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PARENTS' PERSPECTIVES ON THE MARRIAGE OF THEIR DOWN SYNDROME CHILDREN IN SAUDI ARABIA: SOME EDUCATIONAL IMPLICATIONS

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ABSTRACT

Knowledge of causal and nosological aspects of intellectual disability accompanying congenital genetic disorders has led to a movement of inclusivity for people with these disorders. An online survey was conducted to examine the perspectives of parents of children with Down Syndrome on the possibility of their children's marriage and procreation in some Northern cities in Saudi Arabia. Drawing on the results based on the study's 127 respondents, it was found that parents of children with Down Syndrome generally had a positive view about their children getting married, even though there were no reported marriages. Parents expressed concern about their children being more vulnerable to abuse while in a marriage. Therefore, it was concluded to be a lesser-known concern, these parents also showed bias towards the idea of their children bearing children of their own. Various insights were drawn on how the Ministry of Education can improve in providing more information for children with Down Syndrome and their parents about marriage and procreation. The research presents some recommendations.

Keywords: Down Syndrome, Intellectual Disability, Saudi Arabia, Marriage and Children.

1.0 INTRODUCTION

Knowledge of causal and nosological aspects of intellectual disability accompanying congenital genetic disorders has led to a movement of inclusivity for people with these disorders. One of the archetypes of congenital genetic disorders is Down Syndrome which was first described by the English physician, John Langdon Down in (1866).

According to reports, there are 18 Down syndrome cases for every 10,000 births in Saudi Arabia. Among the chromosomal diseases we studied, Down syndrome ranked the highest. The prevalence was 6.6 per 10000 children, compared with 18 per 10000 previously reported (Al Salloum. et al., 2015). Likely, the increasing proportion of children conceived at a later age by mothers is responsible for the high prevalence of these genetic anomalies among Saudi children.

According to Brown's article (1996), the life expectancy of people with Down syndrome has increased as compared to previous life spans. People with Down Syndrome experience the world differently than others and typically encounter challenging social situations. Nonetheless, they have interpersonal needs like any other person, such as the desire to get married and raise a family with children. To live a happy and fulfilling life, people with Down

Volume: 08, Issue: 02 March - April 2025

ISSN 2582-0176

Syndrome need to be given opportunities to pursue education and employment and engage freely in social interactions.

It is still considered taboo for people with Down Syndrome or other intellectual disabilities to get married (Moreira & Santo, 2013). This study focuses on an unusual case of a woman with Down Syndrome marrying and reproducing successfully. She attended schools designed exclusively for students with learning disabilities and special needs and rose as an interactive communicator. As similar to people with Down Syndrome, this woman too reached her menarche at the mean age of 13 years old.

In the past, people with Down Syndrome have been largely ignored for their sexuality. Mentally disabled people have traditionally been viewed as asexual, or hypersexual if they show excessive affection (Carmody, 1996). However, people from all walks of life can exhibit a desire for matrimony, including those with mental disabilities (Smith, 1995).

This study explores the perspectives of the primary caretakers of children with Down Syndrome, particularly their parents and guardians, who play a pivotal role in their lives. It is interesting to examine the extent to which families have considered the possibility of their children getting married and starting families of their own.

1.1 Statement of the Problem

This study aims to focus on the parents` perspectives of children with Down Syndrome, concerning their child's desire to get married and have children, and how they can cooperate. The survey, however, also sheds light on the different challenges and risks that such a pursuit entails, especially for a child with a stigmatized chromosomal anomaly.

Despite having access to a wide range of studies on people with genetic abnormalities, there is not enough literature concerning the taboo of marriage, let alone procreation, in people with Down Syndrome.

1.2 Research Purpose

The purpose of this study is to examine the extent of the relationship between a caretaker's perspective and their child's opinion on matrimony and procreation. It aims to focus on the extent to which parents of children with Down Syndrome express a desire to have their children married and procreate as well. Furthermore, this study aims to highlight the risks faced by a person with Down Syndrome in matrimony, as well as the challenges that their families undergo in offering support. These risks are in conjunction with those mentioned in the paper, "Intimate partner violence profoundly damages physical, sexual, reproductive, and psychological health" (Mojahed, et al., 2020).

