Chapter 84 Mark's Story

Mark Kent

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EXECUTIVE SUMMARY

The personal story of Mark Kent is not an easy one to read or to ignore. This chapter shares the difficult life story of Mark's journey from an individual who was sexually and emotionally abused as a child to one where he is currently in a healthy and happy marriage with four children. Mark attributes this success to his Asperger's Syndrome and the support of his family, but he also realizes he is an exceptional case study. He advocates for much better awareness, sexual education, and overall acceptance on the part of society to ensure others can overcome the same challenges he has faced.

INTRODUCTION

This is not an easy story to read or one to ignore. It is a case study of survival and the on going process of overcoming the impact that society perceives as disability and the bearing that perception has on one individual, Mr. Mark Kent. The voice of individuals with autism spectrum disorder (ASD) is often missing from the research literature (Penwell Barnett & Maticka-Tyndale, 2015) and it is the stories of people like Mark which make that absence even more glaring as his is an important one. It shows the perseverance and reliance of an individual in clarity that only a person speaking for themselves can have.

Mark: ...I'm sure you have come across this. When you are talking to anybody with AS, they describe things in such details it feels like you are almost sat there with them in person.

This chapter provides a detailed account of one person with Asperger Syndrome (AS) who has overcome multiple experiences of sexual abuse; eventually leading to a successful marriage and family with four children. While this story is one with a happy ending, the development of a healthy sexual identity is not easy for many with disabilities, including those with ASD despite frequently linked to a good

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quality of life (Pearlman-Avnion, Cohen, & Eldan, 2017). Research supports a clear rationale for teaching sexuality education to people with disabilities for several key reasons. These are to prevent sexual abuse, to support the development of interpersonal relationships, to prevent challenging behavior, and to promote self-determination (Travers & Tincani, 2010; Travers, Tincani, Whitby, & Boutot, 2014). Unfortunately, for many people with ASD, there are also clear stereotypes or myths surrounding sexuality and disability that also impact experiences. These common stereotypical beliefs about people ASD are 1) sexually immature (that people with disabilities are perpetual children or childlike), 2) asexual (that people with disabilities can't control their sexual urges therefore, so should therefore be made to abstain) (Lesseliers & Van Hove, 2002; MacKenzie, 2018). Mark's story provides multiple opportunities to explore the need for sexuality education and to dispel the myths regarding sexuality and people with disabilities.

METHODOLOGY

This is Mark's story about his own journey of learning and understanding his sexual self, as told through a series of three informal conversational interviews (Cohen, Manion, & Morrison, 2017) conducted over the telephone during a period of four weeks in early 2019. In addition, previous conversations with Mark (in 2015) as well as the chapter he wrote for Coping Mechanisms (Black, 2016) are also included. Ethical Approval was granted from the University of Reading (United Kingdom), Institute of Education's Ethics Committee, and formal consent (BERA, 2004) was obtained from Mark. This project has been reviewed following the procedures of the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

After each interview, transcripts were sent to Mark for any corrections or clarifications with the agreed versions included below. Italics is used to indicate a direct quote from Mark with particular attention paid to verbatim transcription (Poland, 2003) and as such, the words are his own (for example, he refers to individuals who do not have Aspergers Syndrome as 'normal people' which some readers may disagree with). As Kvale (1996, p. 183) states, 'The interviewee's statements are not collected-they are co-authored by the interviewer'. The expressed intention is to try and let the impact of the interviewer be reduced and to let Mark's comments tell his own story through his words and 'voice', with handwritten passages from Mark are also added as powerful additions. For more of Mark's voice, please see his blog https://mark-kent.webs.com/

Cathy and Mark have known each other for over 5 years. They have worked together on the topic of sexuality and sexual identity for those with autism. Mark feels strongly that this is a topic which is often overlooked:

...researchers. Universities, here in England do every <u>other subject</u> But the subject of sex it is not said one word. abouT. This is very very very disgraceful and shameing (email 21 February 2019)

Mark was therefore very happy to be the focus of this chapter. The interviews and correspondence are organised into four main themes: an introduction to Mark, development of a sexual identity, societal views regarding sexuality and disability, and techniques for survival and moving forward.

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