

Ethical tensions in a disability label?

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Paper
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To set the context, let me provide you some information on who we are and what we do.

Jenny (30) came to WWILD for counselling and in the process of her counselling said that she had been sexually assaulted by her brother and father when she was a child. Jenny is able to tell her story in simple terms but it takes her a very long time to tell you anything. There are often long periods of silence where she is recalling information. She is easily confused if you interrupt her thinking at this time, it means that she is unable to tell you what she wanted and becomes confused. Jenny is looking to always please you and will often say yes to questions that she really doesn't understand what you mean. She just wants to make you happy. After a number of counselling sessions she decided that she wanted to proceed with a report to the police and get justice. Jenny was supported to go to the police station where she told the police officer about the abuse that had happened in her life. She was able to recall the story of the assaults but not give any detailed information about dates or times only roughly how old she was when it happened and a rough time of year – (around Christmas, after my birthday). Because these events happened such a long time ago and there were so many reported the police informed Jenny that it would be difficult to find any evidence to support the complaint. They said that they would begin the process of trying to obtain some evidence about the allegations and keep her informed about what was happening and what would happen next. The police kept in touch with Jenny as they went through the investigation and after a long period of the police told Jenny that they were unable to find any evidence that could support her allegations and that the matter would not proceed.

The Victims of Crime Disability Training Program is funded by the Department of Communities Queensland. It is a small state wide program that provides community education to government and non government agencies who work with people with intellectual disabilities in the criminal justice system. The other part of our work is to support people with intellectual disabilities who have been victims of crime during the court process.

People with intellectual disabilities are over represented in the criminal justice system both as victims and offenders (French 2007). They face many systemic obstructions in the justice system. When I teach I am constantly talking about people in terms of their disability labels – people with intellectual disability most commonly. This naming implies a fixed disability identity on to the person as the dominant identity that they possess or enact (Beart 2005), yet it is not the way I see or understand the people I work with.

There is no such thing as a typical day for me. On some days I teach 20 – 30 disability support workers or workers from the legal systems on the issues of vulnerability of people with intellectual disability in relation to crime and victimisation. On others I sit beside a person in the court during a trial and also teach the legal team supporting them how to do that in ways that are meaningful and appropriate. Often my role is to be an interpreter to a lawyer as much as the person I am supporting. What I mean by being an interpreter is the role of giving meaning to the person's stories. When interpreting the person to a lawyer I am teaching the lawyer the context of the life of the person who they are representing. I also provide education on the current research of evidence based practice in working with them in the legal system. When supporting the person I am interpreting often the system and the social construction of disability back to a person in ways that have meaning in the context of their story as a 'victim'.

The legal system is filled with words and language that make little sense to most of us let alone to a person who is a concrete thinker – ideas about truth rights, facts and evidence are not easily shown or explained to a person in plain English ways. Invariably I am encouraging a person to tell the story of what happened to them as the way to mediate this divide. The legal system also brings people into being in ways that they may not recognise themselves – as a victim or an offender of a crime. They may be talked about in terms of a disability label or as a special witness. While a person may say they went to special school – they may say it was because they had epilepsy or were a slow learner, not seeing this as a disability. Susan Hayes (2009) advocates that lawyers and experts indicate a cognitive age to witnesses in a court room as a way of assisting the jurors understand the capacity of the person to give evidence and answer questions. Hayes (2009) argues that by saying, for example, that a witness has a mental age of a 7 year old, the jury will appreciate how the person understands information, but the risk is that the 40 year old man giving evidence will not understand himself as a 7 yr old at all and be offended by this labelling action.