1.3 Significance of the Research

Marriage is important for stable family life, and for maintaining healthy relationships characterized by respect, love, and care for one another. Wood (2004), describes how parents and schools can work together to facilitate appropriate teaching and learning experiences for children with Down syndrome, and how these experiences should be differentiated based on

Volume: 08, Issue: 02 March - April 2025

ISSN 2582-0176

each child's needs and learning style. The topics of marriage, sexuality, and sex education are discussed in Sex and Relationships Education Guidance (2000).

First and foremost, this study is significant to parents of children with Down Syndrome. The results of this study can provide insights to such families on how other families in the same situation perceive the possibility of their children getting married and raising a family. Secondly, this study will be helpful for anyone interested to learn more about disability. Thirdly, to my knowledge, this study is the first study of its kind that takes into consideration the aspect of marriage for the parents of children with Down Syndrome and offers researched evidence and insights for cooperation.

Lastly, this study is significant to the Saudi Ministry of Education, as it can provide useful insights into marriage and family planning for young people with Down Syndrome as they grow into adulthood. Sexual and relationship education in the UK is considerably important for the development of the individual's physical, moral, and emotional abilities.

1.4 Limitations

This study is constrained by the usual limitations of survey-based studies. The study strives to share information gathered from the target population with consent. The COVID-19 pandemic posed restrictions in accessing data from all of the parents of children with Down Syndrome. With absolutely no literature review on the perspectives of marriage in families and people with Down Syndrome disability, the study had to refer to news reports for drafting our following sections.

1.5 Research Questions

This study seeks to examine the parents' perspectives of children with Down Syndrome getting married and raising a family. In particular, it intends to answer the following questions:

- 1) How does the current age and gender of a parent's child with Down Syndrome affect their perspectives?
- 2) Do parents of children with Down Syndrome want them to get married and start a family?
- 3) Is the parent's perspective on their children's marriage dependent on the physical and mental well-being of their child's spouse? In other words, will the parent's perspective change if their child's spouse has Down Syndrome or some other disability?
- 4) Do parents of children with Down Syndrome believe that their children will ever be ready to get married and start a family?
- 5) What recommendations can be drawn for the Ministry of Education to provide greater help to children with Down Syndrome and their parents about the issue of marriage and procreation?

2.0 LITERATURE REVIEW

Down syndrome, a supernumerary chromosome 21 causes a set of clinical characteristics. The Down syndrome is one of the most complex genetic disorders that can survive post-term, and

Volume: 08, Issue: 02 March - April 2025

ISSN 2582-0176

it is the most frequent autosomal aneuploidy that can survive post-term. (Antonarakis.,et.al, 2020)

Even though Down Syndrome is phenotypically variable, Bull (2020), noted that programs have been introduced to capitalize on each individual's strengths. There are guidelines for monitoring and managing the many medical problems associated with Down syndrome, as well as treatment options available.

Meanwhile, the prevalence of the condition has not waned. Instead, Shin et al. (2009) reported that from 1979 to 2003, the prevalence of Down Syndrome diagnosed at birth increased by 31.1% from 0.9 to 1.2 per 1000 live births in the United States. Worldwide prevalence is consistent with this at 1 per 1000 live births as of 2010 (Weijerman & de Winter, 2010). As such, these trends imply that more and more people with Down Syndrome will need support and guidance as they navigate the different facets of adult life. Such support is typically primarily drawn from their parents or other guardians.

A study by (de Graaf et al., 2019), which surveyed over 2600 parents of children with Down Syndrome, found that parents typically have considerable confidence that their children might get to live fulfilling adult lives.

However, de Graaf et al., (2019) focused primarily on general aspects of adult life such as attending to personal needs and hygiene, as well as the standards required for living, and traveling independently.

In Australia, a woman with Down Syndrome completed an undergraduate degree at an Australian university. After graduating, she wrote about her university experience, "I found that the parts of my educational journey were linked to each other like stepping stones. Four main things came from my research: the importance of the journey before going to university; the isolation experienced by students in this situation; how stereotypes might affect students; and teaching methods that can be used to support students during their time at university. This experience changed me as a person. I gained skills and confidence whilst at university, as well as the ability to see where I am going in life. This experience made me feel more part of society." (High, 2021).

Another facet of life experiences is companionship and marriage, Gormly (2019), documented one such marriage between two people with Down Syndrome. At the time of the article's publication, the couple had been married for 25 years.

Concerning aspects related to marriage, Brown (1996), collates seminal literature from the past few decades. Consistent with the discussion in the previous paragraph, Brown (1996), likewise brings up how increased life expectancy and the development of better models of inclusion typically means that people with Down Syndrome have better access to social constructs such as partnership and marriage. Brown (1996), argued that marriage can have a considerable positive impact on the lives of people with Down Syndrome.

