



“Says who?”

Life stories and people with Down Syndrome

by Amie O’Shea

Life stories are a fabulous tool for working with, getting to know, or supporting people with Down syndrome. They are becoming an increasingly popular technique in working with people from several marginalised groups, including people with intellectual disability. Their potential is great as a tool for change in the lives of the story tellers, and those who read them.

When people with Down syndrome and others with intellectual disability were housed in large residential institutions, they were rendered almost invisible to society. Their stories and their lives have been described as “the ultimate ‘lost voices’ in terms of autobiographical records” (Atkinson & Walmsley, 1999 p203). As a group of people who were frequently unable to read or write, people with intellectual disability were uniquely subject to representation by others. So, what professionals had to say about their lives, thoughts, interests, abilities and experiences, was more valued and more “truthful” than anything the person themselves had to say. Dorothy Atkinson and Jan Walmsley, two UK academics who led the way in oral history and autobiographical work in the 1990s, believed that:

“They have been silent because ... the rest of society has chosen not to listen, and has thereby systematically devalued their lives. ... We have not listened primarily because we have believed that people with [intellectual disability] had no capacity for understanding or conveying their own situation or experiences ... Now autobiography holds out the promise that those ‘lost voices’ may yet be recovered.”
(Atkinson & Walmsley, 1999 p209)

The 1990s saw a time when writing about oneself became much more widely available. Where in the past it was only famous people, or old famous people, who would have the chance to write an autobiography or memoir, this had suddenly become more accessible. In recent years, the rise in popularity of the internet and blogging, social networking, online groups and forums have all supported this trend. Reality TV

showed us the journeys of average people through various hardships (losing weight, being locked in a house, entering a singing competition) and shared the stories of their lives both before and during the TV program.

This was also a time marked by the emergence of research and other writing which featured, in different ways, the stories and voices of people with intellectual disability. I remember doing my undergraduate degree and the first time I read a first person story written by someone with an intellectual disability – it blew me away. This was an exciting, and for me, revolutionary time.

I refer to these writings collectively as “life stories” but in fact they can be a number of different things, and referred to by different names. Autobiography, oral history and life history we are familiar with. In my research, “life stories” means “a set of stories from my life”. Testimonio (which in Spanish has connotations of bearing witness, in a legal or religious sense) and the “native informant” in anthropological research are also forms of first-person narrative writing. Digital stories have become popular recently, and life stories can indeed have pictures, drawings, video, or be written in prose or poetry. For me, what defines a life story is that it is a first person account produced and (importantly) owned by the writer.

As noted above, life stories have been used in research as a way of involving the voices of people with intellectual disability. Dorothy Atkinson used oral history and life history in her work on the story of intellectual disability in the UK in a book called *Good Times, Bad Times: Women with learning difficulties telling*

their stories. Closer to home, life stories were gathered by the researchers involved in *Living Safer Sexual Lives*, the first piece of Australian research which sought to explore sexuality and intimate relationships from the perspective of people with intellectual disability. Life stories have also featured in several published books, including *Count Us In: Growing up with Down syndrome*, and *Doug’s Story: The struggle for a fair go*, written by Katie Cincotta with Doug Pentland, a well known Melbourne figure who sadly passed away recently.

There are many benefits in writing a life story. For the story teller, it can be a process, and a product, which is empowering and validating (if it’s written down, it’s real) and provide a sense of achievement. Life stories can be a way of understanding life experiences, both as an individual and as a person with a number of identities. Being able to keep, and later reflect on, their life story provides a one stop shop of memories. It was mentioned to me that life stories provide a great motivator for developing literacy skills. Kelley Johnson, Professor at the University of Bristol, gave a presentation recently which considered life stories as a subversive act. Mabel Cooper, who wrote *Mabel Cooper’s Life Story* with support from Dorothy Atkinson, says:

“Now I’m encouraging other people to tell their stories. I think it’s good, and I think it teaches the public that people with learning difficulties are not going to hurt anyone and all the time we can get people to write their story and tell what happened to them, and publish it ... then it helps everyone.”

There are benefits to life stories for other people as well. For carers and staff working with the story teller, a life story (if it is chosen to be shared) is a wonderful and privileged way of getting to know someone. This is especially useful if the person has limited communication, specific memory difficulties, or another condition such as Alzheimer’s disease. I have seen (anonymised) life stories used to great effect in the training package which came out of *Living Safer Sexual Lives* – especially when read aloud, as the authors recommend. In my own research, life stories are critical in learning about how young women with intellectual disability understand and experience their worlds.

All of this must go with a word of caution, however. Simone Aspis, a self advocate in the UK, has written about the potential for life stories to become another way that people with intellectual disability are colonised, and subjected to another’s gaze, using the guise of a new trend. She challenges the use of life stories for research analysis or use in ways which are inaccessible to the person who wrote the story. I would extend this to the use of other forms of writing and calling them life stories: words written in the first person are not automatically a life story. It would be

very difficult for writing in communication books, individual plans and other forms of paperwork to be life stories.

Another important issue is that of ownership. I’ve said that it is important for the writer to have and to feel ownership over their story. But what happens when the story is written? Are they the only person with a copy, deciding who will read it? In my experience, this is not often the case, and rarely has a simple answer. These challenges relate to the potential for life stories to shift control away from “us” and towards “them”, as described in the beginning of this article.

The process of writing life stories is a whole other article! There are a number of techniques and approaches, as well as practical and ethical considerations involved in writing a life story. In my own research, the life stories are iteratively produced, and we are using Photovoice, a technique which enables participants to take photographs using a digital camera, to represent themselves and their world.

It wasn’t a hard choice to use life stories in my research on the experiences and lives of young women with intellectual disability. But, following a friend’s advice, I first sat down to write my own. This experience gave me a whole different understanding of life stories: how sometimes we choose to include, or not include, particular episodes or parts of our life; how we choose to understand and represent ourselves, all of the time, and how life stories aren’t any different. But the main thing it showed me was that if the finished product was to have a chance of being empowering and a tool for self-knowledge, and all the other things it can be, it needed to say what I needed it to say.

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Amie O’Shea is currently looking for young women interested in participating in life story research she is conducting. For more information contact Amie on aloshea@students.latrobe.edu.au or (03) 9285 5104.