

**Disseminating Resources Online for Teaching Sex Education to People with
Developmental Disabilities**

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Abstract

Sex education is important for individuals with developmental disabilities; however, it is difficult for educators to find resources to support them when teaching sex education. A website, asdsexed.org, was developed to disseminate sex education resources. Using analytic data from the website we explored how dissemination occurs online. We identified (1) how visitors were referred to the website; (2) what search terms were used to look for sex education resources; (3) what content was most frequently viewed; and (4) how visitors engaged with the content. Search engines were the top referrer. Variations on the phrase “body parts” were the most frequently recorded terms. Free lesson plans were the most viewed content. Privacy social stories were the most engaged with content. Online dissemination was a complex undertaking but did allow for potential sex educators to be connected with research-based resources.

Keywords: autism, developmental disabilities, sex education, dissemination, United States

Disseminating Resources Online for Teaching Sex Education to People with Developmental Disabilities

Comprehensive sexuality education (CSE) provides evidence-based, developmentally appropriate, and accurate information about cognitive, emotional, physical, and social aspects of sexuality [1]. Studies of CSE programs have generally yielded positive results with improvements in students' sexual and reproductive health knowledge, attitudes, and behaviors [2]. Unfortunately, CSE is not universally available. Although adolescents with developmental disabilities are considered to be among the most vulnerable populations, they are frequently excluded from or have limited access to CSE [3]. For example, in a study conducted in United State public schools, it was found that the severity of an intellectual or developmental disability, particularly as it relates to expressive communication, decreased the likelihood of students' access to sex education in school [4].

Adolescents with developmental disabilities may also struggle to obtain sexual health information from sources beyond school. Compared to people without disabilities, adolescents with intellectual disabilities were less likely to utilize a health professional or peers to obtain information about sexual health and reproduction [5]. Additionally, while parents can play a critical role in providing sex education, parents of people with autism and other developmental disabilities report difficulty in communicating in a detailed manner appropriate for their child's development [5 - 8]. In fact, research suggests that both parents and educators lack self-efficacy to provide sex education to people with developmental disabilities [6, 8 - 11].

Given the number of barriers they face to obtain access to sexual health information, it is unsurprising that people with developmental disabilities demonstrate lower levels of sexual knowledge than their non-disabled peers [5, 9, 12]. For people with diagnoses such as

autism, which is characterized by challenges in social communication and is commonly associated with intellectual disability, the acquisition of appropriate social skills to facilitate romantic relationships can be especially challenging [13]. Thus, a lack of sex education can negatively impact healthy growth and development.

In spite of these various challenges, there has been progress in identifying how to teach sex education to people with developmental disabilities, as well as what to teach. Although much of the current sex education literature lacks details about implemented programs [14 - 15], some educational strategies have emerged as beneficial for students with intellectual and developmental disabilities such as rehearsal and practice [14], group discussions, integrated games, lectures [15], modeling, role-play [14 - 15], and use of visuals such as images, videos, and models [16]. Additionally, for educators looking to implement a sex education curriculum for people with developmental disabilities within a school context, Sinclair and colleagues [17] have suggested educators work closely with school boards, district personnel, school administrators, general education teachers, families, caregivers, and students.

Although research provides some support and suggestions for educating people on the autism spectrum and with intellectual disabilities, educators struggle to identify the primary goal of sex education and are reluctant to take on the responsibility [12]. This may be, in part, due to the lack of training professionals receive to provide sex education to students with developmental disabilities [10 - 11]. Parents also express feelings of uncertainty for how to communicate with their child on the autism spectrum or with an intellectual disability about topics related to relationships, sexual health, and sexuality [5 - 6, 8]. There appears to be a disconnect between sex education research and the practical implementation of sex education

by educators and parents. This aligns with literature that suggests that a gap between educational researchers and practitioners exists [18].

Educational dissemination research indicates that, given their time constraints, educators seek easily consumable information that addresses a specific classroom need (Behrstock et al., 2009). Therefore, teachers are more likely to confer with a trusted colleague or review websites and practitioner forums than seek out research findings [19 - 20]. Research findings and best practices that are disseminated in publications and practitioner journals are also less likely to reach practitioners because these journals are often not well known by teachers and administrators [20]. Like educators, parents are not frequent consumers of empirical research [21]. For parents of children on the autism spectrum, the internet is often utilized as the primary method to obtain information to support their child [21]. To reach educators and parents, researchers must consider these barriers to access and disseminate resources and information in a way that is practical and convenient to the intended audience.

