"Everyone would like their child to have a boyfriend or a girlfriend." Young People with Intellectual Disability and their Experiences with Intimate Relationships: A Follow-up Analysis of Parents' and Caregivers' Perspectives

Laura Retznik (✉ laura.retznik@medizin.uni-leipzig.de)

University Leipzig <https://orcid.org/0000-0002-5592-357X>

Sabine Wienholz

University of Applied Sciences Merseburg: Hochschule Merseburg

Annellen Höltermann

University Hospital Munster: Universitätsklinikum Munster

Ines Conrad

Leipzig University: Universität Leipzig

Steffi G. Riedel-Heller

Leipzig University: Universität Leipzig

Research Article

Keywords: Lack of Privacy, Sex Education, Public Transportation, Partner Selection, Social Opportunities, Couple Time, Detachment Process

Posted Date: July 15th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-296759/v1>

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Abstract

Background Research shows that people with intellectual disability both want and benefit from relationships. Caregivers play an important role in the development and maintenance of these relationships. Barriers to relationships include lack of privacy, inadequate sex education, and lack of public transportation.

Method The sample included 42 primary caregivers of young people with intellectual disability aged 14 to 25. Interviews were evaluated with the qualitative content analysis.

Results Two-thirds of the caregivers reported the young people having had at least one relationship. The caregivers tended to minimize the importance of the young people's relationships and reported, in equal measure, both positive and negative relationship skills. Caregivers described limited choice in terms of partner selection, lack of social opportunities, and low quality couple time. Parents face the detachment process with ambivalence and wish for a stable partnership for their children in the future.

Discussion Young people with intellectual disability face barriers and limitations regarding intimate relationships. Some young people may keep their partnerships secret to avoid possible restrictions from their caregivers. Their time together is quantitatively high, but qualitatively poor due to a lack of transportation and inclusive services. Caregivers need to support the young people's autonomy and take their relationships more seriously.

Introduction

Young adulthood is a period where starting and maintaining a stable partnership is central [1]. In this sensitive phase individuals with disability face particular challenges because the developmental tasks of adolescence are made more challenging because of their disability [2]. People with intellectual disability do not have the same opportunities and experiences as people without disability concerning relationships; therefore their developmental process is altered [3].

Due to negative attitudes, prejudices, and hostile social norms towards the sexuality of people with disability in the past, it was socially acceptable to assume that their need for intimate relationships was different. People with intellectual disability were supposed to be either asexual and childlike or promiscuous with no need for romantic relationships and needing supervision, protection, and support [4, 5]. Consequently, their need for romantic and sexual relationships was largely ignored [5–8].

In recent years, there has been some progress in recognizing their sexual rights and needs. The normalization movement led to an ideological change that emphasized their right to make their own choices. Several researchers have criticized the normalization principle as being restrictive and lacking direction [9–11]. Results from qualitative research [12–18] and self-advocacy groups show that people with intellectual disability have the right to have intimate relationships and the power to influence practice and policy. Previous studies indicate that they know about their rights, want support to have intimate

relationships, and choice regarding relationships and sexuality [19, 20]. A small body of research has explored intimate relationships in young people between 14 and 25 years with intellectual disability [6, 10]. The existing research has typically examined the relationships of adults with intellectual disability [12–16, 19, 21–24].

Current State of Research

Research shows that romantic and intimate relationships are a human need regardless if a disability is present or not [19, 21, 22, 25]. The great majority of individuals with intellectual disability has had a steady relationship, the male respondents having more partner than the female respondents and the mean duration of the women longer than that of the men [25]. They know theoretical strategies for starting a relationship with a potential partner [26]. People with intellectual disability are generally positive about relationships, enjoy them [19, 27] and tend to link a steady relationship and/or marriage with moving towards a “normal” identity [28]. They wish for friendships, social support, and social networks as a means to establish new relationships [29].

