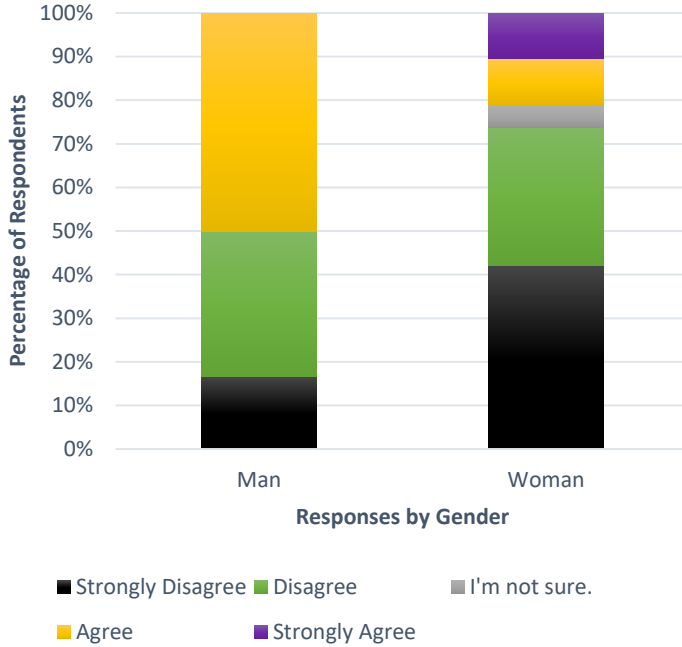




13. I was taught how to let others know what I wanted and what I didn't want in a relationship.

Out of 37 respondents, 13 respondents (35%) strongly disagreed and 11 respondents (30%) disagreed that they were taught how to let others know what they did and did not want in a relationship as an adolescent. 8 respondents (22%) agreed and 3 respondents (8%) strongly agreed they were taught how to let others know what they did and did not want in a relationship as an adolescent. 4 respondents (10% of all respondents) did not respond.

"I was taught how to let others know what I wanted and what I didn't want in our relationship." (Q13)

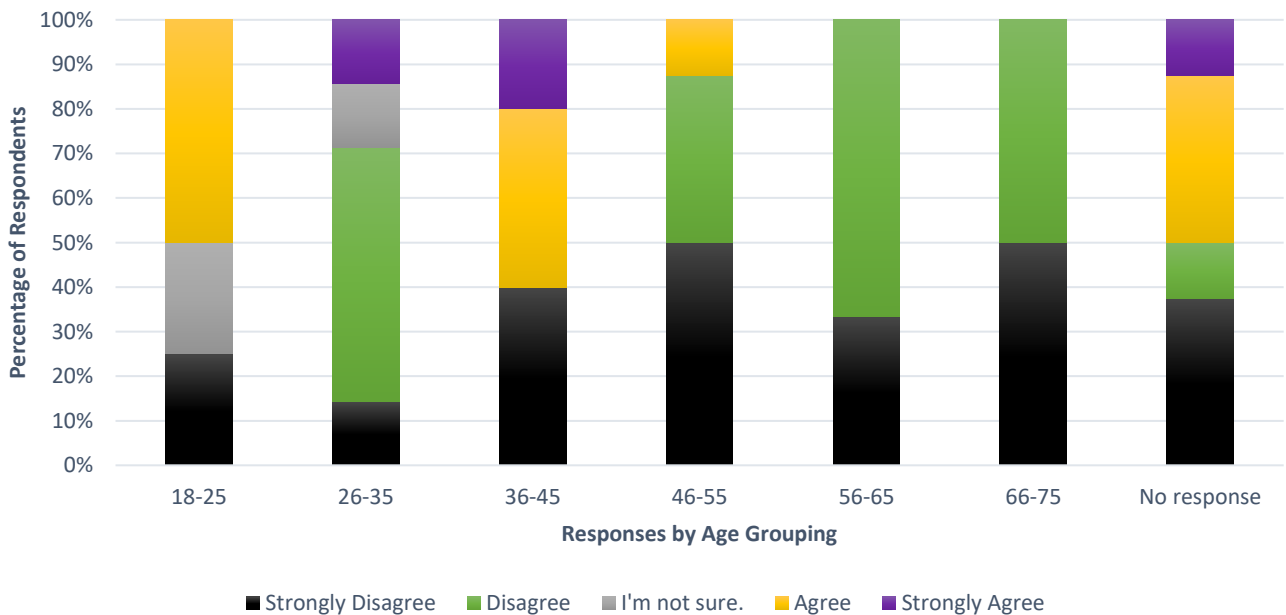


Gender: Similar to question 9 (support in practicing sexual decision making) male respondents seem to have had much greater access to learning about communication in relationships. While about 50% of men agreed that they were taught how to let others know what they wanted and didn't want, only 20% of women reported the same. In fact, 42% of women reported "strongly disagreeing" with the statement which nearly parallels the 50% of men who "disagreed" and "strongly disagreed" altogether.

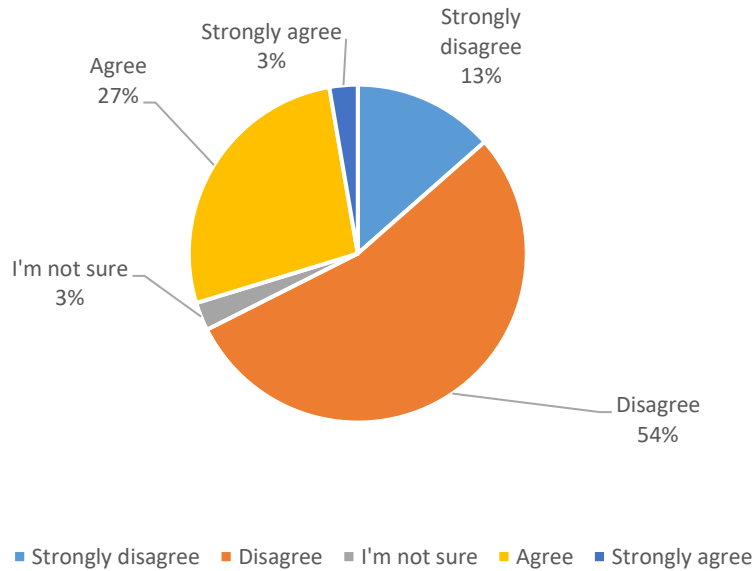
Age: Those in age ranges 56-75 unanimously reported not being taught how to let others' know what they did and didn't want in a relationship. While those in younger groups reported some access to this kind of education, it varied widely between groups. Only 14% of those aged 26-35 and those aged 46-55 reported being taught how to let others' know

what they did and didn't want in a relationship while 60% of respondents aged 36-45 reported the same.

"I was taught how to let others know what I wanted and what I didn't want in our relationship." (Q13, <18)



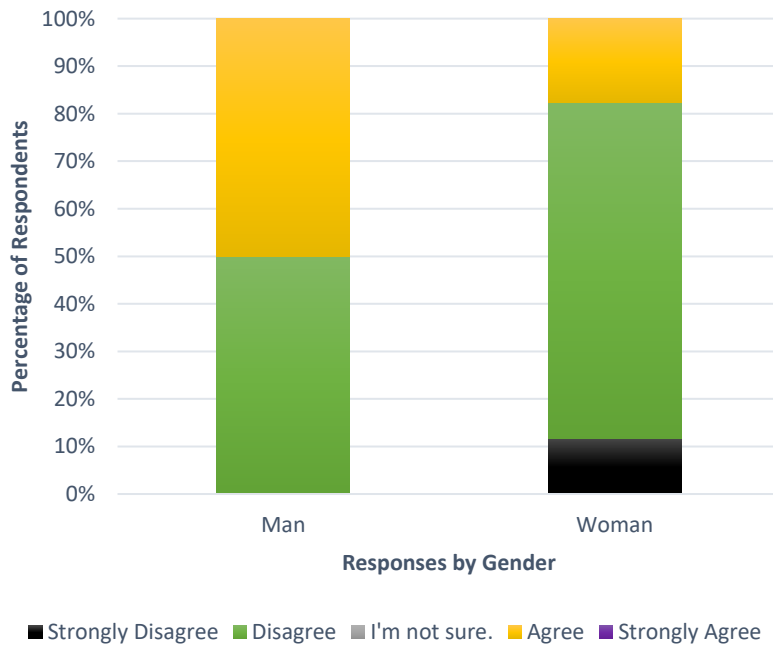
14. I was taught how to find out what other people wanted or didn't want in a relationship. (<18)



14. I was taught how to find out what other people wanted or didn't want in a relationship.

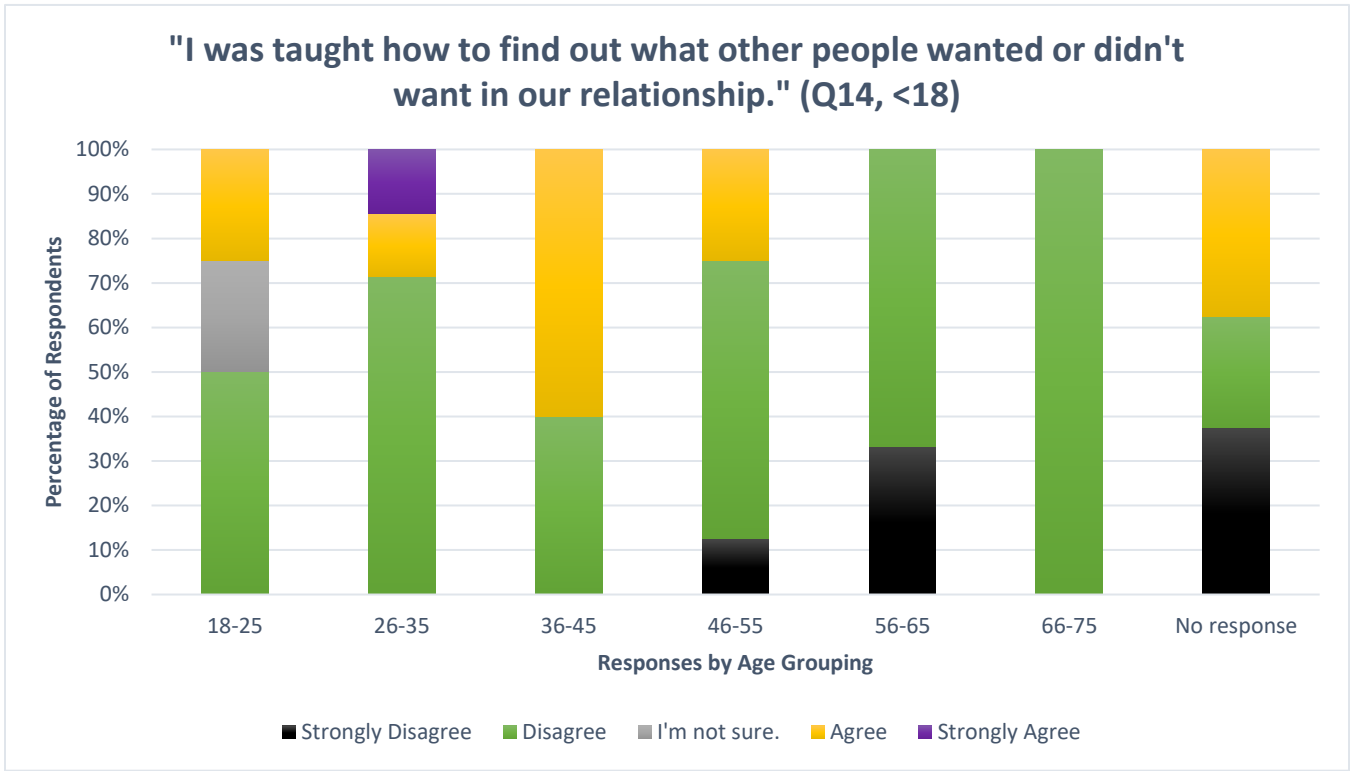
Out of 37 respondents, 20 respondents (54%) disagreed and 5 respondents (13%) strongly disagreed that they were taught how to find out what others did and did not want in a relationship as an adolescent. 10 respondents (72%) agreed and 1 respondent (3%) strongly that they were taught how to find out what others did and did not want in a relationship as an adolescent. 1 respondent (3%) was unsure. 4 respondents (10% of all respondents) did not respond.

"I was taught how to find out what other people wanted or didn't want in our relationship." (Q14, <18)



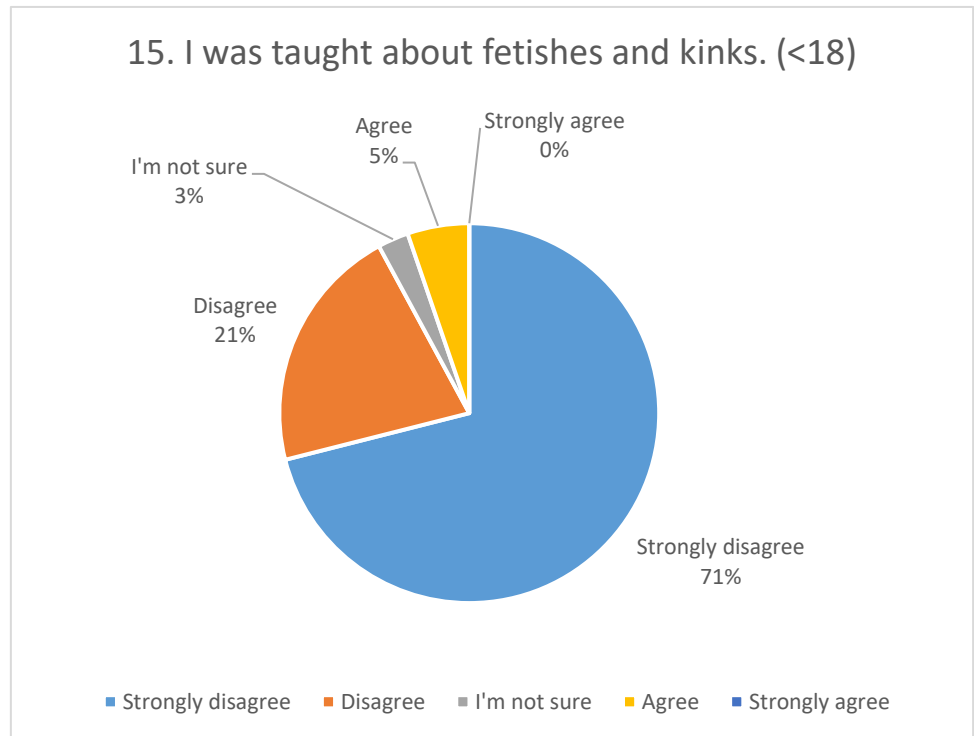
Gender: While the general proportion of men and women who state they were or were not taught how to find out what other people did or didn't want in a relationship during adolescence holds true in Question 13 (if they were supported by adults in learning how to communicate their own relationships needs), there are far lower proportions of "strongly disagree" and "strongly agree" responses.

Age: The proportions of those in each age range regarding agreement or disagreement with this statement almost mirrors the responses provide in Question 13 which asks respondents if they were supported by adults in learning how to communicate their own relationships needs.

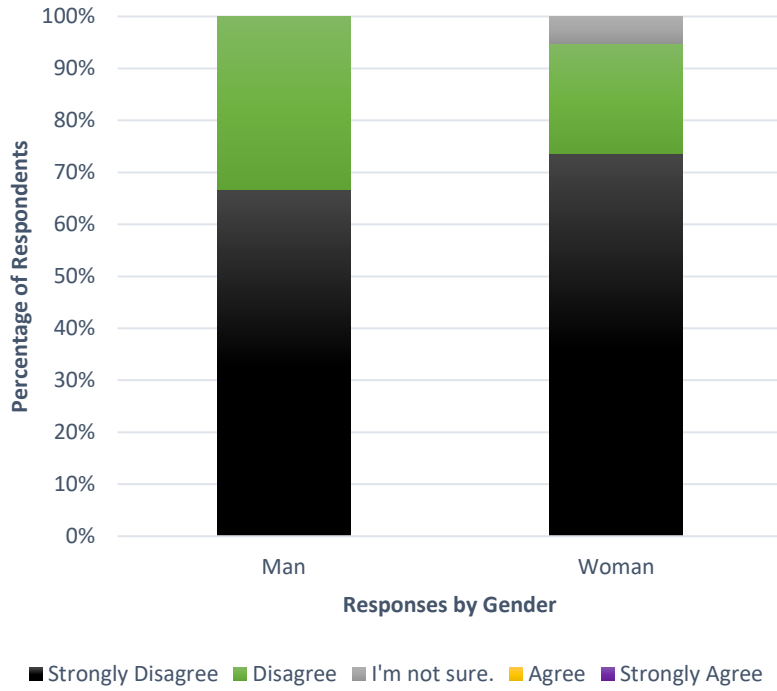


15. I was taught about fetishes and kinks.

Out of 38 respondents, 27 respondents (71%) strongly disagreed and 8 respondents (21%) disagreed that as an adolescent they were taught about kinks and fetishes. 2 respondents (5%) agreed that as an adolescent they were taught about kinks and fetishes. No respondents strongly agreed and 1 respondent (3%) was unsure. 3 respondents (7% of all respondents) did not respond.



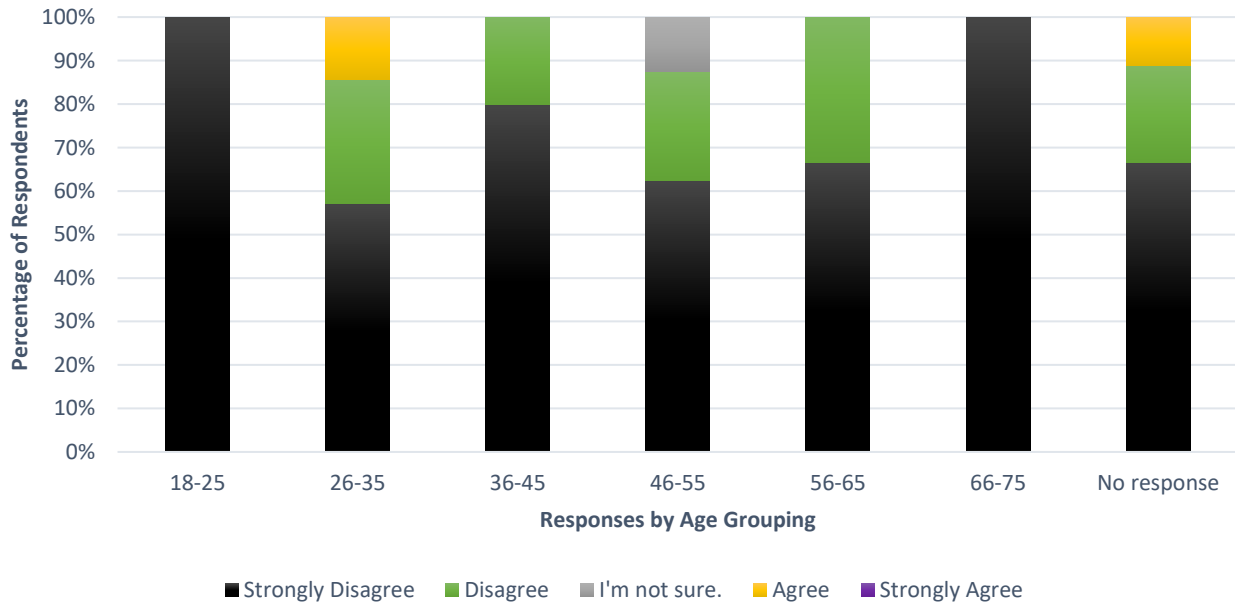
**"I was taught about kinks and fetishes."
 (Q15, <18)**



Gender: No men or women indicated being taught about fetishes or kinks before age 18.

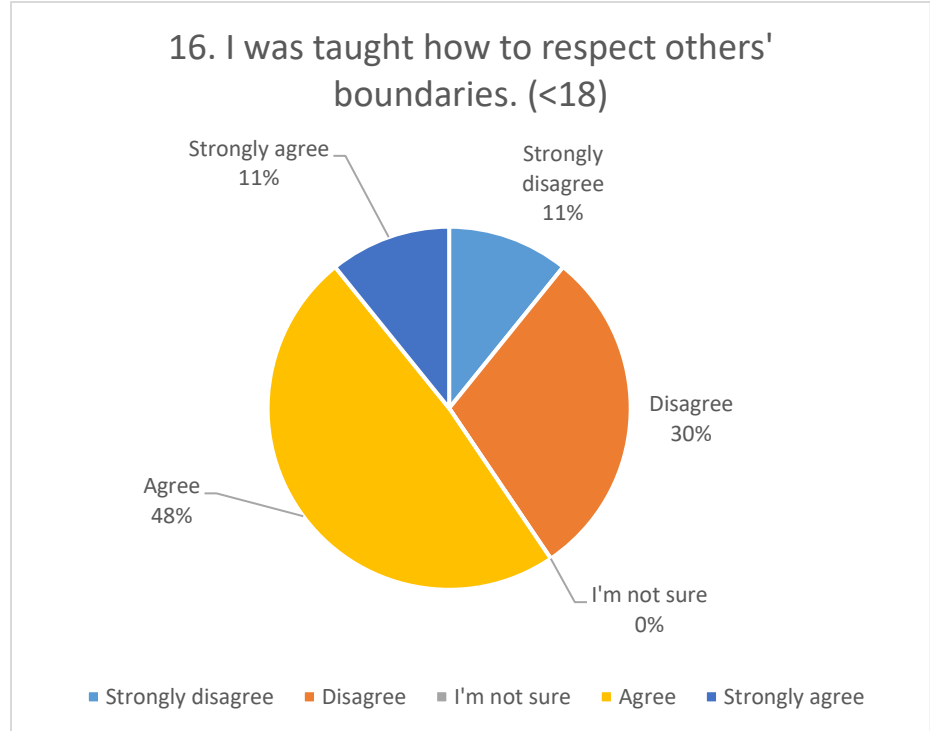
Age: Although the overwhelming proportion of respondents in all age categories responded that they were not taught about kinks and fetishes when they were young, about 13% of respondents ages 26-35 did receive this education as well as about 11% of the respondents who did not disclose their age.

"I was taught about kinks and fetishes." (Q15, <18)



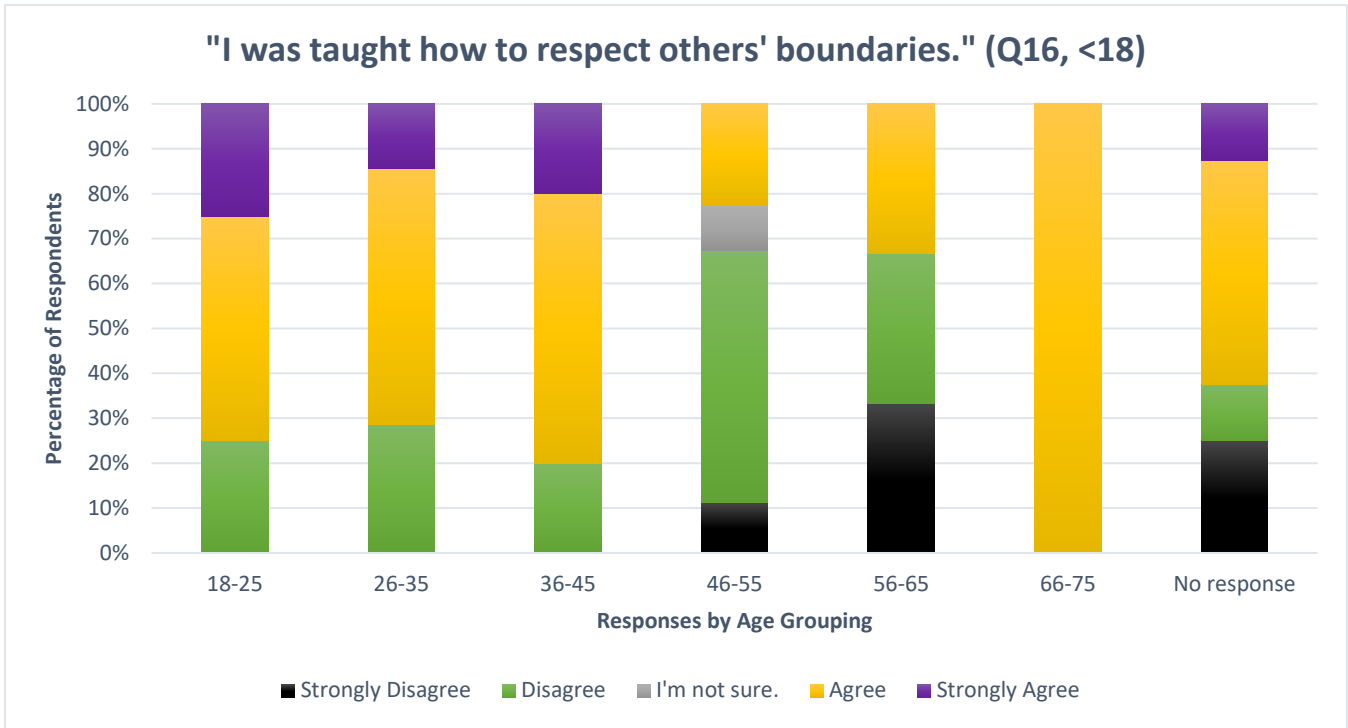
16. I was taught how to respect others' boundaries.

Out of 37 respondents, 18 respondents (48%) agreed and 4 respondents (11%) strongly agreed that they were taught how to respect others' boundaries as an adolescent. 11 respondents (30%) disagreed and 4 respondents (11%) strongly disagreed that they were taught how to respect others' boundaries as an adolescent. 4 respondents (10% of all respondents) did not respond.



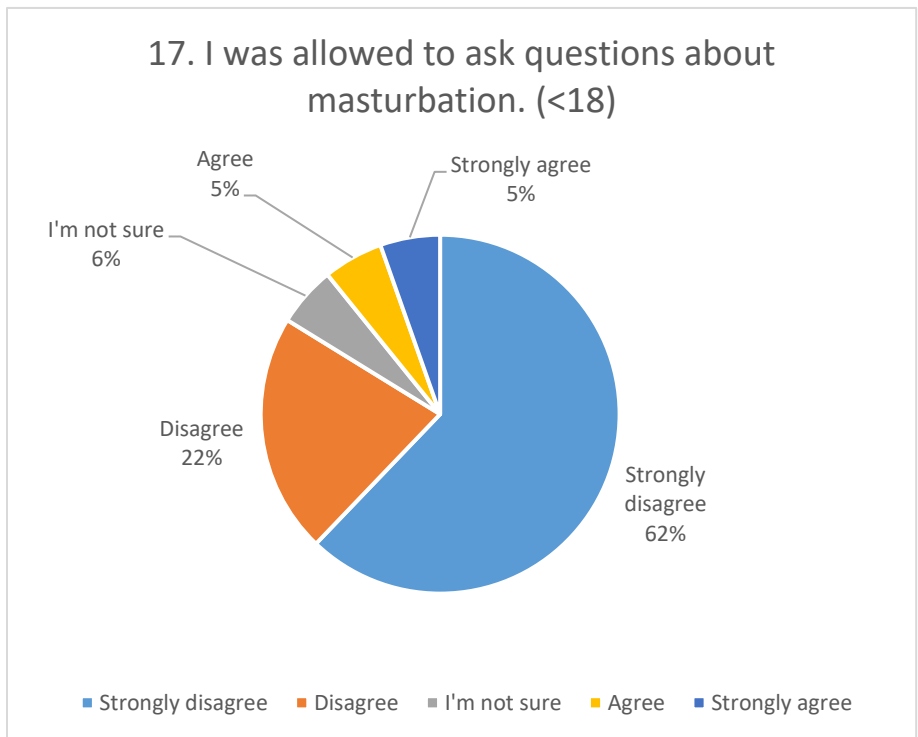
Gender: About 83% of men and 52% of women responded that they “agree” or “strongly agree” that they were taught how to respect others’ boundaries in their adolescence.

Age: At least 2/3rd of respondents in aging 18-45 “agreed” or “strongly agreed” that they were taught how to respect others’ boundaries in adolescence, and all 66-75 year old respondents indicated the same. Only slightly over 20% of those in the 46-55 age group, and only slightly over 30% in the 56-65 age group, reported being taught to respect others’ boundaries during adolescence.

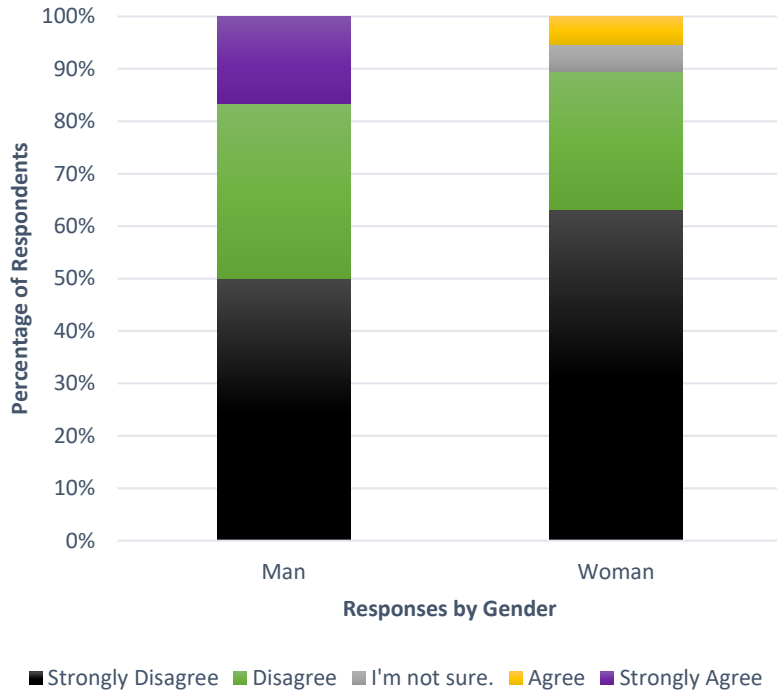


17. I was allowed to ask questions about masturbation.

Out of 37 respondents, 23 respondents (62%) strongly disagreed and 8 respondents (22%) disagreed that as an adolescent they were allowed to ask questions about masturbation as an adolescent. 2 respondents (5%) agreed and 2 respondents (5%) strongly agreed that as a they were allowed to ask questions about masturbation as an adolescent. 2 respondents (6%) were unsure. 4 respondents (10% of all respondents) did not respond.



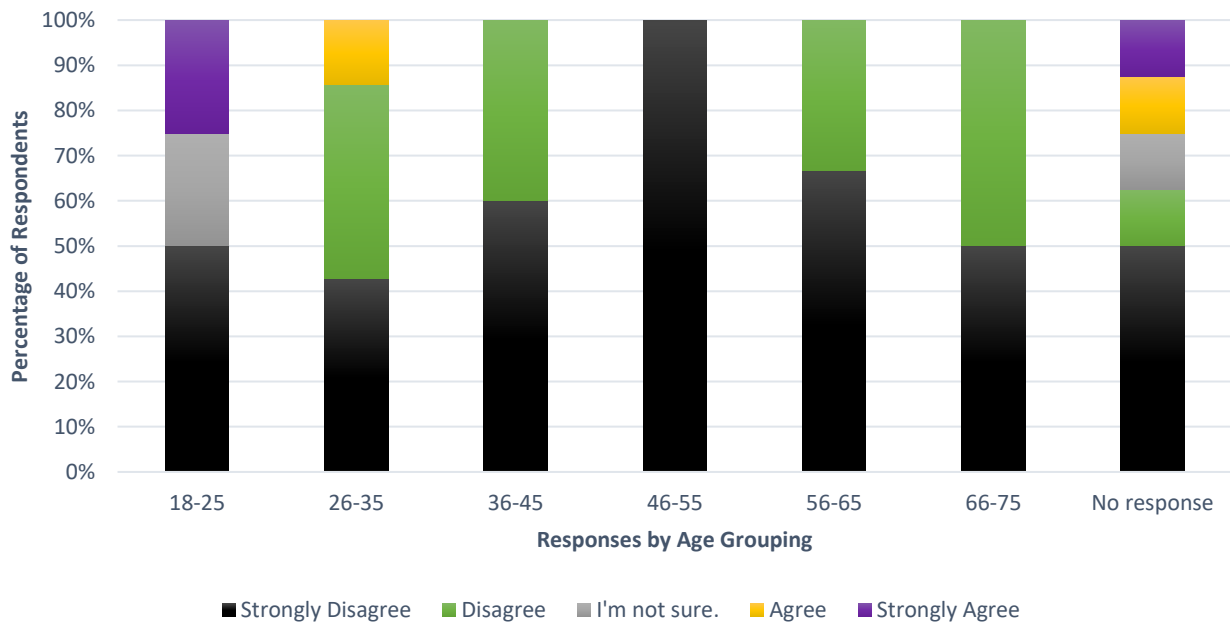
"I was allowed to ask questions about masturbation." (Q17, <18)



Gender: Over 80% of men and about 90% of women responded that they were not allowed to ask questions about masturbation.

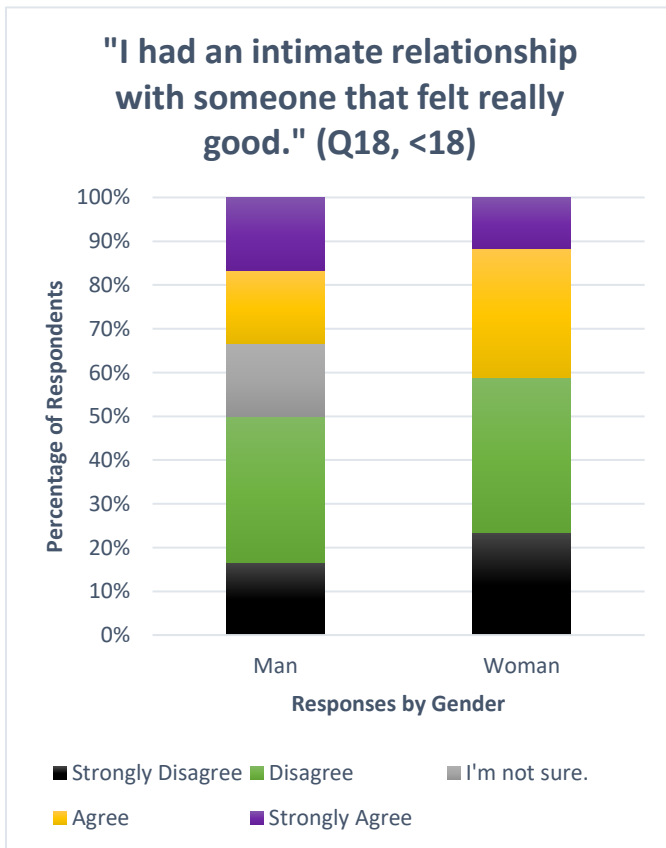
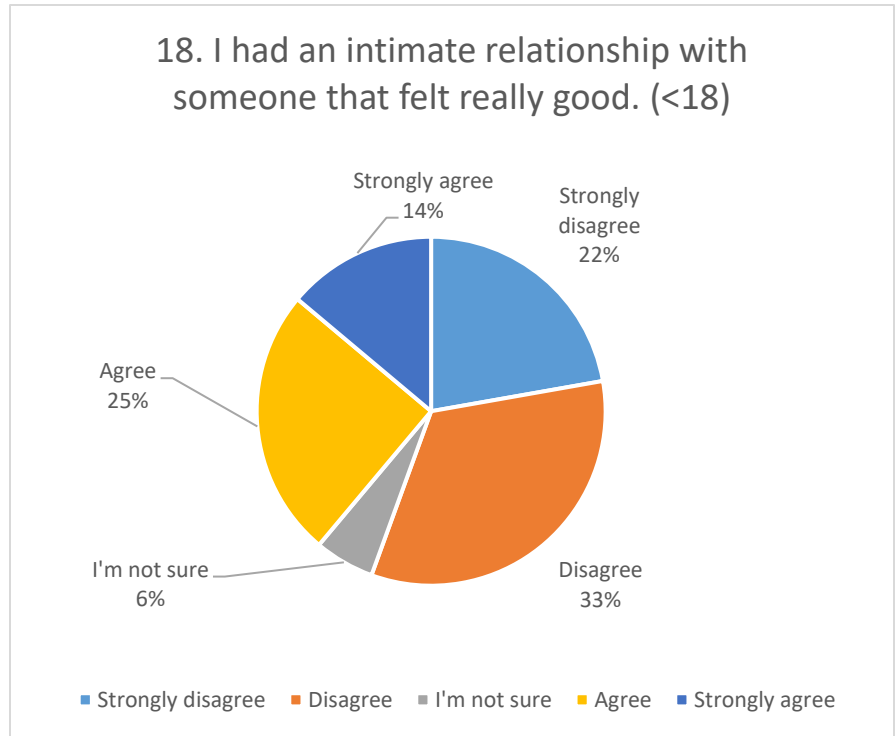
Age: Respondents in all age categories from 36-75 unanimously reported being unable to ask questions about masturbation in adolescence. About 25% of respondents age 18-25 and 15% of respondents age 26-35 reported being allowed to ask questions about masturbation during adolescence.

