



Does Writing in First Person Put the Person First?

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In writing, 'first person' refers to using the voice of the narrator, the person who is doing the writing. It may mean using the words 'l', 'my', 'we', or 'us'. Writing in first person is said to be more personal; the author is talking about themselves. It can engage the reader more than a third person voice using 'he', 'she', 'their', or 'it'.

Ohen (2014) suggested that the valuable characteristics of first person content included ownership, presence, authenticity, and reflection. She stated that 'using a first-person perspective in your written content makes an emotional appeal that helps forge a relationship between you and your reader'.

The phrase 'nothing about me without me' / 'nothing about us without us' has been a cornerstone slogan for members of many groups, including disability groups, for decades. With this principle in mind, personal accounts

written by people with intellectual disabilities have invaluably shaped our understanding of institutions and other life experiences of individuals and, in more recent years, have guided policy and research.

Following from these arguments, it seems natural and logical that writing in first person, hearing the voice of the person with a disability, should be adopted. But what if the person with a disability cannot write, cannot speak, cannot dictate, cannot 'do' writing in first person? One could say that first person should still be used. A



profile written using a/the voice of the person might add authority to the writing. It might enable readers to engage better with the person with a disability. It could make them see the person more as a person, an autonomous being with agency.

But I even struggled to write that previous paragraph. I mean, is it authentically the person's voice on the page, or is it somebody else's' else's voice, interpreting, as best they can, the person's voice? Is the process of trying to have people seen as people actually creating a fictionalisation of a person that fails to acknowledge one of the critical features of the person. That is, some people cannot tell their stories in words.

Does writing in first person for people with PMLD actually violate the assumptions of first person writing? The person does not really own the document; and it may be highly unlikely they are aware of its existence or content. It is not necessarily their presence that is manifest in the documentation, it may not imbue an authenticity, and is it really a reflection of the person's thoughts?

I frequently see these violations in documents when visiting adults with PMLD. The front page of a man's plan says 'ask my permission before you read my plan'; he would probably not understand your question and not have a means to express his permission. Lists of likes and dislikes written in a first person style are attached to the person for years whether they are accurate or not. The risk for exploitation because 'this is what the person says they want' is wide open.

Most disturbingly, the statement 'I like my own space to be alone' stares out of many individual's documents. This interpretation of what the person with a disability might say legitimises and perpetuates the isolation of the person who might be in greatest need for contact. While there may be a tacit agreement by familiar readers who know that the person with a disability did not really write the document, what of the unfamiliar person who reads the document apparently written by a person with PMLD? Do they also enter the agreement that the document is not real, or do they sit in confusion as to who the real author is and why the person is not speaking or writing now?

Of course, these documents may be only as good as the 'ghost writer' who writes the document. Many documents may be very successfully written by the person who truly knows the person best. They may give a rich endearing narrative and ideas to enhance an individual's quality of life.

Cohen stated that 'I believe the use of first-person is a privilege. It connotes a truth, an intimacy, an authentic

perspective, and thus a power unlike any other.' It is a privilege that for the last 4 years I have taken with my toddler son. I've written 'I saw Paw Patrol' and 'I had fun at Lachlan's party' under the photos that I've taken, and given books of these to his grandparents. But perhaps these are documents of leisure, not documents that are meant to be directing high quality support and care. Why is it something that I am comfortable to do with my son, but I cringe when I see it done for an adult with PMLD? Maybe because I'm his mum. Maybe because I know his speech will develop and he will be able to soon say all these things for himself. Maybe because I was there when the events occurred, so, in part, they are my story too.

In terms of the contemporary human rights agenda, maybe it is the power and authority of first person writing that should not be taken from a person with PMLD.

Perhaps instead, a third person writing style would be more authentic and indeed respectful when the person is not writing or narrating for themselves. Perhaps the charade of this faux first person writing should be taken over by a voice that acknowledges that the words are our best guess of what a person might think, enjoy, be challenged by, and desire. Perhaps we should first acknowledge that words and writing are not something that the person uses, and pretending that they do would be inauthentic.

But perhaps I am too literal, and should reconcile myself with our attempts to include each person with PMLD in communities (even the broader disability community). Perhaps it is innocuous and one part of 'all in the detail' that should be left as it stands? Is writing in first person 'getting it right' or not?

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References

Cohn, G. (2014). The power of the first-person perspective. Retrieved from http://meetcontent.com/blog/power-first-person-perspective/

I tried to find some literature exploring the use of firstperson in this way with people with disabilities, but could not find anything. Please let me know if you find any.