Research demonstrates that romantic relationships improve the mental health and well-being of people with intellectual disability [30]. Feelings of trust, security and support are gained from intimate relationships [6, 19, 31] and self-esteem is enhanced as a result of feeling special and cared for [30]. Companionship and sharing affection is central [27] as well as feeling physically close to the significant other [28]. Previous studies indicate that people with intellectual disability desire long-term relationships [21] and most want to live together, marry [6, 27, 31], and have children in the future. Marriage is seen as a marker of life progression [28] and is associated with happiness, a better future [6], acceptance, status, and being special to someone [21].

Partner selection is typically limited to individuals in school or occupational context [6, 21, 22, 24] connecting with persons who have similar disabilities [3]. Facilities for individuals with intellectual disability (residences, schools and workshops for people with disability) provide opportunities to meet potential partner and maintain relationships [19], however the segregated settings also limit partner choice [21]. Studies show that there are not enough opportunities to meet potential partner and enter a relationship [6, 15, 32–35]. Their access to dating potential partner depends on their freedom within the support system and movement [36]. They prefer a kind partner who loves and cares about them and provides practical and emotional support. Personality and companionship are more important to them than physical attractiveness and financial stability [19, 21].

The relationships of people with intellectual disability are similar to partnerships of couples without disability, except that they spent less time together than they wanted [22]. They wish to spend more time and have closer relationships with their partner than people without disabilities [3]. Research shows that they are less likely to have felt close to or to have been in love with someone and often experience higher levels of loneliness as they spend more time under the supervision of adults [37, 38].

The private lives of people with intellectual disability are often characterized by strict boundaries [10, 28], restrictions, and prohibitions interacting and having relationships [6, 19]. As a result they have less privacy when spending time with their partner [30]. Especially women with intellectual disability experience more restrictions by staff and family [15, 39]. Consequently, individuals with intellectual disability lack learning and experiencing spaces [40] having limited social networks to meet potential partners outside of work. This reduces their chances for friendships and first intimate contacts with peers [28]. They wish for more independence and autonomy within their partnerships [3]. The lack of privacy and restrictions often force them to experience partner intimacy secretly to avoid the disapproval of the caregivers [19, 30, 41] as well as preventing further punishment and prohibition [6].

Caregivers are an important source of support for people with intellectual disability in developing and maintaining relationships [24, 27, 30] and during difficult times in the course of the relationship [27]. They teach social skills and assist in the formation of sexual identity [4]. Caregivers also see a strong need for partnership among people with intellectual disability [26]. Parents are aware that their children have fewer opportunities to start intimate relationships than their siblings without disability [35].

Research also describes caregivers restricting people with intellectual disability from developing relationships [19, 27, 30, 42, 43]. One reason for these restrictions are the carers' personal attitudes. If primary caregivers are open-minded and have a positive attitude regarding relationships and sexuality, adolescents will more likely have an increased opportunity to decide for themselves [10]. If their caregivers infantilize and do not see them as individuals with sexual needs, people with intellectual disability tend to adopt this view [7]. Additionally, caregivers often evaluate the sexuality of people with intellectual disability as more inappropriate than their own [4]. Carers also report an ambivalence regarding intimate relationships for people with intellectual disability. On the one hand, carers want them to be happy and share intimacy with their partners increasing their independence. On the other hand, carers fear sexual abuse and unwanted pregnancy restricting their independence and exercising control [3, 10, 26, 30]. Caregivers also cite difficulties with the interpersonal skills, assertiveness, and awareness of social cues of people with intellectual disability [26].

Parents tend to express a more conservative attitude towards intimate relationships of people with intellectual disability than professional staff. Professionals tend to be more supportive of their partnerships and allow them significantly less supervised relationships [23, 44, 45], even at times ignoring institutional rules [46]. Mothers are especially cautious about the intimate relationships of their children with intellectual disability. The protective nature of their relationship leads them to believe that their children are less interested in intimate relationships as compared to parents of children without disability [9]. Furthermore, people with intellectual disability are more reliant on their caregivers to drive them to meet peers. The availability of transportation is dependent on the caregivers' time, energy, and willingness to recognize the importance of spending time with peers [43].

