The Ideal Proxy Informant

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Each year, choosing Christmas presents for the people I am closest to reveals in all its poverty my slender understanding of what pleases them. The problem is multiplied tenfold when attempting to choose for people with learning disability, particularly when choosers are service staff whose relationship with the person is relatively recent and the person has little or no speech. In recent times this problem has apparently been addressed by enabling people to choose for themselves. Offering choice to users has almost become a byword for ethical practice: people unable to do are construed merely to lack experience. This paper considers the situation of people with severe and multiple disabilities whose range of choice-making is extremely limited even when they get plenty of practice. It assumes there are topics on which they need someone to speak for them, a proxy, and that it is important to theorise how that person can do their task as well as possible.

This cannot be taken to be a widely accepted assumption. Clearly, there are advocates who believe every person

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The Ethics of Behavior Modification

Hans S. Reinders

Many people within the disability community have discovered that their lives changed significantly once they began to think positively about themselves and to reject any suggestion that disabled people and their families live deplorable lives. Consequently, the negative impact of the old paradigm of intellectual disabilities with its emphasis on individual pathology has been cast away. However, there is one domain left that seems to be left unaffected by these changes, the domain of the psychology of behavior modification.

Behavior modification (BM) still has a significant impact in the field. This is particularly true in the Anglo-Saxon world were it continues to be regarded as a scientific method for improving the quality of life of people with “challenging” behavior. But its reputation is in decline. The causes of behavioral problems can oftentimes be located in the failing professionalization of care-giving staff as well as the inadequate organization of the team of caregivers rather than “inside” the disabled person. These insights undermine behavior modification as a solution to a problem. BM appears to treat clients as objects to be changed rather than as subjects that can change themselves.

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The science of BM with its emphasis on empirically tested methods is itself the expression of a particular philosophy of science with its own moral underpinnings. Its scientific method is to establish causal connections between events such that it is possible to make reliable predictions about the conditions under which they occur. Understanding behavior is a matter of explaining its necessary and sufficient conditions. Once behavioral problems and learning disabilities can be understood by explaining how they come about, the practical task is to develop instruments based on this knowledge that are allowed to change problematic behavior.

It is important to see that this science abstains from setting moral objectives. What behaviors are desirable or undesirable is not a question for psychology to answer, because that question cannot as such be the subject of scientific explanation. The behaviorist tradition of science understands its own rationality in purely instrumental terms. The normative aims for which the method is going to be used are therefore external to the method itself. This raises the question of from whence the normative objectives of BM are to be derived.

A further implication of this approach is that the separation between “fact” and “value” has important consequences for what is seen as the expertise of the practitioner in the field. Once this expertise is primarily defined in terms of applying empirically tested technology, it follows that questions about norms and values arising in the process must be left to the decision of others. The practitioner’s expertise is restricted to the use of instruments to obtain certain goals without determining these goals.

'It occurs to me that both these implications are sufficient to explain, at least in part, the growing demand for ethical expertise in the field in the last decade. Once it is accepted that issues of values belong to the domain of philosophy rather than the domain of science, and once one considers oneself to be a scientist rather than a philosopher, the conclusion must follow that the value dimension of the practice of psychological intervention requires a discipline of its own. A prime candidate for this role appears to be the discipline of ethics. While science rules in the domain of facts, ethics rules in the domain of values.

Forms of Ethical Reflection

This methodological division of labor between behavioral science and ethics explains the specific form that ethical reflection often has in connection with BM. If science is taken to aim at the production of instruments to control practical problems, it seems quite appropriate to expect the same from ethics. So, ethicists are expected to produce their own instruments such as “guidelines” and “protocols” to secure morally justified procedures of scientific intervention. The interest in this form of ethical reflection explains why ethics developed in close connection with jurisprudence. This is particularly true of the United States where textbooks on moral problems abound in the analysis of legal cases. Both domains are required for external guidance of a scientific practice that does not know how to regulate itself.

