

Ethics and Intellectual Disability

Life Stories: Narratives and Professional Practice

Herman P. Meininger

Parents, pastors, and social workers involved with persons with intellectual disabilities time and again have drawn attention to the destructive effects of a professionalism which manifests itself as a "technology of power." Personal identity, making sense of life, experience of rituals and stories, involvement in a web of meaningful relationships, concreteness, and particularity these elements have been banned from the ruling epistemological paradigm which can be described as institutional, bureaucratic, centralizing, general, foundational, and data-oriented.

The standard approach in professional care and support involves a type of listening to clients in which professionals only hear what seems to fit into the narrow referential framework of their professional training. It involves a type of perception that produces knowledge in terms of a universal science of measuring and classifying empirical

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A Virtue Ethics Perspective on Research

Jennifer Clegg

Some clinical psychologists argue that ethics based on principles which tell us what to do, such as normalization, feminism, or participation, need to be balanced by considering how we act with people (e.g., Hoshmand, 1998). Moral philosophies such as virtue ethics (VE) open a different window onto research ethics. MacIntyre is one of VE's main contemporary exponents (1985, 1991, 1999), developing Aristotle's position that to separate ourselves from a moral community is a fundamental error. This plural and interactional approach to the virtues focuses on courage, justice, and honesty. MacIntyre traced the way that ethics became both individualized and reduced to the single virtue of altruism during the enlightenment. He argues that contemporary ethics mixes fragments of ideas left over from previous eras.

Theories of duty jostle for attention against those of rights or how to identify the greatest good for the greatest number. Deciding which set of rules to

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circumstances and observations. It is the knowledge of the "case history," put down in the records of physicians, psychologists and other professional care workers.

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Opposed to this, is another kind of knowledge consisting of a slow and continuous accumulation of insights, attitudes and habits by gaining new experiences over and over. This is the knowledge that is mediated by telling a life story, (re)writing it, listening to it, and (re)reading it. Stories tell *who* you are, whereas diagnostics express *what* you are. Oliver Sacks has written: "To be ourselves we must *have* ourselves – possess, if need re-possess, our life-stories. We must 'recollect' ourselves, recollect the inner drama, the narrative, of ourselves. A man *needs* such a narrative, a continuous inner narrative, to maintain his identity, his self." I would add to this that, to be able to maintain his identity, his life story also has to be listened to, heard and interpreted by others, confirmed, and questioned. However, care workers prove to have hardly any knowledge of the life stories of their intellectually disabled clients.

Consequently, they often have rather superficial impressions of their clients' personal identities. And, no less important, they lack any conscience of their role as co-authors in the life stories of their clients.

Life stories, and the knowledge they convey, can be used for several purposes. The purpose may depend on the occasion on which the story is told, written, read or listened to. It also may depend on the actor of the telling, writing, reading, or listening. Of course – though not as self-evident as it looks – persons with intellectual disabilities themselves should be seen as prime authors of their own life stories. However, in the construction of their written life stories, family, friends, care workers or researchers may play an important part. Sometimes they serve as assistants or ghost-writers; more often they are readers and interpreters. Their first aim in this writing and reading may be to give expression to the lost voice of the person with intellectual disabilities, to support his growth of identity and self-respect, and to strengthen and confirm him in his own ways of making sense of life.

The story of a life can not only be told from a first-person perspective, it can also be told from a variety of second-person and even third-person perspectives. Thus, a wide variety of interpretations is possible and is reality in most cases. Therefore, Dorothy Atkinson and Jan

Walmsley point to the necessity of asking the following questions when assessing the authenticity of a life story:

- Who initiated the writing/telling of the life story and why?
- Who wrote/told it and how?
- Who owns it?

And I would add another question:

- Who reads it/listens to it, why and how?

By critically investigating the answers to these questions, we may gain a clearer understanding of the actors, objectives, and interpretational perspectives involved in telling, writing, reading, and listening to life stories. Thereby, as Gillman, Swain, and Heyman have emphasized, we may produce a counterforce against the domination of one perspective, one discourse, one interpretation, over others. But most important, we may contribute to the deconstruction of the "objectified and subjugated identity" of individuals as it is reflected in case histories and Individual Program Planning systems, even if called "person-centered." Constructing and keeping a "life story book" is suggested as one of the means of helping individuals to recover their unvoiced stories.

From the perspective of the pro-

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fessional care-givers, the confrontation with another kind of knowing their clients – as mediated by reading, listening to, or even assisting to write a life story – will mean a critical challenge to their usual understanding of professionalism. Professionals should critically evaluate and deconstruct their usual assessment and intervention models and procedures, and their case recording practices, by providing their clients the “stock of stories” needed to re-write their lives.

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A new approach to personalized care and support should therefore be based upon a narrative and hermeneutical model of interpretation and support as opposed to an empiricist model of diagnosis and treatment. Consistent with the latter model is an interventionist character of professional practice. Conversely, processes of (re)constructing and interpreting stories demand a professional commitment in which “presence” and “engagement”, as distinct from “intervention” and “distancing,” are

central characteristics.