Moreover, people with disability appear to have poor sexual and partnership knowledge because of insufficient sex education and avoid discussing this matter with their main caregivers for fear of

disapproval [28]. Parents consider it harder to explain sexual topics to their child with intellectual disability and do it less frequently than with their children without disability [30, 34, 35, 47]. Mothers more likely communicate with them about sexual issues than fathers [48].

To the best of the authors' knowledge, this is the first German survey that questions a relatively large number of primary caregivers of young people with intellectual disabilities about their experiences with intimate relationships. The perspective of the interviewed young people with intellectual disability from this survey has already been presented [49]. The aim of this article is to examine how primary caregivers describe these intimate relationships, including partner selection, contact frequency and future outlook and wishes. In particular, differences between the perspectives of the primary caregivers and the interviewed young people with intellectual disability towards intimate relationships will be discussed in this context.

Method

Participants

The sample included 42 primary caregivers[1] of young people aged 14 to 25 years with mild to moderate intellectual disability, thereof 23 male and 19 female participants. Thirty-three of the primary caregivers were parents and nine were professionals employed to care for these individuals. In our sample, primary caregivers consisted of 29 mothers, four fathers, four female and five male employed caregivers. All primary caregivers and the young respondents with intellectual disability identified themselves as heterosexual.

The 33 parents were between 41 and 63 years old; the average age was 50 years. Three parents had immigrated to Germany from Eastern Europe. Twenty-eight young people with intellectual disability lived with their parents, three with their grand- or foster parents. Twenty-five parents lived in a partnership, including 16 interviewees in a partnership with the child's father or mother.

The nine employed caretakers were between 26-60 years old, the average age was 46. Eleven young people lived in supervised housing or a residence for people with disability; among them were two in their own homes with supervision. The group of employed caregivers consisted of professionals with pedagogical qualifications in the form of legal guardians, occupational therapists, early childhood teachers, educators, and social workers. They were all German. Six had completed vocational training and three had a university degree.

Criteria for participation included the young respondents being aged 14 to 25 years, having the diagnosis of intellectual disability, and the ability to verbally converse. Another criterion was the participation of a primary caregiver in the study. Consent was gained from each main caregiver and each young participant with intellectual disability. They were informed about the content of the study, the voluntary nature of their participation, confidentiality and the right to withdraw their participation from the study at any time. The participants and their primary caregivers received together a compensation of 25€.

Instrument

The semi structured interview guide of the caregivers was adapted from the earlier survey "Youth Sexuality and Disability" [50, 51] and "Family Planning for Young Adults with Disability" [52, 53]. The interview guide was revised based on feedback from a focus group. A pilot test was also conducted. The interview guide included questions about sex education, attitudes about sexuality, the young people's experience with relationships, sexuality, and contraception. The interview closed with questions regarding the caregivers' wishes for the future. The formulated questions regarding the topics relationships and future outlook and wishes from the caregiver perspective are included in the appendix.

Data Collection

The study titled, "Sexuality of Young Adults with Intellectual Disability in Saxony" was conducted from 2014 to 2017. The Ethical Review Committee of the Medical Faculty of the University of Leipzig gave its approval prior to data collection (AZ: 015-15-26012015).

The young study participants (n =42) including their caregivers (n=42) were recruited from seven schools for students with intellectual disability (n=19) and nine sheltered workshops^[2] (n=23) in Saxony, Germany. The caregivers could choose between a telephone interview (n=8) and an on-site interview (n=34). The face-to-face on-site interviews took place mostly at the caregivers' home (n=26). In exceptional cases, the interviews were conducted at the request of the main caregivers in other places (n=8), such as in a park or café. The average interview duration was one hour. The total time for each respondent varied between 22 minutes and 115 minutes.

