

Disability exclusion and rights: The life story of Alice Jamieson

Allison Lynch

Griffith University

Student commentary

Goggin and Newell (2005) claim that “much of the reason for institutionalised apartheid had been due to a fear of disability. This is an all-pervasive fear of those whose difference is threatening to our own sense of well-being and invulnerability” (p. 138). Reflecting on *Today I’m Alice*, the disability memoir of Alice Jamieson (who developed dissociative identity disorder (DID) after enduring years of incestuous abuse) this paper will dispute this claim. Alice’s story and development of DID will be discussed in order to contextualise the author’s position regarding her segregation. Goggin and Newell further assert “there is a need for our community, through continuing education, to embrace the experience and discussion of disability issues within a diversity agenda” (2005, p. 138), an assertion strongly supported in this paper.

Alice’s story

An intelligent, well written and profoundly personal memoir, *Today I’m Alice* (Jamieson & Thurlow, 2009) tells the life story of Alice Jamieson, who from the age of two endured years of sexual, physical and emotional abuse at the hands of her father. Alice’s clear writing style, uncompromising language and blunt truths allow the reader to gain a deeply intimate insight into her life and the harrowing incidents of abuse she suffered. For this reason, I will refer to Alice by her Christian name in this paper. The conventional use of her surname does not convey the appreciation, admiration and respect the author has for Alice sharing her story.

As a child, Alice began having dreams in which she watched a young girl being sexually abused. Her dreams became more vivid and shocking as she grew

older, and as a teenager, she developed anorexia, alcohol addiction, depression and obsessive compulsive disorder (OCD). Both humorous and tragic, Alice recounts in clear, uncompromising prose how she developed alternative personalities as a mechanism to cope with the horrific abuse.

After 100 suicide attempts, more than 600 stitches to her arms, and numerous stints in psychiatric wards, Alice was diagnosed with multiple personality disorder (MPD). MPD, renamed in 1994 as dissociative identity disorder (DID) in the Diagnostic and Statistical Manual - IV (DSM-IV) is a “complex chronic dissociative disorder that develops in the aftermath of overwhelmingly stressful childhood experiences” (Kluft, 2007, p. 784). With the diagnosis came treatment, and it was during treatment that Alice became aware of her ‘alters’, discovering each one of them had their own memories of abuse.

In linking her experiences to modern day film characters, Alice talks about feeling like *The Incredible Hulk* (Letierrier, 2008) and Raymond Babbitt in the film *Rain Man* (Levinson, 1988). Hulk was a man with a broken memory who metamorphoses under stress from a normal person into a big green monster. Likewise, Alice felt herself turn from “being a normal girl ... into a small child lying curled on the bed sobbing in a lake of tears” (Jamieson & Thurlow, 2009, p. 58). Raymond Babbitt, a man with autism, is portrayed as having a photographic memory shot through with holes. Comparably, Alice describes her memory as akin to “a detective novel with pages torn out; the story has jumps, scenes are missing” (Jamieson & Thurlow, 2009, p. 206). The missing scenes from Alice’s life are inaccessible to her, but accessible to her alters. Alice’s alters are what Reinders and Nijenhuis (2006) term traumatic identity states - those which have access and responses to traumatic memories, which Alice herself was unable to face.

Dissociative identity disorder and Alice

An individual with DID exhibits two or more distinct personality states, with each state appearing at different times and governing behaviour at that time (Kluft, 2007; Medical Disability Advisor (MDA), 2013; Reinders & Nijenhuis, 2006; Ross, 2006). It is a serious, disabling and sometimes fatal disorder (MDA, 2013). Research reveals childhood trauma is a significant risk factor for development of DID (Reinders & Nijenhuis, 2006) and that the greater the frequency and severity of traumatic childhood experiences, the more severe the dissociation (Kluft, 2007; Ross, 2006).

Alice reported more than fifteen but less than thirty alters, who were a combination of protectors, persecutors and friends. Each of her alters had their own unique name, age, characteristics, mood, behaviour, habits and memories. Through the defence mechanism of dissociation Alice developed alters in the form of children who materialised singly at different stages of her life, in response to different forms of abuse. Some of her alters were fragmented states, holding one particular memory, while others were complex, full-bodied personalities capable of a range of emotions and behaviours. Alice's nine identifiable alters emerged over her childhood years in the form of girls and boys ranging in age from six months to sixteen years. The alters carried the pain and abuse for her, enabling Alice's daily functioning (Reinders & Nijenhuis, 2006). These children, and countless more who remained in the background, accompanied by a myriad of voices (inside her head) became Alice's family and they would appear when Alice was stressed.