However, we should be very much aware that no written or spoken text can fully embrace and comprehend life as it is lived. All our writing and telling is covered by the veil of the unsaid and the ineffable. Yet, exactly this unsaid and ineffable quality gives a life the weight and significance which makes it worth telling and writing about it. It invites us to respect the mystery of the other.

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A Virtue Ethics Perspective on Research

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follow seems to be the task; yet imagining ethics to be a set of rules is a recent and arguably unhelpful development. MacIntyre (1985) was not concerned with identifying the right thing to do in particular situations, because life is too unpredictable. Instead, he discussed ethical persons living an ethical life, developed in three ways: learning ethical practices through experiencing them with others; creating narrative integrity across our lives; and entering into moral traditions through active membership of an ethical community. The way these relate to clinical intervention in learning disability is considered elsewhere (Clegg, 2000). I focus here on research.

The VE idea of the practice has been criticized as opaque. There could be three reasons for this. First, VE does not generate the expected list of rules or principles, although that is how professional ethical codes are presented. Second, the VE practice combines the observable with the personal; it theorizes not merely actions but the way lives may be oriented towards good. Third, as Potter (2000) observed, practice has been rendered invisible by cognitive psychology. For cognitivists, practices are mere surface expressions of underlying thought processes; whereas for constructionists, practices comprise the

fundamental unit of research.

Ethical practices are expressed in relationships which extend human powers to achieve excellence. If researchers orient themselves towards achieving goods internal to research practice for themselves, participants, and users of research, appropriate relationships and types of communication become obvious. Goods internal to research practice include being fired by curiosity, since without it research is disconnected or dull. Ensuring that local meanings are represented honestly and fairly so that research reflects participant experiences is another good. Ethical practice also requires researchers to cultivate an orientation towards rigor. Concern to achieve high standards enables researchers to welcome critiques, because they stimulate excellence.

Internal goods stand in contrast to those external to a research project, such as having the status of being a researcher, attending international conferences, or publishing in various media. When researchers give external goods priority over internal goods, in VE terms their practices are corrupt.

Since reflection is central to ethics, I re-read an article published with colleagues 10 years ago. This concerned an experimental analysis of interactions between staff and adults with profound learning disabilities (Clegg, Standen and

Cromby, 1991). The reflections it prompted concerned the spirit in which questions were posed and the way participants studied. What I did then, and wish I did still, is collect my own data. I recalled how much spending time with participants enhanced the relevance of this research.

Ethical practice also requires researchers to cultivate an orientation towards rigor. Concern to achieve high standards enables researchers to welcome critiques, because they stimulate excellence.

There are aspects of that research I would not change. Its origin in curiosity about how staff engage the most profoundly disabled people remains a just one. We struggled with rigor when confronting all the problems of reliably and systematically rating interactions with people whose additional disabilities were so varied. And results were used by people with profound disability and staff, because we replaced the ineffective strategy of contingent responding with two more useful ways to facilitate positive interaction.

In hindsight the research lacked justice for participants. Next of kin gave formal consent for clients to

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participate, but informal information that amplified proxy information was ignored.

Some people with profound learning disability turn away from their mirror image. Extrapolation suggests they would refuse to look at their video image if they understood it: perhaps we should treat those persons as having refused consent for videotaping. From the opposite direction, staff were invited to participate informally, but accorded none of the usual rights. Concern about behaving ethically towards people with disabilities made it hard to recognize staff as participants too, so they acquired the strange status of being neither researcher nor researched. MacIntyre (1999) argues that we fail to recognize gaps like this through failing to acknowledge our own past, future and perhaps current dependencies.

Reflecting upon this Ph.D. research inevitably prompted consideration of myself as a researcher and supervisor. This enters the realm of hidden attributes and orientations, familiar territory to a clinician accustomed to personal scrutiny and supervision but not necessarily any more comfortable. It is impossible for an individual to know whether his/her personal integrity has increased or decreased, yet it will not increase without attention. Schön (1987)

noted that although people find it hard to define virtues like integrity and intuition, they find it easy to agree which of their peers showed them. His analysis of the interactions which express those qualities makes an important contribution to our understanding of ethical research practice. Yet Giri (1998) argues that such abilities can be communicated between people but not "linguistified."

Schön (1987) noted that although people find it hard to define virtues like integrity and intuition, they find it easy to agree which of their peers showed them.

If I have arrived anywhere different from the self who set out it is largely due to others who supported my development, not because I am important, but because good research is important for human flourishing and it needs human conduits. Qualities like integrity and courage are as much caught as taught. We need to see colleagues rejecting obvious solutions when something troublesome does not fit, working to remain open to the new and unexpected. Yet the ethical practices, narratives and traditions through which we develop ourselves and our students remain almost completely unknown. That is a task for the next decade.

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“Ethics and Management”: Two Approaches

Hans S. Reinders

Like other sectors of society, “ethics” is on the move in the field of intellectual disability as well. Conferences and symposia address topics such as citizenship for disabled people, or quality of life. One of the most recent developments is to regard the concern about ethics as a feature of “quality care” for professional providers. This means that organizations make transparent their basic values and show how these values operate in daily practice, both in terms of the process and the outcome of services.