Words are powerful and act in multiple ways (Sherry, 2000). In each of our lives we are affected by the words that are used about us and by us – if you are seen to be slow in education you go to the slow class and take up the

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idea that you are slow or can't learn, and so it is for the bad kids, the smart kids etc. This naming starts up a process that we either take up or resist and the same is true of a disability label. Cocks and Stehlik (1996) argue that the way disability is named and constructed underpins the social response – if disability is seen as illness the norm becomes to seek a cure and disability is managed within a health system. The names and terms that define difference of ability have been around thousands of years. The Ancient Greeks talked about the deformed in referring to babies born with birth defects – this was linked to sin and the child was exposed to the elements and allowed to die (Stiker, 2000). Cripple, idiot, freak, monster are all words that can be found in history as terms to signify a disabled body. With the advent of the Enlightenment there was an increased codification of the body based on science and rationalisation – moron, feeble-minded, idiot, retard have been used to script disabled bodies over the last few hundred years (Stiker, 2000; Thomson Garland, 1997). From 1876 until 2008 the American Association on Mental Retardation (USA) was the professional peak body and recognised internationally for research in the field. This year they changed their title to American Association on Intellectual and Developmental Disability in recognition that the name mental retardation holds a negative stigma and is not part of the current language used in the field.

My point is that language is slippery and changes over time and context but it is never neutral. Language is a carrier of meaning making and imposes knowledge and concepts about people when disability labels are the markers used to script a differently abled body. 'You're a freak' is a taunt in the school yard today but at the turn of the century people queued to see people with disabilities who were differently abled freaks in freak shows – freak defined your body and the role you could play in society (Longmore, 2003). Since the 1990's many people with disabilities have sought to reclaim the language used to describe them and have demanded that they are people *first* before the disability (People First Canada). This approach has been widely taken up by people with intellectual disability. This idea is contested by some people with physical disability who advocate that the disability label is a marker of the capacity of their body and they want to claim this as part of their identity (Mairs, 1992); *crip* is often the term iterated in these discussions.

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Today notions of disability are contested and under review as many people with different abilities have taken up roles in the academy and are scrutinising disability theory.

This is a brief introduction to the context of my practice. I want to pose the question – what are the ethics of a name and the language that brings us and the other into being? I am considering here specifically how the name intellectual disability brings a person into being, when it is used in community education. Butler with Salih (2005: 55) argues that language brings us into being in ways that we do not necessarily recognise ourselves. Language for Butler (1990, 1993) brings the body into being.

“..it is not that an identity ‘does’ discourse or language, but the other way around – language and discourse ‘do’ gender. There is no ‘I’ outside language since identity is a signifying practice, and culturally intelligible subjects are the effects rather than the causes of discourses that conceal their workings”

What I understand this to mean is that there has to be a shared understanding that is ‘done’ in language that brings a body (be it intelligible in terms of gender, race or ability) into being. That until language is applied a material body it is not signified – or inscribed with meaning. So I ask how then does the language we use in community education make intelligible, delimit or make unknowable or unrecognisable the ‘other’ we bring into being? When I teach, the ‘other’ I bring into being is named ‘intellectually, learning or cognitively disabled’ as the script written onto the material body. I find myself constantly trapped in language that produces an ‘othering’ of people I hold in high regard. The name invokes stigma and stereotypes that do not re-present an individual’s identity, but impose a culturally intelligible subject.

Within the name is an implied homogeneous grouping that is a flight of fantasy and yet it is a required name and label that allows the participant in training a framework within which to understand and make meaning of the people about whom conversations are undertaken in the course.

This is the ethical dilemma that I find myself caught in via language as a PhD student and as a community educator in a small non government agency. As a student doing a PhD I have a focus on language – specifically - how language is the terrain of identity as a performance. Here I am taking up

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Butler's (1990: 25) notion of performativity "*as a set of acts within a highly rigid regulatory frame*". In taking up this concept I am rejecting or troubling the notion that people with intellectual disabilities have a fixed disabled identity and arguing that they perform their disablement within the confines of the language that limits and delimits their identity. Having come to this point of awareness I find no value in the labels of disablement. From my daily experience I know that *all* people are diverse and different. Ability is a category of being human that is fluid, multiple and contradictory in the same way that all identity categories are – race, gender, sexuality etc. (Hall, 1996).