Inclusion and exclusion

In the absence of a positive attachment with her parents (Colmer, Rutherford & Murphy, 2011) Alice benefited from having a close, secure, loving relationship with her grandfather. Alice's grandfather was her only support during childhood, which as Berger (2013) writes is very important for children with disabilities. During her adult years, Alice formed a strong relationship with 'Rebecca', a woman she met through work. The relationship supported her through difficult times and gave her the strength she needed to seek treatment. The quality of interpersonal relationships and social inclusion is of great importance to survivors of childhood sexual abuse, as relationships may significantly attenuate or exacerbate the impact of previous traumatic experiences (Pistorello & Follette, 1998). Likewise, as Goggin and Newell (2005) contend, people with disabilities do not need people's help; rather they need to be enabled. They need to be embraced in their daily lives by the society in which they live, which is exactly what Alice received from her grandfather and Rebecca when she allowed them in to her life.

The disruptions to memory, awareness, identity and perception associated with DID interfere greatly with a person's functioning, social interactions, relationships and work ability (Spiegel & Lowenstein, 2011). During her childhood and teenage years, Alice knew that she was 'different' to most children her age. She would alternately feel as though she were an infant, a child, and a woman; having

different feelings at different times, but never knowing which feeling belonged to the 'real' Alice. She would cook, clean, run and study continuously and became thought of as eccentric and weird by her family and peers. Clearly, as Berger (2013) maintains, the challenges Alice faced during adolescence were greater for her as a young person with a disability than for her non-disabled peers.

Despite this, Alice resolved to make an effort to fit in. Her efforts were largely futile however, as every time she felt herself getting close to someone (other than her grandfather or Rebecca), she would immediately distance herself. Alice was afraid one of her alters would appear and do something inappropriate or embarrassing that she would be unable to remember. She would often recall events taking place, "but the details were sketchy like an incomplete drawing" (Jamieson & Thurlow, 2009, p. 77). Duggan writes that "our basic instinct is that of a social being; but we can't be social until we know—and are comfortable with—our unique selves" (2011, p. 2). As a person with DID, how does one become comfortable with their unique self? Which of their multiple selves should they be comfortable with in order to fit in at any given time?

Francis describes social exclusion as "the process through which individuals or groups are wholly or partially excluded from full participation in the society within which they live" (as cited in Rawal, 2008, p. 164). It is evident through multiple experiences of Alice's alters, as discussed in her memoir, that she was unable to fully participate as a member of her community and was segregated from those around her. That segregation however was not a result of society fearing her difference as DID is an invisible disability, hidden from most outside observers. Alice's exclusion was caused by her self-isolation, resulting from her fear of herself and her alters (Goggin & Newell, 2005).

Knowing her rights and telling her story

The Convention on the Rights of Persons with Disabilities (CRPD) clearly and unanimously outlines the rights of people with disabilities to live fully inclusive lives within their communities (Berger, 2013; United Nations, 2006a). It is widely acknowledged that women with disabilities are multiply disadvantaged, experiencing exclusion on the basis of their gender as well as their disability, and that they are particularly vulnerable to abuse (Berger, 2013; Goggin & Newell, 2005; United Nations, 2006b). As an adult, Alice was raped at knifepoint by her father when she

confronted him about the abuses of her childhood. The CRPD requires that all appropriate measures should be taken to prevent all forms of abuse; however, also acknowledges that women with disabilities are more likely to be victims of rape and less likely to obtain police intervention (United Nations, 2006a & 2006b). Despite reporting her abuses to the police on two separate occasions, Alice's case did not proceed to prosecution. Alice did however make a claim through the Criminal Injuries Compensation Authority and eventually received a substantial compensatory payment. Despite the fact that her father remained unpunished, Alice took solace in the knowledge that her story was believed by the authorities.

Shaw and Gould in Ellem and Wilson (2010) believe that the telling of one's life story has a therapeutic role in that it assists the persons understanding of significant events and recognises areas in their life requiring change. This was the case for Alice, who wrote that she made her abuse public because deep down there was a wound she needed to bring out into the clean air before it could heal (Jamieson & Thurlow, 2009, p. 271).