The focus on the production of an ethical technology that has been representative for the recent explosion in bioethical literature, has recently come under attack, however. It is under attack from a different approach that relates ethical reflection with culture and the quest for the good. The focal point of ethical reflection is mediated by the question of purpose. A contemporarily fashionable way of framing this question is to ask for “basic values”. Whether one looks at hospitals, or professional service firms, or businesses, many of these organizations are deeply involved in reflecting on purpose: what are we here for? And how can we become excellent in what we do? These are questions that mark the shift in ethical reflection when compared with the interests in controlling moral quandaries.

As a result of this development, a form of ethical reflection has emerged that is capable of raising new and challenging issues. Characteristic for these new issues is that they mark a clear distinction between ethics and law. By focusing on standards of morally acceptable behavior that can be universalized into legal standards, ethics has neglected to think about its contribution to reflect on daily practice and experience. The ethics of being engaged in supporting people with intellectual disabilities to get through their daily life as good as they possibly can, is hardly a matter of running from one emergency to the next. It is much more a matter of learning to see the world from their perspective and then try to empower them. For professionals this means to

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reflect upon their own contribution, upon their habitual conduct and their professional attitudes. Whereas the closeness of ethicists and legal analysts expresses an interest in controlling emergencies, the interest in the ethical skills of professionals is much more concerned with the quality of daily life.

Dealing with the lives of people with intellectual disabilities who are in many ways dependent professionals are prone to condescension and paternalism. In order to attain this level of professional awareness, one needs the skills of recognizing implicit habits, prejudices, expectations, and perceptions. Critical self-reflection from the perspective of the client is a moral task to be mastered by professionals that requires self-knowledge more than anything else.

It is not difficult to see why the ethics of everyday practice is quite different the production of ethical technology. It is also not difficult to see why the science of BM does not look good from this changing perspective. The third roundtable of the SIRG Ethics and Disability (sponsored by the International Association for the Scientific Study of Intellectual Disabilities) will be held in Brisbane, Queensland, Australia, in November, 2003. The theme for the roundtable is: ‘Political philosophies and economic frameworks’.

It is anticipated that by having the 2 events held together that there can be a cross-fertilisation of ideas and an opportunity for a wider group of Australians to access the discussions of the SIRG. An example of this is that Tim Stainton, a member of the SIRG, will also be one of the key presenters of the ASSID conference. Other keynote speakers will be: Brendan Gleeson, Marcia Riaux, Gordan Grant, Carl Haywood, Nick Bouras and Geraldine Holt.

A call for papers for the ASSID conference has now begun. Information can be found at: http://www.rmit.edu.au/Departments/PS/AssidBrisbane2003NationalConferencePromo1.htm

For further enquiries, mail to: lwilson@deakin.edu.au or J.Clapton@mailbox.gu.edu.au

Brisbane in November is a delightful time to visit. The conference, to be held in late spring and timed for after the Rugby World Cup, will be held at the Brisbane Convention Centre, situated across the river from the inner city. The Convention Centre is part of the Southbank complex, which is the re-developed site of Expo 88. Accommodation, public transport, eating and recreational facilities are all in close vicinity.
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with learning disabilities can express themselves if only we make enough effort. I struggle to understand why anyone imagines they could obtain informed consent to, say, research participation from a multiply disabled adult with a developmental age of 3 months. Why is there no countervailing concern about the rights and protections that are discarded when somebody points to a picture that apparently indicates consent, when there is no means of checking what they think they are doing? Perhaps the deeply felt position of such advocates rests on an unexamined belief, that describing any person as so learning disabled they cannot protect their own interests is to treat them as less than human. It is a belief widely encountered in liberal culture: Reinders (2000) has argued such cultures treat non-autonomous people either as potential persons (babies) or as non-persons (foetuses), in which case the intensity of feeling is understandable.

It is a habit of mind that refuses to acknowledge the bodily dimension of our existence, and the benefits conferred on us by others.

There are alternatives to liberal culture. In showing how common it is for philosophers to avoid theorising states of vulnerability or dependency, MacIntyre (1999) argued that an illusion of self-sufficiency obscured their significance to philosophers, and influences many of us. It is a habit of mind that refuses to acknowledge the bodily dimension of our existence, and the benefits conferred on us by others. Hermeneutic philosophers argue that mature dependence, not autonomy, is a legitimate goal of adulthood which fulfils many of our deepest needs. For those who are willing to accept some individuals with learning disability need a proxy for some decisions, the hermeneutic perspective offers responses to the questions 'who should be a proxy, and what should they do?'