Researchers can use the interactive nature of the internet to disseminate findings to a range of individuals [21], such as parents and educators who may be more likely to conduct an internet search than review journal articles. Since internet users are more likely to conduct two- or three-word searches in search engines [22], researchers may be able to reach a broader audience with a website that utilizes search engine optimization [23]. Strategies for such optimization might include providing high quality, useful content, link building by creating relevant content on another popular site that links back to the researcher's website, and social sharing [23]. Social sharing may include leveraging social media content to refer viewers to a website for further information [24]. Additionally, influence on social networking sites can improve search engine rankings [23].

While there is limited research that examines the effectiveness of health promotion interventions utilizing social networking sites [25], the large number of internet users engaging on such sites suggests that they could be a potential source for dissemination of information and resources pertaining to sexual health and education. Social networking sites are quite popular among internet users with rates varying by age: 89% of internet users ages 18-29, 78% of internet users ages 30-49, and 43% of users older than 65 [25]. Additionally, social networking sites are operated to promote sexual health; however, this activity is not necessarily reflected in the scientific literature [26] or geared specifically to disability and sex education.

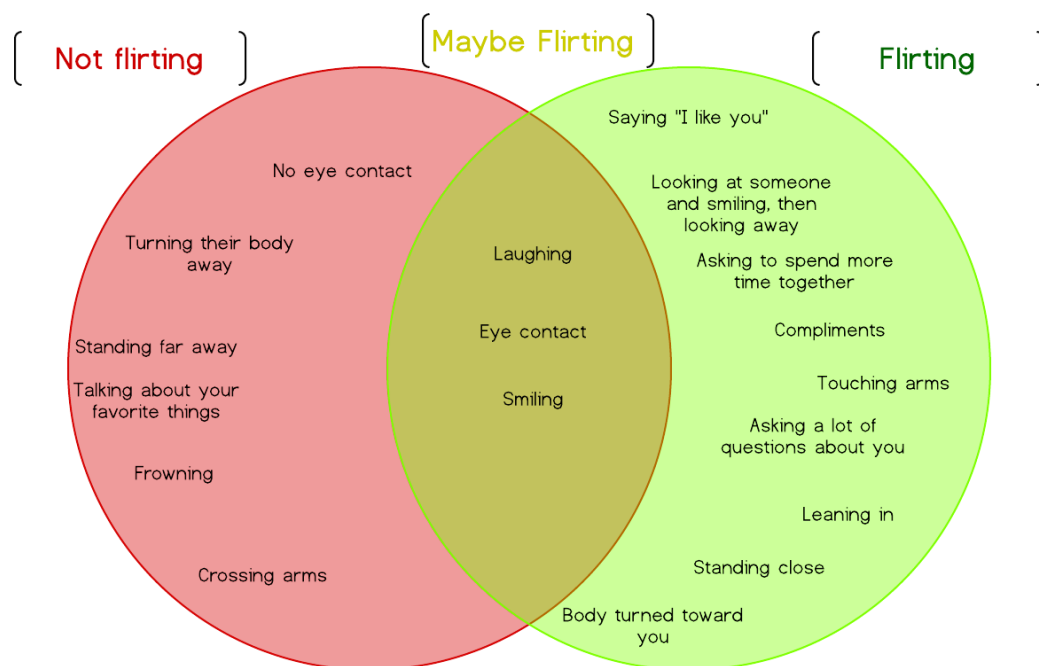
Website Description: asdsexed.org

Asdsexed.org is a website dedicated to disseminating information about how to teach human sexuality to people with developmental disabilities such as autism and intellectual disabilities. The website provides teaching information, curriculum, resources, and an “Ask us Anything” question form. In the teaching information section, there are resources on advocacy, instructional strategies, and educational content. In the curriculum section, there are original lesson plans that can be downloaded for free for middle school, high school, and adult students. The lesson plans provide guidance on how to differentiate for students with intellectual disabilities. There is also information about other free curricula as well as purchasable curricula. The resources are divided by stakeholder groups and topics. For educators, there are visual supports (see Figure 1 for a visual support example found on the website), social narratives, book reviews, media reviews, and information about useful websites. For autistic people, there is a Tumblr page with educational information on sexual topics. For parents and for Spanish Language Speakers, there are lists of resources. The topical resources are in the areas of lesbian, gay, bisexual, transgender, queer, intersex,

asexuality (LGBTQIA); sexual safety which includes both self-protective skills and addressing problematic sexual behavior; adaptive intercourse; body image; masturbation; and sexual health. The website is linked to social media accounts on Facebook, Pinterest, and Tumblr.