Marriage provides the possibility of having a close friend and companion for life, which is not just important in terms of individual emotional development, but also of practical relevance in what might be the typical scenario of people with Down Syndrome outliving their parents or

Volume: 08, Issue: 02 March - April 2025

ISSN 2582-0176

guardians. Various issues about this have been raised, particularly and primarily the challenge and risks of procreation when one or both of the couples have Down Syndrome (Brown, 1996). While there are fertility challenges in this situation, with only 50% of women with Down Syndrome being fertile and with males who have Down Syndrome having lower average sperm count than other men, it is nonetheless possible for people with Down Syndrome to have children (Brown, 1996).

Another challenge is that of cohabiting with another individual, which is different from just learning to live independently. From interviews with adults who have Down Syndrome, Brown (1996), found that they are typically aware of the issues related to marriage and cohabitation and understand the challenges that these involve. Nevertheless, they are usually open to these possibilities and welcome the prospect of getting married and having children. However, some do not want to have children due to the fear that their children would have the same condition as they do.

Another issue that was raised was that people with disabilities in general are at greater risk for sexual exploitation and abuse. Several studies have identified that people with disabilities are often sexually abused as children and/or assaulted as adults, that these crimes are typically severe and repeated, and that the perpetrators generally go unpunished, while the victims suffer emotional, social, and behavioral harm.

Unfortunately, victims with disabilities face inaccessible or ineffective treatment services even after their abuse has been disclosed. (Sobsey, 1991). This might be a real danger for people with Down Syndrome who may not be able to immediately understand that their partner is taking advantage of them (Brown, 1996).

In a study, 26 parents of individuals with Down syndrome were examined to determine the impact of a parenting workshop on adolescent sexuality. Across a group of parents with disabilities, the survey data showed that negative attitudes about sexuality and disability decreased significantly (Frank & Sandman, 2021).

The perspectives of family members are essential in the issue of marriage and procreation among people with Down Syndrome. Family members, particularly parents, typically act as guardians to their children even as they reach adulthood. As such, married life for their children with Down Syndrome would certainly involve them as well. In addition to this, it is also important to consider situations where a person with Down Syndrome would get married to someone who does not have Down Syndrome. Finally, it is essential to identify aspects of these perspectives that can be translated into recommendations in the education of children with Down Syndrome as well as their families.

3.0 METHODOLOGY

3.1 Research Design

This study employs a quantitative, survey-based design. It is the most straightforward way to collect the evidence needed to answer the research questions posed. In selecting this design, it is understood that it is not without its weaknesses, primarily the assumption that participants are willing to provide honest responses.

Volume: 08, Issue: 02 March - April 2025

ISSN 2582-0176

Quantitative data analysis comprises a systematic process of both collecting and evaluating measurable and verifiable data via a statistical mechanism (Creswell, 2007). This can be an issue since family members may have some reluctance to provide their honest perspective when asked about the prospects of their children with Down Syndrome getting married. However, at the same time, sufficient care and consideration must be taken in conducting research involving a vulnerable group such as children with Down Syndrome, even if data gathering will not directly involve them. As such, the study needs to be conducted within these parameters.

3.2 Recruitment

Recruitment is undertaken through the special education schools directory of the public school system in Alqurayyat, Sakaka, Dowmat Aljandal, Hail, and Arar in the Northern region of the Kingdom of Saudi Arabia (KSA). Through the Ministry of Education in the aforementioned cities of KSA, the online surveys had been sent by the department of Education to the Schools. Through the schools, 157 parents of children with Down Syndrome were contacted by Whatsapp and asked if they would like to participate in the study. However, 127 participants willingly responded to the questionnaire.

To ensure sufficient diversity in the sample as needed to answer the research questions, the sampling was stratified according to the age and gender of the child with Down Syndrome. To include families with children that have reached adulthood, older records from up to 15 years ago were included as part of the sampling frame.

3.2 Data Compilation and Analysis

An online survey was sent to the parents who agreed to participate in the study on their Whatsapp. The survey could be answered by the father or mother of the child with Down Syndrome or by their legal guardian.

The survey consisted of three parts.

- > The first part recorded pertinent demographic information.
- ➤ The second part asked about different perspectives of the family member about their child with Down Syndrome getting married and starting a family in relevance to the research questions posed.
- ➤ The last part allowed an open response in which the family member could provide a deeper explanation of their perspectives if they preferred to do so.