I will argue that the ideal proxy needs to have developed an ethical relationship with the person; to interpret the person’s future needs by fusing imagination with shared knowledge; to have some cognitive control over two potential sources of bias; and to be willing to negotiate this knowledge with others involved with the person.

An ethical relationship extends through time spent in engaged presence with the person, where participants use imaginative anticipation to envisage the best human beings both parties could become. It requires the creation of opportunities to enact those possibilities; the ability to recognise and offer a safe level of closeness, and to demonstrate a realistic acceptance of the person. Finally, the proxy needs to be able to transcend specific characteristics and episodes to imagine the whole person, while remaining sensitive to significant changes in their personhood over time (Meininger 1998). Such a relationship requires the proxy to be able to move in the space between self-affirmation and self-effacement (Ricoeur 1992).

Interpretation is an ethical practice that requires such an intimate, I-Thou relationship. In developing an interpretation the proxy’s task is not merely to avoid misunderstanding, but to fuse horizon with the other (Gadamer 1976). This is achieved in part by a hermeneutical consciousness that rejects the neutral party’s alienated perspective by using imagination. Yet cultural ambivalence about learning disability creates a complex backdrop for interpretation, and none of us can think from nowhere. Proxies must avoid treating people with learning disabilities as a blank screen onto which they project their own or society’s needs, fears or desires. Thus a third attribute of proxies is recognition of and cognitive control over potential sources of bias. MacIntyre (1999) argues that before speaking for others we need first to learn how to speak for ourselves, that is, to become reflective thinkers who do not merely trade opinions or strike postures. Proxies need reasons for action that bear scrutiny, and to be willing to change their actions should those reasons fail the test of scrutiny. The ideal proxy also needs to consider how their particular role and relationship to the person affects their views, and take this into account in interpreting their needs. This means that proxies need to be able to encompass another dimension of movement, between imaginative fusion and reflective separation.

The final attribute required of the ideal proxy is negotiating skills, since interpreting what would be best for someone with very limited communication skill is inevitably an uncertain task. They need to be able to negotiate their position with others in the person’s ethical community, since no individual can determine the best interests of someone with learning disabilities on all occasions. Negotiation means neither sticking rigidly to one's...
initial position, nor caving in completely to the position of others: being able to create an agreed position that draws judiciously on elements of both.

Conclusion

In describing the ideal proxy I have proposed four attributes of the ethical relationship, which articulate along two conceptual dimensions. Personal reflexivity as the proxy works in the space available between self-affirmation and self-effacement; and relational reflexivity, as the proxy moves between imaginative fusion with the person and reflective separation from them. As long as their relationship is ethical and engaged, demonstration of these abilities invites us to respect the opinions of someone who speaks for a significantly disabled individual.

References


Dussel’s work should be understood as part of the broader intellectual and political movement that began in Latin America in the 1960s and 1970s. All of its currents have been concerned with rethinking, reconstructing, their particular discipline from the perspective of the poor, the excluded, marginalized, oppressed.
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empirically, technically, and ethically). It concerns the adequate and effective mediators to determine ends.

Dussel's perspective is neither modernist, nor post-modern, but 'transmodern': he defends reason while criticising its distortion in the dominant system (eurocentric, capitalist, imperialist).

Having established the material, formal and feasibility principles, Dussel revisits each, critically from the perspective of the 'oppressed other', the victims of the system. He articulates a practical approach to ethics in a world where the majority are excluded from the possibility of producing, reproducing and developing their lives (from the narrow material sense to the wider social, cultural sense that has to do with living with dignity).

Dussel elaborates the Latin American notion of liberation as a strategic alliance between 1.) external catalytic agents and 2.) oppressed groups themselves. He does this through use of the 'speech act' of interpellation where the communicative community of victims, recognising one another as distinct from the oppressive system, and also recognising their oppression, call to one another and to those within the dominant system who would stand up for them, in order to transform the current social reality.