Figure 1

Signs of Flirting from Asdsexed.org



Given the disconnect between the research base and what practitioners access and have access to, the website, asdsexed.org has attempted to fill this gap by providing sex education information and resources geared towards educators, parents, and people on the autism spectrum in an online format. The objectives of this study were to examine efforts to disseminate information on how to teach sex education to people with developmental disabilities. Specifically, the following four research questions were evaluated: (1) how were visitors referred to the website; (2) what search terms were used to look for sex education

resources; (3) what content was most frequently viewed; and (4) how did visitors engage with the content?

Method

To answer the research questions, we obtained analytics from the website asdsexed.org. [Asdsexed.org](https://asdsexed.org) is hosted by WordPress which provides analytic data through a company called Jetpack. Analytic data is anonymous and comes from code that is embedded into websites. The code tracks what visitors do while on the website, such as which pages they view, links that they click, and time spent on each page. The code also tracks certain features of the visitors, such as how they were referred to the website and what country to which their internet protocol (IP) address is associated. For each research question, we provide the all-time data beginning in 2012 when the website was created and ending in July of 2020.

Jetpack provides raw numbers that were calculated into percentages for referral sources, content viewed, and engagement. In looking at the referral sources, we first looked at visitors. Jetpack records unique daily visitors who meet the criteria of activity to indicate it is a person and not spam. In addition to the referral information provided by Jetpack, we viewed the website's Facebook, Pinterest, and Tumblr pages and counted the posts. We then calculated the average post yields from the information Jetpack provided on the referral sources. To analyze search terms, raw data were collapsed into meaningful units (e.g. slight wording or spelling differences were combined). Search term data only represents a small sample of the search terms used to find the website as not all search engines allow the terms to be recorded by Jetpack. We analyzed all the search terms Jetpack recorded. Data on content viewed and engagement came directly from Jetpack.

Results

Referral Sources

There were 28,724 visitors to the website. The vast majority of referrals (89.96%) came from search engines ($n = 25,840$). In exploring the remaining referrals ($n = 2,884$), social media sites were the next highest referrals: Facebook ($n = 963$, 33.39%), Pinterest ($n = 588$, 20.39%), WordPress ($n = 246$, 8.53%), Tumblr ($n = 146$, 5.06%), and Twitter ($n = 68$, 2.36%). The Birds and the Bees made 281 posts on Facebook, 73 pins on Pinterest, and 133 posts on Tumblr. On average, each Facebook post yielded 3.43 visits to the website, each Pinterest post yielded 8.05 visits to the website, and each Tumblr post yielded 1.10 visits to the website.

In addition to social media referrals, there were direct links from other websites. Although the majority of the direct links ($n = 67$) individually accounted for less than 1% of the remaining referrals, there were some that were frequent referrers: Thinking Person's Guide to Autism ($n = 85$, 2.95%), The Autism Program Affiliate at the University of Illinois ($n = 75$, 2.60%), The Middletown Centre of Autism ($n = 74$, 2.57%), the blog Autistic Kids ($n = 64$, 2.22%), and The University of Wyoming ($n = 64$, 2.22%). Asdsexed.org only has an affiliation with The Autism Program Affiliate at the University of Illinois. Each of the other websites that referred their users to asdsexed.org independently created links on their webpages. The remaining referrals ($n = 77$) were internal links, meaning the visitor was referred from one page to another within the website using hyperlinks.

Search Terms

There were records of 492 unique search terms that were used to access the website on 2,164 occasions. There were 47 concepts represented by the search terms. The majority of traffic captured by search terms was searching for a variation on the term body parts ($n = 800$, 36.97%). Other search terms used to access the website were variations on relationship levels

pyramid (n = 173, 7.99%), masturbation training (n = 121, 5.59%), social stories (n = 113, 5.22%), and sexuality circles (n = 93, 4.30%). Autism was only used in search terms eight times (1.62%) and some form of the word disability was used 20 times (4.01%).

