Towards a relational ethics of encounter in inclusive research contexts. Phil Bayliss

I am concerned with developing an ethics for research in special and inclusive education that addresses the concerns of educational and social care practices for people (children and adults) with ‘special educational needs’, ‘special needs’ or ‘disabilities’. The designation of people *having* ‘special educational needs’ or ‘disabilities’ requires judgment . What if we can be done with judgment?

‘The starting point for this is clarity about who constitutes the group of people who are categorized as having profound and multiple learning disabilities. The recommendations contained in the report ‘Raising Our Sights’ rely upon this clarity to determine who is to be included within the group labelled as having ‘profound intellectual and multiple disabilities’ (Department of Health, 2010, para. 48 cited in Bellamy et al, 2010).

If I baldly write: ‘profound and multiple learning difficulties’ then I engage with what Foucault (Birth of the Clinic, ref) calls ‘spatialization’.

Figure 1 here

Primary spatialization: there is a concept (a ‘disease’ of ‘pathological’ entity): ‘profound and multiple difficulties’. This concept has characteristics (generally relating to developmental or abnormal psychology), which can be defined as diagnostic criteria to define ‘the person’ and the label can be described in shorthand as ‘pmld’. ‘The disease is located in a body’ (secondary spatialization): this child or adult has/experiences ‘pmld’, and the condition of the child/adut can be described through those diagnostic criteria. The child then ‘becomes the disease’. Once diagnosed and recognized the child must be ‘placed’ somewhere in the social environment; the diseased child is located in a social ‘place’. The ‘place’ could be an institution or it could be the system created to support people with ‘pmld’ or the families or carers.

Thus, Bellamy et al’s focus on ‘correct terminology’ acts as a barrier determinant: a barrier between ‘pmld’ and ‘non-pmld’ and such:

‘A shared understanding of terminology or diagnostic terms describing groups of individuals is important for the purposes of strategic development, service planning, and the provision and equity of service delivery’ (Bellamy et al, op cit).

The process of ‘spatialization’ is an example of what Foucault calls a discourse: discourses have the power to create the objects of which they speak. In bringing ‘pmld’, as an abstraction, into visibility, inscribed on the body of the child, the child then becomes subject to the processes of spatialization and is located in a ‘place’. Given, the professionalisation of ‘disability’, in terms of what Foucault calls ‘Governmentality’, where the ‘body’ is subject to the disciplinary regimes of ‘conduct’, the child becomes a ‘case’, where the focus is on ‘what do we do with the child’ (resources, support, care, respite, medical or educational intervention and placement…….)

In the context of research, the research act starts with a question, which assumes judgment –the definition of a ‘case or problem or phenomenon to be studied’ requires knowledge to be able to disclose the object of research, then to pose the question. The answers to the question then add to knowledge, which then increases judgment.

The concern of ‘judgment’ is that of difference. There is a problem with the concept of ‘difference’. To enable ‘difference’, the person who exercises judgment must take a position, a standpoint, (the establishment of a boundary), which enables him or her, though claiming knowledge, to judge (this person is/is not ‘pmld’). This understanding of ‘judgment’ always places the researcher as ‘external’ to the ‘case or problem or phenomenon to be studied’.

How do we reduce (remove) externality? Where do we start? With the concept (primary spatialization)? Do we study children or people with pmld to understand the ‘condition’ in order to define better forms of intervention? Do we start with the child: where the child requires specific (acute or chronic) forms of intervention, do we study the particular ‘case’ in order to derive such intervention (Sp2)? And such intervention practices may have resonance with other children or adults with ‘pmld’ –this with particular reference to question of educational intervention (inclusion) and service provision for adults.

Or do we start with institutions (Sp3)?

Interestingly Mcclimens and Allmark, (2011:5) argue that underlying institutional care, the ‘notion seems to have been that people with LD /Dwere there to be looked after and cared for’. This, more than ever for people with ‘pmld’.