"I was allowed to ask questions about masturbation." (Q17, <18)



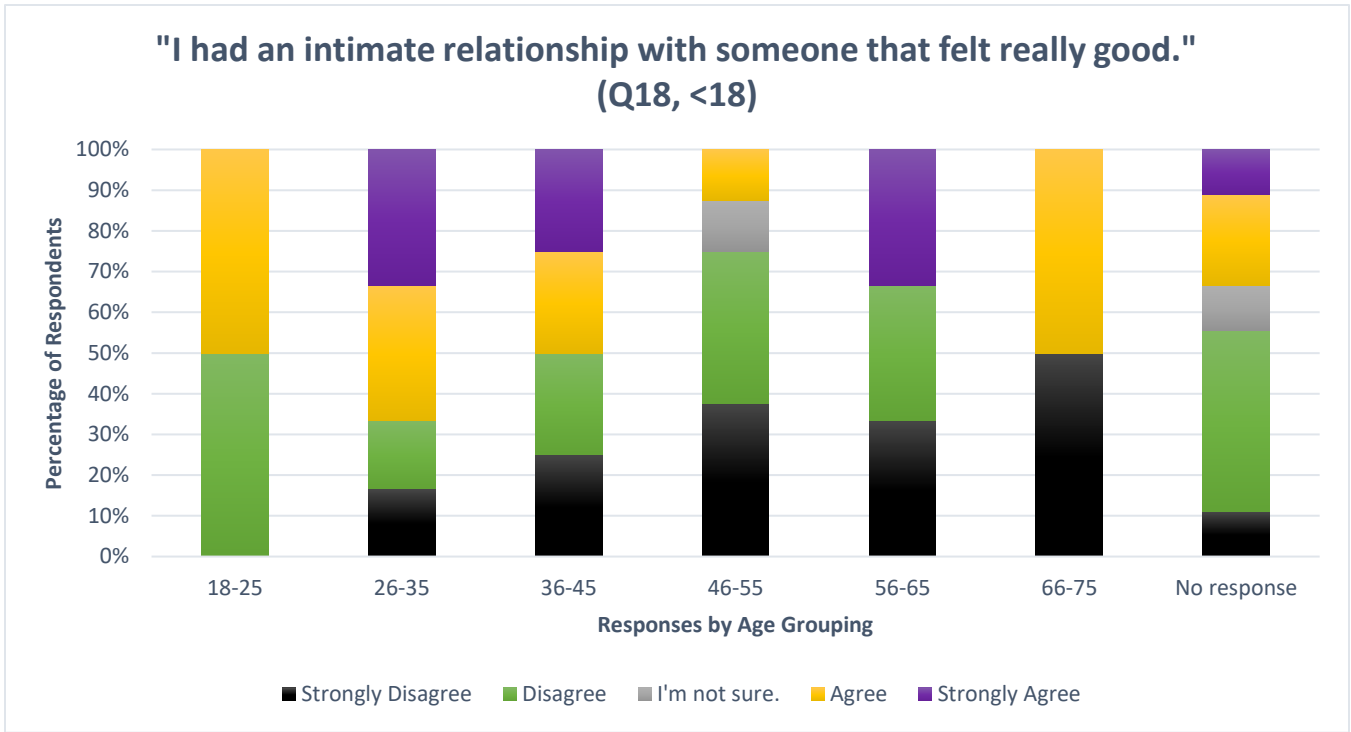
18. I had an intimate relationship with someone that felt really good.

Out of 36 respondents, 12 respondents (33%) strongly disagreed and 8 respondents (22%) disagreed that as an adolescent they had a really positive intimate relationship. 9 respondents (25%) agreed and 5 respondents (14%) strongly agreed as an adolescent they had a really positive intimate relationship. 2 respondents (6%) were unsure. 5 respondents (12% of all respondents) did not respond.



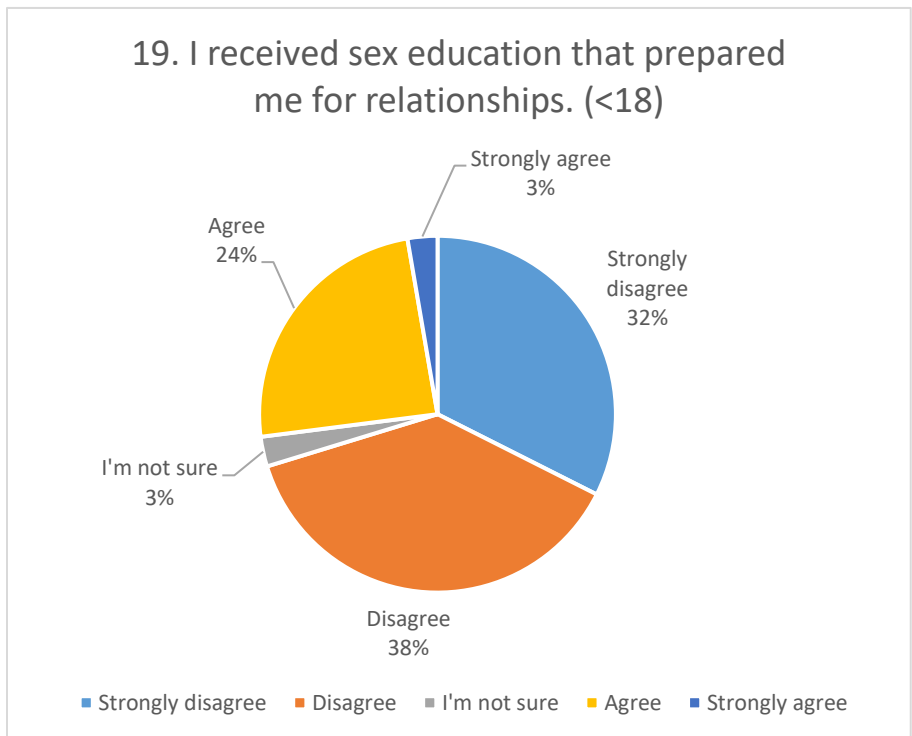
Gender: While the experiences of men and women were similar in terms of having a good intimate relationship, more women responded “strongly disagree” and fewer women responded with “strongly agree”, suggesting that women struggled more to find affirming relationships in adolescence. Only about 40% of women and 34% of men indicated they had an intimate relationship with someone in adolescence that felt “really good”.

Age: About 2/3rd of respondents aged 26-35 felt they had a really good intimate relationship in adolescence. Half of respondents in age groups 18-25, 36-45, and 66-76 felt they had experienced a really good intimate relationship in adolescence. Only about 13% of respondents who were 46-55 had experienced a really good intimate relationship in adolescence. Those aged 66-75 indicated the highest proportion of respondents (50%) who “strongly disagreed” that they had a really good intimate relationship in adolescence.

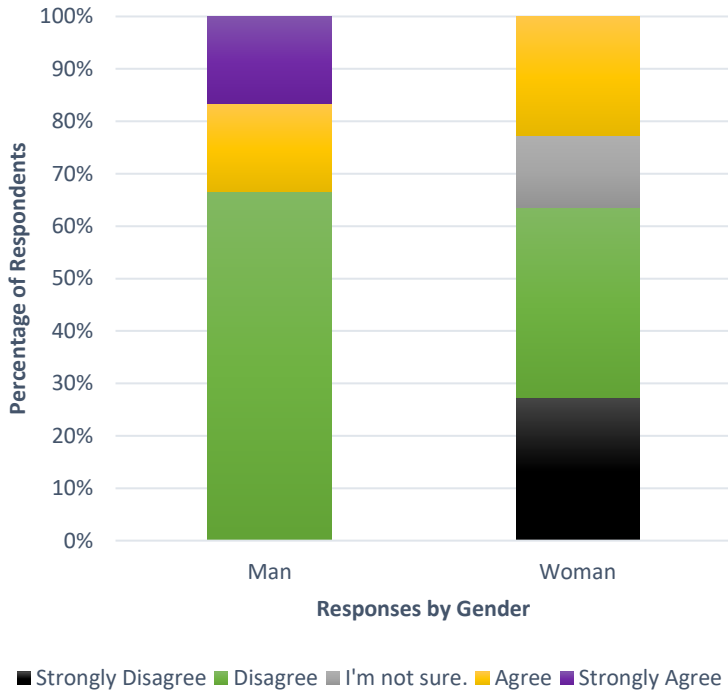


19. I received sex education that prepared me for relationships.

Out of 37 respondents, 14 respondents (38%) disagreed and 12 respondents (22%) strongly disagreed that as an adolescent they had access to sex education that prepared them for relationships. 9 respondents (24%) agreed and 1 respondent (3%) strongly agreed as an adolescent they had access to sex education that prepared them for relationships. 2 respondents (6%) were unsure. 4 respondents (10% of all respondents) did not respond.



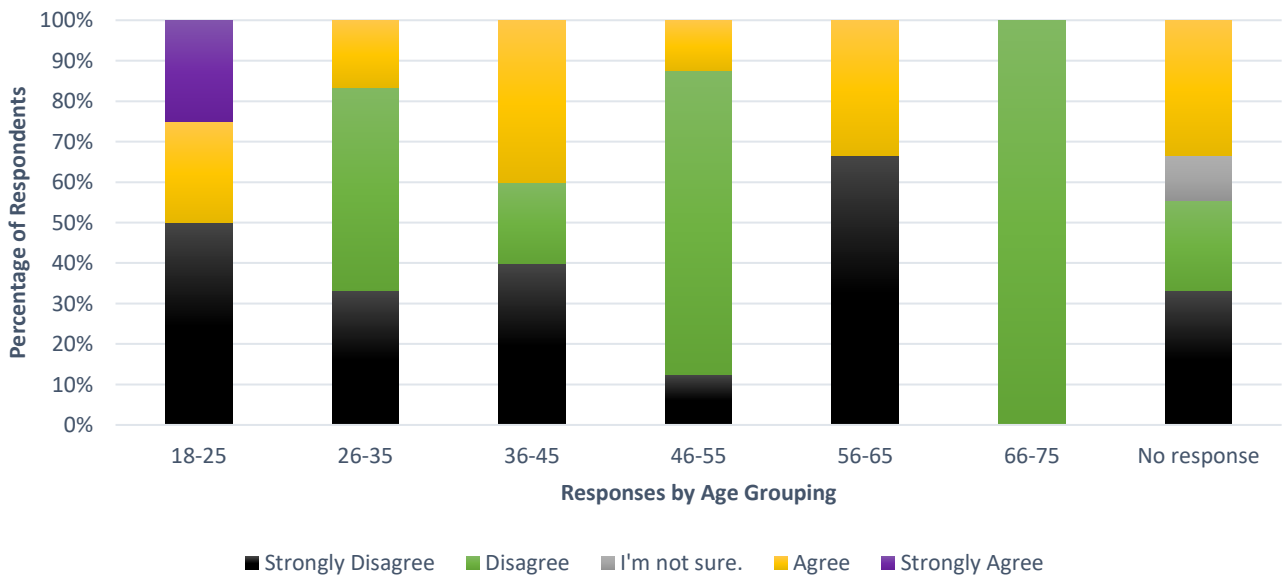
"I received sex education that prepared me for relationships." (Q19, <18)



Gender: Only about 23% of women and 33% of men indicated they received adequate sex education to engage in relationships during adolescence. Only men responded to this question with “strongly agree” (less than 20%).

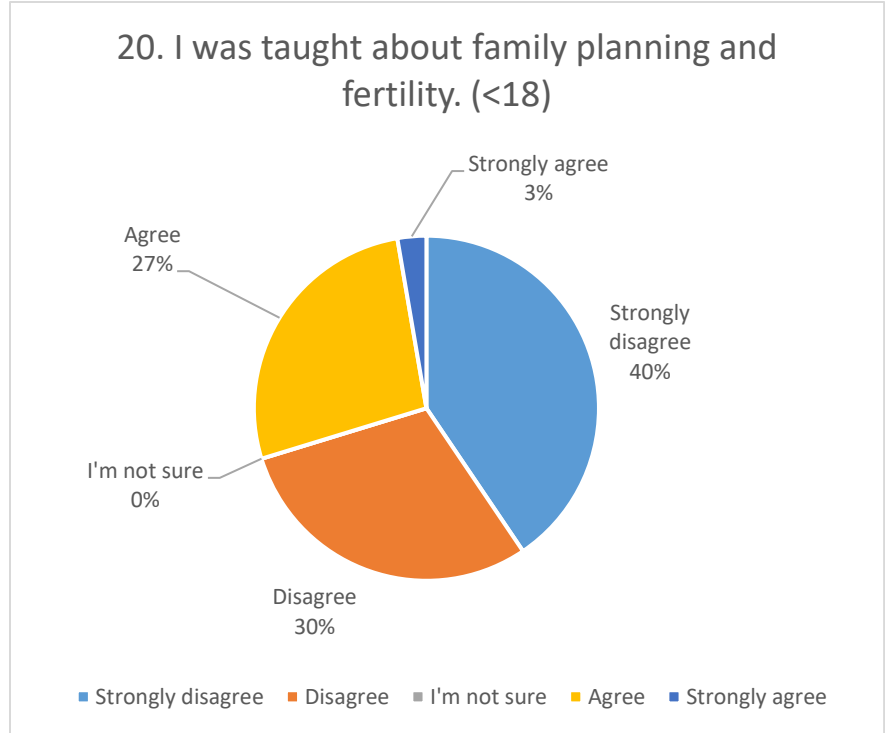
Age: Among age groups, proportions of respondents who received sex education that prepared them for relationships varied widely. At best, only half of respondents ages 18-25 and 36-45 reported receiving sex education that prepared them for relationships in adolescence. Other age groups all indicated at least 80% of respondents did not receive adequate sex education to prepare them for relationships during adolescence. Only those in the 18-25 age range responded with “strongly agree” to this question.

"I received sex education that prepared me for relationships." (Q19, <18)

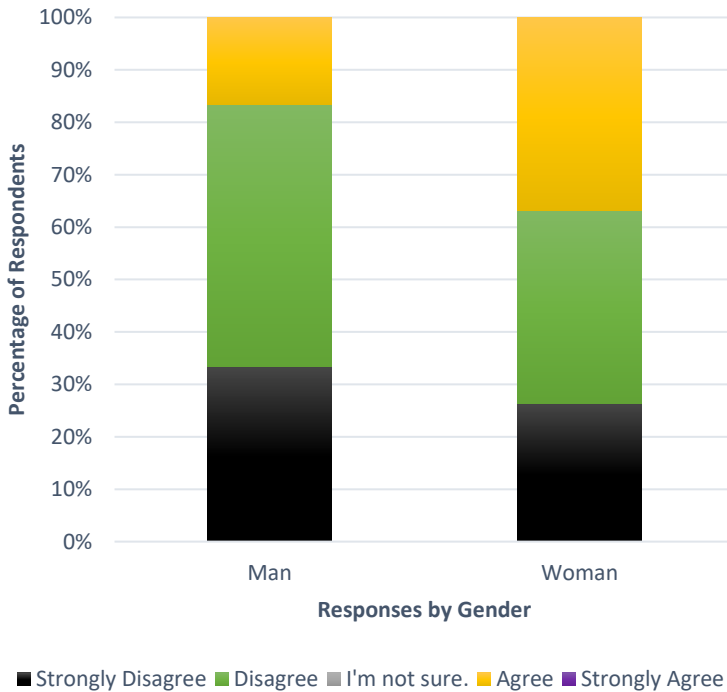


20. I was taught about family planning and fertility.

Out of 37 respondents, 15 respondents (40%) strongly disagreed and 11 respondents (30%) disagreed that as an adolescent were taught about family planning and fertility. 10 respondents (27%) agreed and 1 respondent (3%) strongly agreed as an adolescent were taught about family planning and fertility. 4 respondents (10% of all respondents) did not respond.

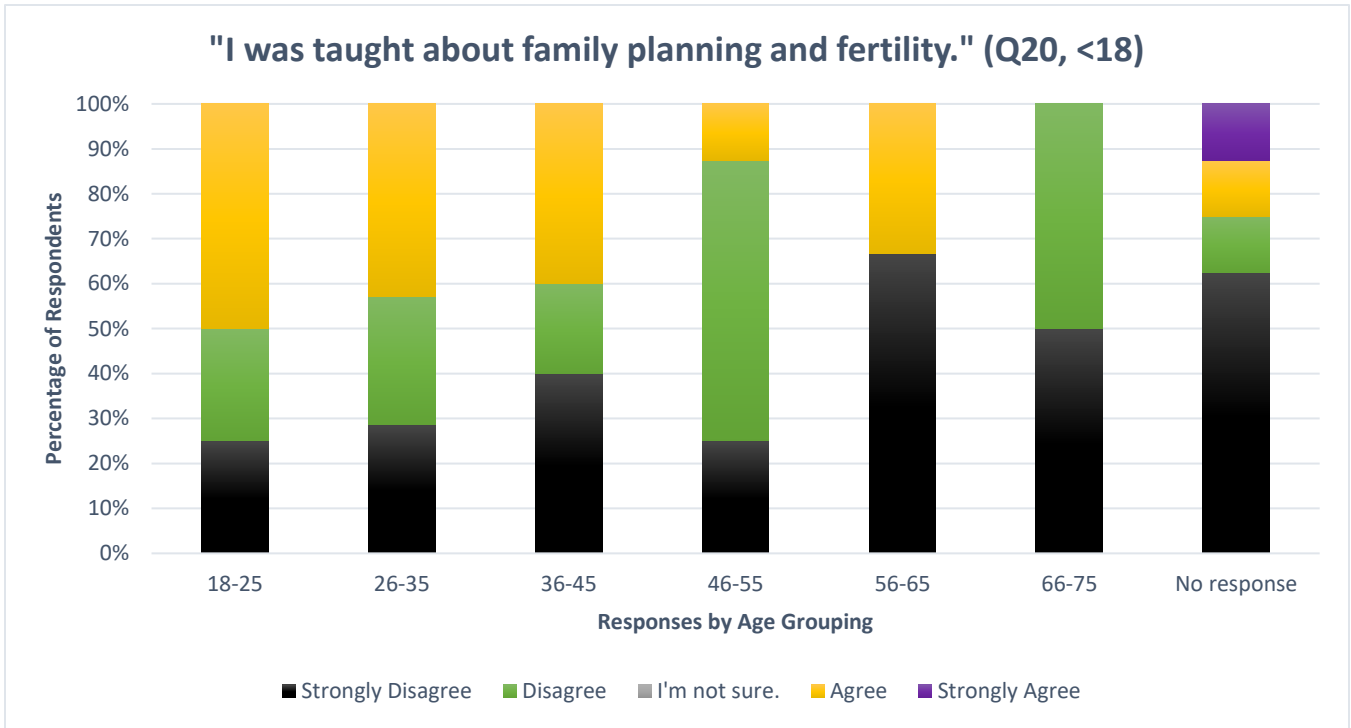


"I was taught about family planning and fertility." (Q20, <18)



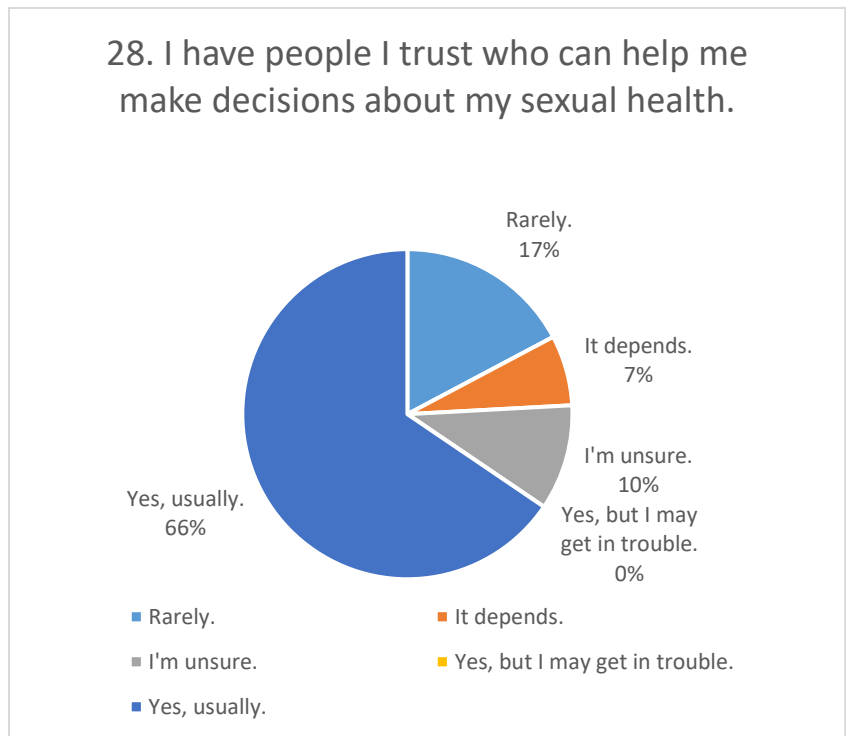
Gender: Over 80% of men and over 60% of women reported not being taught about family planning or fertility during adolescence. 1/3rd of men and 1/4th of women “strongly disagreed” to this question.

Age: The proportions of respondents in each group that indicated they were taught about family planning and fertility during adolescence decreased with age, suggesting sociomedical (including the weakening of the eugenics movement) shifts may have helped parents better understand that disabled people can have families and should be supported in doing so if they so desire. At best, 50% of those in the 18-25 year range indicated they were taught about family planning and fertility in adolescence. All of those aged 66-75 indicated they were not taught about family planning and fertility in adolescence.

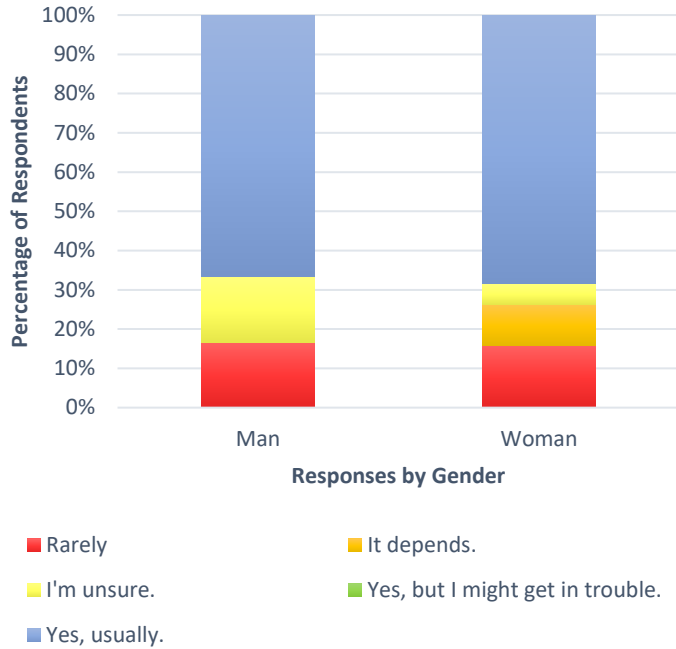


28. I have people I trust who can help me make decisions about my sexual health.

Out of 29 respondents, 19 respondents (66%) indicated that they have someone they trust who can help them make decisions about their sexual health. 2 respondents (7%) only sometimes ("It depends.") have someone they trust who can help them make decisions about their sexual health while 5 respondent (17%) rarely have someone they trust who can help them make decisions about their sexual health. No respondents indicated they worried about retaliation for having someone they trust who can help them make decisions about their sexual health while 3 (10%) were unsure whether they have someone they trust who can help them make decisions about their sexual health. 12 (29% of all respondents) did not respond.



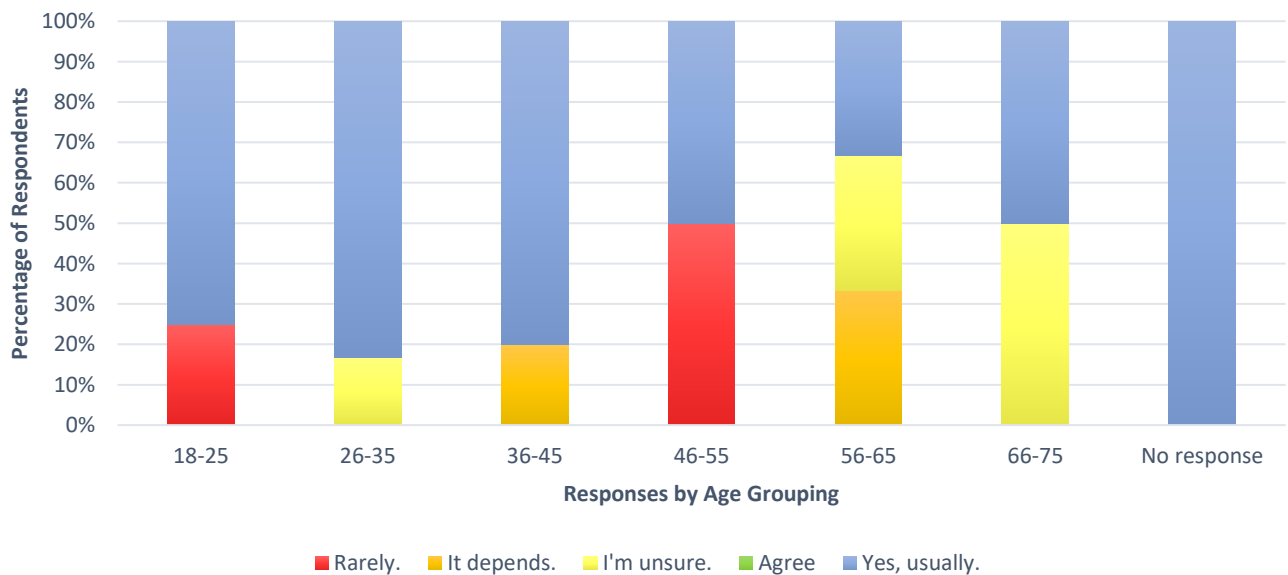
"I have people I trust who can help me make decisions about my sexual health." (Q28)



Gender: While about 15% of both men and women reported rarely having people they can trust to help them make decisions about their sexual health, almost 70% of both reported that they do.

Age: The respondents who indicated they rarely have people they can trust to help make decisions about their sexual health, all were distributed in 2 age groups: 18-25 (15%) and 46-55 (50%). Those aged 46-55 had the highest proportions of respondents who were unsure if they had people who could help and stated that the help they could get from people could be circumstantial. About 66% - 85% of respondents ages 18-45 indicated they usually have people they can trust to assist in this kind of decision making. This drops significantly among those aged 46-55 (50%), 56-65 (33%), and 66-75 (50%).

"I have people I trust who can help me make decisions about my sexual health." (Q28)



Area 3 Conclusions

People with disabilities, especially those in rural areas, experience a unique vulnerability when it comes to medical care and service provision. Those requiring frequent contact with doctors and service providers in rural areas may have only a single option for care, or only a single person from whom to receive resources. This can lead to an even larger power imbalance between medical/service providers and people with disabilities. This creates great difficulty for people with disabilities in setting boundaries or communicating discomfort with providers out of fear they will no longer be seen or supported by any given agency/provider.

1/3rd of respondents indicated that they would not usually feel able to decline services and communicate discomfort with services. In fact, 40% of men reported that they would fear retaliation if they attempted to communicate discomfort with the services they are receiving, and 23-33% of respondents aged 46-65 reported they rarely feel able to communicate discomfort with services. Additionally, over half of the respondents (57%) reported they have experienced being ignored or spoken over by a service provider.

Together, these responses indicate that people with disabilities often have to choose which parts of themselves they need to keep safe and cared for over others. For example, let's consider the experience of a person with spina bifida, who uses a wheelchair for mobility who just moved to a rural town. They are seeking to establish care with their new specialist and realize this doctor is the only spina bifida specialist within a 60 mile radius. When this person sees their new doctor, the doctor speaks over them without even inviting the person to share their own expertise around their body. Now the client who is seeking services must consider several choices and potential outcomes and consequences:

1. **Consideration 1:** If they confront the doctor or report them, will they risk the doctor refusing to work with them, leading them to have to seek out another specialist who may be too far away or too expensive to access? Will they be able to afford the cost of accessible transit to another doctor over an hour away? Or will the doctor be willing to listen and learn?
2. **Consideration 2:** If they confront the doctor or report them, will the doctor shift to engaging in more affirming, collaborative way, or might the doctor report them as "incompetent" to social services, possibly leading forced institutionalization and other legal consequences?
3. **Consideration 3:** If they stay silent and try to emotionally cope with the treatment because they cannot travel so far to find a new specialist, what emotional harm will this case? How might their medical care be limited, inadequate, or harmful if they must continue working with this medical professional who does not understand or respect them?

It is traumatizing for anyone to be forced to break themselves into pieces and weigh which parts need the most support while accepting harm or neglect for others. And yet, this is a daily experience for people with disabilities. This dynamic is highlighted well by the 27% of respondents who experienced the withholding of services unless they complied with a request, even if they were uncomfortable with the request. 50% of those in the 56-65 age group reported having this experience.

Additionally, when people with disabilities report being harmed by service providers, they may be documented as “difficult to work with,” which could limit the person’s access to services. Often when a care worker is reported, they will simply be rotated to another client without any accountability or skill-building expectations; this can lead to the perpetuation of harm against other future clients. Despite the census categorizations for “towns” vs. “cities”, Indiana’s service and medical infrastructure is heavily concentrated in Indianapolis and Bloomington. Although Indiana University Health has many locations, most do not include the kinds of specialists people with disabilities may require, or may not provide the quality of care needed. This may result in people with disabilities having to accept substandard care, inadequate care, or spending additional money to travel. For example, in Indianapolis, there is a cystic fibrosis clinic. Even though the Lafayette area has an IU clinic (IU Arnett), they are not equipped to assist someone with cystic fibrosis for more than a few hours, during which time they primarily make arrangements for the patient to be transported 60 miles to the Indianapolis CF clinic.

41% of respondents indicated they would usually not feel able to report an abusive service provider to another service provider, and 10% (all women) were concerned that doing so would result in retaliation. 31% of respondents indicated they would not usually feel able to report abuse from a non-service provider to a service provider.

Area 3 Results: Access to Affirming Service Provision

All 6 questions covered in this section refer to adulthood experiences.

Declining Services Results Summary

While most respondents (64%) indicated they usually felt able to decline services from a service provider, over 1/3rd reported that their ability to set this boundary with a service provider would be inconsistent and conditional (Q25). 40% of men and 25% of women reported their ability to set this boundary with a service provider would be conditional. At least 55% of respondents in each age group affirmed they would usually be able to decline services.

Communicating Discomfort Results Summary

Like the question about declining services, 63% of respondents reported they would feel able to tell a service provider if they are uncomfortable with receiving certain services (Q24). However, there was much more variation and concern regarding communicating discomfort to a service provider. While 60% of men reported usually being able to convey discomfort to a service provider (same as the question about declining services), the other 40% responded that they feared retaliation for communicating discomfort with services. 70% of women (as opposed to 75% in the question about declining services) reported they would usually feel able to communicate discomfort to a service provider. 5% of women indicated they rarely can communicate this to service providers and 4% indicated they would fear retaliation. At least 1/3rd of respondents in each age group indicated they would usually feel able to communicate discomfort with service provision, and 100% of those 18-25 responded the same. However, 23-33% of those aged 46-65 reported they rarely feel able to communicate discomfort to a service provider. All respondents who feared retaliation were aged 26-35 (16%) and 46-55 (7%).

Being Ignored Results Summary

A common experience for people with disabilities is infantilization, or treatment of adults with disabilities as if they are children. Infantilization may manifest as beliefs such as believing adults with disabilities are unable to advocate or communicate for themselves, that they should not be believed, or that they are universally “incompetent.” 57% of respondents reported that they had at least one experience of a service provider speaking about their body and health to others as if they were not present, or not able to provide information themselves. Half of the men and half the of women who responded to this question had this experience. Age group responses varied, with as much as 75% of those aged 26-35 experiencing this, down to 25% of those aged 18-25 experiencing this.

Abuse from a Service Provider Results Summary

59% of respondents indicated they usually felt able to inform a service provider of another service provider who is abusing them. 34% indicated that reporting an abusive service provider would be conditional, 10% feared retaliation, and 7% rarely felt able to report. 65% of women and 60% of men indicated they usually would feel able to report, while all “rarely” and “fear of retaliation” responses came from women. At least 50% of respondents in each age group responded they usually felt they could self-advocate in this way. All respondents who rarely felt able to report an abusive service provider were aged 36-55, and all respondents who felt concerned about retaliation for reporting were in age groups 18-35 and 56-65.