Data Analysis

All interviews were digitally recorded and fully transcribed. The names of the respondents were anonymized. Transcripts were analyzed thematically using both summary and structuring content analysis [54]. The deductive category formation was based on the questions of the interview guide. Text passages were inductively coded using summary content analysis every time they could not be assigned to a defined category. Coding was carried out using the qualitative data analysis software MAXQDA. After a first category system was created, two authors analyzed it independently. They jointly reviewed and revised the coding framework. The authors subsequently coded the remaining interviews. In addition, data were analyzed descriptively with SPSS version 22.

^[1] In this article, the term caregivers refers to both parents and employed caregivers. If differences between the groups or characteristics of one group are discussed, it will be made clear in the text.

^[2] Sheltered workshops are supervised workplaces for adults with disability in Germany.

Results

The results of the interviews with the main caregivers are presented thematically. First, the number of relationships of the young people with intellectual disability and the perception of their relationships is

presented, next the findings about their separations, partner selection, and contact frequency and finally the caregivers' future outlook and wishes for the adolescents.

Number of relationships

About two-thirds of the main caregivers said that the young people with intellectual disability have had a relationship. Conversely, this result indicates one-third of them were still inexperienced. According to the primary caregivers, a total of 15 young individuals have had two or more relationships (table 1).

Table 1: Number of Relationships

number of relationships	total [n (%)]	male [n (%)]	female [n (%)]
0	16 (38)	9 (39)	7 (37)
1	11 (26)	5 (22)	6 (32)
2	8 (19)	4 (14)	4 (21)
3	5 (12)	3 (13)	2 (11)
4	1 (2)	1 (4)	0
5	1 (2)	1 (4)	0
Total	42 (100)	23 (100)	19 (100)

N=42

On average, the young people had 1.2 relationships with the young men averaging 1.4, slightly more than the young women with 1.1. Parents whose children had not yet had a relationship expressed sadness that their children's aspirations and needs had not been met. For example, Jan's (21 years old) mother said about her son, "That the poor boy was never allowed to have a girlfriend. He is always waiting to have a girlfriend. It's a very high priority for him now that he has carried with him for years – it's actually getting worse."

Perception of the relationships

The perception of the young people's relationship skills from the point of view of the caregivers was equally positive and negative. Slightly more than half of the caregivers judged the ability of the young people to have a healthy relationship as possible and appeared to be supportive of the goal of finding a partner. The mother of Sandra (15 years old) answered the question about her daughter's ability to form a relationship, "Why shouldn't it work?" Malte's (20 years old) mother explained, "He will definitely be shy. But I can imagine that he would be a good, understanding, and considerate partner in a relationship." Some supportive caregivers assume certain pre-conditions for a relationship to be successful, such as a less restricted partner or residing in a group home. On the other hand, slightly less than half of the primary caregivers rate the relationship competence as medium to low. Some carers

pointed to the personality of the young person. For example, Pierre's (18 years old) mother described, "Living in a solid partnership, I think, could be a problem. He cannot or he finds it difficult to put himself in someone else's position. And he does not really have empathy." Furthermore, some caregivers do not see the young people as cognitively and psychologically able to sustain a stable, healthy and equal partnership due to their lack of mental and emotional maturity, dependency, immobility, and high care needs.

Some caregivers spoke rather critically about the adolescent relationships, casting doubt on their lasting nature. Rather than serious partnerships, they perceived these relationships as "platonic," "flirtatious," "hanky-panky" or "little flirtations". Short duration and the lack of sexual activity made the relationships seem infantile and incomplete in the eyes of the primary caregivers. The carers of males observed more frequent and rapid change of partner describing a tendency for serial monogamy among male young people (more frequent partner changes, shorter relationship duration). In contrast, caregivers of females saw more continuous monogamy (fewer partner, longer relationship duration). Female experiences with romantic relationships were described as more stable, calm, and friendly. Tanja's (20 years old) mother described it this way, "She's been with him for a long time. Old couple." In contrast, males are perceived as less serious and more impulsive. According to Björn's (16 years old) caregiver, "He is in love very quickly. And it's always over very fast."