The precepts of the ‘social model of disability’ has condemned this approach in favour of autonomy and ‘voice’, and a shift towards emancipatory paradigms for disabled people, the underlying social environment for people with pmld has not changed, because, in my view, the primary spatialization of ‘pmld’ (or of generalised learning difficulties/disabilities) has not been challenged.

The characteristics of ‘pmld’ (primary spatialization) make it axiomatic within biomedical ethical frameworks that people with pmld (secondary spatialization) are ‘incompetent’, incapable’, ‘unable to exercise moral choices’, ‘lack voice’ and are ‘totally dependent on their care givers’. (Vorhaus 2015: Capabilities, human value and profound disability: capability theory and its application to theatre, music and the use of humour, Disability & Society, DOI: 10.1080/09687599.2014.990086

The main statement of biomedical ethics is the Helsinki Declaration of Medical Ethics (WMA, 2015: accepted 1964 amended severally up to 2013. There have been numerous revisions of the Declaration and the Articles have changed over the years. The following has been taken from the 2015 website. But even then this may not be definitive)

The Declaration states:

Article 6:         The primary purpose of medical research involving human subjects is to understand the causes, development and effects of diseases and improve preventive, diagnostic and therapeutic interventions (methods, procedures and treatments). Even the best proven interventions must be evaluated continually through research for their safety, effectiveness, efficiency, accessibility and quality. (Spatialization 1, 2 and 3)

Article 8.         While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects (Sp1, but……)

Article 9.         It is the duty of physicians who are involved in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects.

*The responsibility for the protection of research subjects must always rest with the physician or other health care professionals and never with the research subjects, even though they have given consent*. (emphasis mine: Doctor knows best…. Differences between expert and lay voices)

Under Risks, Burdens and Benefits:

Article 16.

In medical practice and in medical research, most interventions involve risks and burdens. *Medical research involving human subjects may only be conducted if the importance of the objective outweighs the risks and burdens to the research subjects. (who determines the objective?)*

Article 17.       All medical research involving human subjects must be preceded by careful assessment of predictable risks and burdens to the individuals and groups involved in the research in comparison with foreseeable benefits to them and to other individuals or groups affected by the *condition under investigation*. (Sp1 and 2: the ‘condition under investigation….)

Article 20.       Medical research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of this group and the research cannot be carried out in a non-vulnerable group. In addition, *this group should stand to benefit from the knowledge, practices or interventions that result from the research. (This is strong indication that the ‘vulnerable group’ are different to other groups. In a reverse of normal bioethics, where fro example, animal studies can inform interventions for humans, aa non-vulnerable group cannot be generalised across a ‘vulnerable groups. Also, how can you predict ‘beneficence’?)*

Article 30.       Research involving subjects who are physically or mentally incapable of giving consent, for example, unconscious patients, may be done only *if the physical or mental condition that prevents giving informed consent is a necessary characteristic of the research group*. In such circumstances the physician must seek informed consent from the legally authorised representative.

The issue of consent is underpinned by the principle of **“**beneficence”. Beneficence simply means one ought to do good and doing good is about “benefiting people, helping them, acting – out of respect for their interests- in a way that serves their interests” (Gorovitz, 1982, p.37). Children and adults with intellectual disabilities are judged to be a “vulnerable” population because they are less able to protect their interests (Cuskelly, 2005, or in the case of children with pmld, totally incapable of protecting their own interests). In terms of involvement in research, they are usually judged as not having the capacity to understand what a project involves and so, as being vulnerable to exploitation. Thus, children with SEN are benefited if they are protected by parents or other legal guardians. The principle of beneficence justifies the emergence of the norm of parental consent.