Abuse from a Non-Service Provider Results Summary

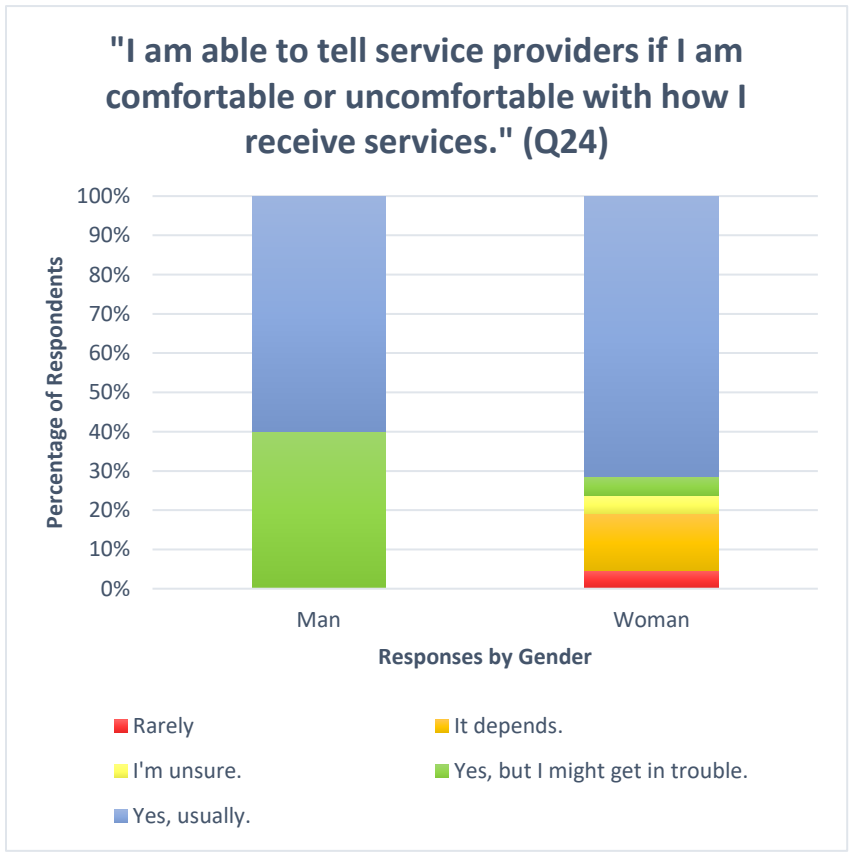
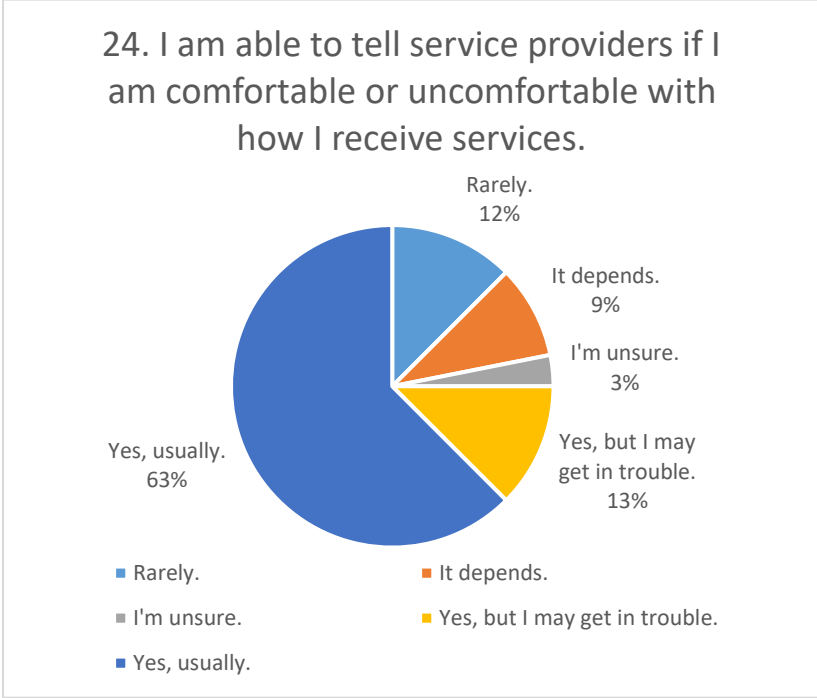
69% of respondents indicated they usually felt able to inform a service provider about someone else abusing them. While 27% of respondents indicated this would be conditional, and 4% indicated they rarely felt able to inform a service provider about abuse, no respondents reported fearing retaliation as they did in the question about reporting an abusive service provider. 80% of men and 65% of women reported they usually felt able to engage in this kind of self-advocacy. At least 50% of respondents in each age group reported they usually felt able to report abuse to a service provider. All those who responded they rarely felt able to report abuse were aged 46-55, and the age group with the largest proportion of responses indicating their ability to report would be conditional were aged 36-45 (50%).

Coercive Services Results Summary

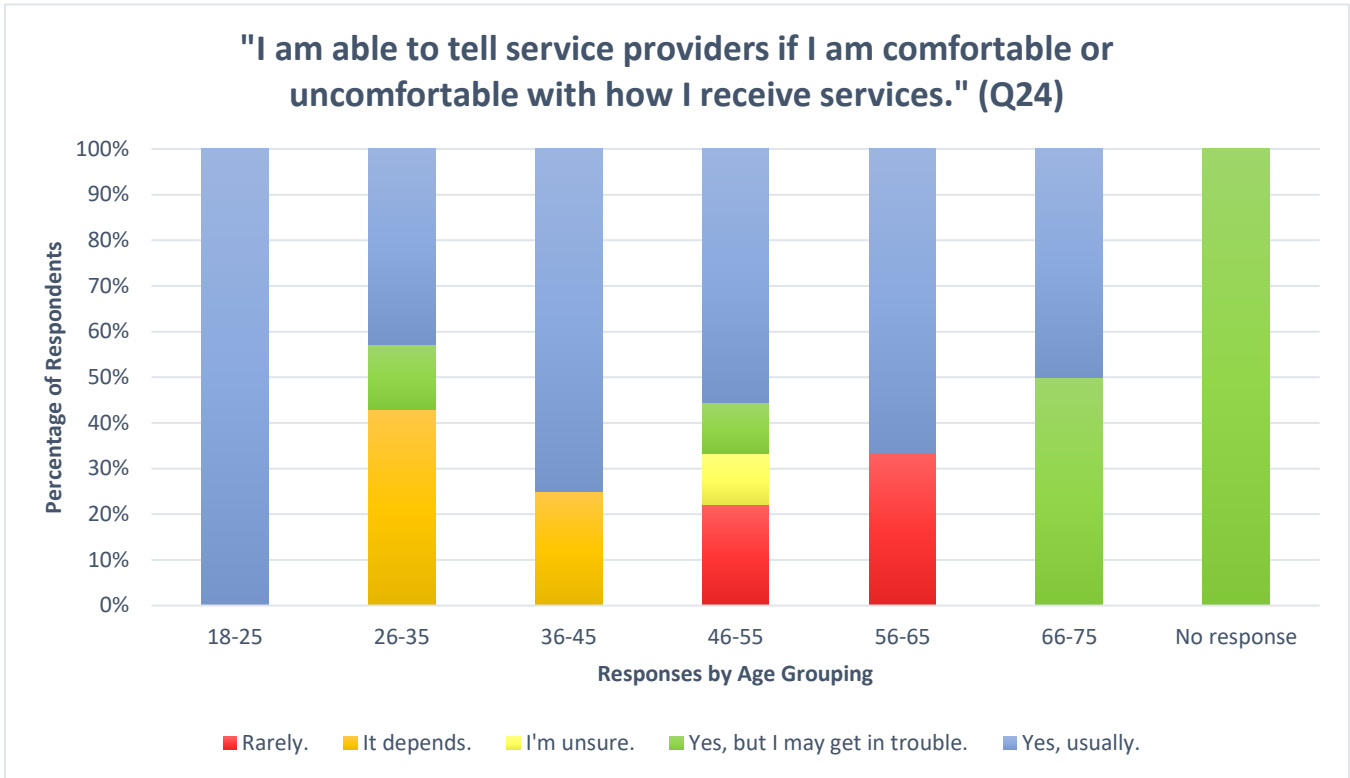
27% of respondents reported having the experience of services being withheld until they complied with an expectation, even if compliance made them uncomfortable. 1/3rd of men and 1/5th of women reported this experience. 22-29% of those in ages 18-55 reported experiencing coercive service provision, while 50% of those aged 56-65 reported the same.

24. I am able to tell service providers if I am comfortable or uncomfortable with how I receive services.

Out of 32 respondents, 20 respondents (63%) indicated that they usually feel able to tell service providers when they are uncomfortable. 3 respondents (9%) only sometimes (“It depends.”) feel able to tell service providers when they are uncomfortable while 4 respondents (12%) rarely feel able to tell service providers when they are uncomfortable. 4 respondents (13%) indicated they worried about retaliation if they were to tell service providers when they are uncomfortable while 1 (3%) was unsure whether they feel able to tell service providers when they are uncomfortable. 9 respondents (22% of all respondents) did not respond.



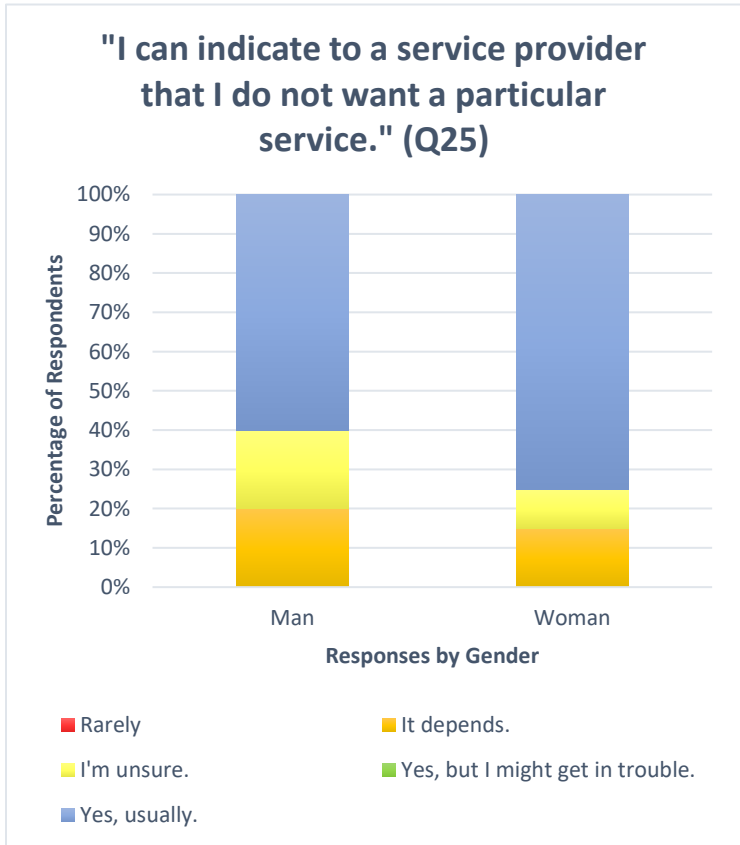
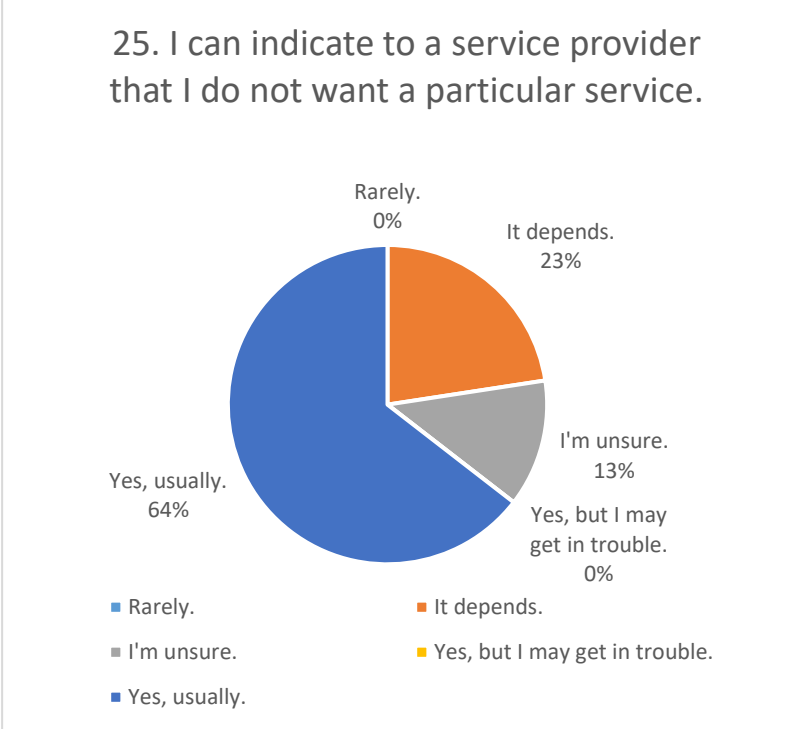
Gender: About 70% of women and 60% of men indicated they are usually able to tell service providers how comfortable they are with how they received services. The other 40% of men responded that they do think they could tell a service provider if they were uncomfortable, but would be worried about retaliation of some kind (such as loss of services). Among women, the other 30% responded with all 4 other remaining response options, but most responded that they felt their ability to speak about their experiences with services they receive depend on circumstances. About 5% of women reported rarely feeling able to convey their level of comfort to service providers.



Age: Respondents ability to self advocate during service provision mostly decreases with age. Those in the 18-25 range unanimously responded that they do usually feel able to inform service providers of their comfort level. Over 40% of those aged 26-35 and about 25% of those aged 36-45 indicated they felt their ability to tell services providers about their level of comfort was circumstantial, suggesting that many people with disabilities may have to advocate differently with different agencies, types of services, or individual providers. 1/3rd of respondents in the 56-65 group and over 20% of those in the 46-55 reported rarely being able to tell service providers about their comfort level. Given the age of the individuals reporting they “rarely” can self-advocate to providers, it’s likely that they have experienced extensive trauma, unwanted touching, and other forms of boundary violation in service provision, making it more difficult for them to be willing to risk self-advocacy in the future. Additionally, half of the respondents aged 66-75 and some in the 26-35 and 46-55 age ranges reported a fear of retaliation for attempting to self-advocate in service provision settings.

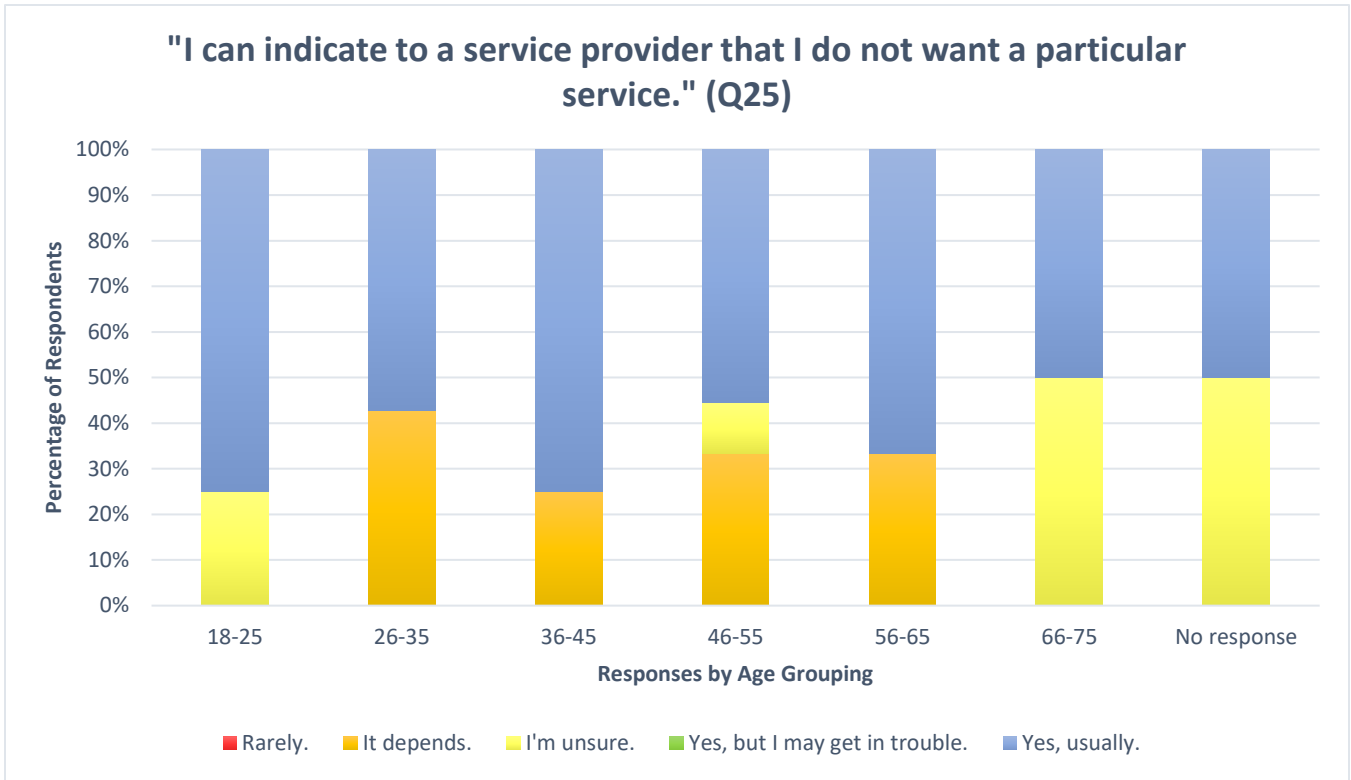
25. I can indicate to a service provider that I do not want a particular service.

Out of 31 respondents, 20 respondents (64%) indicated that they usually feel able to tell a service provider that they do not want a particular service. 7 respondent (23%) only sometimes ("It depends.") feel able to tell a service provider that they do not want a particular service. No respondents rarely feel able to tell a service provider that they do not want a particular service and no respondents indicated they worried about retaliation for telling a service provider that they do not want a particular service. 4 (13%) were unsure whether they feel able to tell a service provider that they do not want a particular service. 10 respondents (24% of all respondents) did not respond.



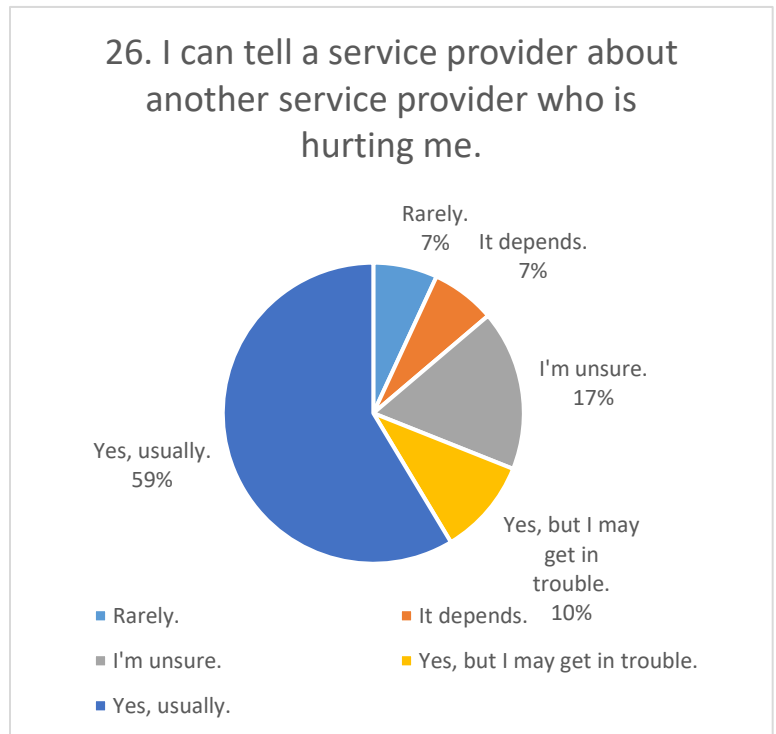
Gender: 75% of women and 60% of men reported usually being able to decline services. Considerable proportions of respondents in both groups indicated uncertainty about their ability to decline services and at least 15% indicated that their ability to decline services would be circumstantial.

Age: At least 50% of respondents in all age groups reported that they usually felt they could decline services. Over 40% of respondents aged 26-35, over 30% of respondents aged 46-65, and 25% of respondents aged 36-45 indicated that their ability to decline services would depend on the circumstances. Half of the respondents in the 66-75 age range as well as about a third of those in the 18-25 age range indicated they were unsure whether they would be able to decline services.

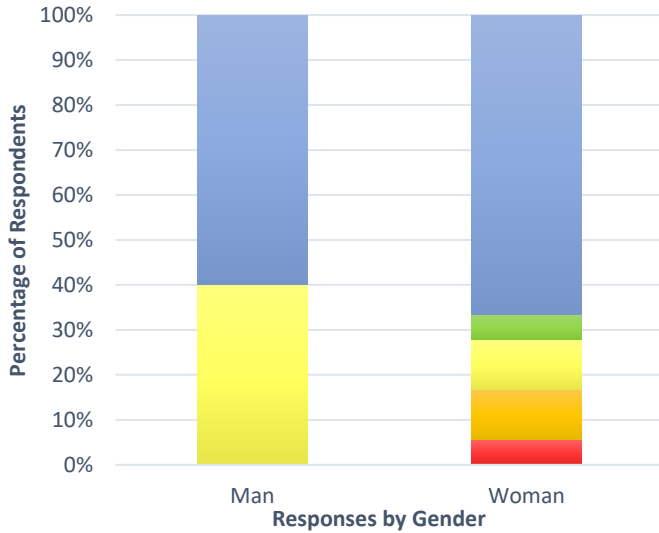


26. I can tell a service provider about another service provider who is hurting me.

Out of 31 respondents, 17 respondents (59%) indicated that they usually feel able to tell a service provider that another service provider is hurting them. 2 respondents (7%) only sometimes ("It depends.") feel able to tell a service provider that another service provider is hurting them. 2 respondents (7%) rarely feel able to tell a service provider that another service provider is hurting them and 3 respondents (10%) indicated they worried about retaliation for telling a service provider that another service provider is hurting them. 5 (17%) were unsure whether they feel able to tell a service provider that another service provider is hurting them. 12 respondents (29% of all respondents) did not respond.



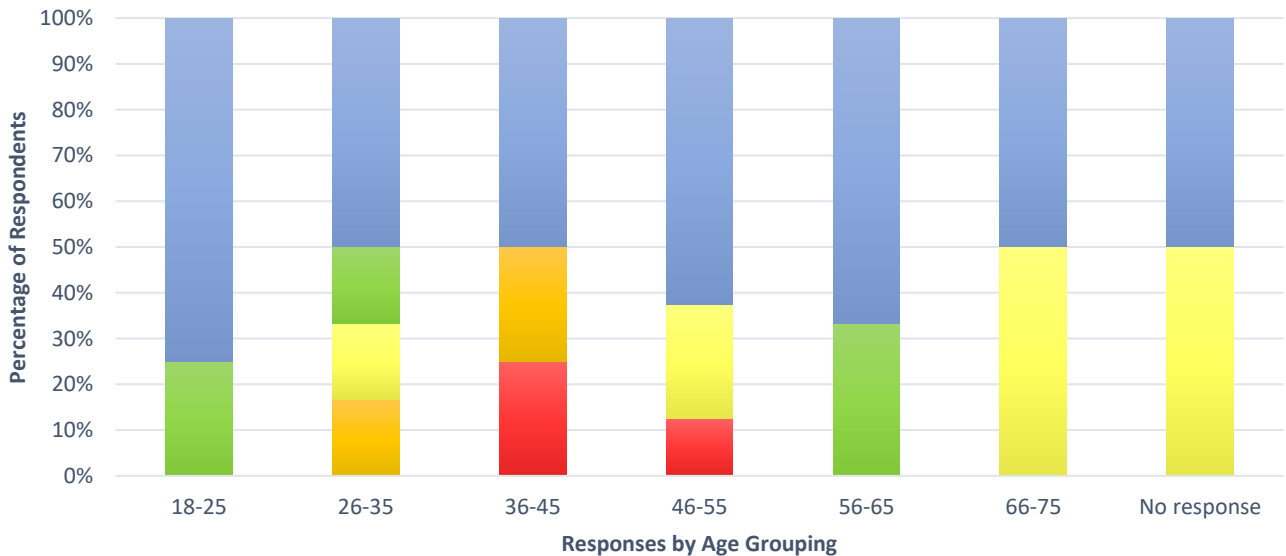
"I can tell a service provider about another service provider who is hurting me." (Q26)



Gender: About a third of men (60%) and women (66%) reported that usually they would feel able to report an abusive service provider. The other 40% of men indicated they would be unsure if they would be able to report an abusive service provider. It is notable that about 5% of women report they rarely feel able to report an abusive service provider.

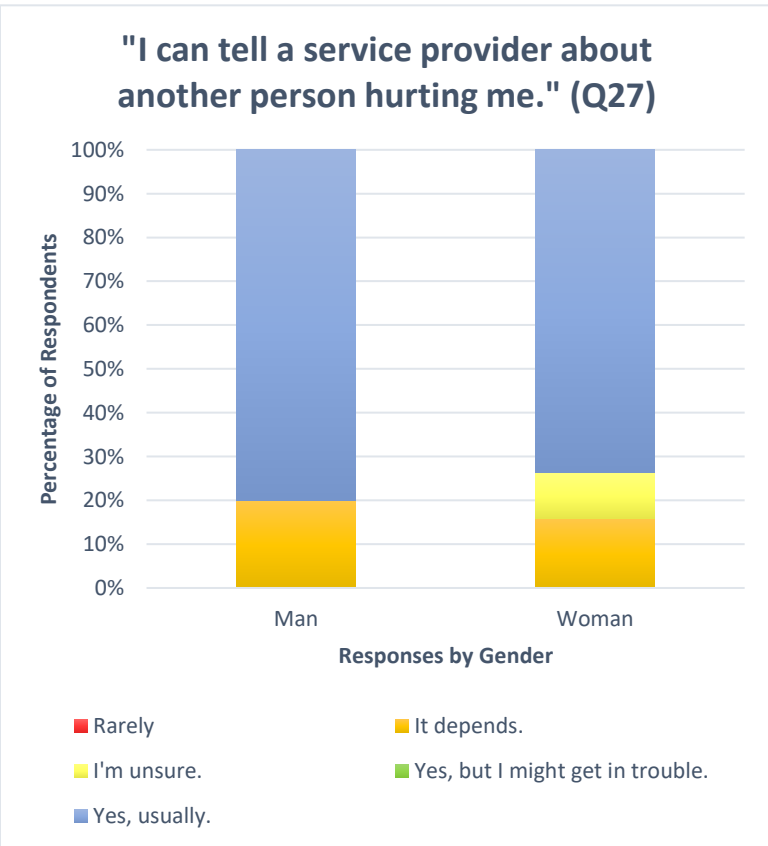
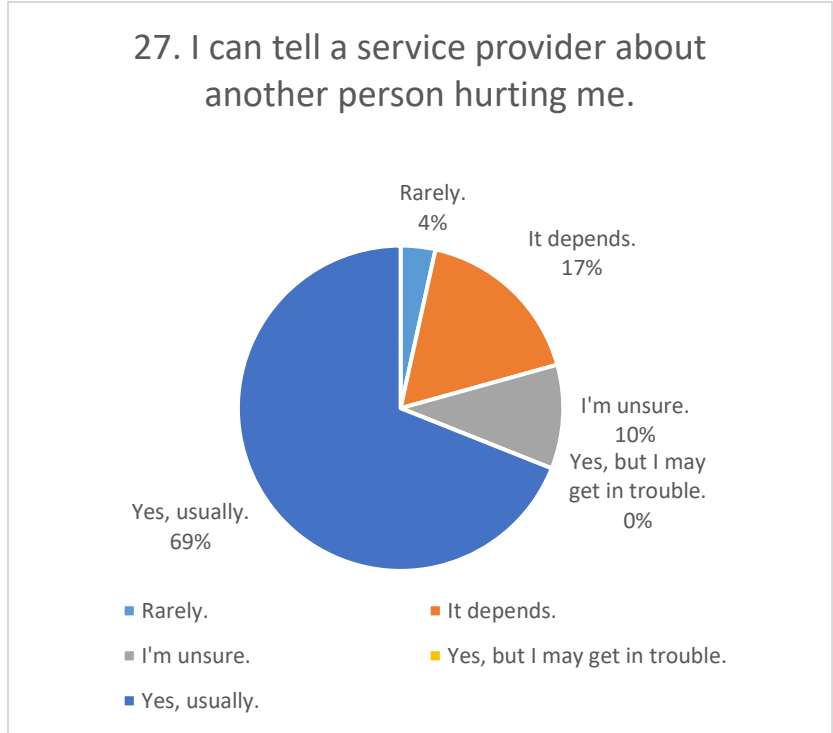
Age: At least 50% of respondents in all ages indicated they would usually feel able to report an abusive service provider. 1/3rd of those aged 56-65 and 1/4th of those aged 18-25, and under 10% of those aged 26-35 indicated they would be worried reporting an abusive service provider may result in some kind of retaliation. About 25% of those aged 36-45 and over 10% of those aged 46-55 indicated they would rarely feel able to report an abusive service provider. Additionally, 50% of those aged 66-75, 20% of those aged 46-55, and over 10% of those aged 26-35 all reported uncertainty about their ability to report an abusive service provider.

"I can tell a service provider about another service provider who is hurting me." (Q26)



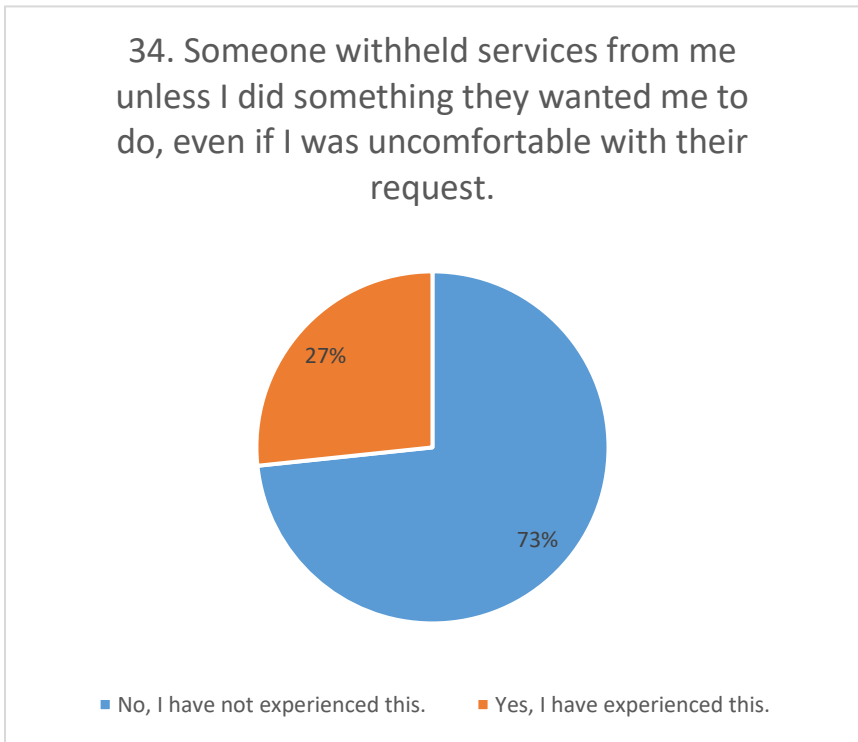
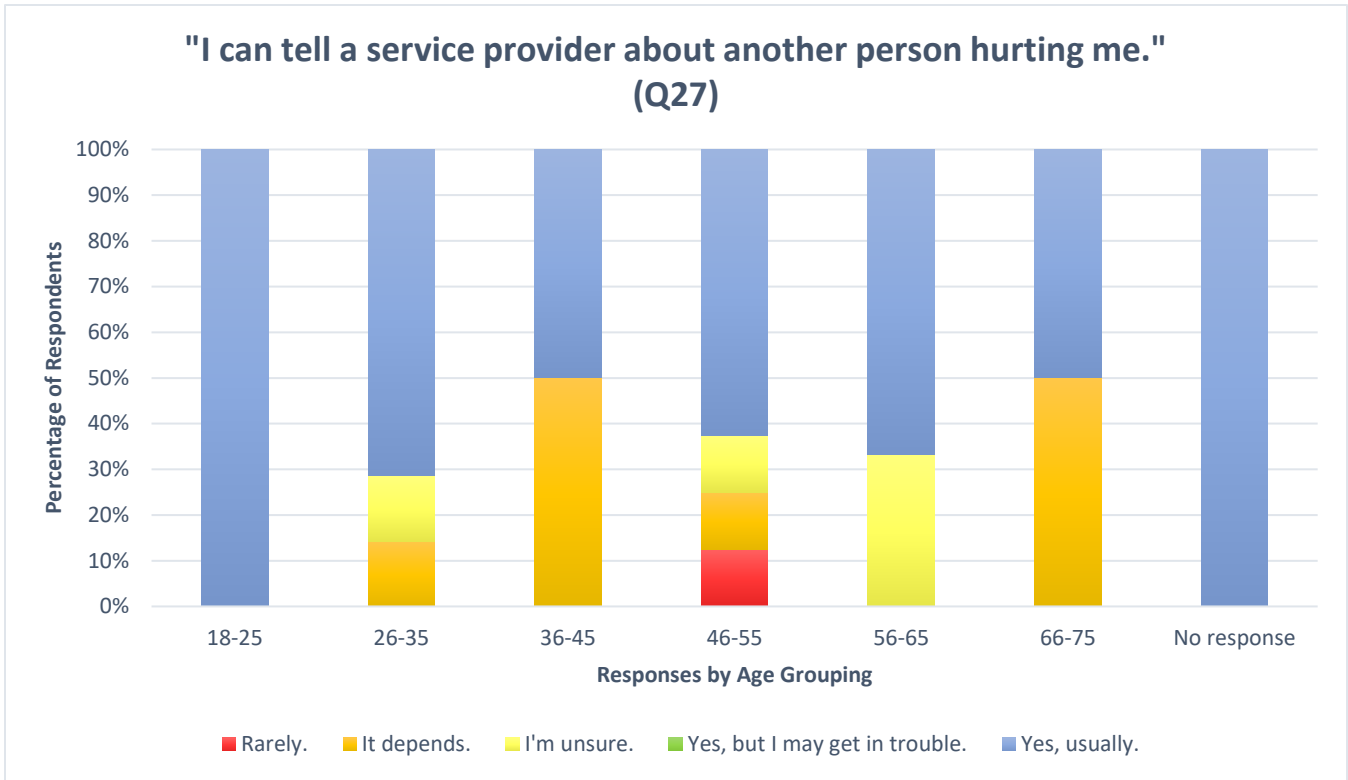
27. I can tell a service provider about another person hurting me.

Out of 29 respondents, 20 respondents (69%) indicated that they usually feel able to tell a service provider about someone else hurting them. 7 respondent (17%) only sometimes (“It depends.”) receives accurate information about to practice safer sex while 1 respondent (4%) rarely receive accurate information about how to practice safer sex. No respondents indicated they worried about retaliation for trying to receive accurate information about how to practice safer sex while 3 (10%) were unsure whether they receive accurate information about how to practice safer sex. 12 (29% of all respondents) did not respond.



Gender: About 66% of women and 80% of men reported usually feeling able to tell a service provider about abuse they are experiencing. 20% of men and about 15% of women indicate that reporting abuse would be circumstantial. Under 10% of women would be unsure whether they would be able to report abuse.

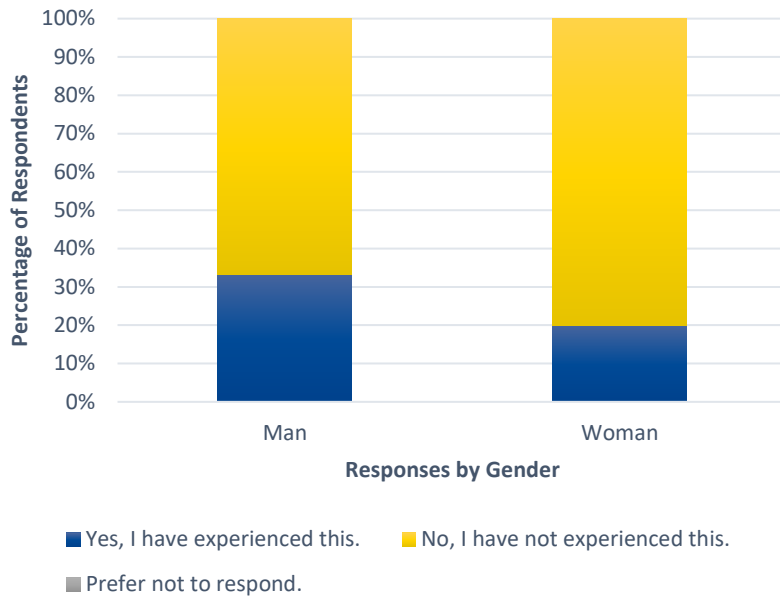
Age: Although all 18-25 year old respondents indicated they would usually feel able to report abuse, only about 70% of those aged 26-35, 2/3rd of those aged 46-65, and 50% of those aged 36-45 and 66-75 would feel able to report abuse. In the case of the 36-45 and 66-75 age ranges, the other 50% of responses stated that their ability to report would be circumstantial. Over 10% of those in the 46-55 age range indicated they would rarely feel able to report abuse.