Separations

The primary caregivers list infidelity, disrespect and lack of loyalty as the main reasons for separations. Break-ups bring periods of depression and great suffering for the young people. Mothers, in particular, expressed concern and compassion for the suffering of their children along with their helplessness to fix the situation. Pierre's (18 years old) mother said, "Well, there were days where he was really down and where a lot of tears flowed. And you sit there as a mom and cannot help. You just know, it eventually stops. But that does not help the child at the moment."

Partner selection

According to the primary caregivers, three-quarters of the young people with relationship experience became acquainted with their partner in school or occupational context. Twelve met their first partner in school, six in sheltered workshops and three at supervised housing or a residence for people with disability. Some of the primary caregivers supported independence when it comes to choosing a partner. They do not want to influence the young people in their choice of partner but are available for advice if the adolescents want it. Some caregivers, especially mothers, take a different approach and try to influence their children on the choice of partner. Stefan's mother reported about her son (15 years old), "There was another one two years ago. And I really advised him to keep his hands off her. It was better that way because she's now a mother."

All respondents stated that the partner of the young people also have a disability. Their reactions to this are varied. On the one hand, there is acceptance and joy about the partnership, which enhances self-

reliance and independence for the adolescents. On the other hand, sometimes parents disapprove of the child's choice and are less accepting of the relationship. The mother of Klara (20 years old) expresses some mixed emotions, "It's the first one where she really landed a neat hit. Except for his physical disability. But otherwise, yes, you have to take it as it is." If their sons are interested in women without disability, this is unimaginable, especially for the mothers. In their opinion, their sons lack important skills and they see no realistic chances for such a partnership. The mother of Simon (25 years old) insists that her son "seeks a partner among their kind".

The main caregivers complain about the small choice of potential relationship partner. In many workshops and institutions, only a few young people of the same age work together, which is why the general partner selection is limited. "I cannot bake him a girlfriend!" describes the mother of Jan (21 years old) this situation. The respondents point out, that especially in rural areas, there is little partner selection and diversity. "We are in the countryside, that's always difficult. It's always the same people. It's hard for the teens here to meet someone outside." says Dirk's (19 years old) caregiver. The majority of the respondents (25 out of 40) would like to have more social opportunities for their children and clients to get together with peers – things like sports, discos, cinemas, dating sites, or joint holiday trips. Moreover, transportation issues prevent them from taking advantage of leisure activities independently. These conditions make it difficult for young people not only to access leisure activities, but also to meet people without disability. Some parents report that local sport clubs refused to open their sports programs to include people with intellectual disability. In addition to excluding people with intellectual disability from regular athletic programs, there are no alternatives offered resulting in a clear discrepancy between the number of leisure activities for young people with and for young people without disability. "There is no compensation. They say they offer sports for the children. But that doesn't happen. It's just for the others." explains the mother of Elisa (18 years old). Inclusive leisure activities were reported to be very rare or nonexistent. The mother of Sandra (15 years old) emphasizes, "But normal children do not want contacts most of the time. It's not the children's fault, but the parents'. The parents do not want the healthy children to play with the sick children."

Contact frequency

Although caregivers describe almost daily contact at school or sheltered workshops, the quality of contact is fleeting and of low quality. Encounters outside this setting are usually difficult to realize due to restrictions such as lack of transportation. The need for caregivers to drive makes the adolescents dependent and burdens the caregivers. Regular meetings of couples at the parents' home is the exception and not the rule. For young people living in supervised housing, geographic distances and restrictive regulations of visiting hours prevent quality time as a couple.

Future outlook and wishes

The caregivers hope that the young people will be able to live independent and self-determined lives. They recognize that the adolescents would like to one day move out ideally to their own apartment with a partner. The interviews with the caregivers reveal agreement in some families and conflicting views in

