

Youth with acquired deafblindness (summary)

The report

The research report is prepared by CFD counseling. The report examines how it feels to be young with acquired deafblindness is like. The report is based on a research review along with interviews with seven young people. Both interviews and review has been conducted in a collaboration between CFD counseling and ISHD.

Why is it significant?

Deafblindness among adolescents is an area, very little research-based knowledge. A few surveys concerning the physical and mental consequences of acquired deafblindness exist. Very few of which address how adolescents themselves describe their lives with acquired deafblindness.

The young people's own experiences are important knowledge, in the process of organizing and developing relevant counseling, which can support their quality of life and well-being.

Highlights from the research report

The research review paints a picture of a disability which affects the lives of adolescents in many different ways, with potentially severe and radically consequences. In regard to adolescents' abilities to participate in various contexts these consequences are significant. Examples of these consequences are tiredness and a lack of energy, which diminish adolescents' possibilities and drive to participate. Additionally, the acquired deafblindness can lead to a pronounced mental burden, which potentially increases the risk of mental vulnerability and disease.

The interviews with the young people indicate that they experience their lives as an act of constant balancing. Balancing between a life that exists in the here and now, and some rough future prospects. The young people need to find a balance between, on the one hand, a diagnosis, which seems like a prognosis, that defines who they are and who they could be, and on

the other hand, a wish to be themselves, with a self-made identity. The adolescents also seek a place to feel safe, and to be viewed as a person with hopes and dreams for the future, and the ability to follow these. A reappearing pattern in the study is *ambivalence*. The young people carry an ambivalence within them, in regard to how, how much, and when, they should make space for the acquired deafblindness in their life.

It is important to be aware of the *potentiality* embedded within the acquired deafblindness. The young people have different ways of dealing with it. Some try to ignore it. Others experience that it takes up so much space, that future plans may seem pointless. The adolescents are sometimes struck by a feeling of resignation. They question, what the point of taking an education and searching for a job is, if they eventually become blind anyway.

The process of recognizing and accepting the acquired deafblindness, proceeds in very different tempos for the adolescents. The variety in which they actively start to consider the acquired deafblindness is significant. Some of them push it away, into the future, and make an active decision not to spend time and energy on it. For some it's a matter of the acquired deafblindness, simply not being a big issue for them at the moment, while others spend time pretending that everything is fine, while they're actually struggling to be allowed to be young.

It is important for the adolescent, that the acquired deafblindness does not become the defining feature about them. In the report the young people tell about experiences where the acquired deafblindness sometimes dominates the perception of the person, and pulls attention away from other personality features. As such, the acquired deafblindness becomes the explanation for everything. Thereby, the personalities and preferences of the adolescents are at risk of being neglected as a relevant framework for comprehending the preferences and behavior of the young individual. From the point of view of the adolescents it is of great importance that they maintain their right to a youth, where they are allowed to explore and unfold their identity. When adults point towards the necessity of

coming to terms with the potential consequences of having acquired deafblindness, it collides with the young peoples' determination to define an identity independent of their handicap.

The report reveals several areas of attention. Firstly, a diagnosis demands an individual translation. On the one hand, a diagnosis can give an explanation to things the young people had previously not been able to understand. On the other hand, it is also a heavy burden to carry for young people. In this regard, the problem is not a lack of knowledge. From the young peoples' perspective, the problem is more precisely, linking the acquired deafblindness to the individual's everyday life; exploring what it means to the young person, and where there is a need for support and counseling.

A second area of attention, is a need for specific attention towards the adolescent who are diagnosed later in life. Although it can be seen as a relief to have an explanation to something that has been inexplicable, it is still a radical change and shock. It appears that there is a need for additional attention and support-work, which can help young people dealing with the emotional reactions, they and the people around them have, to the diagnosis.

Finally, the report highlights, that from the adolescents' point of view, there is a delicate line between being well-meaning, and being patronizing, when adults in their network offer young people support. This suggests that professionals should have a continuous focus on when the well-meaning advice become patronizing. When professionals, well-meaningly, encourage or force the use of helping aids, they take away control from the child or the young person, in regards to how the disability should be handled. In this case, well-meaning intentions risk becoming patronizing and diminish the preferences of the young individual. In the same line of thought, it is important that personal information regarding the acquired deafblindness is not made public, without the child's or young person's consent. A forced openness or relaxed attitude on the behalf of others, can be experienced as exposing. Especially in regards to children, there can be some boundaries that well-meaning adults inadvertently transgress. In such cases, young adults and adults are more able to 'own' the right to share private aspects of oneself, of their own free will, than children are.

Find out more

The entire research report can be downloaded at www.cfd.dk.

The webpage also holds more information regarding counseling for people living with acquired deafblindness.