34. Someone withheld services from me unless I did something they wanted me to do, even if I was uncomfortable with their request.

Among the 30 respondents, 8 (27%) experienced someone withholding services unless the respondent complied with a request. 22 (73%) had not experienced this and 11 respondents gave non-response answers.

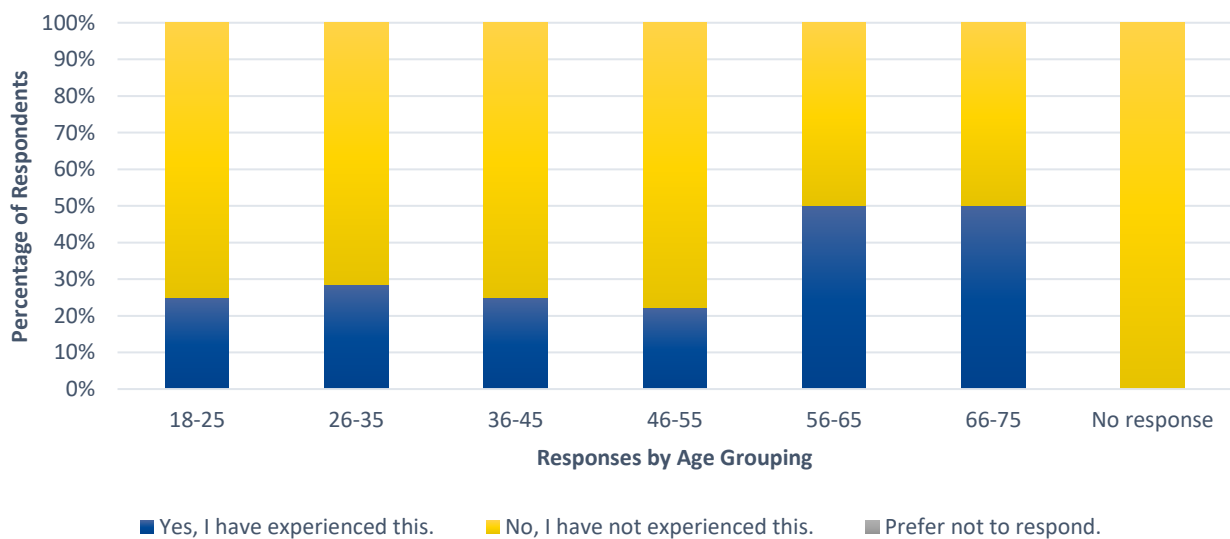
"Someone withheld services from me unless I did something they wanted me to do, even if I was uncomfortable with their request." (Q34)



Gender: About 32% of men and 20% of women reported experiencing coercive service provision.

Age: About 21-28% of respondents aged 18-55 reported having services withheld until they complied with a service provider expectation. 50% of those in the 56-75 age ranges experienced the same.

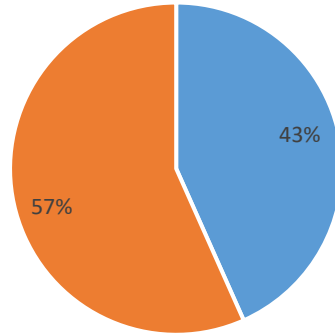
"Someone withheld services from me unless I did something they wanted me to do, even if I was uncomfortable with their request." (Q34)



35. A service provider spoke about my body and health to others as if I was not present or not able to provide information about my own body.

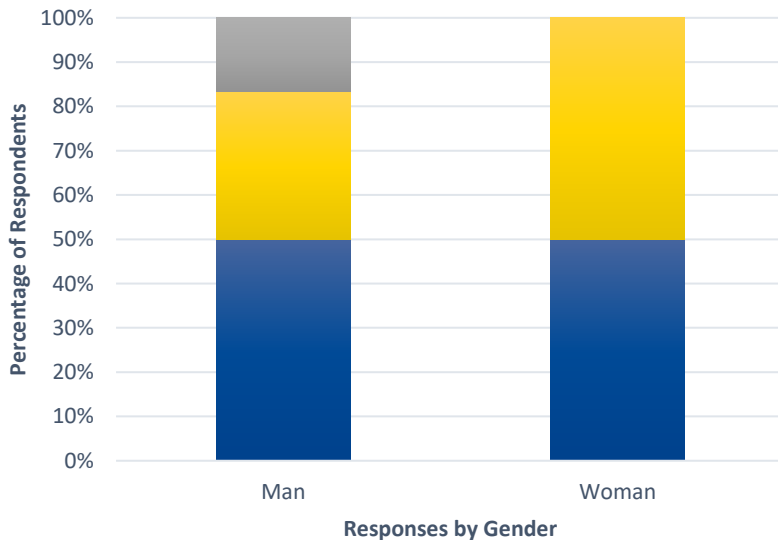
Among the 30 respondents, 17 (57%) experienced a service provider speaking about their body as if they were not present or able to provide information about themselves. 13 (43%) had not had this experience, and 11 respondents gave non-response answers.

35. A service provider spoke about my body and health to others as if I was not present or not able to provide information about my own body.



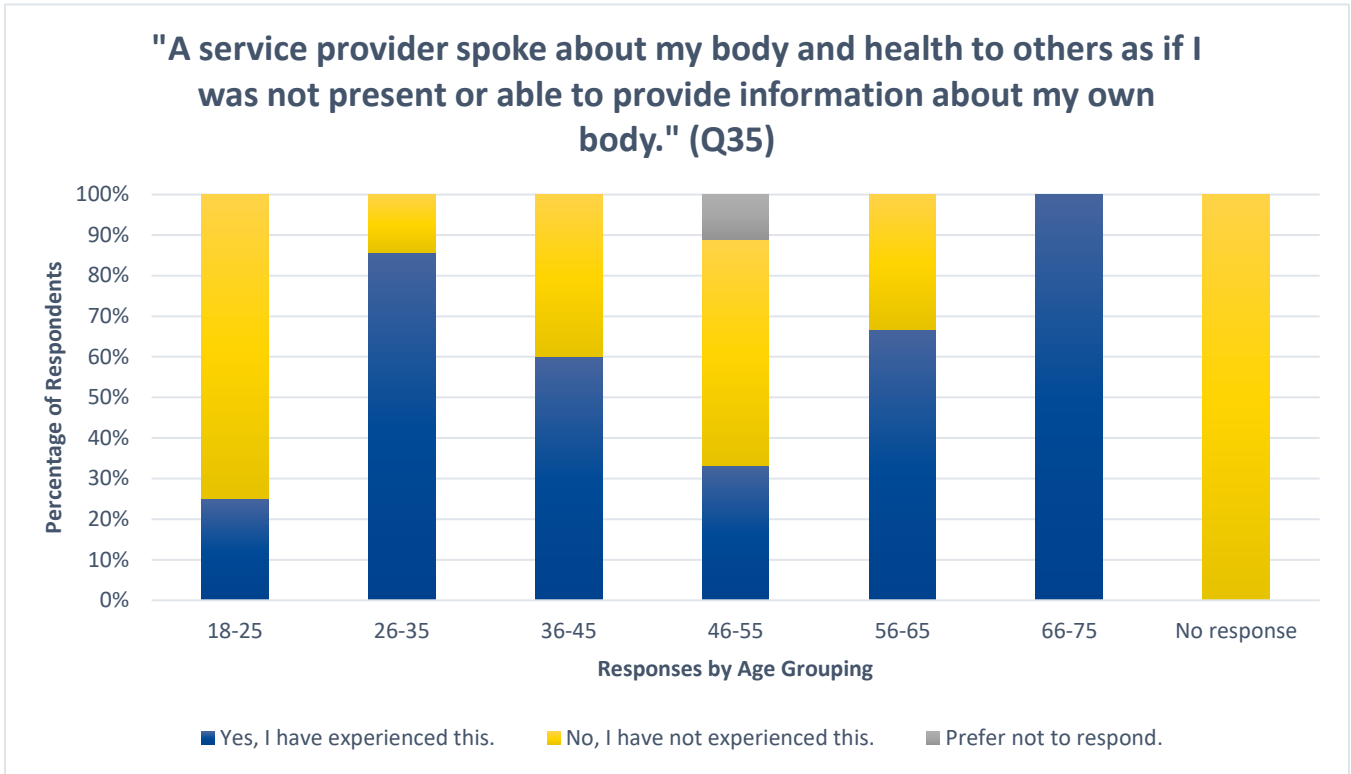
■ No, I have not experienced this. ■ Yes, I have experienced this.

"A service provider spoke about my body and health to others as if I was not present or able to provide information about my own body." (Q35)



■ Yes, I have experienced this. ■ No, I have not experienced this.
 ■ Prefer not to respond.

Gender: Half of both men and women experienced being spoken over/ignored by a service provider. While the other half of women indicated they had not experienced this, only about 33% of men indicated they had not experienced being ignored by a service provider.



Age: Experiences of being ignored by a service provider varied greatly across age groups. At least 60% of respondents in age group 26-45 and 56-75 had experienced being ignored by a service provider. 100% of the respondents aged 66-75 and about 85% of those aged 26-35 reported being ignored by a service provider. About 32% of those aged 46-55 and 25% of those aged 18-25 had experienced the same.

Area 4 Conclusions

Adolescence Experience Conclusions

Youth with disabilities are especially vulnerable to all forms of violence. This comes from a wide range of risk factors, including being trapped among abusive family members, limited social interactions (such as segregated schooling), being forced into service provision settings that are not safe (but may be the only accessible option), and other people taking advantage of those with different information processing and communication styles. These dynamics are compounded by the belief that people with disabilities will never have sex and therefore do not need to be informed about their body, sexuality, or setting and communicating boundaries. While not all the respondents in this survey experienced disabilities during adolescence most did.

About half of all the respondents reported experiencing an abusive intimate relationship and being coerced into sex during adolescence, and nearly 2/3rd of all respondents reported being touched in a sexually violating way during adolescence. Among women, 65% experienced unwanted touching, 55% experienced an abusive intimate relationship, and 17% experienced coerced sex – all during adolescence. Among men, 40% experienced unwanted touching (another 20% were uncertain), 33% experienced an abusive intimate relationship, and 33% were coerced into sex – all during adolescence. Additionally, all respondents aged 56-65 reported experiencing an abusive intimate relationship and unwanted touching during adolescence. At least 50% of the respondents in each age group reported experiencing an abusive relationship and unwanted touching during adolescence. At least 30% of respondents in each age group experienced coerced sex during adolescence.

Note: This survey did not ask if the unwanted touching was related to service provision because we were primarily trying to understand the trauma experienced by people with disabilities. Whether unwanted touching was deemed “medically necessary” or not, does not change that the experience could be potentially traumatic and that the touching was unwanted. While having memories of trauma does not dictate what “counts” as traumatic, it is informative to note that regardless of context of the unwanted touching, most adults found the unwanted touching emotionally memorable enough to report here, indicating it was traumatic for them.

General/Adulthood Experience Conclusions

30% of respondents experienced someone preventing them from engaging in sexual activity with a partner at some point in their life, with especially women and those aged 55-56 affected. In some situations, there may be issues related to safety that result in a guardian stepping in to prevent a likely abusive situation related to intimacy. However, we advocate for supported decision making as a priority so that people with disabilities are empowered to lead the decision-making process in collaboration with loved ones and service providers – just as most people without disabilities do in making major life decisions, including who to have sex with. Having 30% of respondents reporting that they were prevented from sexual activity with a partner is likely excessive and more in alignment with a “guardianship” or “conservatorship” framework rather than a supported decision-making one.

It is also alarming that half of the respondents reported being “told” by someone to touch that person’s genitals even though the respondent did not want to, and that 2/3rd of respondents had experienced upsetting comments about their body. People with disabilities’ bodies are often portrayed and considered as “sickly”, “disordered”, “monstrous”, “defective”, “unhealthy”, “weak”, “overweight”, “deformed”, and “ugly”. These norms around describing disabled bodies creates enormous challenges for people with disabilities to love their body, to develop their own narrative about their body and self-advocate that in their daily life, to build confidence in their body, and to feel desirable to themselves and other partners. Breaking down any person’s confidence by normalizing this language and these beliefs about people with disabilities predisposes them and their potential partners to internalize these messages. In and of itself, this can create significant barriers to building mutually affirming intimate relationships and positive sexual experiences.

Area 4 Results: Experiences with Sexual Violence

Adolescence Results Summary

Abusive Relationships: Over half of the respondents (39% “strongly agree”) reported having an intimate relationship in adolescence that “hurt me more often than not”. 55% of women reported having this experience, and it is notable that all of the “strongly agree” responses were submitted by women (Q12). 1/3rd of men also reported experiencing this kind of relationship in adolescence. 50-57% of those ages 18-55 and 100% of those aged 56-65 reported the same.

Unwanted Touching: 63% of respondents (54% strongly agree) reported that someone touched them “in a private area” during adolescence in a way that made them uncomfortable or upset (Q10). 65% of women (61% strongly agree) and 40% of men reported unwanted intimate touching. Another 20% of men indicated that they weren’t sure if they had this experience, suggesting the number of men who experienced unwanted touching may be quite a bit higher than 40%. At least 50% of respondents in each age group reported they had experienced at least one sexual violation of this kind during adolescence, with 100% of those aged 56-65 reporting the same.

Coerced Sex: 48% of all respondents (31% strongly agree) that they were convinced to have sex with someone when they did not want to during adolescence (Q11). 33% of men and 17% of women reported being coerced into sex during adolescence. Similar to the question regarding unwanted touching, an additional 17% reported being unsure whether they had been coerced into sex. Additionally, all the “strongly agree” responses were submitted by men. 30-50% of those aged 18-45 and 66-75% of those aged 46-65 reported experiencing at least once incident of coerced sex during adolescence.

Adulthood Results Summary

Unwanted Comments: 2/3rd of respondents reported that at least once, someone has commented on their body in an upsetting way, including 85% of women and 66% of men (Q29). 100% across each age group indicated they had experienced this except ages 18-25 (75%) and 46-55 (40%).

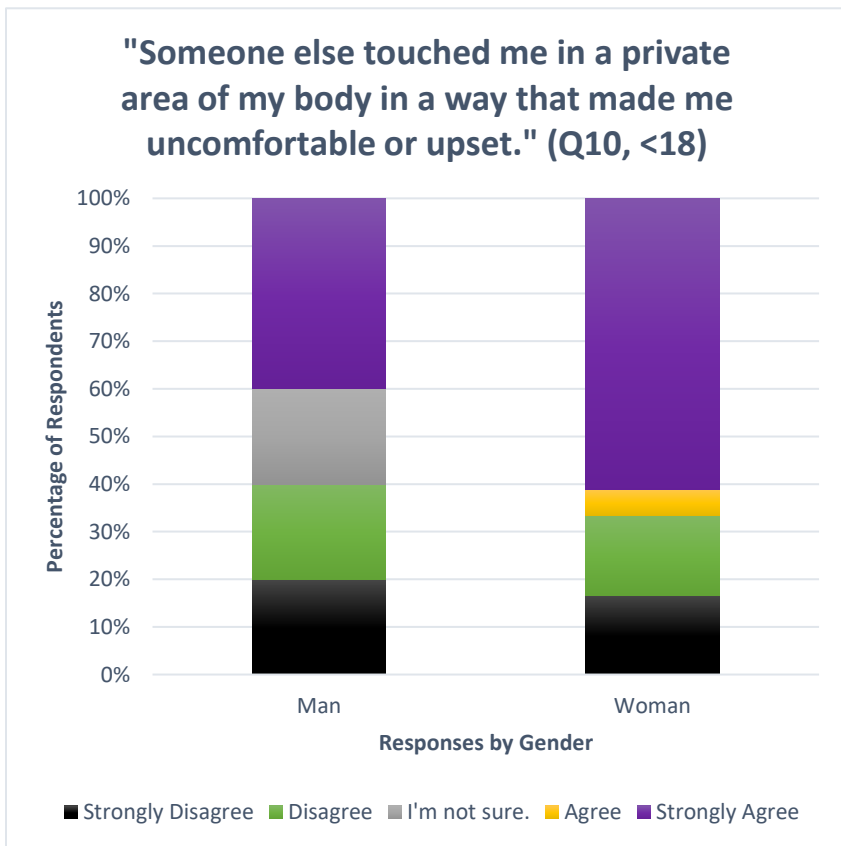
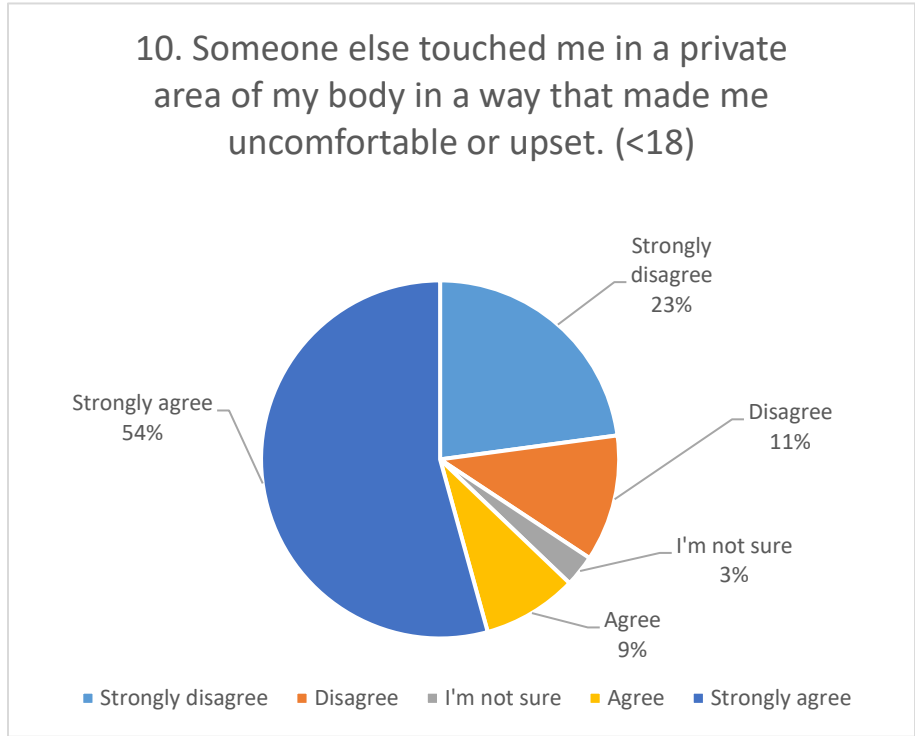
Disrupted Intimacy: 30% of respondents indicated that at least once someone has prevented them from engaging in sexual activity with a partner, including 33% of women and 16% of men (Q33). 2/3rd of those aged 56-65, and 22-43% of those aged 18-35 and 46-55 reported this experience. Those aged 36-45 actually reported they had not experienced being prevented from having sex with a partner.

Unwanted Touching of Someone Else: Half of the respondents reported that someone had instructed (“told”, not “requested”) to touch that person’s genitals despite the respondent not wanting to do so, including 47% of women and 17% of men (Q31). 100% of those aged 56-65, and 40-50% of those aged 18-55 (all other ages) reported having this experience.

Unwanted Touching of Self: 60% of all respondents indicated that someone had touched their genitals/private areas when they did not want to be touched (Q32). 62% of women and 16% of men reported having this experience. Similar to the results related to being told to touch someone else, 100% of those aged 56-65, and 40-66% of those aged 18-55 reported having this experience.

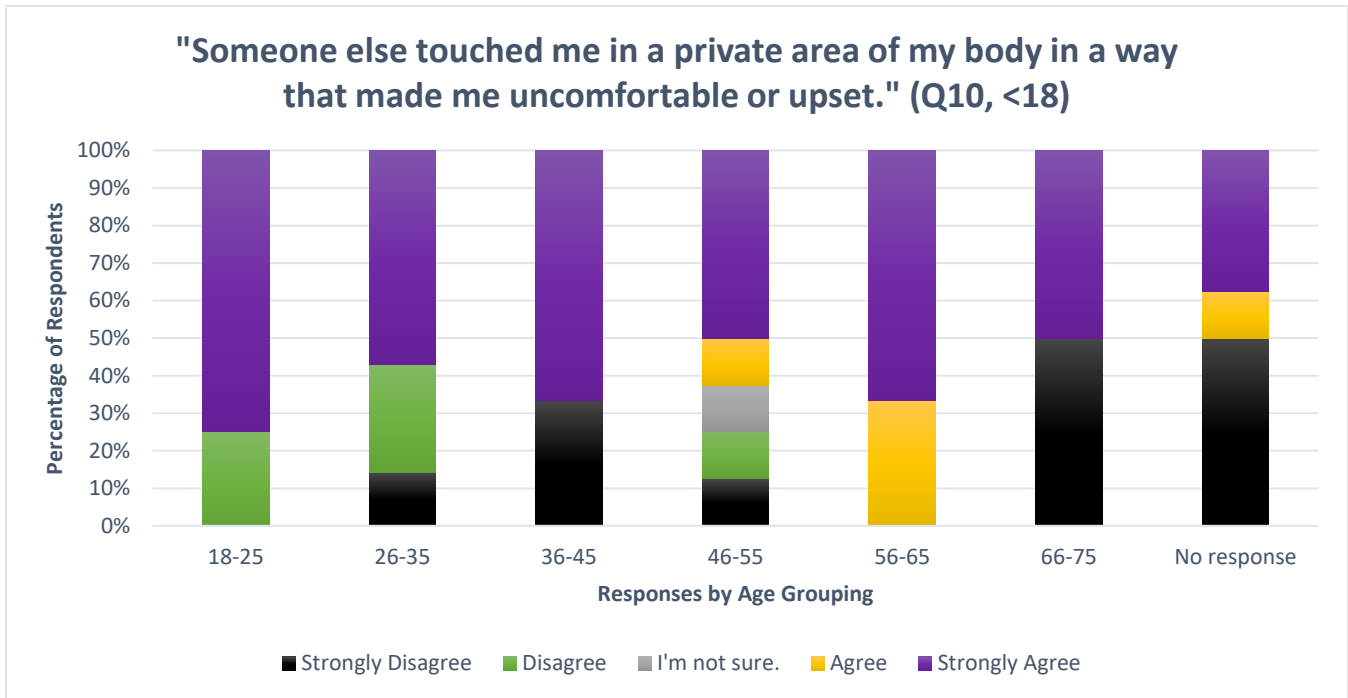
10. Someone else touched me in a private area of my body in a way that made me uncomfortable or upset.

Out of 36 respondents, 19 (54%) strongly agreed and 3 (9%) agreed that someone had touched parts of their body they consider private without consent as an adolescent. 8 respondents (23%) strongly disagreed and 4 respondents (11%) disagreed that someone had touched parts of their body they consider private without consent as an adolescent. 1 individual (3%) was unsure. 6 respondents (15% of all respondents) did not respond.



Gender: About 65% of women and 40% of men reported experiencing a sexual violation or assault during adolescence. About 20% of men indicated they were unsure whether they experienced this, so the number of men who have may be far above the 40% who indicated they did. 40% of men and about 33% of women said they had not experienced a sexual violation or assault during adolescence.

Age: At least 50% of respondents in every age group reported experiencing being touched in an upsetting way during adolescence. About 75% of those aged 18-25, 66% of those aged 36-45 and 56-65, and almost 60% of those aged 26-35 reported experiencing unwanted touching during adolescence.



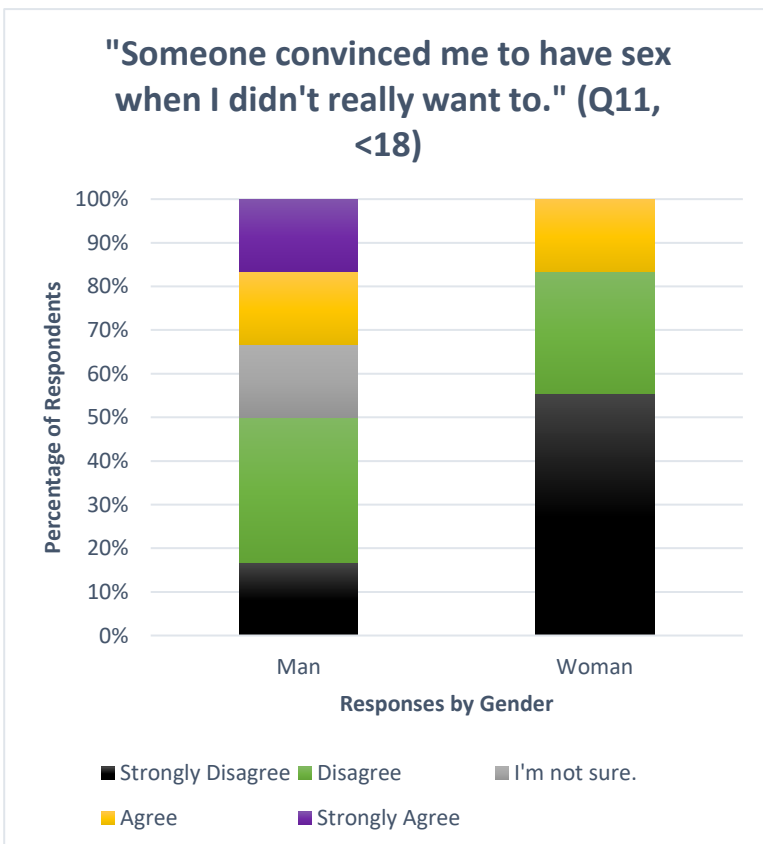
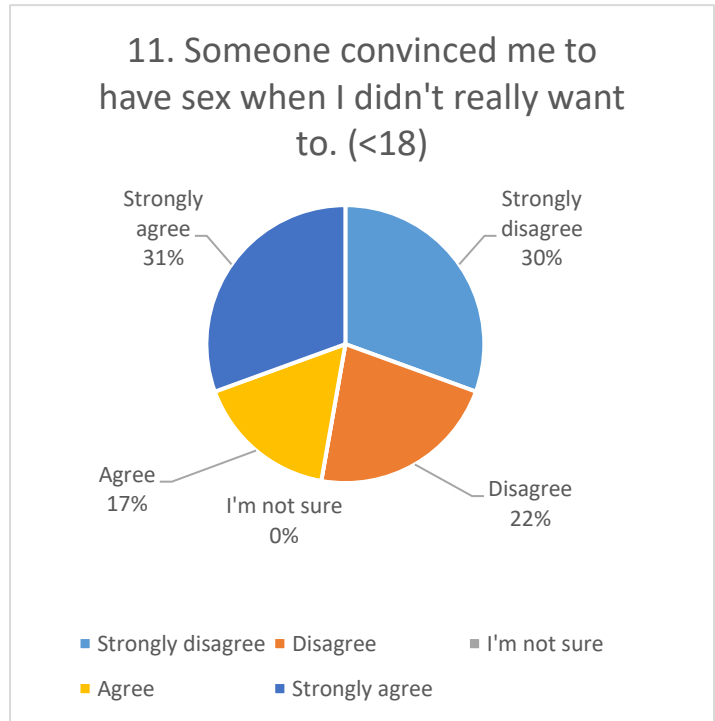
This question elicited responses with the most extreme, bifurcated responses with the majority being “strongly agree” or “strongly disagree” (only 23% of responses selected neither of those choices). This is informative as it demonstrates respondents have some intense connection to this topic, whether they directly experienced sexual assault during adolescence or not. It suggests that people with disabilities are broadly aware of the issue of sexual violence, especially against youth, and the ways in which abusers can take advantage of the vulnerabilities society creates against people with disabilities.

This aligns with data regarding massive rates of sexual violence against people with disabilities, especially those with cognitive, developmental, or mobility disabilities who are prevented from declining services or touching, escape disabled incarceration (psych holds, “asylums”, nursing homes, hospice care, etc), have their communication style understood, and may experience high rates of isolation, possibly leaving them under the “care” or “supervision” of an abuser, especially as minors.

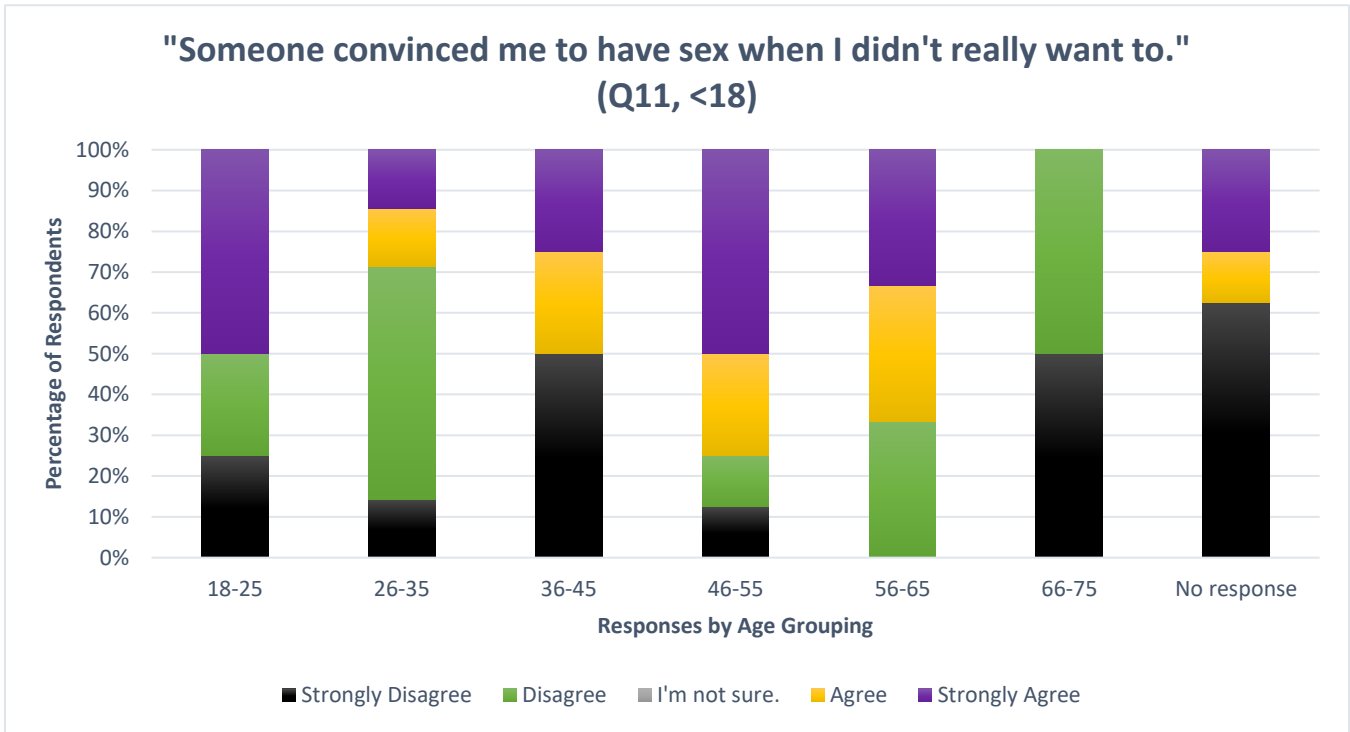
11. Someone convinced me to have sex when I didn't really want to.

Out of 36 respondents, 11 respondents (30%) strongly disagreed and 8 respondents (22%) disagreed that someone had coerced them into sex as an adolescent. 11 respondents (30%) strongly agreed and 6 (17%) agreed that someone had coerced them into sex as an adolescent. 5 respondents (12% of all respondents) did not respond.

Gender: Over 80% of women and 50% of men who respondents indicated they had not been coerced into sex during adolescence. About 33% of men and about 17% of women reported being coerced into sex as an adolescent, and about 17% of men were unsure whether they were coerced into sex as an adolescent.

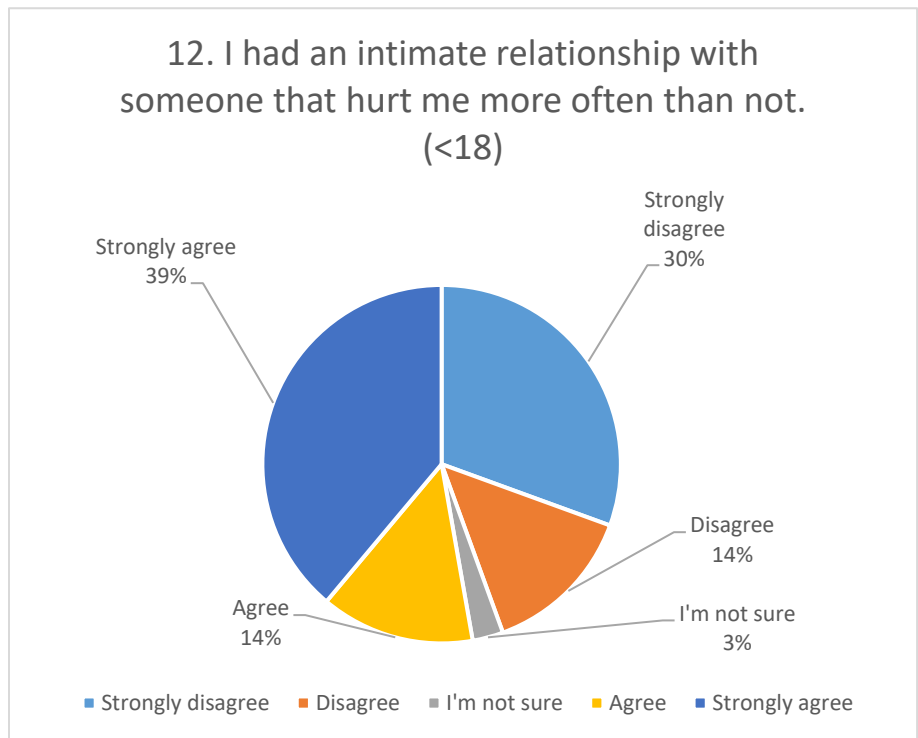


Age: Other than the 66-75 age group, at least 1/4th of all other age groups reported being coerced into sex during adolescence. About 75% of respondents aged 46-55, 66% of respondents aged 56-65, and 50% of respondents in both 18-25 and 36-45 reported experiencing coerced sex during adolescence. Similar to question 10 regarded unwanted touching, there are mostly "strongly agree" and "strongly disagree" responses from survey participants.

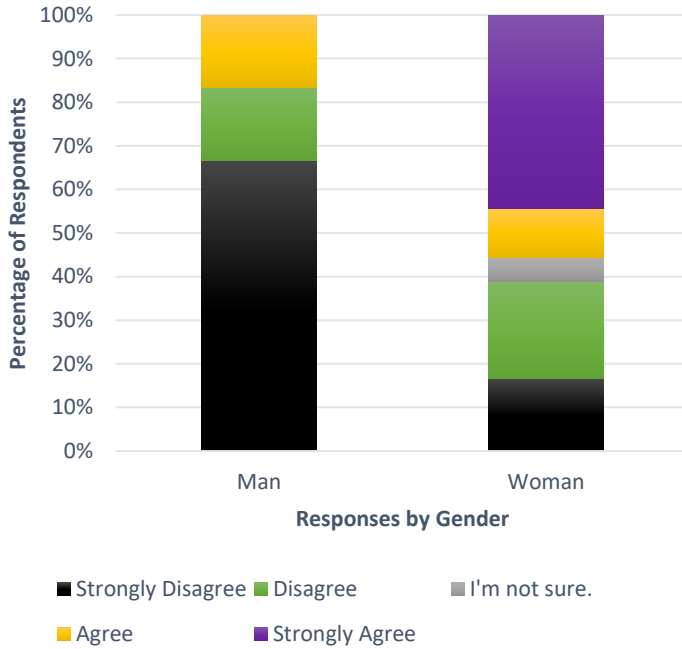


12. I had an intimate relationship with someone that hurt me more often than not.

Out of 36 respondents, 14 respondents (91%) strongly agreed and 5 respondents (14%) agreed they had at least 1 abusive intimate relationship as an adolescent. 11 respondents (30%) strongly agreed and 5 (47%) agreed that they had at least 1 abusive intimate relationship as an adolescent. 1 respondent (3%) was unsure. 5 respondents (12% of all respondents) did not respond.