The ‘subjects’ who become the ‘objects of research’, have ‘conditions’ (children, children who are different…..) and are assigned a status by those who judge. The subjectivity of the ‘objects (children) is ignored to the extent that the action undertaken upon them, or through them, does not transgress a universal, normative, humanitarian ethic (‘it is important to listen to those who have a voice’…..), but conforms to a Utilitarian/Benthamite ethic of the ‘greatest happiness for the greatest number’. The process of normativity then becomes a process of ‘subjection’. Children and adults are ‘subjected’ to processes where they become the subject of ‘cases’. The researcher acts ethically in gaining ‘informed consent’ from ‘authorised representatives’. In the process of the research, the ‘subjects’ become ‘objects of study’ (as representative of the ‘condition’), and health care professionals, once ‘consent’ has been obtained, exercise judgment regarding the specific ‘case’: *The responsibility for the protection of research subjects must always rest with the physician or other health care professionals and never with the research subjects, even though they have given consent (WMA. 2015)*.

This view has been extended to include a normative review by an ethics committee (where ‘consent’ is not readily available’), which is subject to issues concerning ‘value of contribution’ of the research. The responsibility for maintaining ethical practice has shifted from the individual (health care professional) to a committee (Mcclimens and Allmark, 2011). It is not clear how committees escape ‘spatialization’ (if at all –a research question?).

Expert knowledge and knowledge which is generated through the examination of cases explores concepts (‘conditions’), bodies and ‘institutions’ (social spaces), which through the operation of discursive practices, create the objects of those practices’.

‘The particular type of truth that Foucault is concerned with, is not, e.g. that children with learning difficulties can be identified within the first year of formalised instruction but rather with the regimes of discourse/practice or power/knowledge which permit such statements to emerge and be legitimated as truth” (Mayo, 2007:106)

It is interesting that at the heart of the ethics of research is something ‘we’ do to ‘them’. The ethical frameworks apply to ‘us’, in that they ensure that we do not do harm to ‘them’? What happens to ethics if we reversed this. What would be the ethical behaviour of a ‘research subject’?

Unless the ‘spatialization’ of ‘pmld’ is challenged, the discursive practice of ‘pmld’ (or ‘disability’ as a whole) results in ethical debates around descriptive, normative, deontological ethics and applied ethics, as exemplified by the Helsinki Declaration.

Descriptive:

Descriptive ethics simply describes the moral choices people make and the values that are held in a particular society. It only states the facts and gives descriptions of the reasons people give to justify their moral choices (Thomson, 2005).

A few examples may shed more light on descriptive ethics.

A historical case: reporting on the infamous case of Willbrook study, descriptive ethics would describe it as a study during which people with intellectual disabilities were purposefully injected with hepatitis, so that the researchers could observe the natural history of the disease (Beecher, 1966). The injection with hepatitis is a moral fact and the observation of the development of the disease is the reason that researchers gave to justify their moral choice. The ontological status of ‘people with intellectual difficulties’ is not challenged in the ethical deliberation of the ‘boundary of difference’. These people are ‘outside’ and can thus be experimented on. The more recent adoption of normative ethics for this group of people, brings ‘them’ inside the moral compass of research, but still does not challenge their ontological status of ‘learning disabled’. We do not inject people with learning difficulties with potentially life-threatening serums, but we do investigate them to understand, for example ‘short term-memory’ (Gathercole and Pickering, 2000).

A more recent example: the exclusion of children with disabilities from what may be called “mainstream” research (Cuskelly, 2005). The exclusion may be a result of the belief that the lives of children with disabilities are so different or extreme that including them in the research may disturb the “normality” of the findings. For example, it may be counter-productive to include children with language difficulties, such as Down’s syndrome or deaf children (Chapman *et al.*, 2002; Blamey, 2003) in a research of some aspect of typical language development. In the field of learning disability the population was seen as 'vulnerable' and with the long-lasting influence of eugenics and the asylum programme their care was thought to be best carried out away from public scrutiny and under medical control For those living with learning disability this movement towards inclusion in research grew in parallel with academic commentary and culminated with the publication of ‘A problem with inclusion in learning disability research’, which acted as a rallying point for those professionals, academics, clinicians and individuals who saw value in sharing research agendas.