As regards the data analysis, relevant descriptive and inferential statistics are conducted to analyze the results gathered from the survey. All statistical tests are conducted at a significance level of 0.05.

4.0 RESULTS

4.1 Participant Demographics

There were 127 participants recruited for the study who answered the questionnaire. The average age of the children with Down Syndrome from those families is 12.98 ± 2.48 . The

Volume: 08, Issue: 02 March - April 2025

ISSN 2582-0176

distribution of the children in terms of age is shown in Table 1 below. Data were analyzed using SPSS Statistics 22.0. In descriptive statistics (frequency), the goal is to make data easier to understand by summarizing and describing it. They help identify patterns by giving brief observations and summaries about a particular set of data, which can help us understand it. Typically, these summaries use quantitative data (Conner, 2017).

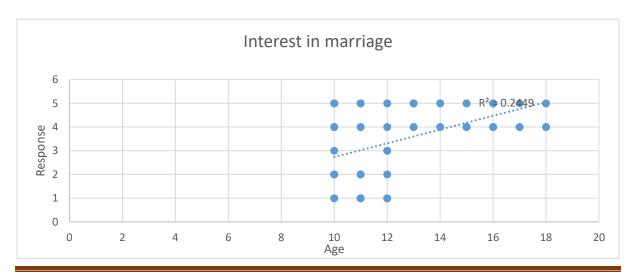
Table 1: Age Distribution

Age	Frequency
10	24
11	24
12	18
13	11
14	8
15	16
16	15
17	4
18	7

As shown in Table 1 above, the study was able to capture a sample that is representative of different ages. This is important since the current age of the child with Down Syndrome may affect the perspectives of their parents or guardians about marriage and relationships. In terms of gender, 60 (47%) of the children with Down Syndrome were male and 67 (53%) were female.

4.2 Perspectives about Marriage

A majority (66%) of the respondents indicated strongly that their children have expressed the desire to get married. As shown in Figure 1 below, this response is highly correlated with the age of the child (p<0.05). This is reasonable since it is more likely for people, in general, to bring up the issue of wanting to get married as they grow older. The study has used a scatter plot with a Least-Squares Best-Fitting line. A correlation test was performed in the figure below.



Volume: 08, Issue: 02 March - April 2025

ISSN 2582-0176

Figure 1

In terms of engaging in actual marriage, it was found that none of the children of the surveyed families, even those who had reached adulthood were married. There are many possibilities as to the cause of this outcome. For people with Down Syndrome in Saudi Arabia, engaging in relationships or romance is not common, even outside the country. The social conservativeness within the country is mainly due to Saudi Arabia's religion and culture, as well as the persistent stigmas about children with Down Syndrome.

However, for ex-pats, it is necessary to note that dating in Saudi Arabia is still considered a taboo, and thus, pursued in quite a secrecy. An individual's parents choose their bride or groom after they reach the legal age of marriage, and it is largely governed by the families' traditional values (Valentine, 2021).

However, when asked if the parents would like their child to get married if they wanted to, a large majority responded in unison and agreed. A total of 107 (84%) agreed, out of which 85 (67%) of them were in strong agreement. This shows that the parents are in the best interests of their children, and believe that they should have the opportunity to experience all facets of life.

In addition, an overwhelming proportion of the respondents (90%) strongly agreed that they would continue to support their child after marriage. It is also notable that 71% of respondents believed that their child would be responsible enough to be in a marriage when the time comes. However, all of the respondents agreed that people with Down Syndrome will find married life more challenging than people without Down Syndrome.

This provides an important contrast, where parents and guardians express both their desire to have their children experience marriage if they wanted to, and their apprehension that engaging in marriage will be more difficult for their child than other people. People with Down Syndrome typically face significant intellectual challenges. Another common belief is that they have a limited social understanding, which might be why many also experience significant difficulty on an interpersonal level (Cebula, et.al., 2008).

In terms of the sufficiency of information about marriage for children with Down Syndrome, a majority (66%) either disagree or strongly disagree that they have sufficient information as parents or guardians about this. At the same time, 71% disagree or strongly disagree that enough is presently being taught to their children in school about this. This means that from the perspective of the parents, there is considerable room for improvement in terms of how the educational system currently addresses the subject of marriage for students who have Down Syndrome.