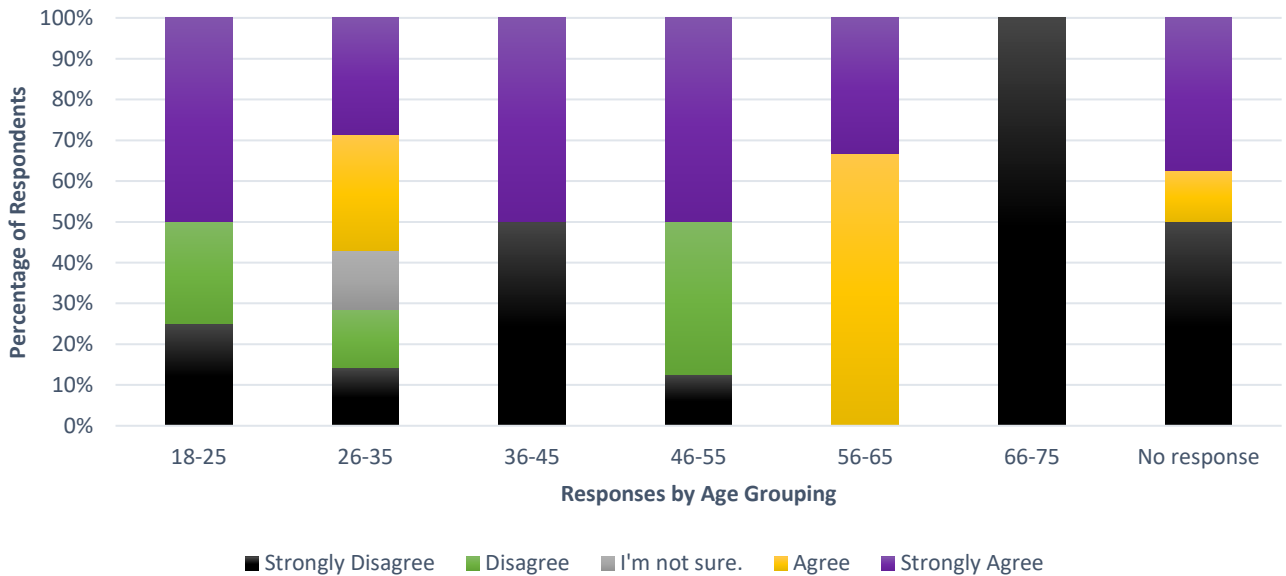
"I had an intimate relationship with someone that hurt me more often than not." (Q12, <18)



Gender: About 83% of men reported not experiencing an abusive intimate relationship, suggesting that during adolescence men either had more affirming intimate relationships or possibly had fewer (if any) intimate relationships during adolescence. About 56% of women indicated they did experience an abusive relationship in adolescence, with 44% “strongly agreeing” that they experienced this. About 4% of women also indicated they were unsure whether they had an intimate relationship that was abusive.

Age: All respondents aged 56-65 reported experiencing at least one abusive relationship during adolescence, and 50% of those in age groups 18-25 and 36-45 reported the same. Around 30% of those aged 26-35 experienced at least one abusive relationship during childhood, while those in the 66-75 age group reported no experiences with abusive intimate relationships during adolescence.

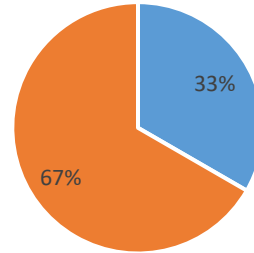
"I had an intimate relationship with someone that hurt me more often than not." (Q12, <18)



29. Someone commented on my body in a way that I found upsetting, even if I did not know why it was upsetting.

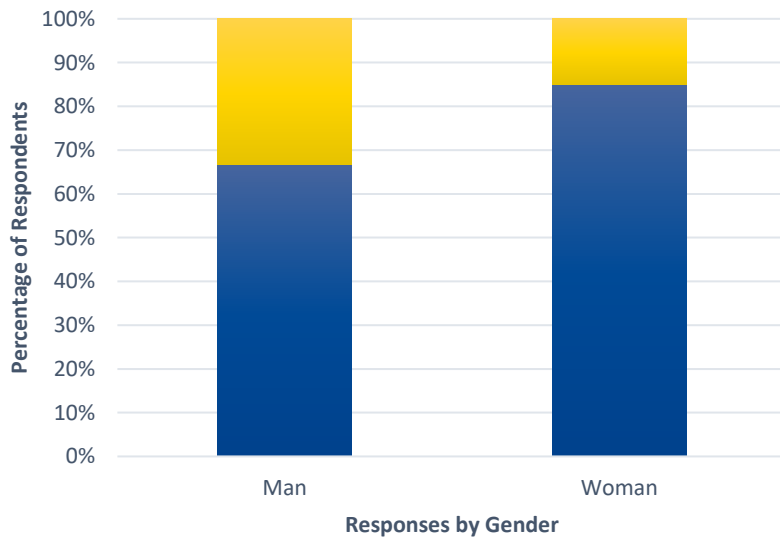
Among the 32 respondents, 27 (84%) experienced someone commenting on their body in a way that made them uncomfortable while 5 (16%) had not. 9 respondents gave non-response answers.

29. Someone commented on my body in a way I found upsetting, even if I did not know why it was upsetting.



■ No, I have not experienced this. ■ Yes, I have experienced this.

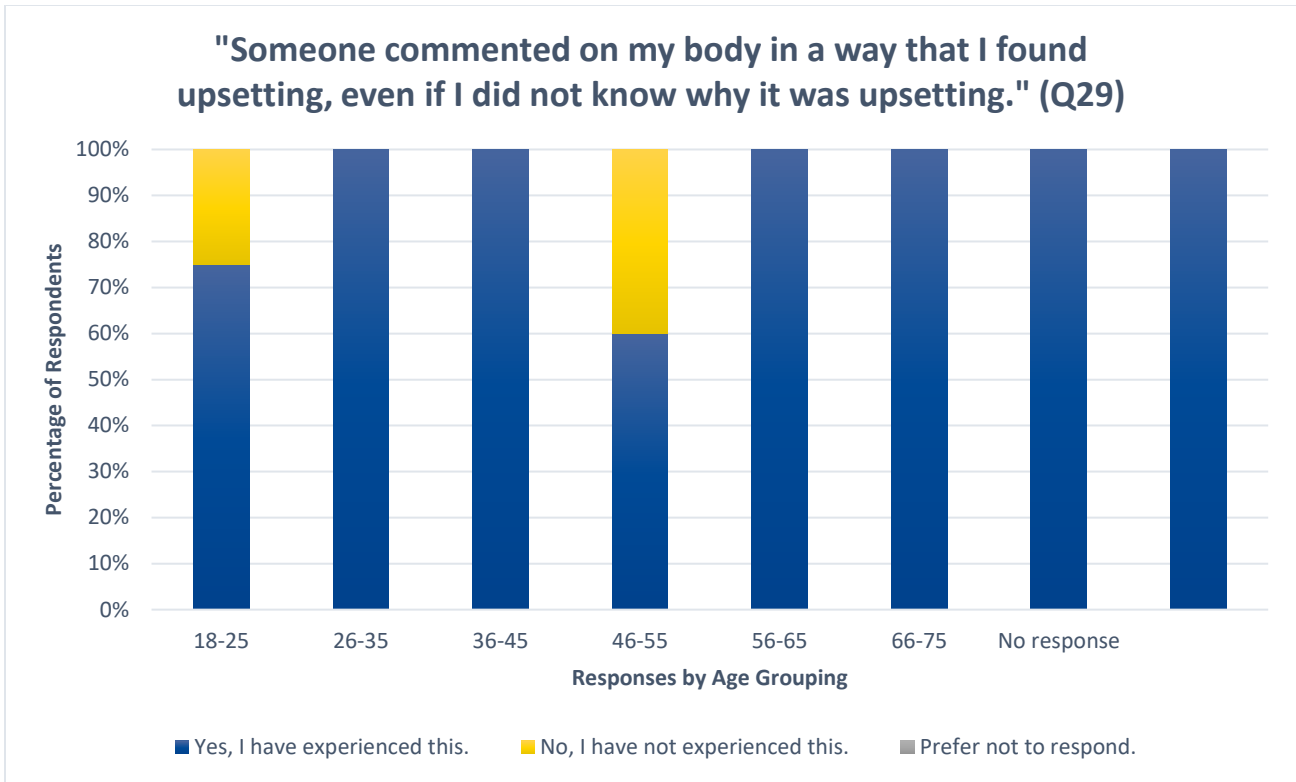
"Someone commented on my body in a way that I found upsetting, even if I did not know why it was upsetting." (Q29)



■ Yes, I have experienced this. ■ No, I have not experienced this.
 ■ Prefer not to respond.

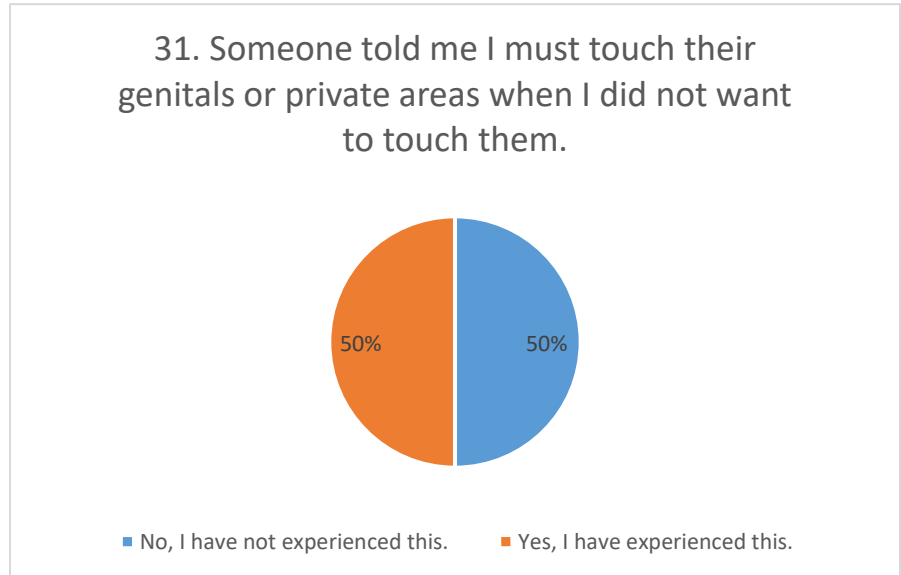
Gender: About 84% of women and 67% of men indicated they had experienced upsetting, unwanted comments about their body. About 33% of men and 16% of women reported they had not experienced this.

Age: 100% of most age groups reported experiencing upsetting, unwanted comments about their body except those in age groups 18-25 (75%) and 46-55 (50%).

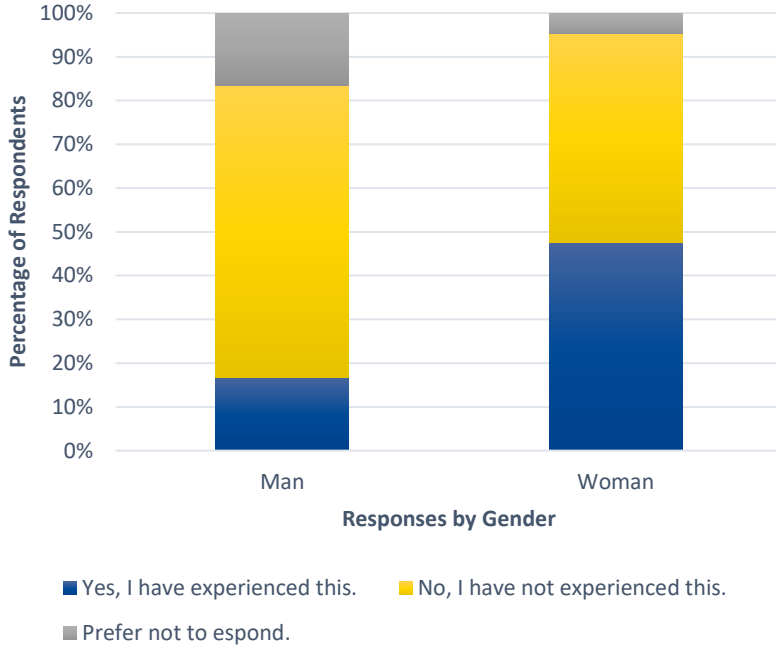


31. Someone told me I must touch their genitals or private areas when I did not want to touch them.

Among the 30 respondents, 15 (50%) experienced someone coercing them into unwanted touching while 15 (50%) had not. 11 respondents gave non-response answers.



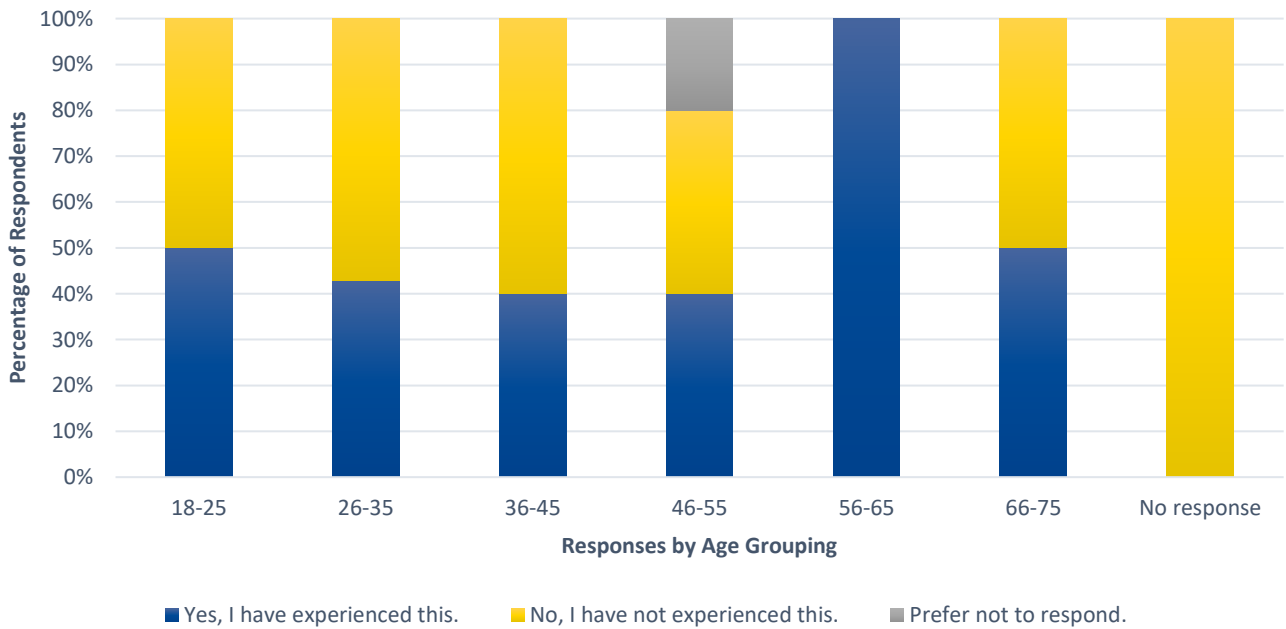
"Someone told me I must touch their genitals or private areas when I did not want to touch them." (Q31)



Gender: Although half of the respondents indicated they had experienced being forced to touch someone else's genitals, 3 times the proportion of women (47%) reported this experience compared to men (17%).

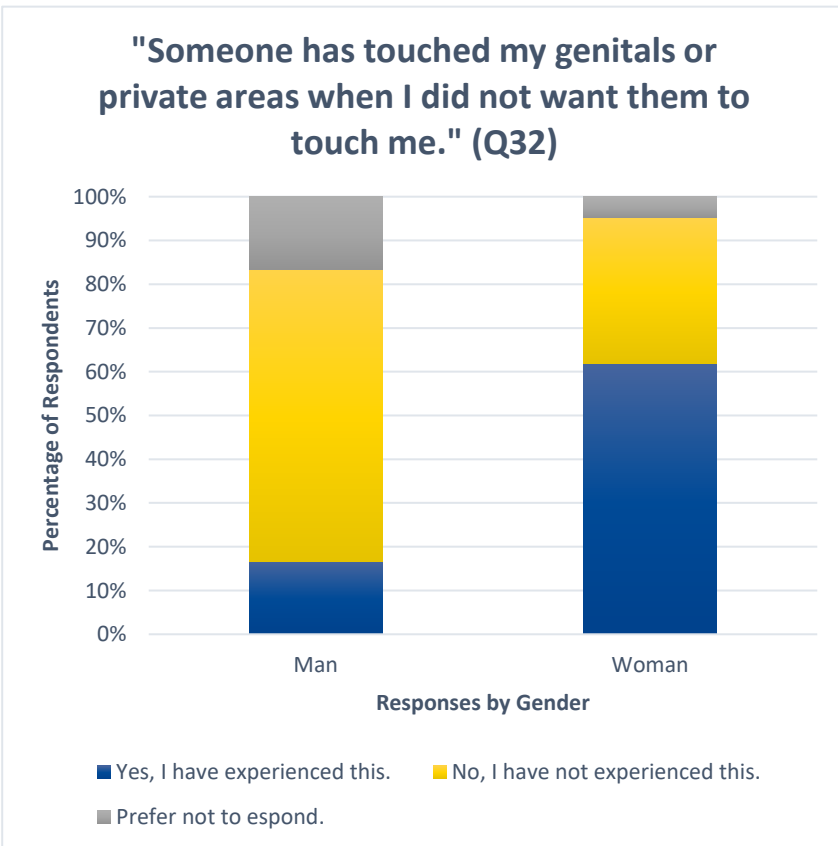
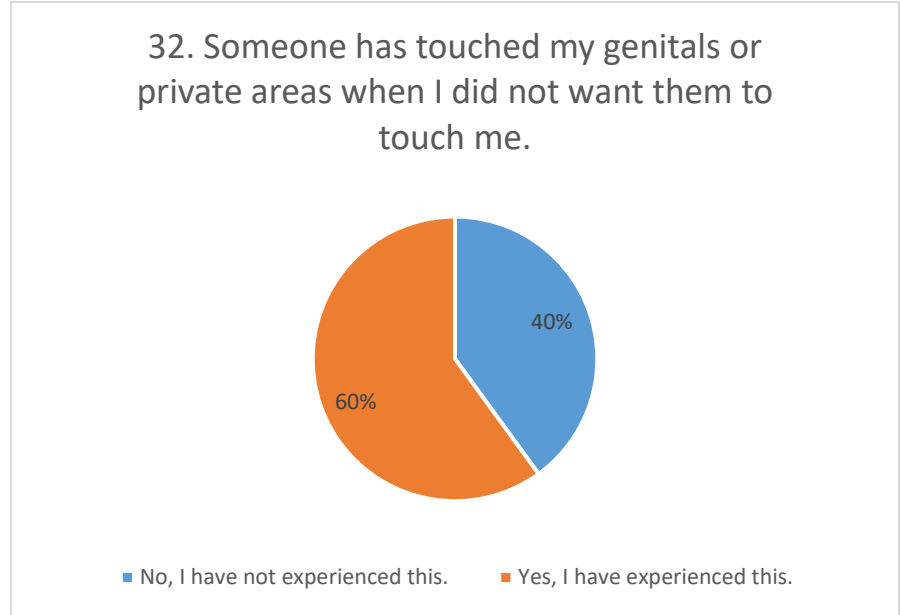
Age: Between 40-50% of respondents in age groups 18-55 and 66-67 reported being coerced/forced into touching someone else's genitals. All respondents aged 56-65 reported having this experience across their lifetime.

"Someone told me I must touch their genitals or private areas when I did not want to touch them." (Q31)



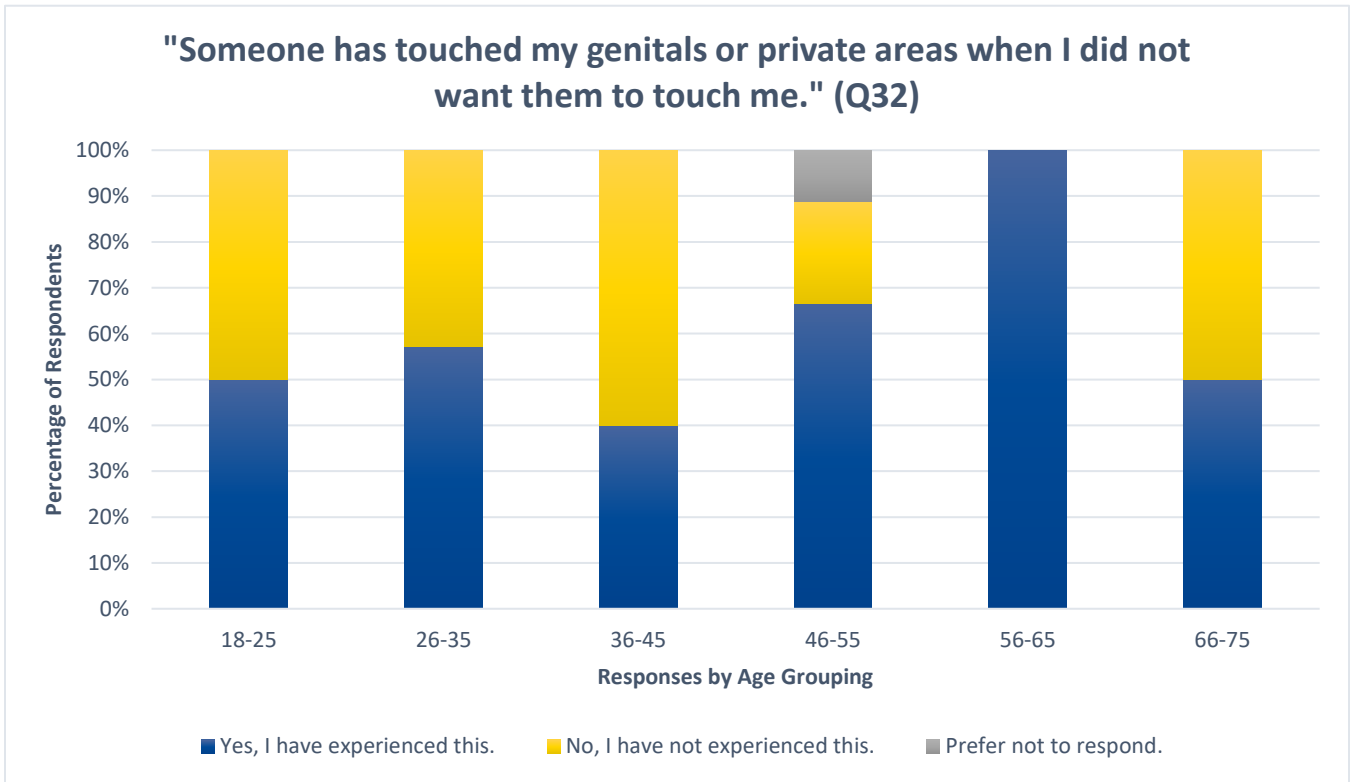
32. Someone has touched my genitals or private areas when I did not want them to touch me.

Among the 30 respondents, 18 (60%) experienced someone coercing them into unwanted touching while 12 (40%) had not. 11 respondents gave non-response answers.



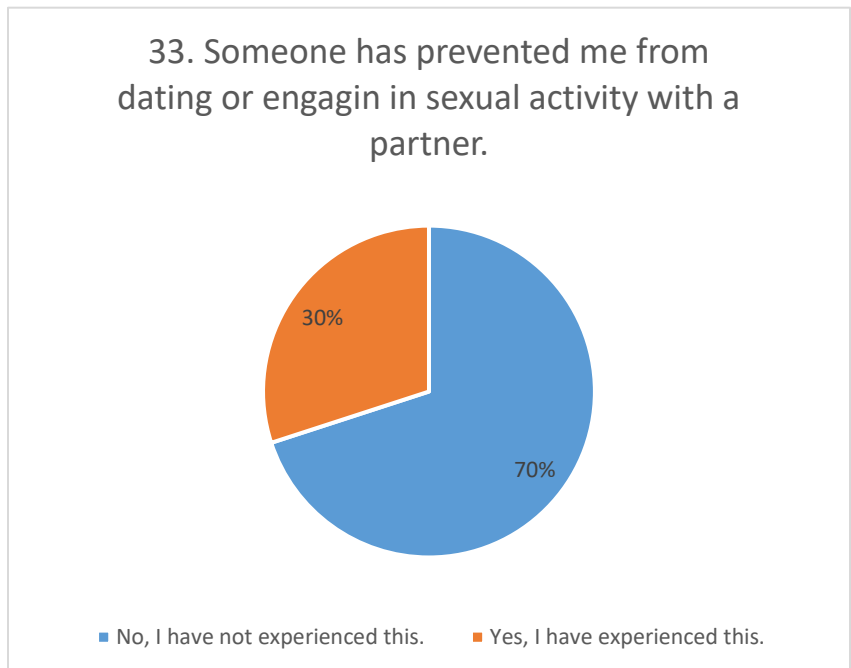
Gender: Almost 4 times the proportion of women (62%) reported experiencing unwanted genital touching compared to men (16%). About 63% of men and 33% of women stated they had not experienced unwanted genital touching across their lifetime.

Age: At least 40% of respondents in all age groups and all respondents in the 56-65 age group reported experiencing unwanted genital touching at some point in their life. About 65% of those aged 46-55, about 56% of those aged 26-35, 50% of respondents aged 18-25, and 40% of respondents aged 36-45 experienced unwanted genital touching in their lifetime.

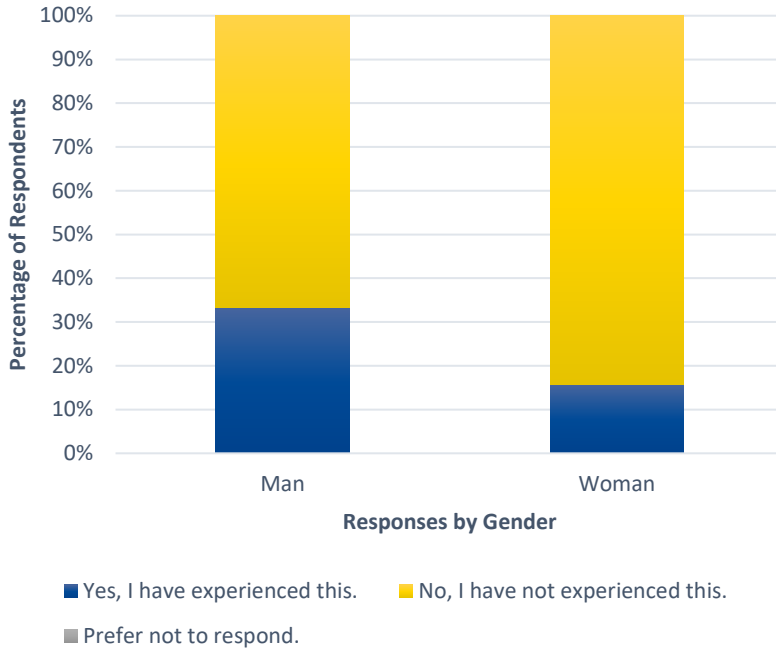


33. Someone has prevented me from dating or engaging in sexual activity with a partner.

Among the 30 respondents, 9 (30%) experienced being prevented from an intimate relationship while 21 (70%) had not. 11 respondents gave non-response answers.



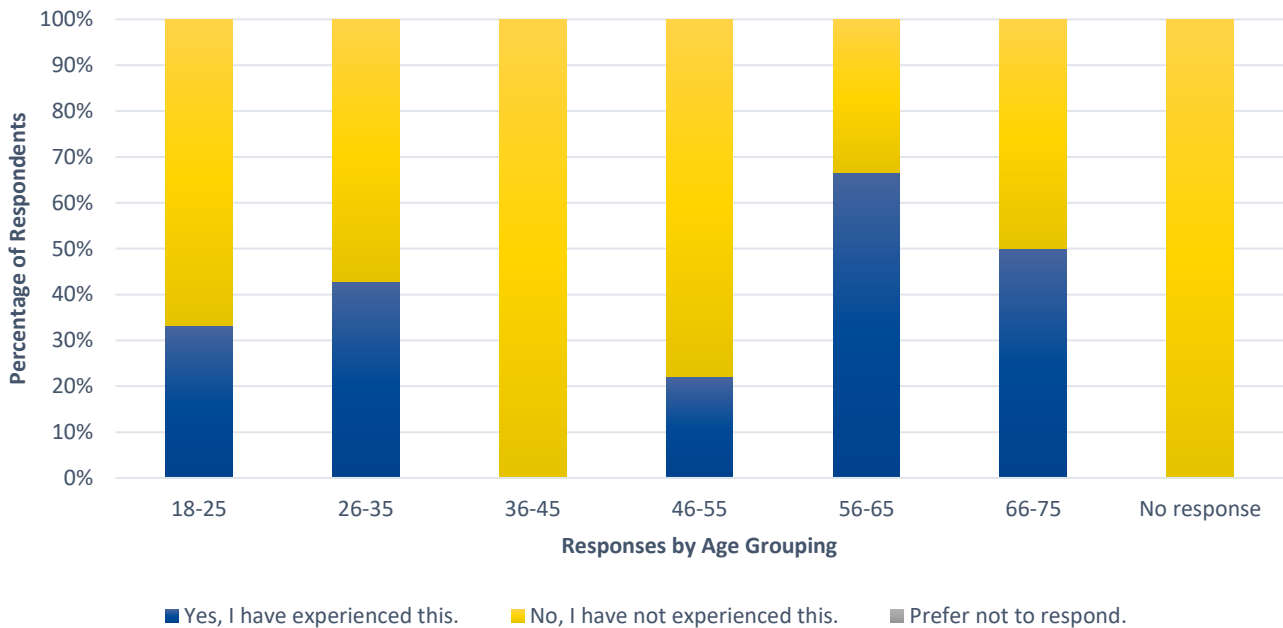
"Someone prevented me from dating or engaging in sexual activity with a partner." (Q33)



Gender: There was over twice the proportion of men (33%) who experienced being prevented from engaging in an intimate relationship compared to women (16%).

Age: Those in age group 36-45 was the only group who reported not ever experiencing being prevented from engaging in an intimate relationship. About 2/3rd of those aged 56-65 and one half of those aged 66-75 reported being prevented from engaging in an intimate relationship at some point in their life. About 43% of those aged 26-35, 33% of those aged 18-25, and 22% of those aged 46-55 experienced being prevented from engaging in an intimate relationship.

"Someone prevented me from dating or engaging in sexual activity with a partner." (Q33)



Area 5 Conclusions

Note: To be concise, the questions referenced will be referred to as the title listed in the “report summary” below so that instead of writing the entire question each time, the topics can be referenced more quickly.

Only 15-36% of respondents impacted by any of the 7 experiences described in this section reported any given experience. Other than the experiences of being ignored and coercive services (both had 36% reporting and 36% not reporting), all other experiences had significantly more people who chose not to report, sometimes even several times the number who chose to report. For example, only 28% of those who experienced someone telling them to touch their genitals reported the experience, while 50% had decided not to even attempt to report.

Reporting Disrupted Intimacy: The most severe case of this out of the experiences asked about in this survey, was respondents experiences with disrupted intimacy. Only 15% of those who experienced being prevented from engaging in sexual activity with a partner reported this, while 69% stated they would not be reporting. One reason why this disparity may exist is that it is likely a family member or some other person that is consistently, personally in the life of the respondent who intervened. In that case, it would be enormously challenging emotionally and logistically for a person with a disability to report this incident. Additionally, if the respondent’s legal guardian intervened, the guardian would most likely have full legal authority to do so, regardless of the desires of the respondent.

Reporting Being Spoken Over/Ignored & Experiencing Coercive Services: Out of the 7 reporting decision questions in this section, the two that the most people reported were their experience with being ignored and coercive services (36% of people impacted by each of these reported). This may be because it may be difficult to figure out how to report unwanted comments or receiving inaccurate information, and reporting direct sexual assault can be emotionally and logistically challenging (especially since most perpetrators are family members or caregivers). Additionally, experiences of being ignored and coercive services may be more difficult to avoid reporting if they directly impact the person’s ability to acquire adequate, affirming services in resource limited, rural areas. Being ignored and coerce services may also be more likely to have witnesses, such as other medical/service providers, caregivers, or advocates, reducing some barriers to reporting.

Gender Differences in Reporting: There were very stark gender differences in reporting decisions among respondents. In the situations of receiving inaccurate information about their body, being told to touch someone else's genitals, experiencing unwanted touch from someone else only women reported at all. In most of these experiences, men indicated they intend to report but had not yet done so, often in similar proportions to women who already reported. For example, in regard to being given inaccurate information about their body, 25% of women reported while 25% indicated they intend to report. Among those who experienced coercive services, 40% of women reported while only 25% of men did – but another 25% of men indicated they intended to report. The only circumstances in which a larger proportion of men reported compared to women were in regard to unwanted comments about their body (33% of men vs. 24% of women) and disrupted intimacy (32% of men vs. 17% of women). The most even reporting proportions between men and women were regarding experiences of being ignored, in which 20% of men and women reported.

Age Differences in Reporting: There were some interesting patterns regarding reporting between age groups. As a reminder, only those who indicated they had each experience are included in the reporting data and there were participants within each age group represented in this area. However, note that as the original survey sample size was only 42 and these questions are being responded to by portions of the whole set of participants, these values are often based on small numbers of participants. No age group cluster of respondents indicated reporting all 7 experiences. Those aged 18-25 reported experiences in all areas except coercive services but those aged 26-35 only reported experiences of unwanted touching (both kinds) and coercive services. Those aged 36-45 reported experiences of receiving inaccurate information and being ignored. Those aged 46-55 reported all experience other than disrupted intimacy and being ignored. Those aged 56-65 reported unwanted comments, disrupted intimacy, coercive services, and unwanted touching of someone else.

Area 5: Experiences Reporting Sexual Violence

This survey did not strictly define “reporting.” Therefore “reporting” may mean notifying a service or medical care provider, a guardian, family member or friend, law enforcement, civil rights agency, etc. This section is primarily looking at what proportion of people knew they could seek help and felt empowered to do so. The 7 questions here are all related to general/adulthood experiences and are questions asked earlier in the survey focused on service provision and sexual harm. Those who responded to this question are only survey participants who indicated they had the experience described in the original question.

Unwanted Comments (Q36 – based on Q29): Out of the 33% of participants who reported experiencing someone commenting on their body in a way that was upsetting, only 22% reported the incident and 59% responded that they do not plan to report this. 1/3rd of men and 1/4th of women reported, and 1/3rd of those aged 56-65, 1/4th of those aged 18-25, and 15% of those aged 46-55 reported this experience.

Inaccurate Information (Q37 – based on Q30): Out of the 67% of respondents who reported experiencing someone giving them inaccurate information about their body, only 17% reported this and 50% indicated they do not intend to report. Only women (25%) indicated that they reported this incident, while 25% of men indicated that they intend to report this. 50% of those aged 18-25, 33% of those aged 36-45, and 17% of those aged 46-55 reported this experience.

Unwanted Touching of Someone Else (Q38 – based on Q31): Out of the 50% of respondents who indicated that someone told them to touch the person’s genitals even if the respondent did not want to, 28% reported while 50% indicated they do not intend to report. Only women (45%) indicated they reported this experience while 1/3rd of men indicated they intend to report. 40% of those aged 46-55 and 1/3rd of those aged 18-35 and 56-65 reported this experience.