Normative and Deontological Ethics

Normative ethics examines the norms of typical appropriate behaviour according to which people *should* perform (Perle, 2004). It examines the norms by which people make moral choices and involves questions about one’s *duty* (what one *ought* to do – deontological questions) and questions about *values* that are expressed through moral choices (what constitutes ‘a good life’ – axiological questions). Once ‘values’ have been normalised, a set of practices can be defined to guide moral choices (deontological ‘rules’).

Normative ethics takes a step further than descriptive ethics. If descriptive ethics reports a moral choice, normative ethics looks at a statement and asks: *‘Is it right to do that?’ (*Thomson, 2005). This change in position refdlects the Nuremburg and Helsinki Judgments of biomedical research ethics.

For example, descriptive ethics states: “Child’s consent is required for the participation of children with SEN in research”. Then normative ethics asks: “Is it right to ask child’s consent for the involvement of children with SEN in research?” If the answer is “yes, it is right to ask child’s consent”, then it seems that the moral of consent is *axiologically* valued as a good practice in life because it protects children’s right to make autonomous decisions whether to participate or not in research. Since consent is a value, professionals that want to involve children with SEN in research have the *deontological* duty to ask for their consent. However, the answer may be “no, it is not right to ask child’s consent” because for example, children with SEN may not understand what the participation in a research project involves and so, they cannot protect their own interests (Cuskelly, 2005). If their ability to provide informed is compromised, they seem vulnerable to exploitation (Roberts & Roberts, 1999). Since child’s consent is inadequate, a new need is emerging. Normative ethics attempt to cover this need by establishing new ethical norms. In this case, parental consent or consent by other legal guardians seems to respond to the need of extra protection for children with SEN and ensure that their rights will not be violated. Since parental consent is an axiologically valued practice, researchers ought to follow the norm.

This view has been extended to include review by an ethics committee (where ‘consent’ is not readily available’, but is subject to issues concerning ‘value of contribution’ –it is common in most institutions for social care to have self-advocacy groups of people with LDDs (reified shorthand), but to quote a manager from an ‘autism facility’. They have their say, but we ignore it anyway. This exemplifies the discrepancy between expert and lay opinion (McLimmens and Allmark, op cit)

## Applied Ethics

Applied ethics is the most important and immediate aspect of ethics. There would be no interest in ethics if it was restricted to theoretical and philosophical discussion about values (Thomson, 2005). Applied ethics examines the moral choices that have been made under the scope of an informed meta-ethical discussion on values and principles. After conceptualising the different perspectives that moral theories offer and the tensions between values, what will the moral choice be in a specific situation? Will the researcher judge this child as ‘having/being SEN’, and as such, as incompetent, competent or just different? Once defined as a ‘subject’ or an ‘object’, will the researchers then follow normative or deontological guidance and ask for parental consent, child’s consent, a review committee or skip consent altogether (this is particularly relevant if we understand ‘educational intervention’ as form of ‘tertiary spatialization’ –discipline and governmentality in Foucault’s terms (see: ref)? Will the researcher involve children in research as active participants and as aware subjects? What will be the moral choice in a particular situation? Applied ethics is the informed moral decision on a specific case after exploring the “roots” of the ethical dilemma.

Acting Ethically

Acting ethically it is not simply a matter of following a set of guidelines included in ethical codes. It is not just about having the will to follow guidelines, but about problematising and adopting a phronetic approach in the Aristotelian sense, which means to be practically wise in knowing how and where to follow norms (Dunne, 1993). After all, “codes of ethical professional conduct in educational research are only ever relatively finished products” (McNamee, 2001:315). This is why they are always up to revision and why the universality of their application or their orthodoxy is a highly controversial issue (McNamee, 2001).

Even though a meta-ethical approach challenges different sets of values, it still proceeds from having decided on a particular ‘frame’ or ‘standpoint’ to applying that framework to the ‘research object’. Where I am arguing that the choice of ‘standpoint’ is in itself an ethical choice, then the research act becomes one of presenting questions of multiplicities, of differentiation, or challenges to judgment, which undermine the idea of ‘codes of professional conduct’. Here, we need to reframe the questions of ethics and possibly move to a post-structuralist approach to understanding –especially with regard to emerging ideas of complexity.