When I work as a counsellor with a person I am engaged in a process of hearing the story a person tells to bring themselves into being. There is an intimacy in this relationship that does not require the naming of difference, rather there is a process of me opening to hear the essence of what a person is telling. In the framework of narrative inquiry I am working within a conceptual view that all people tell stories as a way of making meaning of themselves and their experience (Chase, 2005). In these conversations there is no pull or ethical challenge for me and it is this work that inspires and rejuvenates me. I am working knowing that I can never really know another because I am as delimited by my language with which I can hear and understand them as they are confined within the language available to them to tell themselves (Chase, 2005).

The larger part of my work is done at a distance to the individual. I am a community educator in a program that seeks to educate parents, carers, disability workers and people in the justice system about the evidence based practice of working to support people with intellectual, learning and cognitive disabilities. Here are the seeds of my dilemma. How can I teach this information (which seeks to support fairness and equitable treatment in the justice system) without drawing the subject into being as 'intellectually disabled' knowing that I reject the construction implied in the name and label? I also know that that many people may not recognise themselves in the name and language I use to 'tell' them.

Hall & Du Gay (1996) describe the way that words take up meaning so that they are shared within a culture to describe things and beings as the foundation for shared knowledge and interaction. Here is the trap as I see it.

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There is no way for me to undertake this education without using the words that have this shared cultural meaning for without these names and labels the people I re-present are unknowable or unintelligible. For them to achieve just outcomes in the justice system their individual difference needs to be named as the means by which they can request special measures aimed at ensuring fairness and equitable treatment. The name operates in multiple ways – none good or bad per se but all dangerous (Foucault in Sharpe 2005: 103). The danger in intellectual disability as a label is invoked in notions of deficit, stigma, poverty of opportunity to live a good life and devaluation (Wolfensberger, 1972). I am also mindful that in using a particular language I am making up people (Hacking, 2006) in ways that impose categories that have an effect in how a life is *allowed* to be lived.

The term intellectual disability brings into being a cultural intelligibly, a knowledge, image and/or idea about a person so labelled. Yet each person is different and diverse and has a vast range of skills and limitations, as do we all. No two people are the same; no matter how seductive it is to believe the label creates a homogeneous grouping, this is not a reality. When I use the label to describe some of the shared characteristics that make a person vulnerable in the justice system (Perske, 1991), like acquiescence and concrete thinking, I know that people will experience and exercise these in different ways with different levels of potency. However the characteristics are also part of what make people so vulnerable in the justice system. When a person just says yes to a question that they don't understand it can have the effect of sending them to prison. The ethical dilemma is constantly to measure the danger of the doing the naming against the risk of not doing the naming. Each action contains possible benefits and costs.

Most of the police and lawyers I work with are troubled by the way that many people with “mild or moderate” (again I am trapped in language to give you clarity about what I wish to describe) intellectual difference hide their disability. Because this means that they (the police and lawyers) are not able to advocate for the special measures that can protect them (the person with an intellectual disability) in the criminal justice system. What is operating here is what Edgerton (1963) calls the ‘cloak of competence’ which a person uses to escape the stigma (Goffman, 1963) that is the effect of having the label of

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intellectual disability. Again I am caught in language; to fail to name the difference can lead to the possibility of not achieving just outcomes but to iterate and reiterate the label imposes an identity within which a person does not necessarily recognise themselves. Is it ethical to demand that a person acknowledges this disability when they do not recognise themselves within the naming? Is it ethical not to name them so they can hide their disability but they are not able to access equitable treatment in the justice system?

There is potency in the power of language that can and does lead to better outcomes for people with intellectual disabilities, but there is also a danger in the 'doing' of language (Butler, 1997).

I wish I could tell you that I have found an answer or a solution to this tension that I face in my work, but I can only tell you that I am constantly on shaky ground. I know that I hold the view that disability is a performance. What I also know is that it is the language performance that makes intellectual disability culturally intelligible. I don't know how to hold both of these ways of being into an ethical balance except on a person by person, place by place, time by time positioning of how I will re-present a person who is 'othered' by 'intellectual disability'. I am delimited by the regulatory framework of language that ables bodies.

Maybe what is important is that I talk about the struggle imposed for me in language and we think about new ways of making the 'other' intelligible.

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