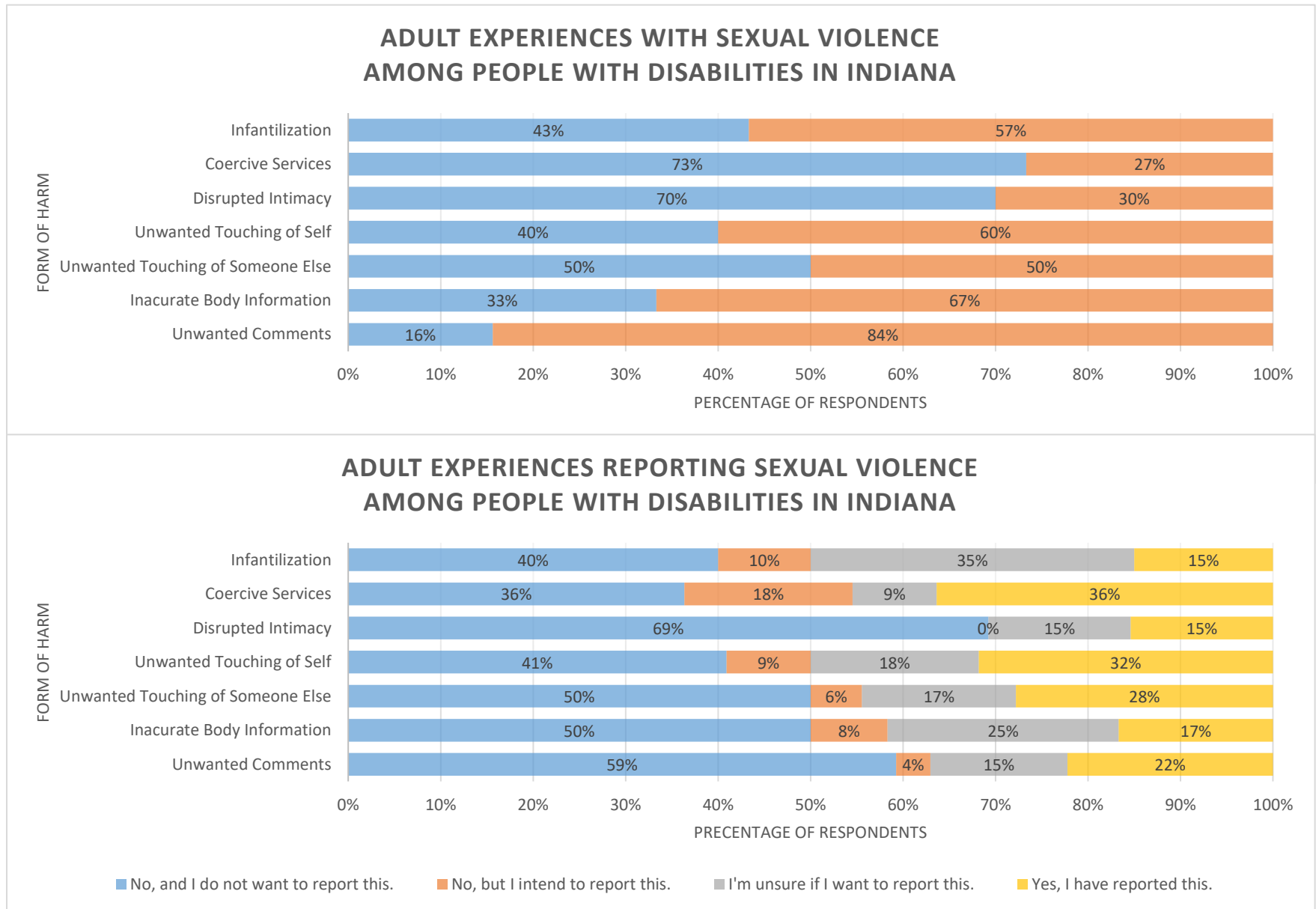
Unwanted Touching of Self (Q39 – based on Q32): Out of the 60% of respondents who indicated they had experienced someone touching their genitals/private areas when they did not want to be touched, about 1/3rd reported while over 40% indicated they do not plan to report. Only women (47%) indicated they had reported this experience while 1/3rd of men indicated they intend to report. 55% of those aged 46-55, 33-40% of those in age groups 18-35 reported this experience.

Disrupted Intimacy (Q40 – based on Q33): Out of the 30% of respondents who indicated they had experienced someone preventing them from engaging in sexual activity with a partner, only 15% reported while 69% indicated they do not plan to report. 1/3rd of men and 17% of women reported this experience. 100% of those aged 18-25 and 50% of those aged 56-65 reported – but no other age groups did so.

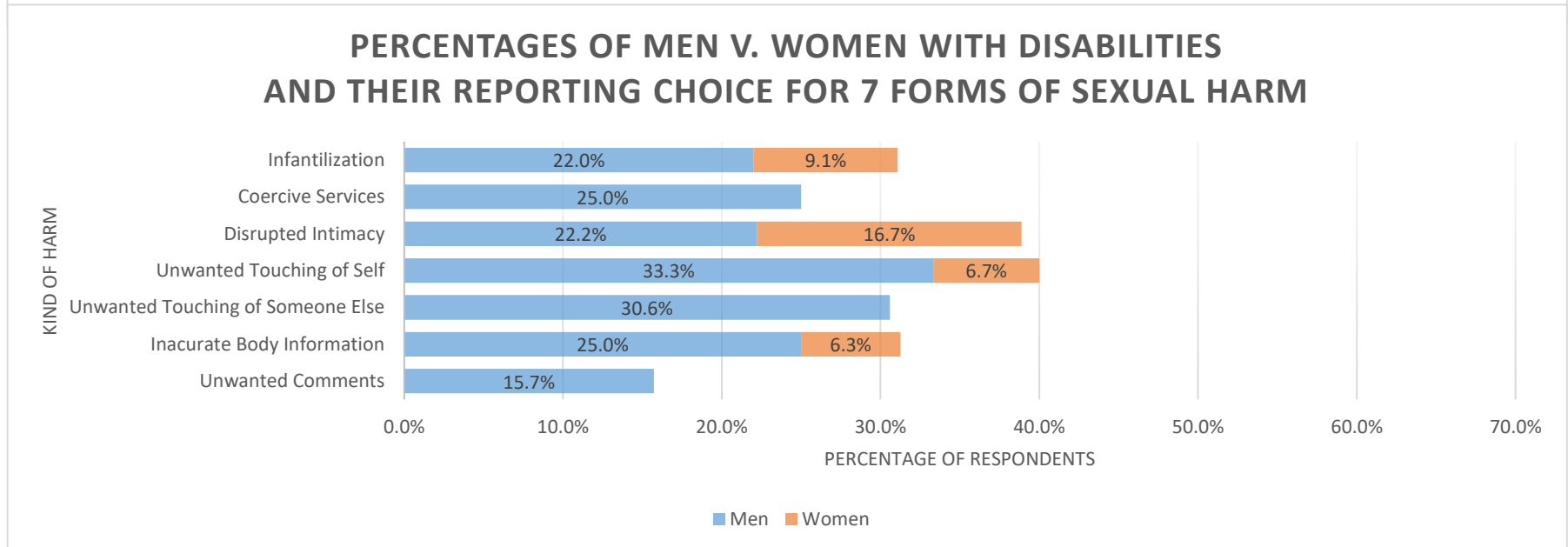
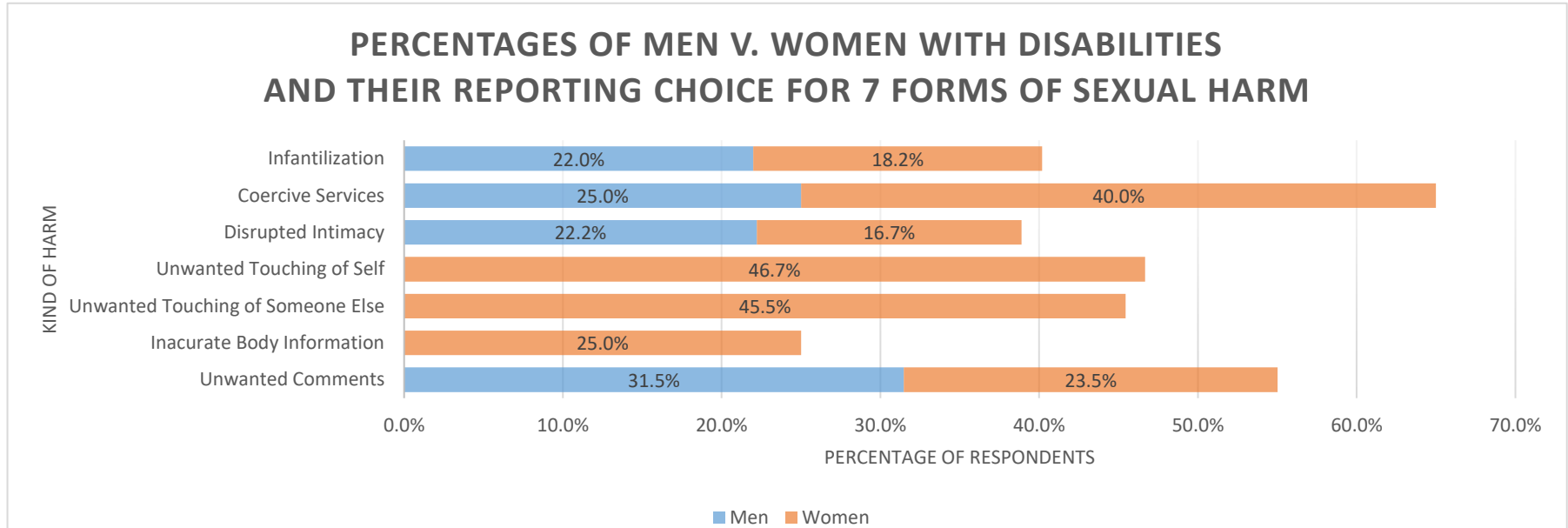
Coercive Services (Q41 – based on Q34): Out of the 27% of respondents who indicated they experienced someone withholding services unless the respondent complied, even if it made them uncomfortable, 36% reported and 36% indicated they do not plan to report. 40% of women and 25% of men responded that they reported this experience and another 25% of men indicated they planned to do so. 100% of those aged 56-65, 50% of those aged 26-35, and 33% of those aged 46-55 reported this experience.

Being Ignored (Q42 – based on Q35): Out of the 57% of respondents who experienced a service provider speaking about their body and health to others as if they were not present or not able to provide information about their own body, 36% reported while 36% indicated they did not plan to report. 20% of men and women indicated they had reported while 20% of men and 7% of women indicated they intended to report this experience. 50% of those aged 18-25 and 1/3rd of those aged 36-45 reported – but no other age groups did so.

Area 4 & 5 Comparison: Experiences of Sexual Violence vs. Reporting Decisions



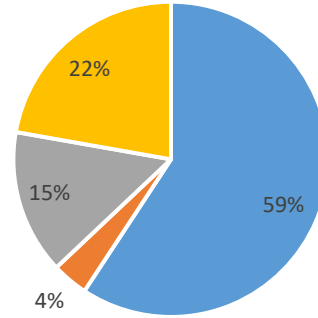
Area 5 Comparison: Gender Comparison of Reporting Decisions



36. Someone commented on my body in a way that I found upsetting, even if I did not know why it was upsetting.

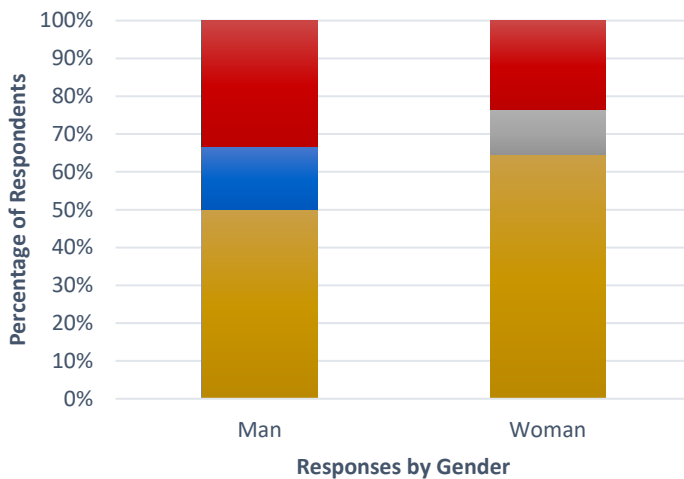
Among the 27 respondents who experienced someone commenting on their body in a way that was upsetting, 6 (22%) had reported this experience while 1 respondent (4%) indicated intending to report the experience and 16 (59%) had not reported and didn't intend to report this experience. 6 respondents (25%) were unsure whether they wanted to report this experience. 14 respondents gave non-response answers.

36. Someone commented on my body in a way that I found upsetting, even if I did not know why it was upsetting. (Reporting)



■ No, and I do not want to report this. ■ No, but I intend to report this.
 ■ I'm unsure if I want to report this. ■ Yes, I have reported this.

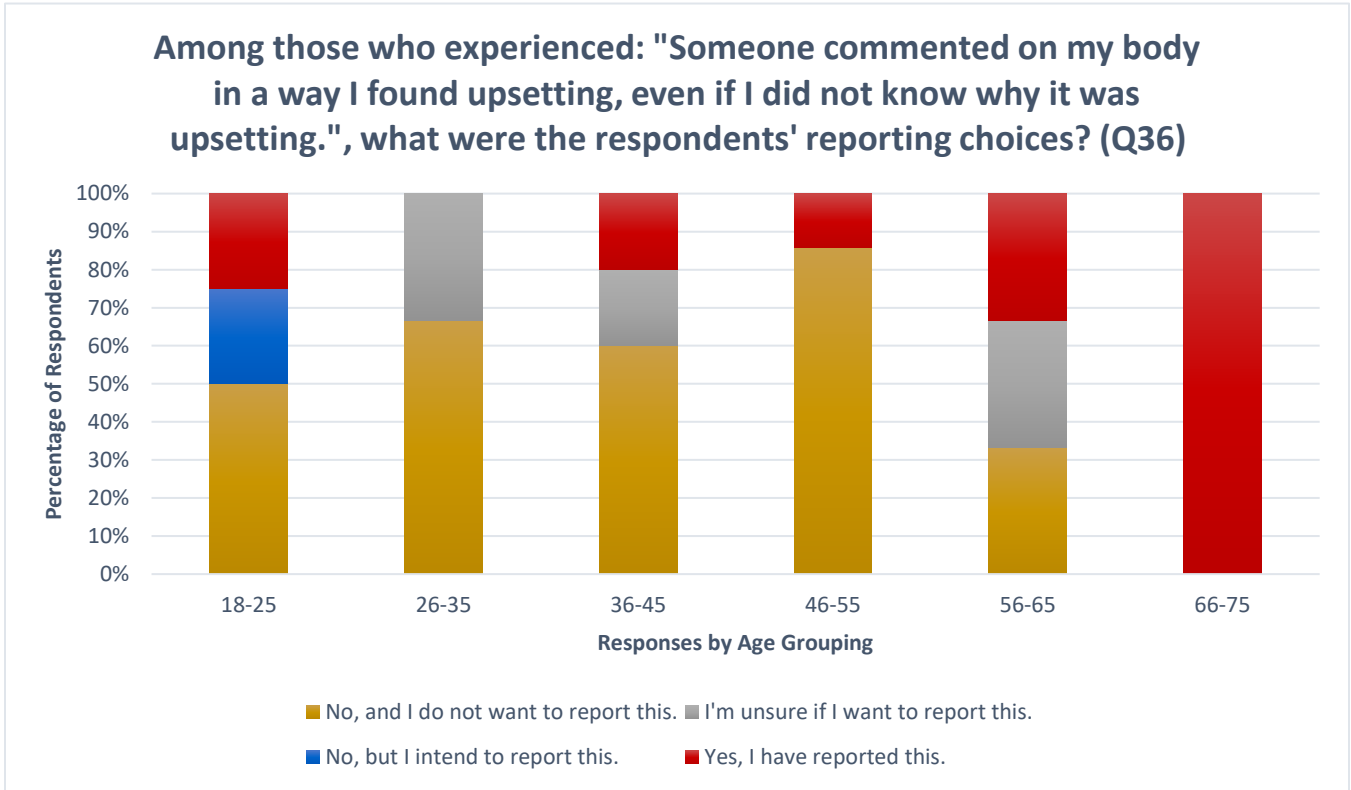
Among those who experienced: "Someone commented on my body in a way I found upsetting, even if I did not know why it was upsetting.", what were the respondents' reporting choices? (Q36)



■ Yes, I have reported this.
 ■ No, but I intend to report this.
 ■ I'm unsure if I want to report this.
 ■ No, and I do not want to report this.

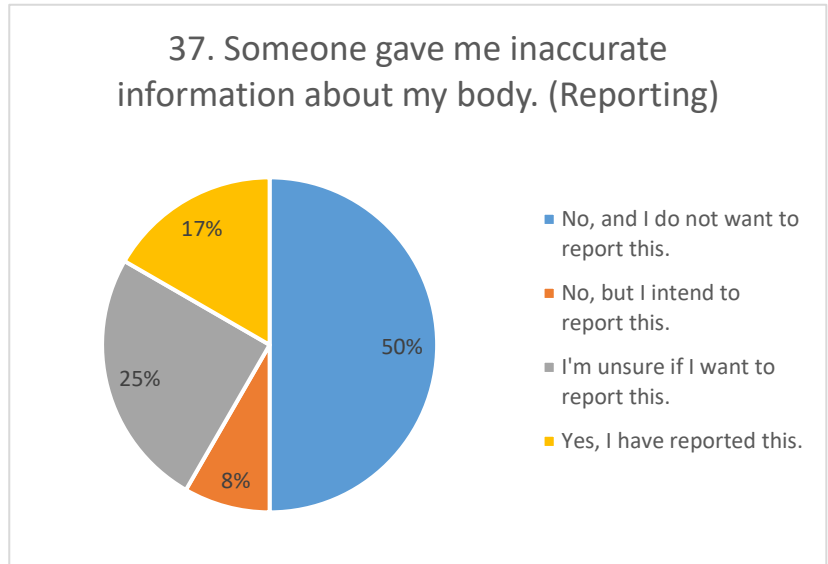
Gender: About 2/3rd of men and 1/4th of women indicated reporting at least one incident of someone commenting on their body in an upsetting way. 2/3rd of women and 1/2 of men indicated they have not and will not be reporting this experience. About 16% of men indicated that they do intend to report this experience and about 11% of women indicated that they are unsure whether they want to report this.

Age: The proportion of respondents who reported this experience spread across all age groups except those aged 26-35. All of those aged 66-75 indicated reporting at least one incident of someone commenting on their body in a way that was upsetting. About 33% of those aged 56-65, 25% of those aged 18-25, 19% of those aged 36-45, and 15% of those aged 46-55 indicated they had reported at least one incident of having their body commented on in an upsetting way.

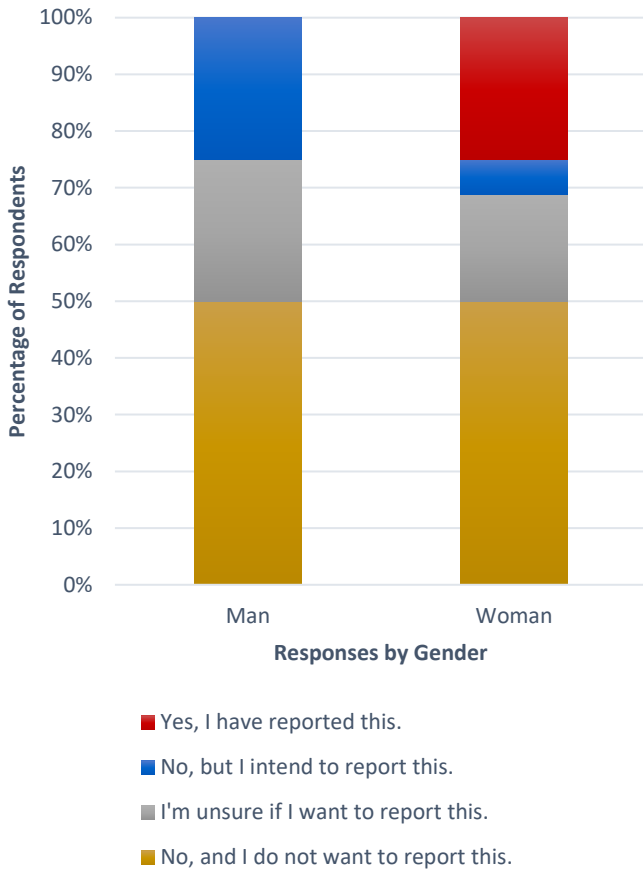


37. Someone gave me inaccurate information about my body.

Among the 24 respondents who experienced someone providing them with inaccurate information about their body, 4 (17%) had reported this experience while 2 respondents (8%) indicated intending to report the experience and 12 (50%) had not reported and didn't intend to report this experience. 6 respondents (25%) were unsure whether they wanted to report this experience. 17 respondents gave non-response answers.



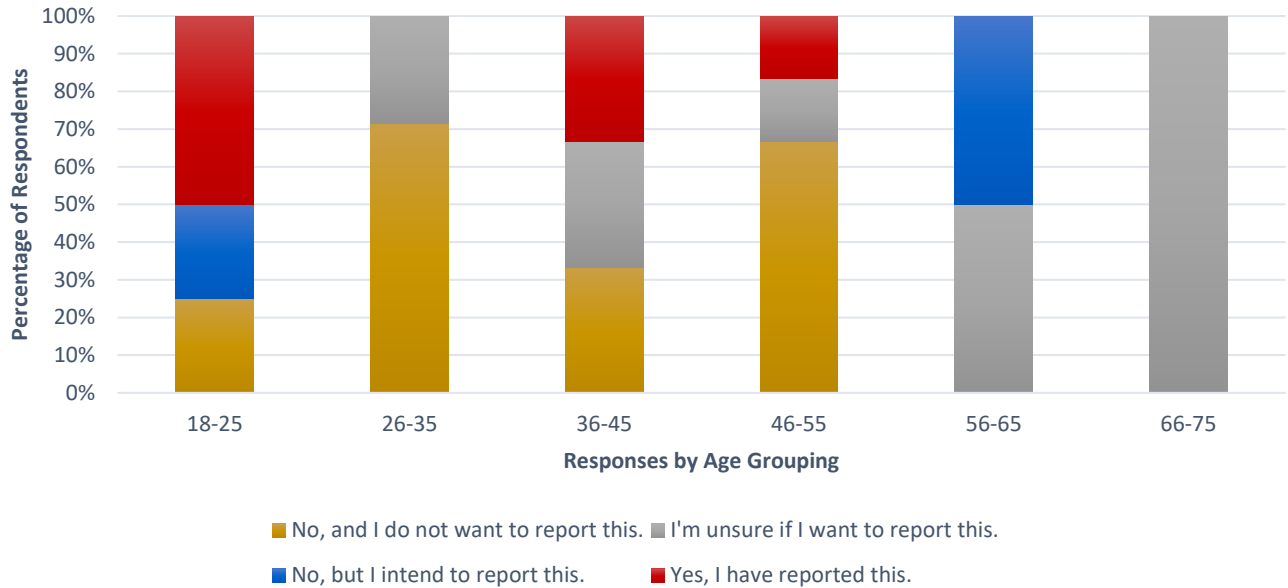
**Among those who experienced:
 "Someone gave me inaccurate
 information about my body.", what were
 the respondents' reporting choices?
 (Q37)**



Gender: Half of both men and women indicated they had not reported and did not intend to report an experience of being given inaccurate information about their body. 25% of men indicated they would like to report this incident and the same proportion of women responded that they had already reported this incident. About 7% of women also indicated they plan to report this incident. 25% of men and about 18% of women responded that they were uncertain whether they wanted to report being given inaccurate information about their body.

Age: About half of the respondents who indicated they have reported an incident of being given inaccurate information about their body were in the 18-25 age range (50% of respondents in this age group indicated they had reported). About 35% of those aged 36-45 and 15% of those aged 46-55 responded that they reported an incident of receiving inaccurate information about their body. Most of respondents in age groups 26-35 (72%) and 46-55 (66%) indicated they did not plan to report. Those unsure of whether they wanted to report were distributed across all age ranges except 18-25. Those who intended to report were either in the 56-65 (50%) or 18-25 (23%) age ranges.

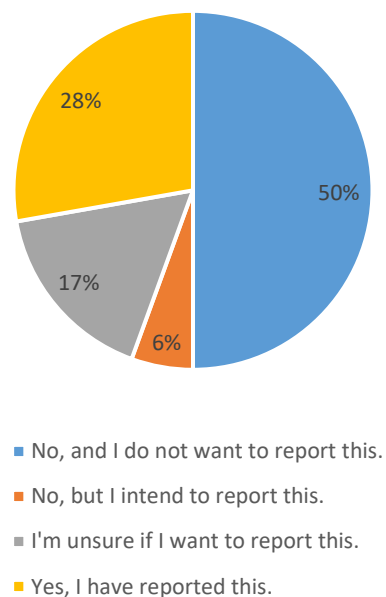
Among those who experienced: "Someone gave me inaccurate information about my body.", what were the respondents' reporting choices? (Q37)



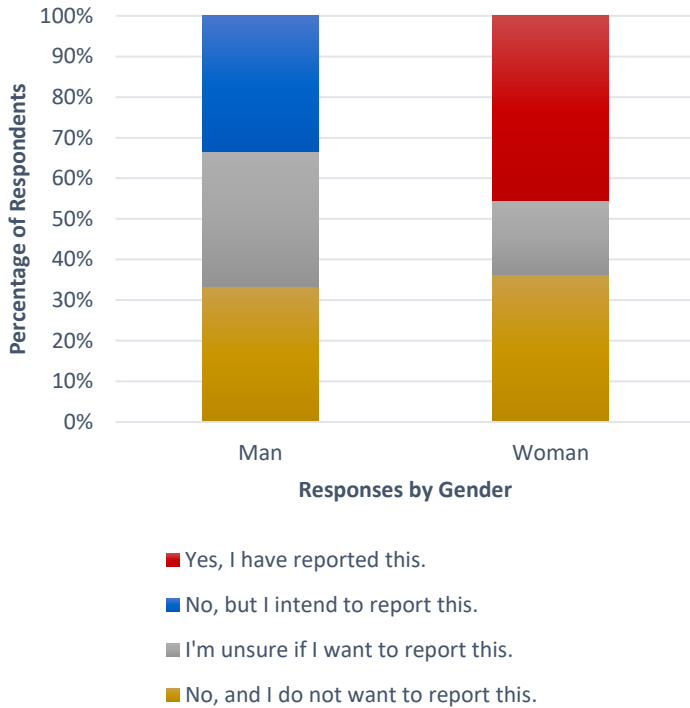
38. Someone told me I must touch their genitals or private areas when I did not want to touch them.

Among the 18 respondents who experienced someone telling them they must touch their genitals or private areas when the respondent did not want to, 5 (28%) reported this experience while 1 respondent (6%) indicated intending to report the experience. 9 (50%) had not reported and didn't intend to report this experience. 3 respondents (17%) were unsure whether they wanted to report this experience. 23 respondents gave non-response answers.

38. Someone told me that I must touch their genitals or private areas when I did not want to touch them. (Reporting)

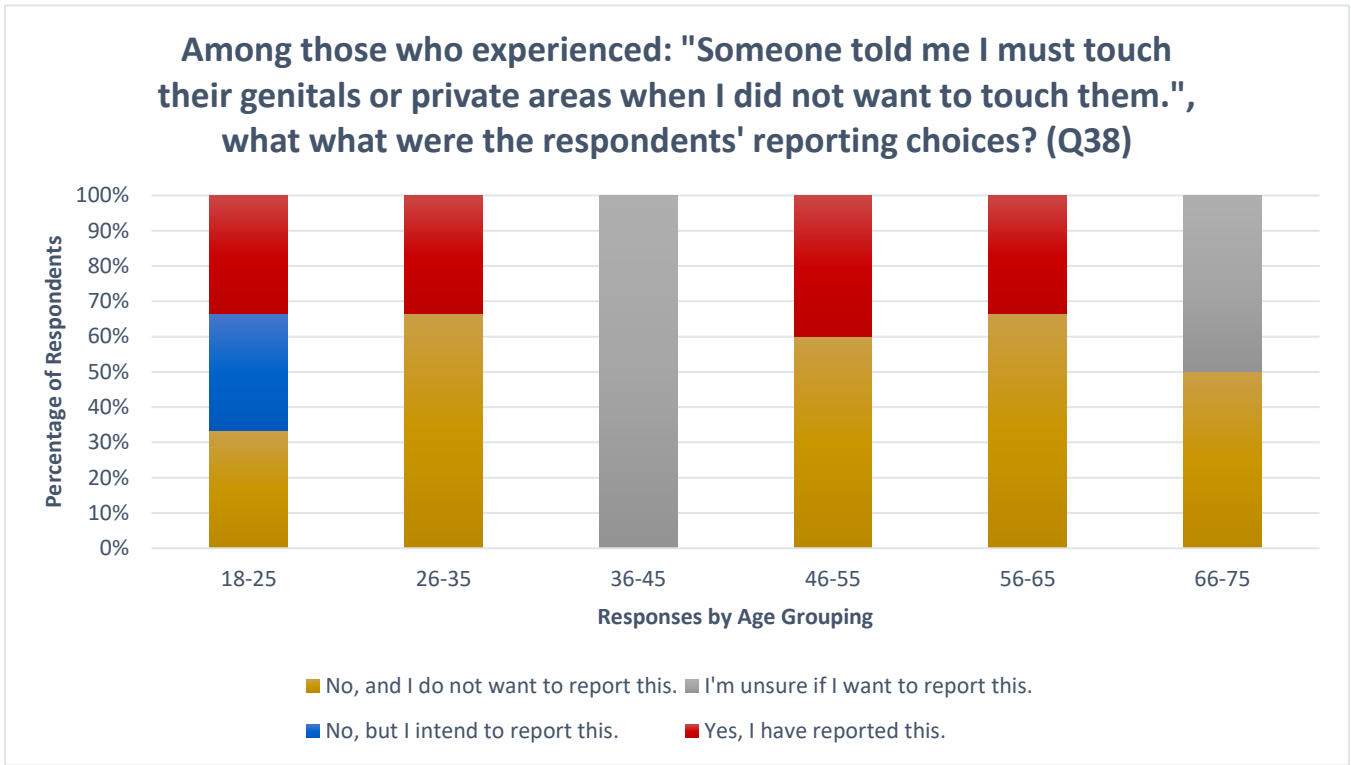


Among those who experienced: "Someone told me I must touch their genitals or private areas when I did not want to touch them.", what were the respondents' reporting choices? (Q38)



Gender: Among those who experienced having someone try to coerce them into unwanted sexual contact, about 1/3rd of men and women indicated they did not intend to report this, and another 1/3rd of men and about 19% of women were unsure whether they wanted to report. 45% of women who had experienced this indicated that they had reported the violation while about 33% of men indicated that they plan to report.

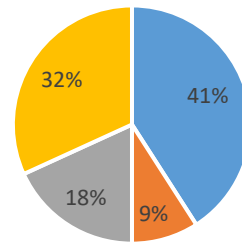
Age: 40% of those aged 46-55, and about 1/3rd of respondents in age groups 18-35 and 55-65 indicated that they had reported at least one experience of attempted coerced touching. All of the respondents who intend to report were in the 18-25 age range (25%). All of the respondents who were unsure whether they wanted to report were aged 36-45 (100%) and 66-75 (50%). The remaining respondents who did not intend to report were spread across all age groups except 36-45, ranging from 1/3rd of the age group (18-25) to 2/3rd of the age group (26-35 and 55-56).



39. Someone has touched my genitals or private areas when I did not want them to touch me.

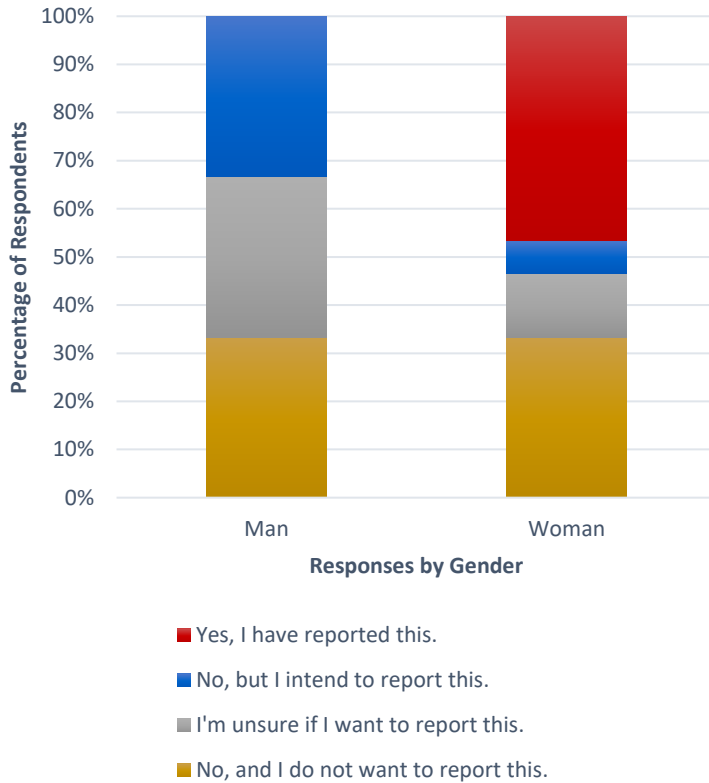
Among the 22 respondents who experienced someone commenting on their body in a way that was upsetting, 7 (32%) had reported this experience while 2 respondents (9%) indicated intending to report the experience and 9 (41%) had not reported and didn't intend to report this experience. 2 respondents (9%) were unsure whether they wanted to report this experience. 19 respondents gave non-response answers.

39. Someone prevented me from dating or engaging in sexual activity with a partner. (Reporting)



- No, and I do not want to report this.
- No, but I intend to report this.
- I'm unsure if I want to report this.
- Yes, I have reported this.

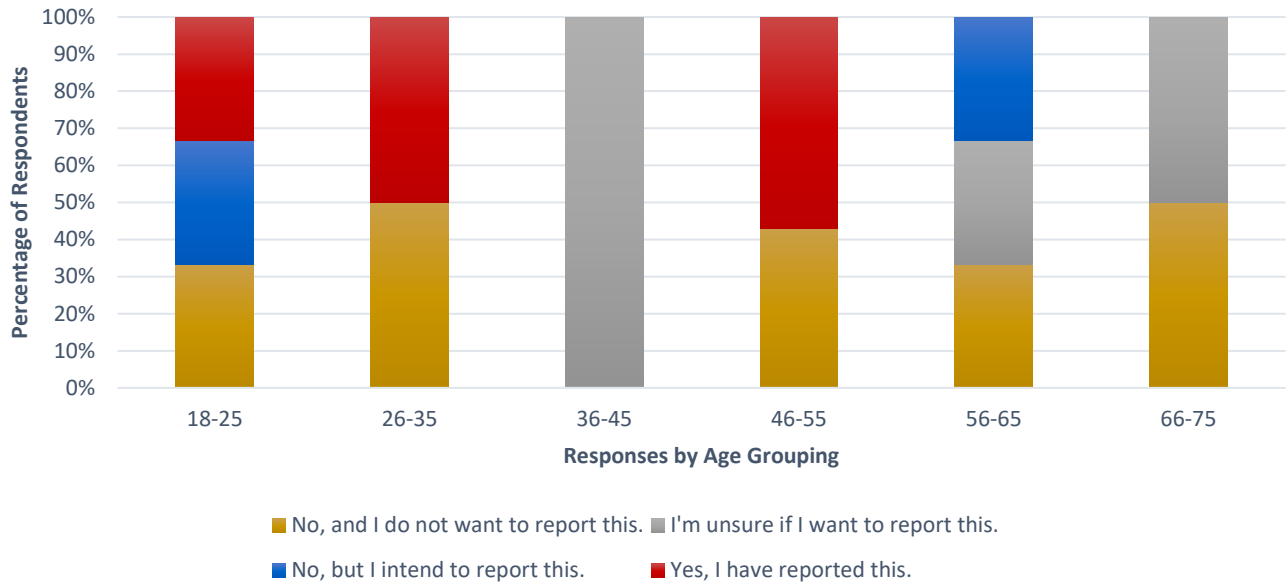
Among those who experienced: "Someone has touched my genitals or private areas when I did not want them to touch me.", what were the respondents' reporting choices? (Q39)



Gender: Among the respondents who experienced unwanted genital touching, men indicated that 1/3rd of them did not intend on reporting, 1/3rd of them was unsure if they wanted to report, and 1/3rd intend to report. About 47% of women indicated they had reported, about 33% indicated they did not intend to report, about 10% were unsure if they wanted to report, and about 5% indicated that they intend to report.

