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ORIGINAL ARTICLE

The concern of parents regarding the sexuality of their child with a mild intellectual disability[☆]



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Summary Parents of children with an intellectual disability want to participate in the sexuality education of their offspring. Yet, they believe that this task is a difficult challenge to accomplish effectively. That is why this text focuses on the training needs of ten parents of students from a high school that specializes in mild intellectual disability. During a focus group meeting, participants had the opportunity to express their concerns about their children's sexuality but also about their own needs in terms of support to enable them to be better at fulfilling their role as sexuality educators. The comments received were analyzed using a systemic approach to highlight their training needs based on the description of current situations. The main outcome of this meeting is that parents perceive their children as vulnerable beings that must ensure sexual competence to know how to act in sexual situations. A critical analysis of parents' needs questions their educational intentions in order to provide training that focuses on pragmatic goals with humanistic goals.

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Introduction

Thirty years ago, many parents refused to acknowledge the sexual needs of their children with an intellectual disability.

Since then, attitudes have changed and the new generation of parents consider their children as sexual beings motivated by sexual desires (Desjardins, 2005). In this regard, it is undeniable that the role of parents is crucial when it comes to the sexual development of their children. However, some of them find it difficult to effectively assume the role of sexuality educator. The research in this field highlights the fact that they do not consider themselves competent enough to help their children to have a fulfilling and responsible sex life. For example, the Quebec survey by Picard and Morin (2010) reports that three-quarters of parents feel they lack information about relationships and sexuality of people with mental retardation. Therefore, it seems necessary to

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allow these parents to acquire knowledge about their children's sexuality. To date, most of the training programs seek to empower parents to improve their skills in their role of sexuality educator (Dupras and Dionne, 2010). However, if educational tools must be offered to them, it is important to establish places where parents can discuss their concerns and their aspirations: "In addition, let's emphasize the importance of creating a space for parents to express themselves in complete confidence, it is to say that can express their pain, their fears and their dreams before starting to learn the skills designed to develop a know-how with their children" (Côté, 2002, p. 54).

The purpose of this article is to describe the process and the results of a meeting with a group of parents in order to identify their concerns about the sexuality of their children with an intellectual disability and their training needs regarding sexuality education. This study sought answers to three specific questions: How can we explain the lack of parental involvement in the sexuality education of their children? When parents are involved, how do they do their children's sexuality education? How to train parents about sexuality education?

Method

The focus group participants were recruited through a social worker from a Montreal high school that specializes in intellectual disability. A total of ten people showed up to the meeting, including two couples. Seven women and three men were present with an average of 45.4 years. Half of them had completed pre-university studies and the other half had a university degree. In addition, five of them were married and the rest were living in a common-law relationship with their partner. Their children, five girls and five boys with a mild intellectual disability, had an average of 13.7 years.

The focus group technique was used to collect the comments from the participants (Puchta and Potter, 2004). This qualitative method targets a response from a specific group of people regarding a product or a service. It has the advantage of facilitating the gathering of information on the concerns of parents regarding their children's sexuality. This method of data collection calls for the free and spontaneous expression of participants who interact with other group members in an equal relationship.

According to the systemic approach (Altschuld and Devraj Kumar, 2010), the concept of need is defined as the measurable difference between two situations: either between what is (current situation) and what should be (desirable situation). Needs represent issues that individuals or organizations face in their daily activities. A semi-structured interview grid developed for the purposes of this study consisted of four general questions about the current situation (How does the sexuality of your child manifest itself? What are your concerns about the sexuality of your child?) and the desirable position (What would you like in order to better fulfil your role as a sexuality educator? How would a training program for parent-guardians benefit you?).

The meeting was held in the evening in a room inside the school, the principal and the social worker were present. The main author of the article led the meeting with the

assistance of the second author. All participants signed a consent form stating that the research team uphold the strictest level of confidentiality regarding their answers to the demographic questionnaire and their comments during the focus group. Furthermore, participants were informed they could withdraw at any time from the meeting and that support was available if needed.

The qualitative approach was used to do the analysis of needs. This type of approach produces and analyzes descriptive data from interviews (Deslauriers, 1991). More specifically, the grounded theory methodology has been chosen to identify the meaning given by the parents to their children's sexual manifestations and sexuality education, then to combine it in an explanatory diagram (Paillé, 1994). The content of the conversations was recorded (with the permission of participants) and transcribed to a computer as a verbatim. Descriptive data were coded in order to classify them and conduct an initial analysis. From the question organization, two main categories of thought were identified: the perception of the sexual needs of their children and the perception of the training needs of parents.

Results

The perception of their children's sexual needs

Some parents have found that their child is interested in sexuality by expressing it verbally, by getting information or with physical manifestations. Through the course of the focus group, it became apparent that these children, despite their disabilities, have love and sexual needs they seek to fill: *Since he was little, he was really... very, very attracted. He once told me: "Mom, I cannot wait to make love"* (M5) (legend: M for mother and F for father). Parents also noted that their children are interested toward emotional and romantic relationships. In other words, they hope to have romantic conquests and success within their peer group. Yet, these children are at an exploratory stage, easily binding and separating themselves with other students: *He changes girlfriend two, three times a week* (M1). Parents have described their children's social life as most often limited to the home and the school. Opportunities for socio-sexual encounters are thus greatly reduced. Similarly, parents reported that their children hardly have any occasions to meet people and to create a social network. For example, going to the park usually involves meeting friends. But according to some participants when their intellectual disabled children go there, they are most often stigmatized or rejected: *And he is very very childish, and we do not let him go play at the park with kids his age or anything because the last time we did, he was ridiculed, made fun of* (F1).

According to participants, their children's main weakness is their vulnerability. This feature means that they can easily be attacked. Their ability to anticipate and avoid dangers is limited, hence the need for protection: *What I mean is that often we can trust our children, but it's the others. Me, it's the others I'm more afraid of than my daughter* (M8). On the other hand, parents have portrayed their children as naive beings who sin by overconfidence and simplicity, by ignorance, thoughtlessness and inexperience. *Her trust in strangers is blind. We are afraid she'll be abused: Because,*

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