others. Malte's (20 years old) mother hopes that her son will be able to find happiness in an assisted living facility: "If he feels comfortable in the group, if that works and he is well looked after." Mike (22 years old) and his mother are not in agreement about the future. She states clearly, "I say, 'How do you imagine that? You need furniture. You have to pay rent. You have to pay the water. You have to pay electricity.' I say, 'It's not that easy. And you cannot do that with the little money you earn.' He looked surprised then." Jan (21 years old) did not want to move out, even though his mother wishes for him to do so. She reports, "Jan will surely have to move out at some point, which he does not want, we've talked about that often enough. 'I still have parents, I do not have to go to a home.' But I think he has to someday. But I'm afraid of that because nobody's as nice as me." The statements about the process of separation show the parents' ambivalence. On the one hand, parents are competent experts about their children. On the other hand, parents know that they are not infinitely available and need to find long-term alternatives for the care of their son or daughter. For the most part, there is an acceptance of the need for the child to move out alongside of fears and worries about the situation. "My biggest concern for Erik is if he can handle leaving our family. Whether he gets along easily with himself and his life. But at some point it's time he builds his nest too." says Erik's (20 years old) father.

Apart from living independently, parents would like to see their children finding a partner. "Everyone would like their child to have a boyfriend or a girlfriend." states Malte's (20 years old) mother. Tim's (25 years old) mother says, "I want him to get so far that he wants to move out on his own. That he sees this as a gain for himself. That he is happy there too. And yes, if it would fit and he would also find a girlfriend, with whom he then perhaps shares a room at the supervised residential group. I would wish him that, this satisfaction, being happy with a girlfriend. And to have a good life as well. A relatively self-determined life, as much as possible." The parents' ideas about their children's future partnerships vary greatly. They range from the hope that over time the young individuals can acquire the competence to form a lasting relationship to the wish that their child's individuality is accepted, to very concrete behavior and attitude patterns that their partner should fulfill. Janina's (17 years old) mother wishes "that she finds a boyfriend who loves her the way she is. I think that's the main thing. And on that she can build a relationship. With disability or without disability."

Discussion

The majority of the caregivers agreed that the young people with intellectual disability desire an intimate relationship. From our sample, only a small minority of the adolescents stated they did not want a relationship at the moment [49]. This consistent wish to have an intimate relationship is unsurprising and in line with findings from previous research [19, 21, 22, 25].

With regard to relationship experience, there were clear differences between the interview statements made by the young people and those made by their caregivers concerning the number of partner. In fact, 16 caregivers reported that their child or client had never had a relationship, while only eight young people classified themselves as inexperienced. Further, caregivers also stated that only 19 of the adolescents had one to two partner, while 25 of the young people said that they had one to two relationships [49].

Thus, caregivers seem to not know about all of the adolescent's relationships. It can be assumed that the young people do not communicate openly with their parents about their relationships, purposely keeping them secret avoiding the upset and disapproval of their caregivers, as well as preventing further restrictions and punishment [6, 19, 30]. The adolescents could also be embarrassed or not have learned to talk about intimate relationships [41]. Moreover, caregivers' attitudes towards intimate relationships of people with intellectual disability may influence whether the adolescents want to share their experiences with their caregivers.

Furthermore, the results show a tendency for longer and fewer relationships (continuous monogamy) among the female young people and shorter relationships with more frequent partner changes (serial monogamy) among male young people. This result is consistent with the findings from Gil-Llario et al. (2018) and Eastgate et al. (2012). The stereotype that people with intellectual disability are either promiscuous or asexual [4, 6] was not confirmed in this study. According to caregivers, promiscuous behavior was very rare. The majority of the young people had a fair and reserved approach to relationships.

About half of the surveyed caregivers expressed doubts about the general ability of the young people to form stable relationships. There was a clear tendency to trivialize the existing relationships of the adolescents they support and downplay their seriousness. The other half of the caregiver respondents reported that the young people demonstrated a standard-compliant and rather reserved approach to sexuality and partnership. The young people themselves also declared their relationships to be full-fledged and established [49]. This difference in attitudes between some caregivers trusting and enabling young people with intellectual disability to form relationships and other caregivers doubting and trivializing these relationships has not been previously described in literature. Described so far was the caregivers' ambivalence between enabling people with intellectual disability to have intimate relationships and protecting them from exploitation by restricting their independence [3]. It could be argued that caregivers need to support the young people's autonomy and take their relationships seriously because the lack of sex and short duration are no reason to regard their relationships as infantile and incomplete.