Age: Those who reported at least one incident of unwanted genital touching encompassed about 58% of those aged 46-55, 50% of those aged 26-35, and about 32% of those aged 18-25. About 1/3rd of those aged 18-25 and 56-65 indicated that they intend to report this incident. All of those aged 36-45, 50% of those aged 66-75, and about 33% of those aged 56-65 responded that they are unsure whether they want to report. Remaining responses indicating the respondent does not plan to report included 50% of those aged 26-35 and 66-67, about 42% of those aged 46-55, and about 33% of those aged 18-25 and 56-65.

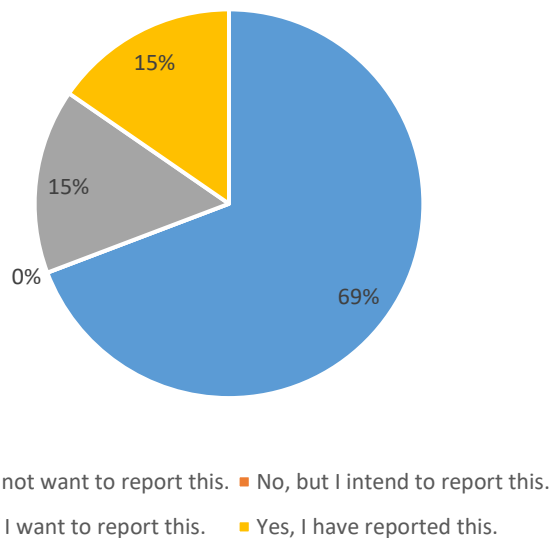
Among those who experienced: "Someone has touched my genitals or private areas when I did not want them to touch me.", what were the respondents' reporting choices? (Q39)



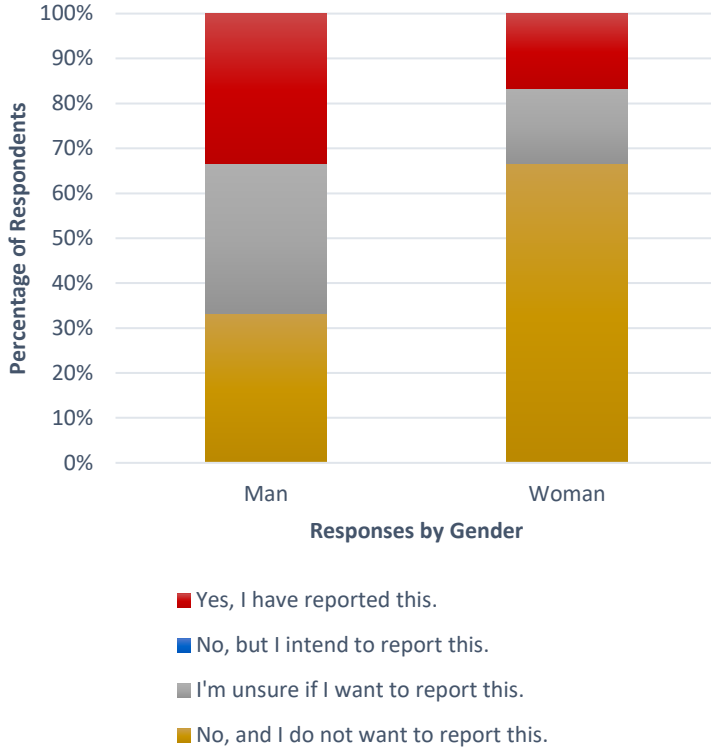
40. Someone has prevented me from dating or engaging in sexual activity with a partner.

Among the 13 respondents who experienced someone preventing them from engaging in an intimate relationship, 2 (15%) had reported this experience while no respondents indicated intending to report the experience and 9 (69%) had not reported and didn't intend to report this experience. 2 respondents (15%) were unsure whether they wanted to report this experience. 28 respondents gave non-response answers.

40. Someone has prevented me from dating or engaging in sexual activity with a partner. (Reporting)



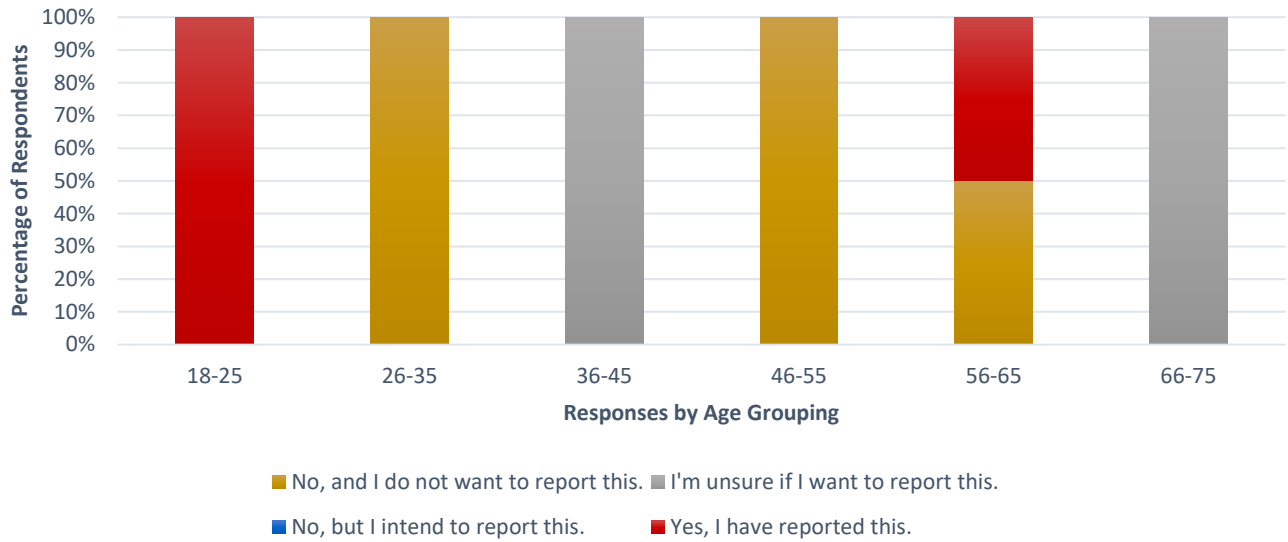
Among those who experienced: "Someone prevented me from dating or engaging in sexual activity with a partner.", what were the respondents' reporting choices? (Q40)



Gender: About 32% of men and 18% of women indicated they had reported at least one experience of being prohibited from engaging in an intimate relationship. About 66% of women and 33% of men who experienced being prohibited in at least one intimate relationship responded that they do not intend to report this experience. About 33% of men and 16% of women were unsure whether they wanted to report.

Age: Among respondents who experienced being prevented from engaging in an intimate relationship, the responses were highly siloed by age range. 100% of those aged 18-25 and 50% of those 56-65 indicated they had reported this experience. 100% of those aged 26-35 and 46-55, and 50% of those aged 56-65 responded that they do not intend to report. 100% of those aged 36-45 and 66-75 indicated they are unsure whether to report.

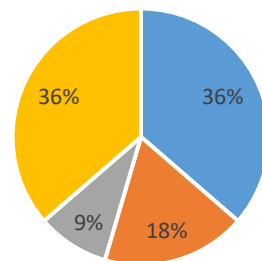
Among those who experienced: "Someone prevented me from dating or engaging in sexual activity with a partner.", what were the respondents' reporting choices? (Q40)



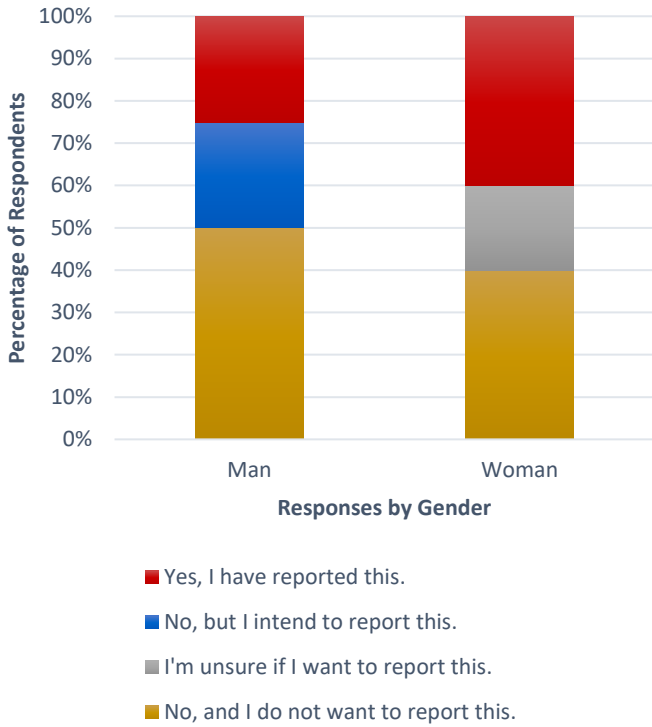
41. Someone withheld services from me unless I did something they wanted me to do, even if I was uncomfortable with their request.

Among the 11 respondents who experienced someone withholding services unless they complied with a request, 4 (36%) had reported this experience while 2 respondents (18%) indicated intending to report the experience and 4 (36%) had not reported and didn't intend to report this experience. 1 respondent (9%) was unsure whether they wanted to report this experience. 14 respondents gave non-response answers.

41. Someone withheld services from me unless I did something they wanted me to do, even if I was uncomfortable with their request. (Reporting)



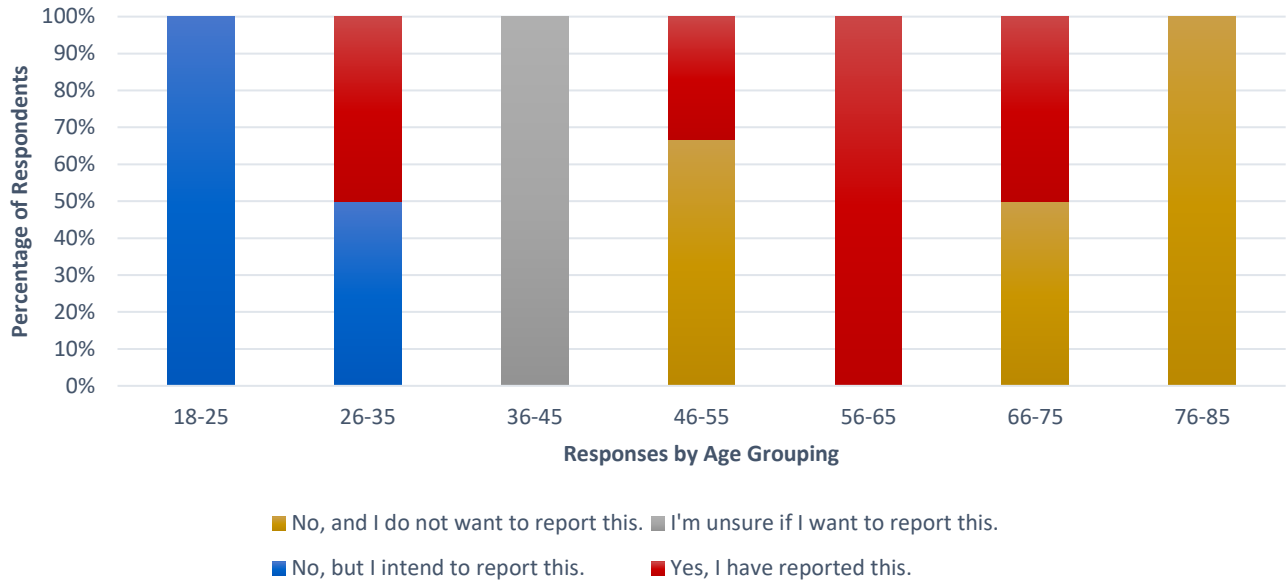
**Among those who experienced:
 "Someone withheld services from me
 unless I did something they wanted me to
 do, even if I was uncomfortable with the
 request.", what were the respondents'
 reporting choices? (Q41)**



Gender: Among the respondents who experienced services being withheld without compliance, 40% of women and 25% of men indicated they had reported this experience. 25% of men indicated they intend to report and 20% of women indicated they were unsure whether they wanted to report. 50% of men and 40% of women indicated they do not intend to report.

Age: Among respondents who experienced services being withheld based on their compliance, responses were highly siloed by age range. All those aged 56-65, 50% of those aged 26-35 and 66-76, and about 33% of those aged 46-55 indicated they had reported at least one of these kinds of experiences. All those aged 18-25 and half of those aged 26-35 indicated they intend to report. All of the respondents who were unsure whether they wanted to respond were aged 36-45 (100%). All of those aged 76-85, about 67% of those aged 46-55, and half of those aged 66-75 indicated they do not plan to report this experience.

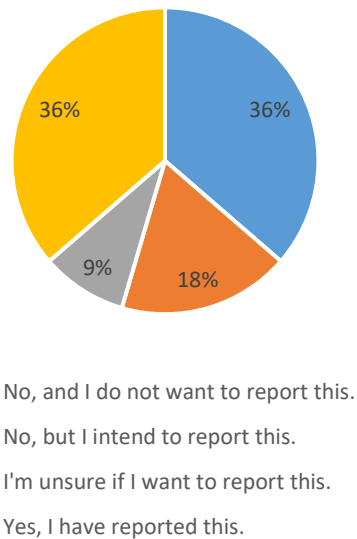
Among those who experienced: "Someone withheld services from me unless I did something they wanted me to do, even if I was uncomfortable with the request.", what were the respondents' reporting choices? (Q41)



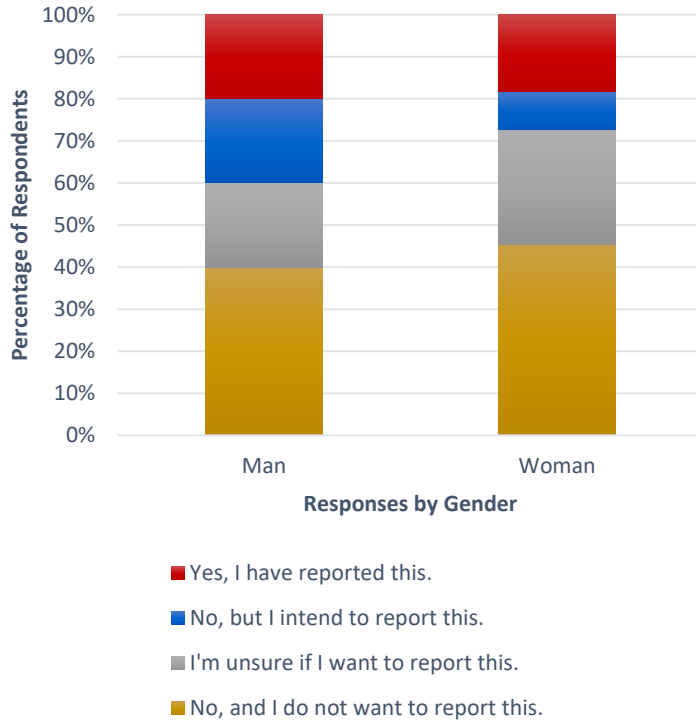
42. A service provider spoke about my body and health to others as if I was not present or not able to provide information about my own body.

Among the 20 respondents who experienced a service provider speaking about their body as if they were not present or able to provide information about themselves, 3 (15%) had reported this experience while 2 respondents (10%) indicated intending to report the experience and 40 (59%) had not reported and didn't intend to report this experience. 7 respondents (35%) were unsure whether they wanted to report this experience. 21 respondents gave non-response answers.

42. A service provider spoke about my body and health to others as if I was not present or not able to provide information about my own body. (Reporting)



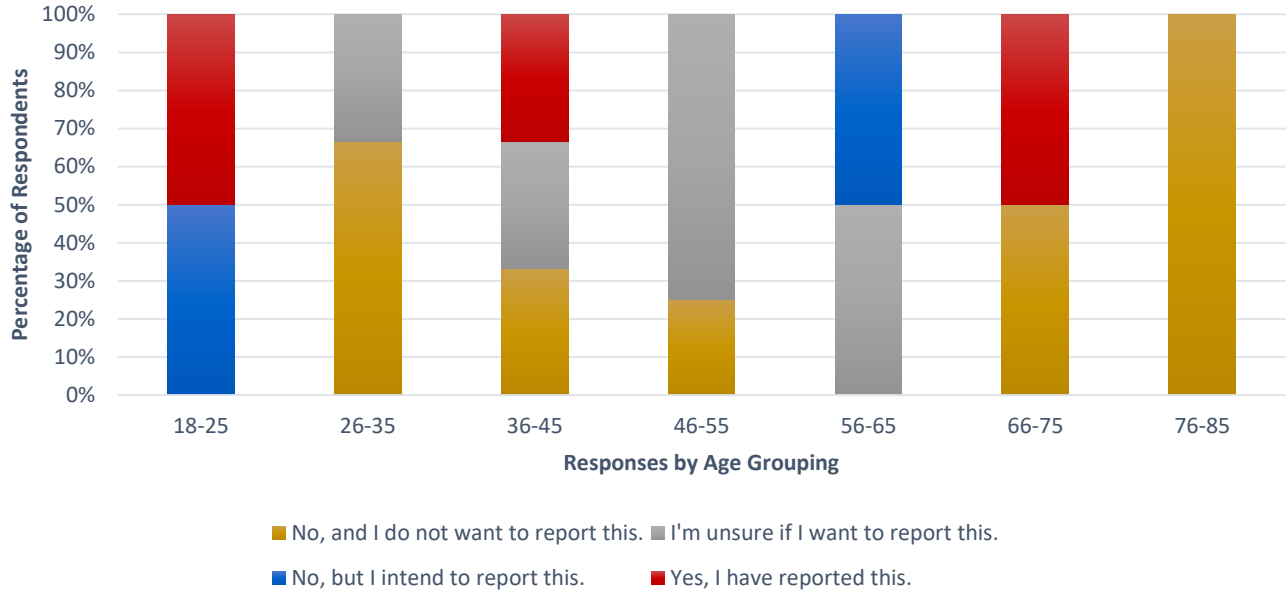
Among those who experienced: "A service provider spoke about my body and health to others as if I was not present or not able to provide information about my own body.", what were the respondents' reporting choices? (Q42)



Gender: Among those who experienced a service provider speaking over/for the person, About 20% of men and 18% of women indicated they had reported at least one of these incidents, while 20% of men and about 7% women indicated they planned to report. About 45% of women and 35% of men responded that they would not report this, and about 30% of women and 20% of men were unsure whether they wanted to report.

Age: Half of those aged 18-25 and 66-75, and about 33% of those aged 26-35 reported an experience being ignored indicated they did report the experience. Half of those aged 18-25 and 56-65 intended to report this experience. All those aged 76-85, about 66% of those aged 26-35, half of those aged 66-75, a third of those aged 36-45, and about a fourth of those aged 46-55 responded that they do not intent to report. Those who were unsure whether they wanted to report were distributed across ages 26-65, including 75% of those aged 46-55 and half of those aged 56-65.

Among those who experienced: "A service provider spoke about my body and health to others as if I was not present or not able to provide information about my own body.", what were the respondents' reporting choices? (Q42)



Demographic Question Results

Disability Experiences

The question requesting disclosure of the respondents' disabilities provide respondents with 6 disability "types" to select from as well as an option to convey they experience a disability not covered by the discrete response options. This question was formatted as a multiselect (non-mutually exclusive response options) question so that respondents could identify all their disabilities. Out of 34 respondents who disclosed their disabilities, 20 (59%) are neurodivergent, 13 (38%) experience chronic illness as a result of biological differences (genetics, autoimmunity, etc), 11 (32%) have a physical disability, 8 (24%) have a cognitive and developmental disability (IDD), 8 (24%) have a sensory disability, and only 2 (6%) experience a pathogen-based chronic illness. 4 respondents (12%) also have disabilities not covered by the previous categories and 7 (17% of all respondents) did not respond to the question.

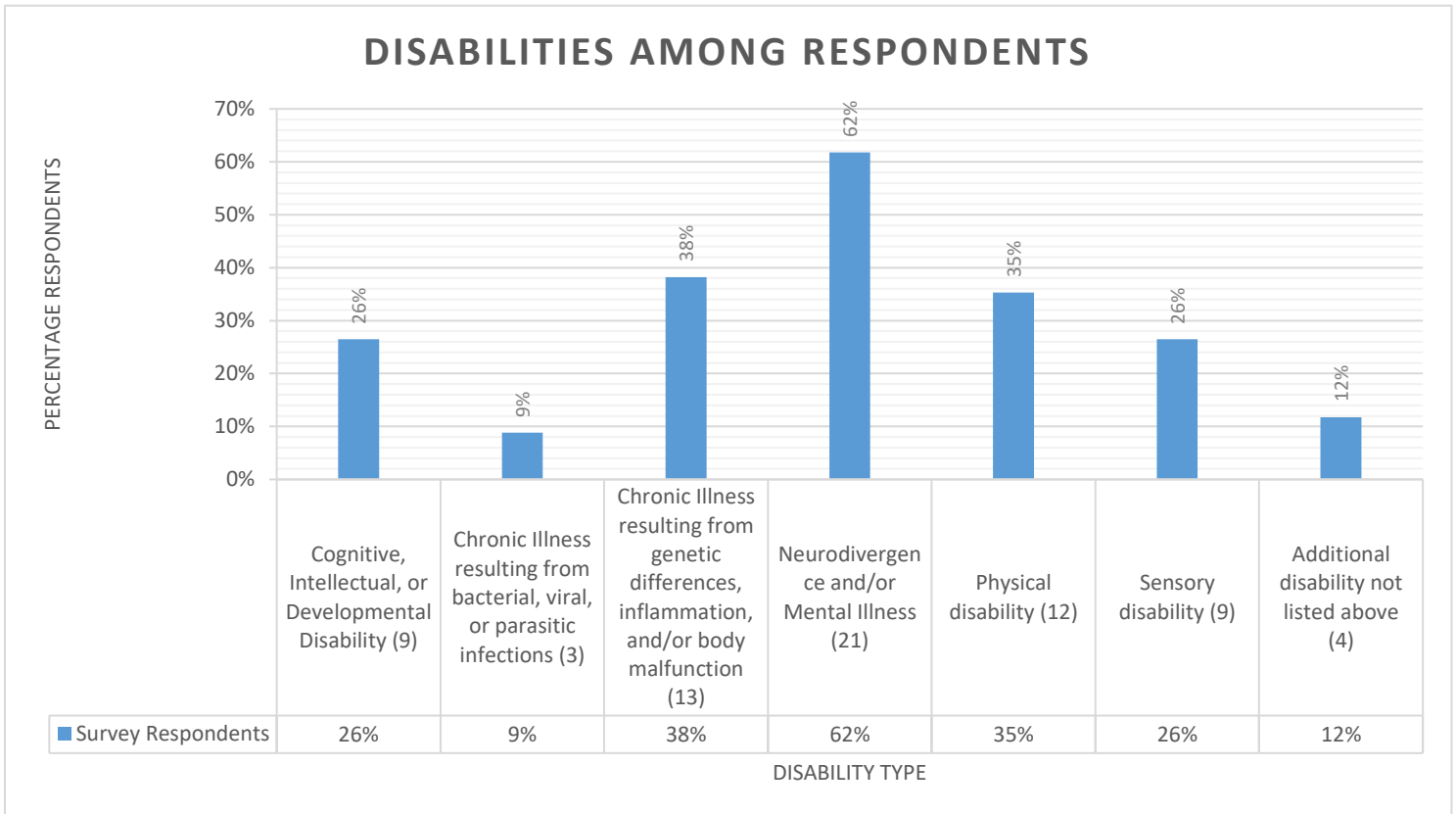
Q18. Please let us know which disabilities you experience. Please select all that apply to you.

The image shows a survey question with six options, each in a rectangular box. The third and fourth options are highlighted in green, indicating they are selected. The options are:

- Cognitive, Intellectual, or Developmental Disability (examples: down syndrome, traumatic brain injury, cerebral palsy, fetal alcohol syndrome)
- Chronic Illness resulting from bacterial, viral, or parasitic infections (examples: chronic lyme disease, HIV, HPV)
- Chronic Illness resulting from genetic differences, inflammation, and/or body malfunction (examples: diabetes, cystic fibrosis, Chrones disease, chronic fatigue syndrome)
- Neurodivergence and/or Mental Illness (examples: autism, ADHD, bipolar, attachment or personality disorders, depression, post-traumatic stress disorder)
- Physical disability (examples: spinal cord injury, muscular dystrophy, arthritis)
- Sensory disability (Deaf, Hard of Hearing, Blind, Low Vision, etc)
- Additional disability not listed above

Image description: A screen shot of the survey question, "Please let us know which disabilities you experience. Please select all that apply to you." Below the question/prompt are 6 disability type options including 1. Cognitive, Intellectual, or Developmental Disability (examples: down syndrome, traumatic brain injury, cerebral palsy, fetal alcohol syndrome), 2. Chronic Illness resulting from bacterial, viral, or parasitic infections (examples: chronic lime disease, HIV, HPV), 3. Chronic Illness resulting from genetic differences, inflammation, and/or body malfunction (examples: diabetes, cystic fibrosis, Chrones disease, chronic fatigue syndrome), 4. Neurodivergence or Mental Illness (examples: autism, ADHD, bipolar, attachment or personality disorders, depression, post-traumatic stress disorder), 5. Physical disability (examples: spinal cord injury, muscular dystrophy, arthritis), 6. Sensory disability (Deaf, Hard of Hearing, Blind, Low Vision, etc.), as well as a final option, "Additional disability not listed above". In this sample image, options 3 and 4 are selected.

While it would be interesting to compare our disability demographics with Indiana and Indiana counties, the [American Communtiy Survey](#) data does not provide recent disability demographic data and the ACS/U.S. Census data on people with disabilities is very limited. For many years, the ACS has generally found that about 19% of Indiana’s population experiences a disability based on their criteria. Based on Indiana’s population being about 6,700,000 as of 2019, this suggests that there are about 1,273,000 people with governmentally recognized disabilities in Indiana. Currently, the ACS does not request demographic data for the various disabilities we have gathered here. Instead, they specifically collect demographic data on people with disabilities based on a few criteria regarding what the person “cannot” do based on non-disabled standards. These categories include those “with hearing difficulty”, “with independent living difficulty”, “with ambulatory difficulty”, “with vision difficulty”, “with self-care difficulty”. This data also does not include informal diagnoses.



We chose to collect data differently than the government currently does for a number of reasons. First, we do not operate from a “deficits” model of disability. We do not find value is exclusively collecting data from people based on what they are seen to be unable to do based on non-disabled perceptions. Additionally, the U.S. government model of collecting information on disability is too limited as it does not provide a comprehensive look at disability types and experiences, it ignores strengths-based aspects of disabilities, and does not recognize the immense difficulty people with disabilities often have in acquiring a formal diagnosis and other forms of government recognition and support.

Developing categories for disabilities is tremendously difficult due to how easily disabilities may overlap, the fact that many people have multiple disabilities, not all people with disabilities agree with what constitutes a disability, and the categorization of disabilities is often culturally, historically, and medically complex. For example, people who are Deaf and/or hard of hearing often consider themselves a cultural and linguistic minority, not as people with disabilities. Other Deaf folks may consider themselves as neurodivergent, as someone with a developmental disability, or even as having a physical disability. Other people who are Deaf may consider it offensive to be listed as someone with a physical disability or developmental disability.

Among those who were willing to further describe their disabilities in a follow-up free response question, respondents described experiencing the following disabilities described below. Individuals often listed multiple disabilities, but for anonymity, we have listed each disability identified individually. Disabilities are generally categorized by the survey response options. If there are multiple responses indicating the same disability, the clinical diagnosis is listed along with the number of respondents who disclosed that disability, followed by the language provided by the respondents. Other than single letter spelling corrections (for clarity) language used below is exact language used by respondents.

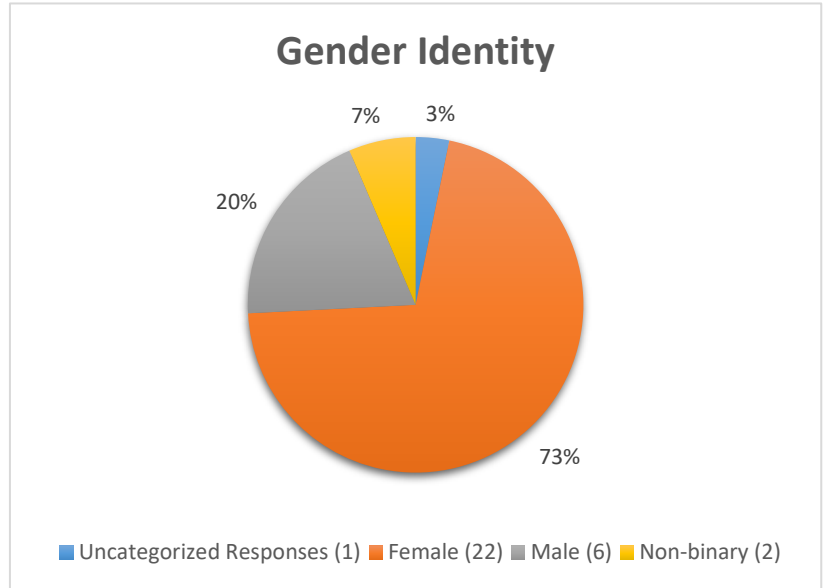
- Cognitive and developmental disability (IDD) (26%)
 - Autism
 - Mild mental retardation
- Chronic illness caused by a pathogen (9%)
 - Polio & post-polio syndrome
 - Chronic lyme disease
- Chronic illness as a result of biological differences (genetics, autoimmunity, etc) (38%)
 - Fibromyalgia (N=2)
 - Charcot Marie Tooth (Degenerative neuromuscular disorder)
 - Lupus
 - Mastocytosis
- Neurodivergence (62%)
 - ADHD (N=2)
 - Anorexia (N=2, “Anorexia” and “Atypical Anorexia”)
 - Bipolar
 - Depression (N=5, “Clinical depression”, “Depression”, “Major Depressive Disorder”)
 - Generalized anxiety (N=4 “Anxiety” and “Generalized anxiety”)
 - Panic attacks
 - PTSD (N=2, “PTSD” and “cPTSD”)
 - Traumatic Brain Injury (TBI)
- Physical disability (35%)
 - Avascular necrosis in multiple joints
 - Chronic migraines
 - Chronic pain
 - Cirrhosis of the liver
 - Ehlers Danlos Syndrom, hyperflexible variation (hEDS)
 - Irritable Bowel Syndrome (IBS)
 - Lymphangiomatosis, lymphadema, mixed lymphangioma
 - Multiple symptom atrophy
 - Paraplegia wheelchair user
 - Walking cane user
- Sensory disability (26%)
 - Deaf
 - Blind since birth
 - Sensory processing differences

Gender Identity

Q11. Please describe your gender:

Image description: A screen shot of the survey question, "Please describe your gender:"

The question requesting disclosure of the respondents' gender was open response. Out of 31 respondents who disclosed their gender, 22 (73%) were women, 6 (20%) were men, and 2 were non-binary (7%). 1 respondent provided a response that could not be categorized (3%). 10 respondents (24% of all respondents) did not disclose their gender.

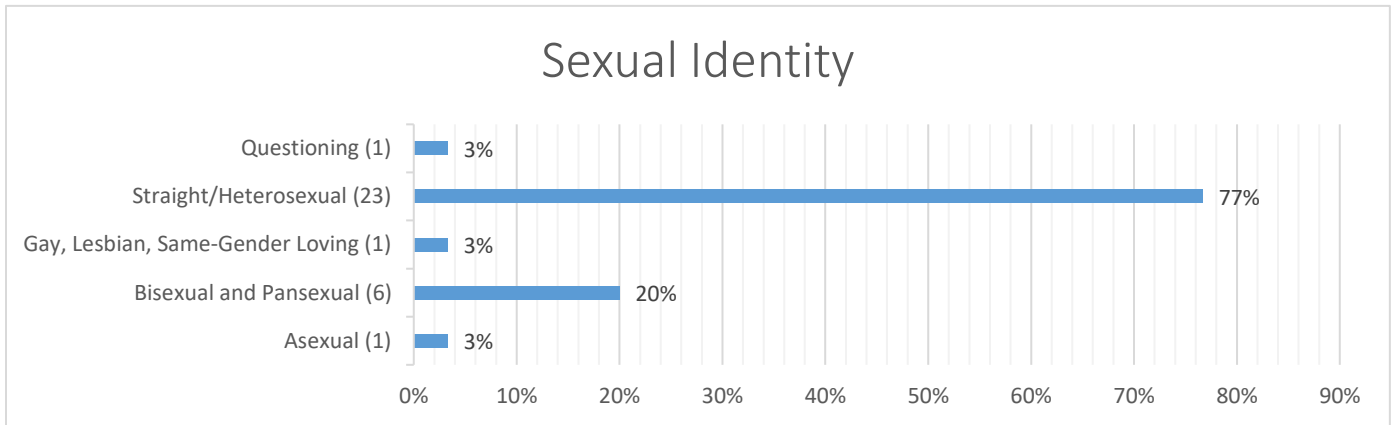


Sexual Identities

Q12. Please describe your sexual identities (for example, gay, pansexual, asexual, heterosexual, etc):



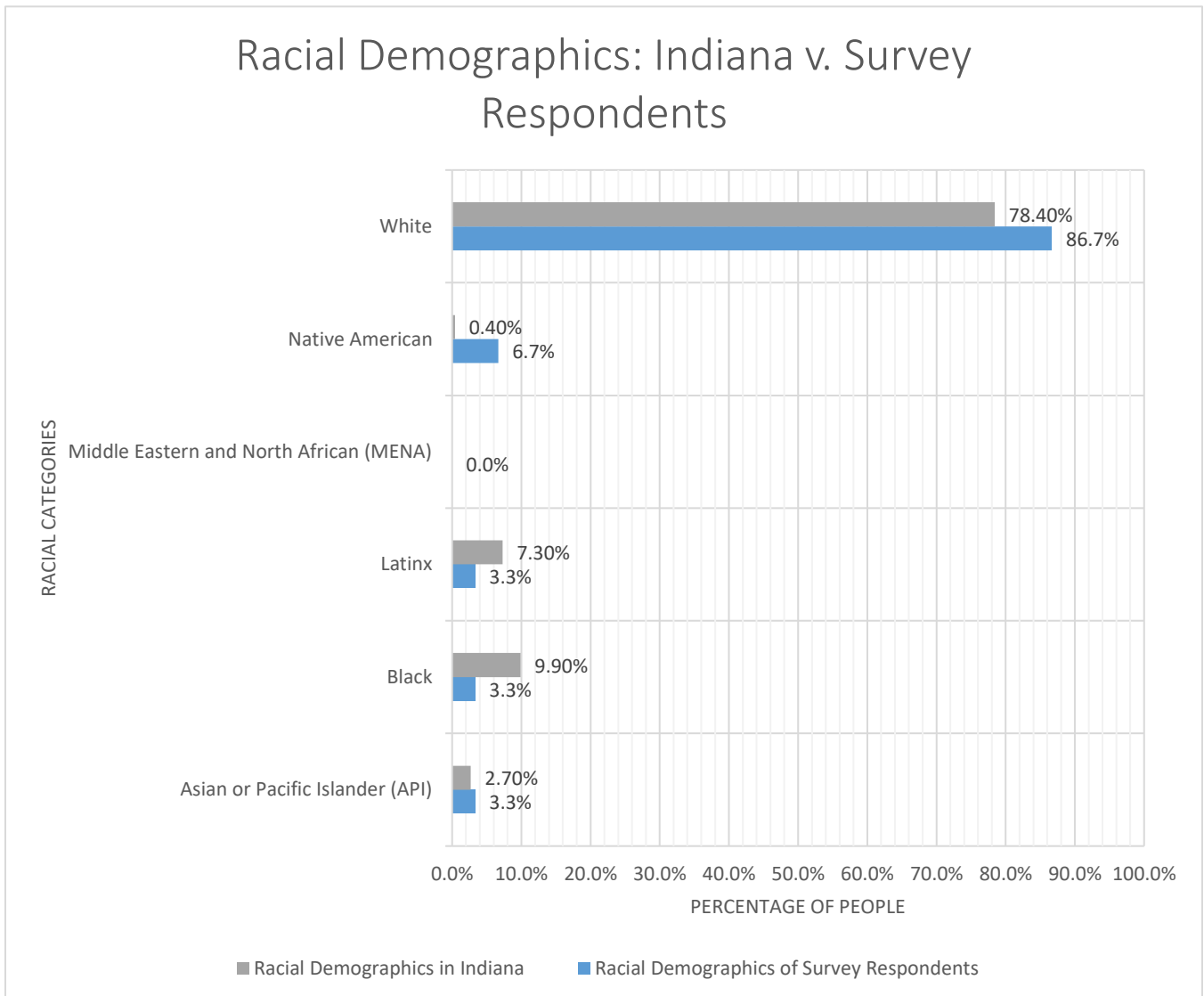
Image description: A screen shot of the survey question, “Please describe your sexual identities (for example: gay, pansexual, asexual, heterosexual, etc.):”



The question requesting disclosure of the respondents’ sexual identities was open response (non-mutually exclusive options). Out of 30 respondents who disclosed their gender, 23 (77%) were straight, 6 (20%) were bisexual or pansexual, 1 (3%) was lesbian , 1 was asexual, and 1 was questioning. 11 respondents (27% of all respondents) did not disclose their sexual identities.