Content Viewed

There have been 44,280 views of unique content pages on asdsexed.org. The top views were of The Birds and the Bees lesson plans which were original lesson plans for teaching sex education to youth on the autism spectrum (n = 16,166, 36.51%); Privacy Social Stories which was a review of the website “Living Well with Autism” (n = 8,024, 18.12%); The Circles of Sexuality which was a review of a framework for understanding human sexuality (n = 2,491, 5.63%); Relationship Pyramid which was a visual support for explaining relationships developed at The Autism Program Affiliate at the University of Illinois (n = 2,136, 4.82%); Explaining Anatomy which was original content that explained reproductive anatomy in plain language (n = 2,037, 4.60%); Masturbation Training which was a review of a masturbation training program (n = 767, 1.73%); Having a Middle School Boyfriend which was an example of a social narrative for teaching appropriate romantic behavior (n = 504, 1.14%); Signs of Flirting which was a visual support that explained flirting behavior (n = 463, 1.05%); and Intimacy Activity which was an activity that could be used to teach about sexual behavior (n = 443, 1.00%).

Engagement: Links Clicked and Downloads

There were 6,676 clicks to external content; however, this was widely distributed over many links (n = 177). The top ten links were to Living Well with Autism: the site that hosted the privacy social stories (n = 652, 9.77%); Resources for People with Autism: The Birds and the Bees Tumblr site (n = 527, 7.89%); Advocates for Youth: the site that provided more information about the Circles of Sexuality (n = 416, 6.23%); Vanderbilt’s Healthy Bodies

Toolkit: a free online toolkit for teaching about sexual health to people with intellectual disabilities (n = 384, 5.75%); How Cast: a video about how to manage crushes linked in one of The Birds and the Bee's lesson plans (n = 248, 3.71%); Autism Speaks Puberty and Adolescence Toolkit: a free online parent guide (n = 138; 2.07%); The National Center for Deaf-Blindness: a sex education curriculum for people with significant support needs (n = 106, 1.59%); Asdsexed.org developer's website (n = 104, 1.56%); Mayer Johnson Sexuality Pictures: the company that produces "Boardmaker" which is a popular software for making visual supports (n = 102, 1.53%); and Asturias: a free online guide for teaching about human sexuality and disability in Spanish (n = 101, 1.51%). Some of these links are no longer functional: the Advocates for Youth page, The National Center for Deaf-Blindness Page, and the Asturias page.

Discussion

Given that internet websites may be one of the best ways to reach educators and parents [21], it is important to understand the features and outcomes of this type of dissemination effort. This study provides insight into the ability of a low-cost, off-the-shelf website to disseminate research-based sex education resources for people with developmental disabilities. The technological features used in the website asdsexed.org require no programming skills and cost approximately \$100 annually to maintain. Given these meager resources, this type of dissemination effort would be available to many sex education experts. Although the cost and expertise needed to develop the website are reasonable, it still requires a considerable degree of time to build and update. Thus, it is important to understand the benefits of the dissemination efforts. As indicated by the results of this study, there is a complex relation between what is developed and what gets disseminated organically online.

Most traffic coming to asdsexed.org came through search engine referrals. Based on the analysis of the search terms, it was unclear how much of that traffic was actually seeking sex education resources for people with developmental disabilities. Search engines use complex algorithms to guide potential visitors to websites that are challenging to manipulate [22] so it is unclear how the website could be developed differently to better attract visitors. As high-quality search term optimization is outside of the expertise of most content experts, it is important to note other strategies for using the website as a useful dissemination tool. Sex education experts should plan their dissemination around internet searches and face-to-face communication about the website, for example, by talking about the website during trainings and public engagement.

Link building is another strategy that can facilitate online dissemination and bring visitors to the website who are likely interested in the content. Link building also increases the effectiveness of search engines [23]. Asdsexed.org did not request sites post a link to their website, which is a common strategy for link building. However, several websites such as the University of Wyoming and the Thinking Person's Guide to Autism independently linked to asdsexed.org and identified the website as a useful resource. Although relative to search engine referrals, there were not many referrals from other reputable websites, it is likely that those coming from other websites were highly interested in the content provided by asdsexed.org and thus suggest effective dissemination.