4.3 Perspectives About Who Children Marry

In terms of the characteristics of the people that parents and guardians would prefer their children with Down Syndrome to marry, Table 2 below provides some insights. As shown in Table 2, a majority of the respondents would prefer that their child get married to someone who does not have any disabilities. Respondents were comparably lukewarm towards the idea of their child marrying someone with disabilities or specifically Down Syndrome. This further explains the phenomenon observed in the previous section of none of the respondents' adult children with Down Syndrome engaging in relationships.

Volume: 08, Issue: 02 March - April 2025

ISSN 2582-0176

As shown across various studies, there is a strong tendency for people with Down Syndrome to engage in relationships with other people with disabilities (Brown, 1996). Thus, a prevailing stigma against this may contribute adversely to the ability of people with the condition to engage in relationships. Furthermore, the results highlight an underlying desire of families to ensure that their child will be properly taken care of should he or she get married, which is more likely if they were to marry someone without disabilities who can take care of them. The study has used Descriptive Statistics. The sample mean and sample standard deviation is in the table below.

Table 2: Characteristics of Prospective Spouse

	Mean	Standard Deviation
Someone who does not have any disabilities	4.273438	0.928252
Someone who has a disability	2.882813	1.355195
Someone who also has Down Syndrome	2.859375	1.20193

4.4 Perspectives about Readiness

Risk

The respondents were almost unanimous in expressing their discomfort about having their children married to someone who does not have any disabilities.

Table 3 below shows details of their responses. The study has used Descriptive Statistics: Sample proportions in the table below.

Table 3: Risk of Abuse in a Relationship

	Agree	Strongly Agree
Sexual Abuse	47.24%	52.76%
Emotional Abuse	50.39%	49.61%
Physical Abuse	53.54%	46.46%

All of the respondents either agreed or strongly agreed that their child with Down Syndrome has a higher risk of suffering sexual, emotional, or physical abuse in marriage compared to other people.

The study of Byrne (2017) did confirm that sexual abuse is more prevalent among adults and children with disabilities.

More women than men reported sexual abuse from their intimate partners in a study of 350 people with learning disabilities in the United States (Platt, et al., 2017). This meta-analysis was carried out by Mailhot et al, (2021) using English and French studies. Sexual assault was more common among women with disabilities.

A sensory impairment was found to be the most significant risk factor. A link between learning disability and victimization was not specifically addressed in the study, even though women

Volume: 08, Issue: 02 March - April 2025

ISSN 2582-0176

with learning disabilities were included. In this article, 162 reports on sexual assault and abuse of victims with disabilities are analyzed. According to the findings, abuse and assault are frequent and chronic. They frequently cause significant damage to the victim, and they are rarely reported to authorities (Sobsey, 1991).

In addition to this, 100% of respondents either agreed or strongly agreed that they feared for their child's safety in a marriage. Melberg (1994), explains that some parents and professionals have difficulty allowing their children with Down syndrome to mature into adulthood, to become 'whole adults,' or adults with adult relationships.

The respondents also expressed unanimous concern and desire to continue being closely involved in their children's lives. All of the respondents either agreed or strongly agreed that they need to become closely familiar with whomever their child decides to get married to and that they will continue to become involved in their children's lives after marriage. All of the respondents strongly agreed that they will not allow their child to marry someone if they thought there is a risk of abuse.

These responses were not found to be related to either the age of the children or the child's gender. In terms of the educational aspects, 53% of the respondents either disagreed or strongly disagreed that they have enough information about abuse in relationships involving people with Down Syndrome. Furthermore, almost 60% either disagreed or strongly disagreed that enough information is being provided to them or their children through the school system.

4.5 Procreation

A large majority of 94% of the respondents reported that their child does not show any interest in having children of their own. Furthermore, 96% of the parents and guardians either disagreed or strongly disagreed with wanting their children with Down Syndrome to have children. The respondents unanimously agreed that their children do not have the responsibility needed to raise children of their own and that raising children would be considerably more difficult for people with Down Syndrome. A range of child and family factors, along with a focus on developing skills to function independently, constrained mothers from promoting autonomy in their children (Gilmore, 2016). Table 4 below explains the result.

Table 4: Perspectives about Procreation

	Disagree	Strongly Disagree
The child wants to have children	75.21%	18.90%
Parents want their children to have children	72.13%	24.25%
Parents believe their child is responsible enough to have children	0.00%	100.00%

However, at the same time, all of the respondents also either agreed or strongly agreed that childbearing is a human right, even for people who have Down Syndrome, and that they would help their child raise children if their child ever decides to procreate. These responses showed no correlation to the age of the children or the child's gender.