Young people with disability face numerous obstacles entering into and maintaining relationships. One of the reasons for the young people's inexperience in relationships is the lack of potential partner. In the present study, the young people with intellectual disability form an isolated and excluded group with little freedom to act, which thus (involuntarily) remains among itself. They move primarily within their institutions (schools for students with intellectual disabilities, workshops, residences) and rarely have contact with peers without disability. There is a lack of inclusion in social spaces such as sports clubs and discos. Literature has described the dearth of learning and social spaces, as well as the reduced unsupervised time with peers, that impact and limit chances to meet potential relationship partner [15, 32–34]. This naturally reduces their opportunities to start a relationship [6, 35, 55]. The interviewed caregivers report that the adolescents need logistical support to meet each other and are critical of limited social circles (especially in rural areas). These findings are consistent with the opinions of the interviewed

young people with intellectual disability [49]. Results also show that according to caregivers, three-quarters of the young individuals got to know each other in school and professional context. These limited and limiting meeting spaces regulate the choice of partner by providing a determined selection of potential relationship partner. This result has already been described in other studies [21, 22]. The couples spend most of their time together within their regular institutions, and less often in self-selected places due to lack of transportation or lack of inclusive services. As a result, their time together is quantitatively high, but qualitatively poor with few options for intimacy and privacy.

The interviewees wish for an independent and self-determined life for their children and clients. However, especially parents also express ambivalence. They support the process of detachment and evaluate it as a basic prerequisite for an independent life but fear for their children's wellbeing. The parents are aware of the finite nature of their own availability and seek long-term care alternatives for their children. To some extent, the caregivers' own need for autonomy also plays a role. Some fear that their children will be less well off in a new form of living than at home and do not trust in the ability of their children to live independently. Overall, a future change in living environment is unavoidable. In this context, caregivers often wish that a new relationship would be formed when the child's living arrangements change.

Practical implications

Caregivers need and want more training to support individuals with intellectual disability in forming and maintaining romantic relationships [23]. To ease the fear and insecurity that caregivers have discussing relationships and sexuality, resources such as trainings, appropriate materials and exchange offers between parents would be helpful. Materials written in easy language with simple graphics could assist caregivers talking about intimate relationships with young people with intellectual disability [35]. Information and training would also sensitize the caregivers to be more understanding of their relationship needs of young people with intellectual disability. More support would empower them to address relationship issues and would reduce their fear and insecurity around sex education. A differentiated proactive approach and dialogue between adolescents and their caregivers should be encouraged by health care professionals. If caregivers proactively support their children's and clients' sexual identity in the transition to adulthood and have a positive attitude towards their sexuality, this would have a positive impact on the future intimate relationships of young individuals with intellectual disability. Caregivers need to understand that just because the young individuals do not ask questions, this does not mean they do not have questions or are not interested in intimate relationships.

The young people with intellectual disability are described in the present study as an isolated and excluded group with few chances to meet potential partner. If they have a partner, the quality of contacts is very limited. More barrier-free leisure activities, preferably in the areas of sports, discos, cinemas, or joint holiday trips, should be offered by schools and clubs to enable young people with intellectual disability to participate more in social life. In addition, offers such as inclusive online dating platforms should be created and promoted. The lack of an inclusive school system in Germany maintains the status quo that inclusive social opportunities are almost non-existent. The caregivers should be

encouraged to provide opportunities for adolescents with intellectual disability to meet their peers. It is important to people with and without disabilities to get in touch with one another at social events and that the willingness to become inclusive grows. Infrastructure problems should be considered when creating social programs in order to include people from rural areas. Access to public transportation should be encouraged. The rejection of social participation of people with intellectual disabilities by sport clubs or other associations should not be tolerated, but communicated and changed accordingly. A disability should no longer be a distinguishing feature in the use of leisure facilities. The interviewed parents indicated that they need support during the often complicated detachment process. Counseling services, as well as information events on various subjects (e.g. separation from the parental home, alternative forms of housing), would help to support parents and adolescents.