The ideas here are highly relevant to the work of supporting people disabled by intellectual difficulty who meet together to reflect on their situation and work together and with allies to change it (e.g. People First and other groups).

But the approach raises some problems when we consider people who, so disabled by intellectual difficulty, are unlikely to be able to be self-conscious, to be able to recognise or articulate their own situation, or to mobilise effectively. This is not to question Dussel's contribution, but rather to indicates some profound difficulties in complying with the discursive and feasibility aspects.

The perception of what "decision making" on behalf of disabled person meant was that this referred to major decisions... Everyday decision making on immediate, practical, 'minor' matters was not mentioned... This is where boundary critique may be helpful. The practice of boundary critique comes from the field of critical systems theory and practice (see Midgley, 2001, for an overview). A key notion is that the boundaries of systems should be subject to debate and challenge. Innovations, reforms, interventions, treatments, and so on are all intended improvements that are meant to alter a system or some parts of it. What is to be included or excluded in the scope of the improvement is a vital consideration: something seen as an improvement given a narrowly defined boundary may not be seen as an improvement if the boundaries are extended. Defining the boundaries of an improvement is an ethical issue, requiring the exercise of value judgements.

The most elaborated framework for boundary critique is to be found in Ulrich's (1983) critical system heuristics. This again draws on discourse ethics, Habermas's version. Ulrich too recognises that not all those affected by an improvement could possibly be involved in dialogue, (also Dussel's critique of Apel). So, Ulrich asks, what questions need to be covered to ensure that the interests of the potentially affected are respected?

For Ulrich there are two types of boundary judgements, with respect to 1) the boundary of the social system to be considered, vs. its environment, and 2) those affected vs. those involved.

Ulrich suggests twelve key questions that can be worked through for any system / improvement. The questions fall into four groups:

a) the sources of motivation for the improvement in question: the value basis.
b) the sources of control / the basis for power.
c) the sources of expertise assumed to be adequate to the realisation of the improvement.
d) the sources of legitimation to be considered for the improvement.

Ulrich argues for the inclusion in the process of enquiry of "witnesses" who represent the concerns of those who are likely to be affected but who are not involved. Their role is to contest the boundary judgements being made by the three categories of those involved - the client (in this sense those commissioning the improvement), the decision-maker, and the planner.

This issue is particularly pertinent in human service systems, where there may

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be a persistent tendency to marginalise and distort the interests of the least powerful interest group, those who depend on the service.

Ulrich therefore suggests a way of dealing with the central problem of the inability to participate for practical reasons. This might help in defining more concretely the minimum requirements for the effective discharge of the responsibilities of an advocate. It might also help pragmatise (make practical and feasible) the sometimes romantic notions of listening to the wishes of the person disabled by intellectual difficulty in person centred planning approaches. If the person cannot actively and intentionally tell us, there is little mileage in a rhetoric that seems to imply that they can if we are good enough at listening.

But there is a problem. The above approach is designed for a deliberative forum so it would have applications to major decisions about individuals or about systems. But decisions taken in a deliberative forum, while affecting major matters, could only ever account for a part of people’s lived, day-to-day experience.

While major ethical dilemmas have received much attention in the literature, a study in our service suggests that the experience of intellectually disabled people is subject to a multitude of decisions inherent in the discretionary nature of everyday life and the everyday tasks of supporting people. Major decisions were subject to checking, challenge, scrutiny, discussion, but minor ones were not. The perception of what “decision making” on behalf of disabled person meant was that this referred to major decisions (where to live and who with, restriction of freedoms to protect person, sex, major expenditure, medical treatments, etc.). Everyday decision making on immediate, practical, ‘minor’ matters was not mentioned, nor apparently understood as decision making in the same sense, and therefore unlikely to be the conscious object of an ethical understanding or questioning.

We are therefore left with a challenge of how to improve the visibility of ethical dilemmas in the ordinary everyday praxis that shapes profoundly impaired people’s experience. The contributions of Dussel and Ulrich give us some help with this, but it is the incorporation of an ethical praxis into everyday support and caregiving that still remains the biggest challenge.


A full version of this paper can be found at: http://publications.compsy.org.uk/

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