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EDITORIAL

Count me in...or out

Peter McGill, Tizard Centre

Labels matter. Yet the process by which labels are acquired is, perhaps inevitably, messy and variable. In the world of learning disability, labels increasingly matter since, whatever their downside, they may make a person eligible for support not otherwise available. But whether an individual needs support will depend not just on the individual but also on the circumstances of their life, what they are expected to do, on the nature of the society of which they are part. So, Chris Goodey suggests, in his article on the history of “learning disability”, many people who might now be labelled as having a learning disability would not have been so labelled in the past when expectations of, for example, academic learning did not exist for the majority of the population. This is a fascinating notion which is worth dwelling on for a moment. We are all somewhat prey to notions of inevitability – our lives have to be the way they are. Even if we don’t believe simplistically in fate, we do tend to see the way things turn out as being in some way logical. We manage to maintain this sense of constancy against a backdrop of incredibly fast change. It is only when we stop to look at changes over somewhat longer periods of time or at differences between different cultures that we realise the myth of this apparent inevitability. So, Goodey suggests, it is not inevitable that an individual with specific characteristics will be defined as having a learning disability since the nature of the definition of learning disability will change substantially over time, reflecting broader, societal changes.

This, of course, creates some difficulties if you are in the business of trying to count people with learning disabilities. Claire Stuart describes the process of doing this in Scotland, and Roy McConkey and Sarah Craig make comments reflecting their Irish experience. In an organised society with a commitment to provide support to people less able to cope independently, it is clearly vital that we gather information about the number of people with learning disability and, if possible, the nature of their needs. But it is also important to consider how changes in society may change the number of those who are counted in without there being any fundamental change in individual characteristics. The archetypal example of this is the reduction of those labelled “poor” in circumstances where the income of higher earners has been reduced so that, with relative definitions of poverty, some are no longer so defined. The kinds of mechanisms now being used in several countries to count people with learning disabilities may then have a broader relevance to research on changing relative conceptions of learning disability (and, depending on the mechanism, possibly also autism).

None of this might seem to have much to do with the involvement of people with learning disabilities in storytelling, as discussed by Nicola Grove and further considered by Lois Cameron. But, as both authors note, stories are very important. The stories we tell about ourselves are part, perhaps, of the process by which we maintain constancy (that sense of inevitable narrative) in our own lives. Many people with learning disabilities do not have such stories and, even worse, don’t have anyone to tell stories about them. Properly told stories about the lives of people with learning disabilities will often illustrate, even over a relatively short period of time, the contingency of people’s lives and labels. Take “challenging behaviour”, for example. All too often, once someone has acquired this label, it becomes impossible to shift. In the past people got stuck in long stay institutions even when there was considerable evidence of variation in their behaviour over time,

reflecting, essentially, the way in which they were treated (e.g., Di Terlizzi, 1994). Even now, once in the system of residential schools, assessment and treatment units, out of area placements and so on, it becomes extremely difficult to break free of the label. In such circumstances it is vital that we get our stories straight. This includes the stories told to others, which have to counter the apparent (but not real) inevitability of the “career” (Goffman, 1959) being imposed and remind us all of the contingency of labels, especially this one. Most important of all, it includes the stories the person is supported to tell themselves. Here we need a narrative that’s, very much, not inevitable. We need people to believe that times will change, their lives will improve, they can hope for the future. If there isn’t an Arthurian myth for this, perhaps we should write one.

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