Limitations

There are some limitations in the current study. The study participants agreed to be interviewed and talk about intimate relationships and sexuality. As a result, the caregivers may represent a more progressive and involved part of the demographic. Furthermore, consent was gained from the main caregiver and each young participant with intellectual disability. Consequently, potential participants could not take part in the study if not both agreed and the results may be missing a part of caregivers' and young participants' reports. Criteria for participation included the young people having the diagnosis of intellectual disability and the ability to verbally converse. This excluded all potential participants that were not able to communicate verbally and their respective caregivers. A further limitation was the unintentional fact that only heterosexual and cisgender caregivers and young participants took part in the study. Another limitation is the binary language regarding gender used within the interview guides for the young people and the caregivers. The interview guide did not offer space for respondents who are not cisgender to state their gender or choice of gender in their sexual partner. Furthermore, the topics sexuality and contraception were additionally presented in the previous article regarding the perspective of the interviewed young people with intellectual disability [49]. This article concentrates solely on relationship issues because this topic turned out to be very important to parents and caregivers and we wanted to present these results in a comprehensive and complete manner. It is planned to address the parents' and caregivers' perspectives on sexuality and contraception in a subsequent article.

Conclusion

Study results show the complexity of relationship-based issues faced by caregivers who support young people with intellectual disability. Caregivers describe the majority of the young people with intellectual disability as quite experienced with partnership but some caregivers tend to trivialize these relationships. Caregivers also describe limited options when it comes to partner selection in connection with a lack of social offers and low quality couple time. All young study participants who had had a relationship had a partner with a disability. This is not surprising as most met their partner in a school or occupational context. Parents also face the detachment process with ambivalence and want a stable partnership for their children in the future. The results indicate that the lives of individuals with intellectual disability are

still to some extent restricted due to a lack of accessibility. Thus, societal attitudes towards intimate relationships disadvantage them and limit them in their everyday lives. We recommend trainings, appropriate materials in easy language and exchange offers for the caregivers and parents to ease the insecurity and fear to discuss relationships and sexuality with people with intellectual disability. More support would empower them addressing relationship issues. Furthermore, more barrier-free leisure activities should be offered for people with intellectual disability enabling them to participate more in social life.

Declarations

Acknowledgements We warmly thank the young participants and their caregivers who took part in this study.

Funding The study was funded by the Federal Centre for Health Education (grant number 4-43/4.12/14-he).

Conflict of interest All authors declare that they have no conflict of interest.

Availability of data and material The data and material will not be made publicly available.

Ethics Approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was obtained from the Ethical Review Committee of the Medical Faculty of the University of Leipzig (AZ: 015-15-26012015).

Consent to participate Informed consent was obtained from all participants included in this study.

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Appendix

The following questions were formulated regarding the topics relationships and future outlook and wishes. The questions were as follows:

- What experiences has your daughter/son had so far when looking for a partner? (Has your daughter/son already been in a steady relationship? If yes: How often? How did they meet each other? What were the reasons for a separation?)
- Does your daughter/son currently have a steady relationship? ((If yes) How long have they been together? Does the partner have a disability? Which disability? How often do they see each other? What do they mainly do together? Can the two meet outside without help and in the absence of third parties? If no: Whose help are they primarily seeking?)
- How do you personally perceive your daughter's/son's experience with relationships?
- Would you make use of services designed to help your daughter/son to meet people of the same age? (If yes: What kind of services would you like to use?)
- How do you estimate your daughter's/son's ability to be in a steady relationship? (Where do you see strengths/difficulties?)
- Do you talk to others about your child's sexuality and partnership experience? (If no: Why not? If yes: With whom? How do those addressed react to the topic? How do you feel about the reaction?)
- What are your hopes and wishes about the future of your daughter/son?
- What are your greatest worries about the future of your daughter/son?
- Have you ever spoken to your child about their ideas about the future? (If yes: What did you talk about?)