Racial Identity

The question requesting disclosure of the respondents’ race and ethnicity was open response (non-mutually exclusive options). Out of 30 respondents who disclosed their race, 26 (87%) were white, 2 (7%) were Native American, 1 (3%) was Latinx, 1 was Black, and 1 was Asian or Pacific Islander. There were no responses from self-disclosed Middle Eastern or North African peoples and 11 respondents (27% overall) did not disclose their racial or ethnic identities. 1 individual was biracial. Based on [2020 U.S. Census Data](#), this means that White people were over-represented by almost 8 percentage points and Indigenous people were over-represented by 6 percentage points among survey respondents compared to Indiana generally. The survey respondents significantly under-represented Black and Latinx people compared to Indiana while Asian and Pacific Islander (API) survey respondents and Indiana residents were represented fairly equally. The U.S. Census does not count Middle Eastern or North African as a racial group demographics, yet, and we did not receive any MENA responses. However, the number of survey respondents is so small that we cannot ascribe statistical significance to our percentages of participants by racial group compared to U.S. Census Data.



Faith Background & Orientation

The questions requesting disclosure of the respondents' faith background and current faith orientation were both open response. The first question read, "What faith or religious community did you grow up in, if any?" and the second question read, "What faith or religious community do you belong to now, if any?" Responses were then placed into common faith and non-faith groups represented in the U.S. Below includes a detailed explanation of the responses included in each category for those categories which had multiple responses.

- **Agnostic**
- **Athiest:** "athiest", "not applicable", "none"
- **Buddhist**
- **Catholic:** "Catholic", "Catholicism, Christianity", "Roman Catholic"
- **Christian Protestant Evangelical or Fundamentalist:** "fundamentalist", "Southern Baptist", "Pentecostal", "Missouri Synod Lutheran", "Nazarine", "Brethren", "Baptist", "Community"
- **Christian Protestant General:** "Protestant", "Christian", "Methodist", "Church of England", "Christian, in various denominations", "Reconciling United Methodist", "Non-denominational", "non-denominational christian", "christian, questioning", "Quakers"
- **Christian Orthodox**
- **Hindu**
- **Jewish**
- **Muslim**
- **Pagan:** Wiccan
- **Sikh**
- **Other:** "Unicult"*

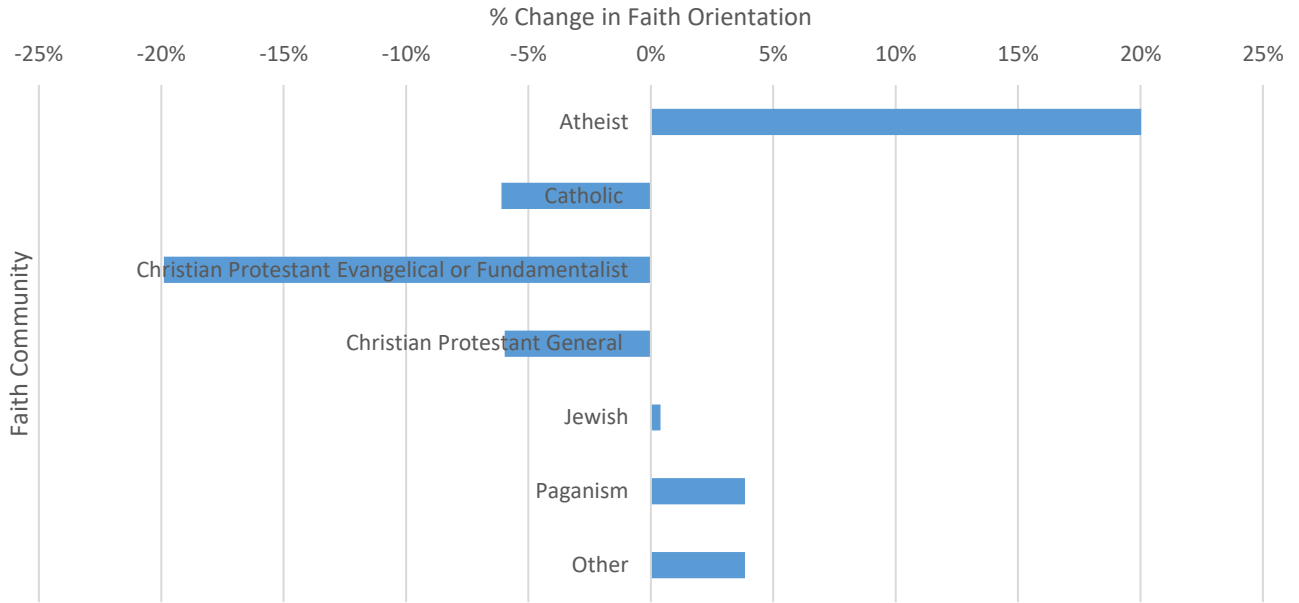
*Note: Unicult is a semi-spiritual movement originating from one user on Tiktok. It does, in fact, have many qualities in alignments with cult organizations such as undue influence and an enmeshment in disinformation and conspiracies. Given these qualities and the fact that it's not affiliated with any organized religion or larger faith community, it is in an "other" category.

Faith Background: Out of 29 respondents who disclosed their faith background, 14 (86%) came from a general protestant background, 8 (28%) came from an Evangelical background, 4 (14%) came from Catholic backgrounds, 2 (7%) were raised in athiest households, 1 (3%) came from a Jewish background. 12 respondents (29% overall) did not disclose their faith background.

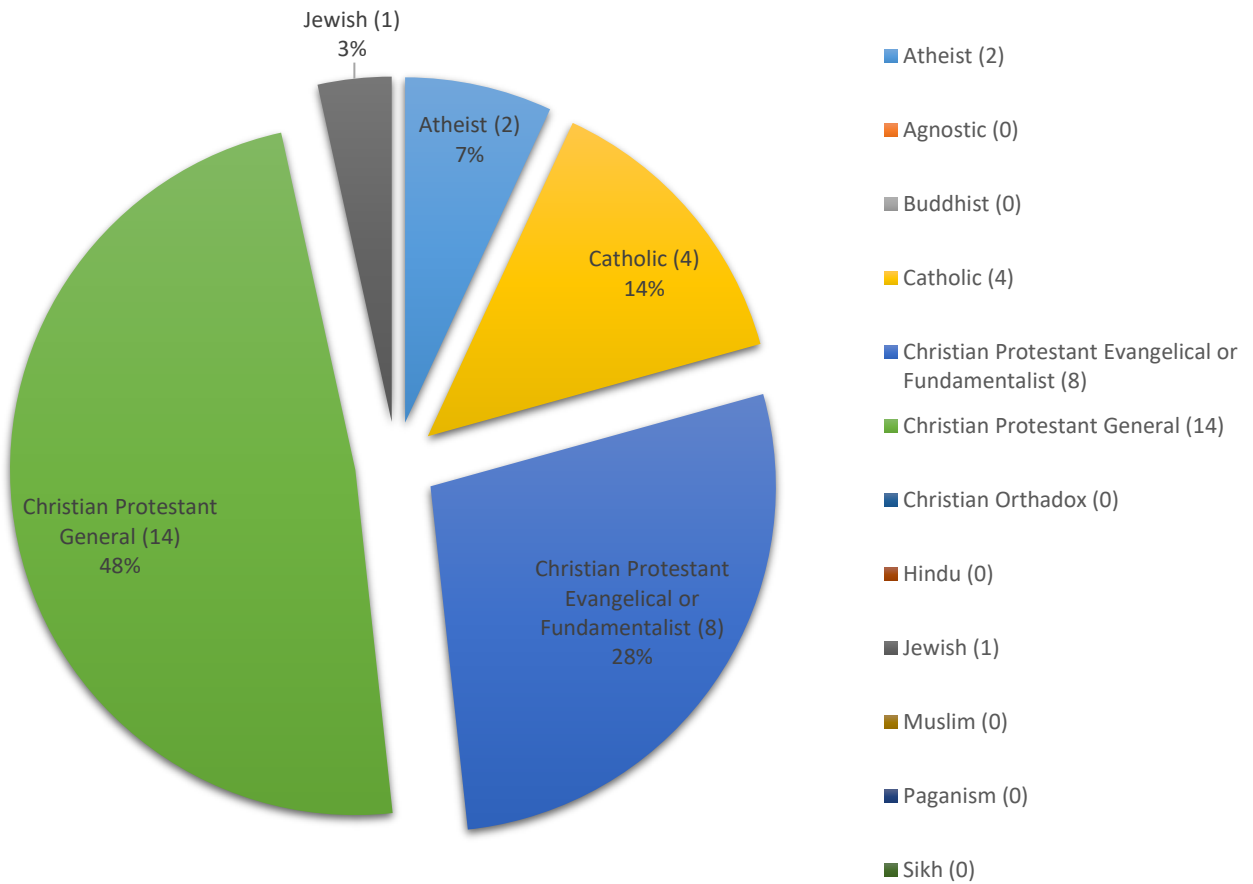
Faith Orientation: Out of 26 respondents who disclosed their current faith or non-faith orientation, 11 (42%) were general or mainline protestants, 7 (27%) were Athiest, 2 (8%) were Evangelical, 2 (8%) were Catholic, 1 (4%) was Jewish, 1 (4%) was Wiccan, 1 (4%) was Agnostic, and 1 (4%) was in "unicult".

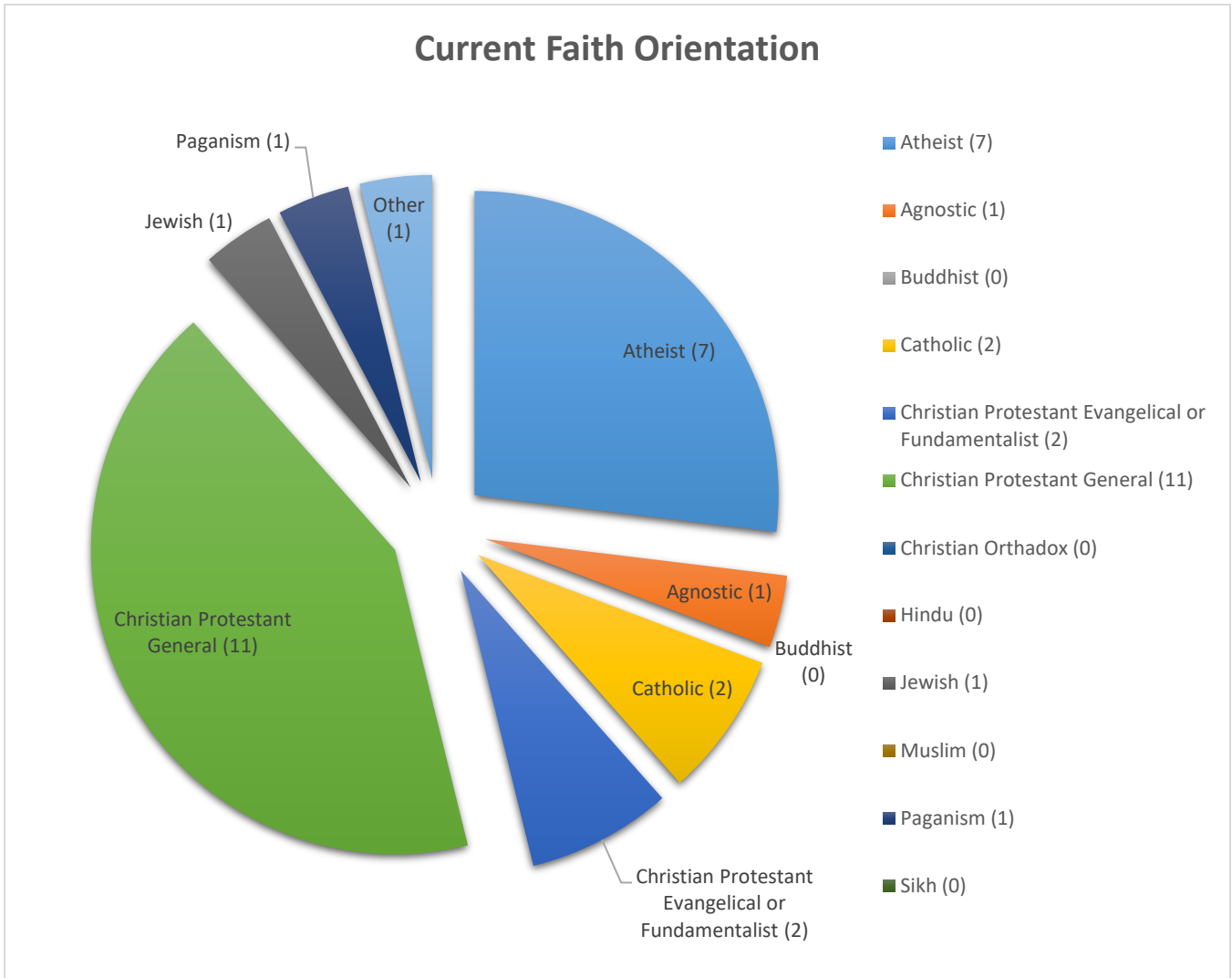
Shifts in Faith: Overall, respondents shifted away from Evangelical christianity, protestant christianity, and Catholicism and shifted towards athiesm in adulthood. Among those whose faith identity changed from adolescence to adulthood 3 Protestants and 2 Catholics became Athiests, 3 Evangelicals became mainline Protestants, 1 Evangelical became a Pagan, and 1 Evangelical became Agnostic. 1 Evangelical continued ascribing to Evangelicalism but changed branches/sects. 1 Evangelical became a follower of unicult.

Shifts in Faith Orientation Between Adolescence & Adulthood



Faith Background

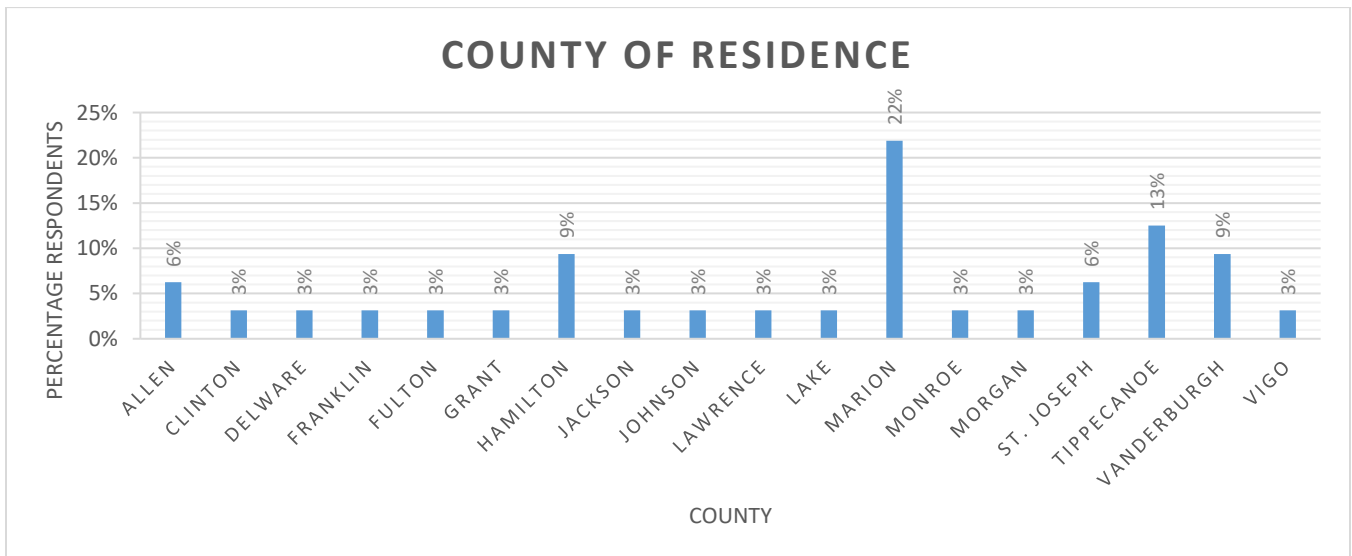




Respondent County of Residence

Out of 41 respondents, 32 individuals disclosed residing in 17 out of 92 Counties in Indiana, while 9 people (22% of respondents) declined to disclose their county of residence. To access how effectively the survey reached all Indiana regions and counties, the counties listed may be grouped by the Indiana Statewide Independent Living Council (INSILC) Center [Regions](#) (plus underserved counties). Indiana Counties listed below in alphabetical order and grouped by INSILC Center Regions. Respondents disclosed residing in 9 out of 10 INSILC Center Regions. Respondent counties of residence are underlined in the organized bullet points below. Additionally, the 4 counties (Marion, Tippecanoe, Vangerburgh, Hamilton) with the greatest number of respondents are located in 3 different regions of Indiana. This distribution indicates an effectively broad scope of reach regarding survey marketing, especially given that there were 41 respondents in total and all marketing was conducted online (email, social media, webinars/speaking engagements).

- **INSILC Region 1 (Greater Indianapolis Doughnut Counties):** Boone, Hamilton, Hancock, Hendricks, Johnson, Marion, Morgan, Shelby
- **INSILC Region 2 (Southwest Counties):** Daviess, Dubois, Gibson, Greene, Knox, Martin, Pike, Sullivan (plus unserved: Perry, Posey, Spencer, Vanderburgh, Spencer)
- **INSILC Region 3 & 4 (Northwest Counties):** Lake, Porter (plus unserved: Benton, Carroll, Cass, Clinton, Elkhart, Foutain, Fulton, Jasper, La Porte, Marshall, Miami, Montgomery, Newton, Pulaski, St. Joseph, Starke, Tippecanoe, Wabash, Warren, White)
- **INSILC Region 5 (Central Northeast Counties):** Blackford, Delaware, Grant, Howard, Madison, Randolph, Tipton
- **INSILC Region 6 (East Central Counties):** Decatur, Fayette, Franklin, Henry, Rush, Union, Wayne
- **INSILC Region 7 (Central South Counties):** Bartholomew, Brown, Crawford, Jackson, Lawrence, Monroe, Orange, Washington (unserved: Clark, Crawford, Floyd, Harrison)
- **INSILC Region 8 (Southeast Counties):** Dearborn, Jefferson, Jennings, Ohio, Ripley, Scott, Switzerland
- **INSILC Region 9 (Northeast Counties):** Adams, Allen, DeKalb, Huntington, Jay, Kosciusko, LaGrange, Noble, Steuben, Wells, Whitley
- **INSILC Region 10 (West Central Counties):** Clay, Owen, Parke, Putnam, Vermillion, Vigo



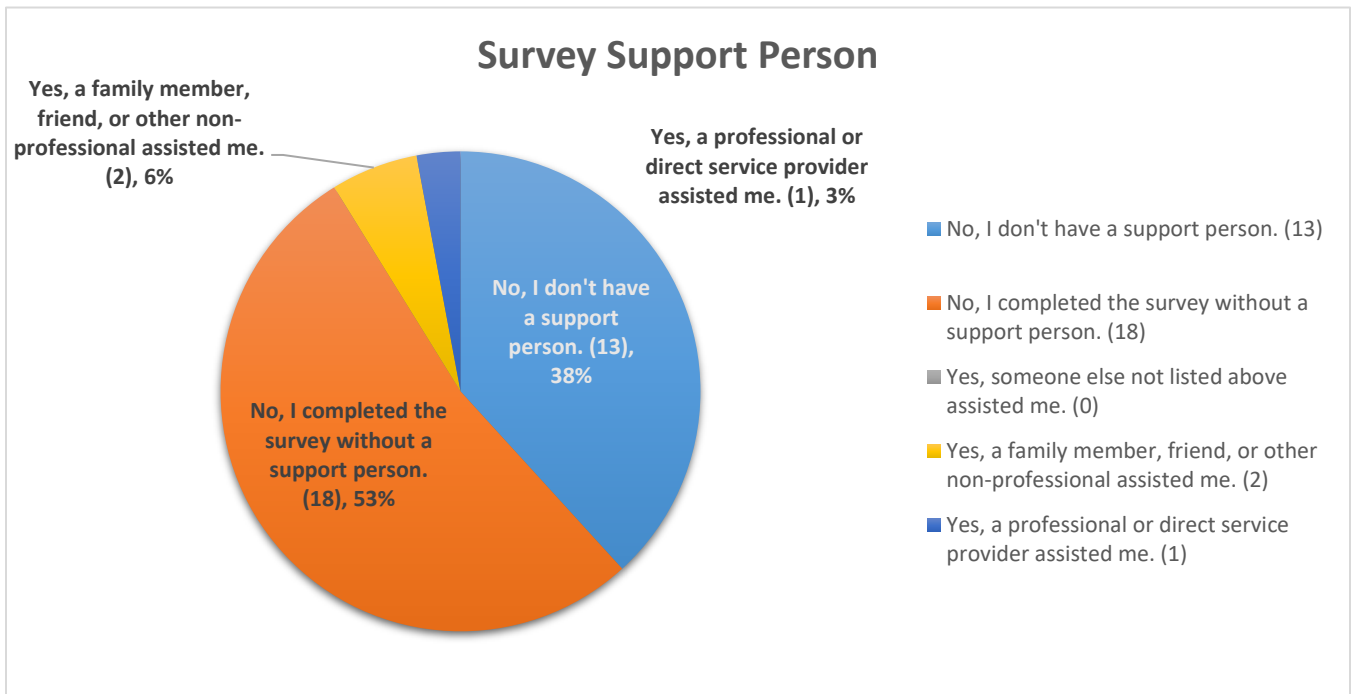
Support Person Data

“Did you complete this survey with the assistance of a support person? Please select any responses that reflect how you completed the Survey.” Out of the 34 people who responded to this question, 18 (53%) did not complete the survey with a support person (but suggests they do have a support person) and 13 (38%) stated they do not have a support person. 2 individuals (6%) indicated that a family member or other non-professional support person helped them and 1 individual (3%) indicated that a professional support person helped them complete the survey.

Q20. Did you complete this survey with the assistance of a support person? Please select any responses that reflect how you completed the survey.

- Yes, a professional or direct service provider assisted me.
- Yes, a family member, friend, or other non-professional assisted me.
- Yes, someone else not listed above assisted me.
- No, I completed the survey without a support person.
- No, I don't have a support person.**

Image description: A screen shot of the survey question, “Did you complete this survey with the assistance of a support person? Please select any responses that reflect how you completed the Survey.” This image has the last response option out of 5 options, “No, I don't have a support person.” Selected.



Addendum

Survey Format

Survey introduction provides information about the survey purpose, respondent eligibility, response guidance, and disability and survivor support. Likert scale questions 1 – 20 (Section 1) were focused on experiences of bodily and sexual harm and empowerment as well risk and protective factors related to sexual violence among people with disabilities while under the age of 18. Section 1 concludes with a free response question to gain ideas from respondents about how caregivers and mentors could have better educated them about safer sex and healthy sexuality as a young person.

Likert scale questions 21 – 28 (Section 2) focused on the risk and protectors factors related to sexual violence among adults with disabilities in Indiana. This section concluded with two open response questions about how the respondents faith background impacted their experiences with their disability and sexuality.

Likert scale questions 29 – 35 (Section 3) asked respondents to identify ways they have felt harmed by others or disempowered to advocate for themselves. Likert scale questions 36 – 42 (Section 3) then invite respondents to explain whether they have or intend to report any of the incidents of harm listed in questions 29-35. Section 3 concludes with a free response question asking how the report was concluded if the respondent has ever reported harm by a service provider. This question was included to identify how thorough and clear the reporting response process is from the perspective of survivors with disabilities.

Final questions ask the respondent about their identities including gender, sexuality, race, age, faith, county of residence, disabilities, and the involvement of a support person. At the ends of section 1 and 3, respectively, are free response questions inviting respondent feedback to improve the survey.

Survey Introduction

The following text is in the first “introduction” portion of the survey. Respondents must confirm they understand and agree to the information provided in the intro.

Welcome!

Welcome to the official "Body Wellness & Independence Among Hoosiers with Disabilities Survey" for adults with disabilities in Indiana. This survey was created by a coalition of people with disabilities and people without disabilities, self-advocates, service providers and professionals, and caregivers through the Indiana Disability Justice Task Force (IDJ).

Survey Purpose

This survey seeks to identify whether people with disabilities in Indiana are experiencing sexual violence, sexual harassment, and bodily restriction; and if people with disabilities in Indiana are experiencing access to information about bodily autonomy, sexuality, and supported sexual and romantic decision-making. We hope that this preliminary assessment sheds light on the magnitude of healthful and harmful experiences people with disabilities in Indiana are experiencing, especially in regards to sexual and romantic wellness.

Who May Complete This Survey

Any adults with disabilities who are residing in Indiana may participate. "Disability" for the purposes of this survey follows the social model for disability. Therefore, disability may include developmental and cognitive disabilities, physical disabilities, mobility disabilities, sensory disabilities, chronic illness, neurodivergence, mental illness, etc. Please feel free to invite a caregiver, friend, or other trusted support person to help you complete the survey.

Anonymity and Confidentiality

All information submitted in this survey will be completely anonymous as well as confidential. The settings for this survey are such that no personally identifiable information will be collected. Data analysts and project leaders will not be able to ever connect an individual survey to any individual person. The responses will be released only as part of a group summary in which no individuals' answers can be identified.

How Survey Responses Will be Used

The purpose of this survey is to gain an understanding of the body and sexual health experiences of people with disabilities as self-reported by people with disabilities. Therefore, data collected will mostly be presented as a whole so that data analysts can look for larger trends. All information shared in this survey will be used only by the IDJ and our collaborators to better guide the coalition's efforts to support body and sexual wellness of people with disabilities in Indiana. This may include (but is not limited to) developing more detailed or updated surveys in the future, advocating for changes in policies at service provision agencies, applying for greater grant funding for more robust sexual violence prevention programming, and/or developing educational campaigns to support comprehensive sexuality and healthy relationship education for people with disabilities, caregivers, and service providers, among other strategies.

Participation Options

Ways to participate in this survey include online or on a paper survey which can be mailed to you. To request a paper survey be mailed to you, please email indisabilityjustice@gmail.com or text or call Skye Kantola at 317-721-4294.

Brief Guidance to Support Persons

If you are assisting a person with a disability to complete this survey, be mindful to clearly convey the meaning of questions and response options. Do not encourage a particular response to the questions based on your beliefs regarding the questions.

Definitions

Please find a [list of definitions](https://indisabilityjustice.org/definitions-related-to-disability-justice-and-sexual-wellness/) for various words used in this survey: <https://indisabilityjustice.org/definitions-related-to-disability-justice-and-sexual-wellness/>. **We recommend that you open the Definitions page (by clicking on the link) in another tab for reference as you complete the survey.**

Resources

Here is a list of statewide and by-county [sexual violence and domestic violence resources](https://indisabilityjustice.org/sexual-domestic-violence-organizational-resource-list/) in Indiana: <https://indisabilityjustice.org/sexual-domestic-violence-organizational-resource-list/>.

Here is a list of statewide and by-county [disability services resources](https://indisabilityjustice.org/disability-services-in-indiana-resource-list/) in Indiana: <https://indisabilityjustice.org/disability-services-in-indiana-resource-list/>.

By continuing with this survey, you (the survey respondent) are indicating that you understand all the guidelines and survey information provided here and you agree to participate in this survey with the understanding of how information will be used and how it will not be used..

A Major Limitation: Religion

During the pilot of this survey, respondents requested that we add questions about religion and faith, which we did. We asked respondents both about the faith they were raised in, if any, and what faith they currently practice, if any. The detailed demographics are included in the Demographics section. However, we lacked the resources to complete a cross analysis of how faith background and practice impacted the experiences of respondents as we did with gender and age.

In the pilot survey and this one, some of the respondents indicated religion being used against them as disabled people. As a third of the respondents came from an evangelical background, almost half came from a non-evangelical protestant background, and most of the remainder came from a Catholic background, religious cultural norms definitely played some factor in the experiences of sexual wellbeing and harm among disabled people in Indiana. In particular, Christianity is sometimes applied in a way that encourages people to treat disabled people as “eternal children”, or a “curse” on themselves or their family. Some forms of Christianity are applied in a way that encourages people to view disability is an almost-holy form of “suffering” that glorifies god, or that disabled people are perpetually in need of “saving” from themselves and society by non-disabled people. All of these tropes, in their own ways, support the abuse and neglect of disabled people, and prevent them from participating in society as equal, full human beings worthy of respect who should be supported in living their lives guided by their needs and desires – just as non-disabled people do.

Many forms of Christianity (especially evangelical sects), either overtly or implicitly, stress a gender binary and heterosexual partnerships. Specifically, there is a pervasive norm that men’s sexual development and desires are “natural” and “uncontrollable”, while women are expected to be socially and sexually submissive to male partners and help men to control their sexual desires. This places an absurd and impossible expectation on girls and women to “keep men’s desires in check” while neglecting their own sexuality. For many boys and men, this results in them not being supported in developing affirming communication skills, a framework for self-reflection, or a focus on mutual affirmation in relationships. Additionally, this view that men are all “sexually dominant” convinces many men that they cannot experience sexual violence, or encourages them to remain silent for fear of being perceived as “not masculine” enough. We hope others will explore this intersection further.

Report Limitations: Research & Next Steps

This report is not peer-reviewed research and does not include research citations. While the data is statistically significant, it is not representative of people with disabilities in the U.S, or even in Indiana. IDJ hopes that this information will help inform more rigorous research as well as organizational and community action to end violence against people with disabilities.

The assertions we make in this report are guided by research we've read previously as well as stories and experiences of people with disabilities. This survey was developed and implemented through an annual grant, which means that each year we worked on this, we were unsure if we would receive funding the following year to continue. In fact, one of our partner organizations lost this funding in the 2020-2021 cycle, resulting in a core leadership member having to leave that position and IDJ no longer having access to that funding. Multiple other leadership members' positions were disrupted by COVID-19, funding changes, and life changes. There were also changes in leadership within some anti-violence organizations which shifted their priorities away from our projects.

These dynamics made it impossible for us to develop the relationship with a university Institutional Review Board (IRB) or people who hold Ph.D.'s for this project. As our funding was never enough to adequately support our projects, we often had to forego partnerships that may have enhanced this project because we refused to work with people without compensating them. Therefore, we did not have the funding, time, or resources to conduct the extensive question testing needed to develop a research-level study, or to include citations to support all our assertions, such as those in many of the "conclusion" sections.

It is exciting that we were able to collect responses from people with disabilities of such a wide age range, genders, faith backgrounds, and residential locations, and people with so many kinds of disabilities. However, we received responses based on those who had been impacted by our work previously (such as those who joined our listserv) and their connections, which means the sample of people was not randomized.

Some Notes on Survey Language Choices

We have been intentional in the language we have used to build this survey. Many people outside of public health and the movement to end violence do not commonly use intense language such as “rape” or “sexual assault” and that language may be overwhelming or triggering to many potential survey participants. Sometimes these words are so politicized or culturally unique that people have wide ranging ideas about what they mean that could alter the responses we received in unpredictable ways.

For example, many people perceive sexual assault only as something “done to” a victim, but it can also include forcing or coercing a victim to “do something” to someone else. This understanding could be especially detrimental to men who may have been forced into intercourse in a way they perceive as “active participation” – which would skew our data in a gendered way. Alternatively, some people think “sexual assault” means someone must be severely physically injured, which is not the case. Because there is such a varied understanding of topics related to violence, we found it more practical and clear/plain to ask participants to respond to questions that were concrete and specific. So instead of asking whether someone has been sexually assaulted, we asked them to disclose, if they wanted to, whether someone had ever touched them when they did not want to be touched, for example.

Additionally, one of the ways many survivors cope with trauma, especially early and/or repeated trauma (of which we know people with disabilities have high rates of experiencing both, often simultaneously), is to compartmentalize or use less “intense” language to understand and describe their experiences. This can be especially true for those who experienced abuse or neglect from family members and caretakers, of which people with disabilities are generally more frequently near to as a result of various forms of imposed isolation. When someone close to a survivor is also abusive, it can be difficult for any person to reconcile their positive feeling for that person while also coming to terms with the trauma they experienced from that person. To address this dynamic, we tried to use neutral language in some situations despite the fact that they would be referred to differently in the professional field.

For example, question 34 asks respondents if they had experienced: “Someone withheld services from me unless I did something they wanted me to do, even if I was uncomfortable with their request,” instead of asking if they experienced: “A service provider coerced me into accepting a service.” This also addresses the fact that many people may not be familiar with what “coercion” means, so this also prioritizes using concrete, plain language.

2021 CSNDA Credits

Project leaders are listed below in alphabetical order along with the roles they took on in developing, implementing, and analyzing the 2021 Community Strengths, Needs, and Desires Assessment.

Aiden Powell: Pivot table analysis (allowed us to include weighted gender and non-weighted age cross analysis with quantitative results)

Cierra Olivia Thomas-Williams: Survey developer and editor, participant recruiter/marketing

Haleigh Rigger: Survey developer

Jen Milharcic: Survey developer and report editor

Jody Michele: Survey developer and report editor

Nicole Blackburn: Report editor

Skylar Ashton Kantola: Project lead, survey developer, participant recruiter/marketing, data analysis, report writer

Tammy Themel: Survey developer and report editor