Now, one may think that the rising concern about ethics is laudable because it shows that people are concerned with right and wrong, and doing well rather than evil. But there is reason to be cautious. There is a need for the distinction between what is real and what is fake. In assessing the “ethics” of their organization people are tempted to lose themselves in advertising. To regard “ethics” as a label for quality care is a bad idea because it lures people into the vice of paying lip-service to virtue. After all, value talk is just that: talk, and nothing else. A concern for “ethics” is a costly affair because, when real, it is intrinsically self-critical so that service providers can hardly use it to advertise the quality they deliver.

These reflections suggest that there is an issue here of how to

manage the concern for the ethics such that it does some good for professionals and their clients. I believe that there is a philosophical distinction that might be helpful in this connection. The concern for ethics can be regarded as an end in itself, but it can also be used as a means to something else. It can be substantial, in the literal sense of aiming at something that stands on its own, and it can be instrumental in the sense of being in service to another objective.

Values are not instrumental but expressive. That is, they express who we are in the sense that what we value is what gets us going. Values are not just beliefs, but motivations. Values have motivational “pull.”

It is quite easy to see what it would mean to use value talk in an instrumental way. If advertising one’s organization as being concerned with values helps to sell one’s product, why not use it for that purpose? If a concern for “ethics” does well in public relations, let’s go for it. If clients are attracted by the values of individual choice, and self-determination, let’s put these values on top. If they are attracted by family values, let’s have family values, and so on.

There is something amiss with

the instrumental approach to “ethics”, however. It is based on a mistaken conception of values. Our values are part of who we are. They are not goods that we can dispose of as if they were external to ourselves. Values are much like our bodies. We do not *have* values, we *are* our values! Values are not instrumental but expressive. That is, they express who we are in the sense that what we value is what gets us going. Values are not just beliefs, but motivations. Values have motivational “pull.”

The mistake of the instrumental approach to values is quite clear. We can surely seek to foster the values that our clients are interested in, but only because they are our own. Otherwise we should admit that we seek to foster them not for their own sake, but for the sake of something else: consumer satisfaction, for example. Surely, consumer satisfaction is an important value for service providers, and there is nothing wrong with that. “Consumer satisfaction,” however, is indiscriminate for a variety of activities. A furniture store may seek consumer satisfaction, just as a law firm, or a hospital. But in order to achieve consumer satisfaction, each of their activities must be performed well. To be a good hospital one needs to embody a particular set of values which is dis-

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tinct from the values that are inherent to legal practice, or business. What this argument suggests is that specific kinds of practices—business, medicine, legal counsel—have their own internal goods, such as profit, health, or justice. Consequently, a substantial approach to ethics by those who participate in these practices seeks to achieve particular values for their own sake. If it is our job to care for people with intellectual disability, and we are motivated to do it well, then we will pursue the values inherent to the practice of caring.

In a recent book, the Harvard business school professor David H. Maister has made an argument for “true professionalism” in service firms. His interest is primarily in what it is like *to be* a professional. According to Maister, the key to true professionalism is not to know the right thing but rather to find the strength and courage to do it. That is to say, true professionals are motivated in certain ways rather than others. Service firms are nowadays attuned to their mission statements, core business, master plans, strategic planning decisions, all available in elegantly printed flyers and brochures. The problem with this plethora of ambitions, according to Maister, is that they merely reflect what these firms say they want to happen, which is something quite different from actually making it happen. In other words, real

professionalism is about having the *skills* as well as the *character* to do what we say we believe should be done. The notion of character is crucial in this account of the true professional in that it refers to steady dispositions and inclinations in a person to do things in certain ways.

In thinking about ethics and management, I conclude from Maister’s views, the task is to get people motivated in such ways that they embody what the organization stands for. Value talk may serve an opportunistic concern about “ethics” because it can be advertised as a sign of quality care. But it cannot be instrumentalized as an embodiment of professional life. As such it can only be substantial. That is to say, the true professional in support of people with disabilities aims at particular moral values for their own sake, because she has the character to be motivated by these values. If so, this implies that the task for managers concerned with ethics is to help and support their professionals to develop professional character rather than use it as a label for quality care.

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Just Out from the University of Notre Dame Press

*The Future of the Disabled in Liberal Society
An Ethical Analysis*

Hans S. Reinders

The Future of the Disabled in Liberal Society questions developments in human genetic research from the perspective of persons with mental disabilities and their families. Hans S. Reinders argues that when we use terms such as “disease” and “defect” to describe conditions that genetic engineering might well eliminate, we may also be assuming that disabled lives are deplorable and horrific. Reinders points out that the possibility of preventing disabled lives is at odds with our commitment to the full inclusion of disabled citizens in society.

The tension between these different perspectives is of concern to all of us as genetic testing procedures proliferate. Reinders warns that preventative uses of human genetics might even become a threat to the social security and welfare benefits that help support disabled persons and their families.

For further information, see the University of Notre Dame Press website: <http://www.undpress.nd.edu>.

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