How do we determine the ethics of being a ‘research object’? What is the meaning of such a question? How can a ‘research object’ formulate normative or deontological procedures to guide their behaviour, not as an agent of research, but as the object of that research, particularly for ‘people with pmld’ who are deemed ‘incompetent’.

Values, post-structural and complexity issues: standpoints, frames and relational ethics

The blurring of the discourses surrounding spatialization argues for an ‘ethics of encounter’ (Deleuze and Gattari, 1987) located in *Eudaimonia* (‘human flourishing’ Nussbaum, 2001), which does not lead to a normative or deontological ethics, in that an *eudiamonistic* encounter is an emergent system of knowledge creation and transformation, not the measurement of predictable hypotheses, external to the ‘case or problem’, but which is located in the experience of ‘persons’.

‘Since at least the time of Galileo, physicists have considered *frames of reference*, how to communicate between those frames, and how different frames may be more or less useful in a particular problem. Among other things, these frames help to define a relationship between a researcher and the system being studied and influence how the boundaries of the system are determined.

As an example of the usefulness of considering frames of reference carefully, Einstein’s general and special theories of relativity are ultimately about how things appear to observers in different frames.

This use of frames, however, has several important, and usually unexamined, consequences. First, the observer’s frame, in classical physics, always leaves her outside the system under consideration: the observer is not examined, whereas the system is exactly that which is examined. Second, the choice of frames helps to define *a priori* the important observables for a system under consideration, and it is assumed that the choice of variables is done “objectively” (i.e., all researchers will choose the same variables and measure them with identical results). (Ricca, 2008:115/116).

Lastly, as the lens of a camera limits what the photographer sees, the (classical) choice of frame largely cuts the system off from the world and from the researcher. By doing all this, the researcher can be, and usually is, treated as a passive recorder of information coming from the system’

Frames decide ‘standpoints’ (where do I ‘point the camera’?) and my frame as a researcher requires us to judge what is the best standpoint. Where do I stand? What frame do I use? The conceptualization of the frame/standpoint is driven by concepts.

Deleuze (1980) was concerned (as a philosopher) to construct ‘concepts’:

‘A concept is a brick. It can be used to build the courthouse of reason. Or it can be thrown through the window. What is the subject of the brick? The arm that throws it? The body connected to the arm? The brain encased in the body? The situation that brought brain and body to such a juncture? All and none of the above. What is its object? The window? The edifice? The law the edifice shelters? The class and other power relations encrusted in the laws? All and none of these. ‘What interests us are the circumstances’ (Deleuze and Guattari, 1987: xi)?

The decision to frame concepts as ‘bricks’ or ‘cameras’ in the particular way requires ethical choices. These can be normative or deontological, but they could also be seen as relational.

Complexity theory and non-linear dynamics, however do not construct the world in ways, which (following Martin Buber, 1966) require an ‘I-it’ relationship –as the objective ‘inside’ and ‘outside’, which can be viewed from a standpoint (generally where, as argued above, the researcher is ‘outside’ the system they are investigating). Instead a idea of relational ethics, sees the researcher in an ‘I-Thou’ relationship, where ‘the researcher’ and ‘the researched’ co-constitute each; they are co-relational, but also that the ‘object’ stands in co-relationships with the rest of the ‘objects’, which forms an ontology of intervention (education, service delivery etc.).

Ontology here resembles a rhizome not a ‘tree’ (arborescent) structure (Deleuze, 1980). A rhizome acts as a network of interrelated circumstances (what is called in discourse terms a ‘conjuncture’: history, participants how/why did the participants come together at this point of time?

This does not mean that the researcher stands as an ‘insider’ (participant observer), instead the dynamic ‘object’ under scrutiny only comes into existence through the co-relation of the researcher and the researched through action.