Owen (in Ellem & Wilson, 2010) and Goggin and Newell (2005) identify that the telling of stories of vulnerable people is an exercise of social justice as it gives voice to people who have traditionally been silenced by society. As Longmore writes "it seems that some of us are going to have to talk frankly about what it is really like for us disabled people" (2003, p. 231). Alice's co-writer Clifford Thurlow confirmed this to be the case for Alice. He advised that the publication of Alice's book, the fact that her story was believed and brought to the public eye, and the accompanying financial security it brought, has had a healing effect on Alice (personal communication, September 17, 2013). Through the sharing of stories and telling of personal narratives, opportunities are presented for society to diversify, become educated about, and embrace difference. It is diversity, created by individual difference that makes us all equally valuable human beings (Berger, 2013).

Conclusion

Although it is acknowledged that there is support in disability research literature (that literature being beyond the scope of this paper) for the Goggin and Newell (2005) assertion that much of the reason for [segregation] has been due to a fear of disability (p. 138), it has been demonstrated that in relation to Alice Jamieson, their

claim is unsubstantiated. Alice's solitary life was a devastating aftershock of her disability, for which her father was ultimately responsible. Her family and wider community also bear a degree of responsibility resulting from their inaction and lack of intervention or adequate support. It remains forever unknown how Alice's story may have been told if social workers, teachers, parents and medical professionals had a greater awareness and understanding of the tell-tale signs of childhood sexual abuse and DID. Continuing education and acceptance of disability (Goggin & Newell, 2005) and its causes is fundamentally crucial if we are to value our fellow human beings.

References

- Berger, R. J. (2013). *Introducing disability studies*. Colorado: Lynne Rienner Publishers, Inc.
- Colmer, K., Rutherford, L., & Murphy, P. (2011). Attachment theory and primary caregiving. *Australian Journal of Early Childhood, 36*(4), 16-20.
- Duggan, M. (2011). *Mike's story*. Retrieved from https://bblearn.griffith.edu.au/bbcswebdav/pid-596275-dt-content-rid-1166403_1/courses/7004HSV_3135_LG/Mike%20Duggans%20Story.pdf
- Ellem, K. A., & Wilson, J. (2010). Life story work and social work practice: A case study with ex-prisoners labelled as having an intellectual disability. *Australian Social Work, 63*(1), 67-82.
- Goggin, G., & Newell, C. (2005). *Disability in Australia: Exposing a social apartheid*. Sydney, Australia: University of New South Wales Press Ltd.
- Jamieson, A., & Thurlow, C. (2009). *Today I'm Alice*. London, UK: Pan Macmillan Publishers Limited.
- Kluft, R. P. (2007). Multiple personality disorder. In G. Fink (Ed.), *Encyclopedia of stress* (2nd ed., pp. 783-790). London: Academic Press.
- Leterrier, L. (Director). (2008). *The incredible hulk* [Motion Picture]. USA: Marvel Studios.
- Levinson, B. (Director). (1988). *Rain man* [Motion Picture]. USA: MGM.
- Longmore, P. (2003). *Why I burned my book and other essays on disability*. Philadelphia: Temple University Press.
- Medical Disability Advisor [MDA]. (2013). *Dissociative identity disorder*. Retrieved from <http://www.mdguidelines.com/dissociative-identity-disorder>
- Pistorello, J., & Follette, V. M. (1998). Childhood sexual abuse and couples relationships: Female survivors' reports in therapy groups. *Journal of Marital and Family Therapy, 24*(4), 473-485.
- Rawal, N. (2008). Social inclusion and exclusion: A review. *Dhaulagiri Journal of Sociology and Anthropology, 2*, 161-180. doi: 10.3126/dsaj.v2i0.1362
- Reinders, A. A., & Nijenhuis, E. R. S. (2006). Psychobiological characteristics of dissociative identity disorder: A symptom provocation study. *Biological Psychiatry, 60*, 730-740.
- Ross, C. A. (2006). Dissociative identity disorder. *Current Psychosis and Therapeutic Reports, 4*(3), 112-126.

Spiegel, D., & Lowenstein, R. J. (2011). Dissociative disorders in DSM-5. *Depression and Anxiety, 28*, 824-852.

United Nations. (2006a). *Convention on the rights of persons with disabilities*. Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>

United Nations. (2006b). *Enable: International convention on the rights of persons with disabilities*. Retrieved from <http://www.un.org/disabilities/convention/pdfs/factsheet.pdf>

Biographical notes

Allison Lynch is a Griffith University Alumni having completed a Bachelor of Criminology and Criminal Justice Studies and a Master of Human Services (Childhood Studies). Allison is passionate about advocating for those who suffer childhood trauma and preventable hardships and is committed to raising awareness of how others can do the same.