In contrast to the previous sections, only 38% of respondents said they either disagreed or strongly disagreed with having enough information about procreation for people with Down

Volume: 08, Issue: 02 March - April 2025

ISSN 2582-0176

Syndrome. This indicates that the families of people with Down Syndrome hold a strong opinion regarding their children's procreation. Even though these families acknowledge procreation to be everyone's decisive right, they strongly disagreed with wanting their children to have children of their own.

Since there is a possibility of Down Syndrome recurrence in these marriages, such families should consider raising their children with new yet heightened responsibilities (Moreira & Santo, 2013). The respondents are divided about the sufficiency of information in schools for children with Down Syndrome; about 48% disagree or strongly disagree with the quality and quantity of available information.

5.0 DISCUSSION

People having down syndrome are intellectually disabled. The results of the quantitative survey and questionnaire suggested that children with Down syndrome wanted to get married and their parents also think their children should be engaged with someone who prohibits relationships before marriage in Saudi Arabia. Whereas, parents also want programs about their married life should be introduced in schools in that those children can get an education about the challenges of the marital relationship. Parents also don't want another disabled person as a life partner for their children to make them more uncomfortable. The research is based on qualitative analysis in which 127 participants answered the questionnaire related to the children having down syndrome should get married or their life becomes more challenging.

The parents and the children both agreed on having a marital relationship. A scatter plot with a Least-Squares Best-Fitting line was performed in the research in which it is concluded that most parents want their children to get married. The research proposed that people's behavior is unfavorable towards down syndrome persons, resulting in an overestimation of their handicap. The government must introduce educational campaigns and efficient awareness programs about the marriage of intellectually disabled persons who are suffering from down syndrome which involves the understanding of social obstacles by integrating down syndrome persons at both the social and familial levels (Alhaddad, 2018).

The standards of World Health Organization should be applied in the Saudi Health ministry to facilitate children with down syndrome. The parents also want their children to get engage in physical activities such as sports. Further parents wanted a healthy lifestyle for their children which brings effective positive reinforcement. For the awareness of children having down syndrome, social media also need to develop campaigns for developing the lifestyles of intellectually disabled children (Rakha, 2022). Children with down syndrome show less social performance, which supports that caregivers of these children should give more time and attention to them to remove their hesitation to get social (Alahmari, 2022).

6.0 CONCLUSIONS AND RECOMMENDATIONS

Life's advancements, longevity, and inclusivity have led to new social roles but have overlooked marriage issues. According to Brown (1996), relationships and marriages are crucial to the quality of life of people with Down syndrome. He emphasizes the importance of preparing people with Down syndrome for life so that these opportunities can be realized. In Denholm (1992), adolescents with intellectual disabilities share similar attitudes toward moral values, friendships, and fashion inclinations as their peers without disabilities. While fewer social interaction opportunities exist for these children, this trend may begin to spread.

Volume: 08, Issue: 02 March - April 2025

ISSN 2582-0176

A lack of studies in the areas of relationships, marriage, and parenting, especially focusing on socialization opportunities offered to people with intellectual disabilities, has been reported by (Conod & Servais, 2008). In this study, it was found that there is a prevailing hesitancy among families as regards having their children engage in relationships and start a family. The hesitancy was found to be much higher about procreation. Families are more open to their children getting married but are less so with the prospect of them having children of their own. Families believe that both getting married and having children are going to be much more challenging for people with Down Syndrome, but likewise expressed that they would be very supportive of the child if he or she decides to engage in such an enterprise. The age of the child was found to be commensurate with interest in engaging in a conjugal relationship, but no correlation could be drawn to anything else. Gender was not found to be a significant factor.

On the other hand, sexual education is often overlooked by parents of children with Down syndrome, though their needs and sexual development are the same as those of other children (Awaru, 2020).

The results identified various areas in which the Ministry of Education can strengthen measures to educate children with Down syndrome and their parents, particularly in the area of risks for abuse among people with Down syndrome engaging in relationships, and, allocate a lesson to educate about characteristics, potential risks, and family awareness. In the UK, schools are legally obliged under The Learning and Skills Act (2000) to provide sex and relationships education to all pupils (Sex and Relationships Education Guidance, 2000).

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Volume: 08, Issue: 02 March - April 2025

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