Given the popularity of social media, it is a powerful tool for dissemination [25], but again, the relation between making social media posts and directing traffic back to the website is complex. Of the social media referrals, it is unclear whether they were referred directly from asdsexed.org's social media pages or from others who had posted about the website on social media. Social media posts created by asdsexed.org both recirculated

exciting content from other sources (e.g. they linked to news articles, upcoming events, or additional resources) and posted content that directly linked back to the website. Although this may be a more effective strategy for disseminating resources, it is a less effective strategy for directing traffic back to the main website. For asdsexed.org, Pinterest was an important referer, especially considering referrals per post. This may be because all Pinterest referrals link back to asdsexed.org. The effectiveness of Pinterest is consistent with previous research that has found educators to use Pinterest to find resources [27].

The majority of visitors to the site viewed the original lesson plans developed by asdsexed.org called “The Birds and the Bees” series. Visual teaching supports and social narratives were also among the top viewed content. This suggests that asdsexed.org was effective at disseminating sex education resources. The supplemental content on how to teach sexuality education to people with developmental disabilities was not viewed nearly as often as content that provided instructional materials or reviews of instructional materials. This is consistent with previous research that suggests that educators look for information online to meet a specific need [19].

Although viewing is one level of engagement, clicking on links embedded in the website suggests a deeper level of engagement and interest in the content provided [24]. Compared to information about commercial curriculum which is often very expensive, information about free curriculum and resources had more clicks and thus deeper engagement. This suggests that those seeking resources for teaching sex education to people with autism or other developmental disabilities may have limited financial resources.

Another topic with deeper engagement was resources for people on the autism spectrum. This suggests that there may be an audience for online-based sexuality instruction for people on the autism spectrum and with intellectual disabilities. There are recent efforts to

provide more direct instruction online. For example, the Organization for Autism Research (OAR) has produced a series of online modules [28], and the National Council on Independent Living (NCIL) has produced a series of YouTube videos [29], both providing sexuality education online which targets people on the autism spectrum and those with intellectual disabilities respectively. When asdsexed.org attempted to provide content directly to autistic individuals they used Tumblr, which had a vibrant online autistic community. Tumblr's popularity has dramatically decreased [30]. A challenge of disseminating information online is the constantly evolving nature of the internet. The changing popularity of various platforms, linking to outside content that may not always be available, changing in website functionality, and shifting algorithms creates a context in which it is difficult to control dissemination efforts. Despite this challenge, off-the-shelf low-cost website resources seem to provide a viable opportunity for disseminating resources for research-based information on how to teach sex education to people with developmental disabilities.

Limitations

There was a limitation to the search term data: not all search engines allow their terms to be recorded by the analytic software. Thus, it is difficult to tell if the terms we have recorded were a random sample of the terms used. The search terms do seem to contextualize some of the highest viewed pages as there was a correspondence with which terms were used, sites visited, and interactions. Despite this limitation, some individuals, likely with no prior knowledge of asdsexed.org, were connected to the website's resources through internet search engines, so it remains an important indicator to explore. Future research can also explore how visitors use the website from their perspective by designing a study where the researcher watches how participants interact with the website. This could yield insights into

how the website could be improved to make it more accessible and thus improve its dissemination capabilities.

Conclusion

Many people with autism and developmental disabilities are excluded from sex education during adolescence and this is an area where there is no universal support in adult service programs. There is increasing awareness that sex education is a vital need for people with developmental disabilities throughout the lifespan. Although there are educators and providers who are willing to provide sex education, it is unlikely that they have had formal training on how to do so. This study explored the extent to which educators could be connected with reliable information on teaching sex education. The results indicate that tens of thousands of visitors explored sex education content online. Although their motivations for doing so were not always clear, thousands of visitors engaged with content that supported CSE instruction for people with developmental disabilities.

Declarations

This study was conducted without external funding. Neither author has conflicts of interest to disclose. Additional details regarding the data can be obtained by contacting the corresponding author. The first author was responsible for conceptualizing and conducting the study, analyzing the data, and writing the manuscript. The second author assisted with analyzing the data and writing the manuscript. The analytic data used in this study are not considered human subjects data and therefore no IRB approval or consent was sought. A research advisory board of autistic adults consulted on the research.

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