‘Let this be called “participatory knowing”. To emphasize, the key aspect of participatory knowing, or consensuality, is that the “knowing subject” becomes inscribed in context and thus epistemically intimate with “thou” (Again, let us be mindful that if used ‘it’, how this term tends to trigger objectification.) Here, “object” is reconceived from being something that lies outside subject, “out there, ”independent of perceiver, to becoming a phenomenon continuous with self, unfolding *creatively* through the self’s perception. Now, the knower is part of what comes to be known, and the observer is part of the observed’ ( Bai & Banack, 2006:13 ).

If I am ‘part of what comes to be known’, then ethics need to be consciously stimulated so that the experience which that ethic clarifies can be transformed into *new knowledge which transforms the knowledge that created it’* (Le Moigne, 2007:123).

‘This ring that grounds the understanding of our relationship with the world and with ourselves does not describe our *desire for lucidity,* our refusal to be resigned *to doing without understanding,* since we know that *to try to understand, it is necessary to do* and that *to do assuming the responsibility for our acts, it is necessary to try to understand.* The intelligent action demands the recognition of the third included in the relation action and reflection, between experience and knowledge, between Pragmatics and Epistemics.

Here, in the context of research in ‘special education’ or ‘disability’ (and we would argue, for education in general), the research act, as a relational ethics

’has the potential to ‘transform the knowledge that created it’.

‘To simplify just a bit, principles and moral theories function within this method to organize, explain, criticize, and extend our intuitive responses to cases, but those very responses can, in turn, help us to amend and sharpen our principles and theories when they prove inadequate to the complexities of emerging cases’. Arras, (2013)

The development of a research ethics, based on relationality make take the form of a Deleuzean ethics:

‘A Deleuzean renoun­ces life in opinion and representation in the hope of finding life in experience ‘ and ’Deleuzean ethics counterpose affir­mation to judgment: they restore encounter. Ethics concern relations rather than representations. (Goodchild, 1996:207).

Here, an ethical encounter is mediated by *eudaimonia* (Nussbaum, 2001:31ff) – my personal (emotional) engagement with ‘human flourishing’. The incorporation of a personal understanding of what constitutes ‘human flourishing’ (whether this be civic or personal love, friendship, concepts of nurture, social justice…. ) guides my relationality to the ‘object’ of encounter, through an emotional affirmation of engagement with that ‘object’. *Eudaimonia* cannot lead to a normative or deontological ethics, in that an *eudiamonistic* encounter is an emergent system of knowledge creation and transformation, not the measurement of predictable hypotheses.

Let me end with an illustration Gaita, 2000, cited in Vorhaus (2015)

‘(Gaita’s story is about how one person behaves towards another). Gaita tells a story about how in the 1960’s he had worked in a psychiatric hospital where some patients had been kept for over 30 years. The patients were judged to be incurable, they looked to have lost all self-respect and individuality, and they were often treated brutally, although a few psychiatrists worked hard to improve the conditions of patients and some even spoke of their ‘inalienable dignity’. One day a nun arrived at the ward: [E]verything in her demeanour towards them – the way she spoke to them, her facial expressions, the inflexions of her body – contrasted with and showed up the behaviour of those noble psychiatrists. She showed that they were, despite their best efforts, condescending, as I too had been. She thereby revealed that even such patients were … the equals of those who wanted to help them. (Gaita 2000, 18–19)

The nun’s behaviour was striking ‘for its power to reveal the full humanity of those whose affliction had made their humanity invisible’ (Gaita 2000, 19–20).9 What is rendered visible here is not one capacity or several, but someone’s ‘full humanity’, an idea that is not the same as but is related to ‘the whole of him or her’. The suggestion is that love and other expressions of care can serve to reveal what is most precious about someone, which is not any one characteristic, and which may be evident in spite of the dormancy or absence of many of the features that are distinctive of human beings, but which renders them as the equals of others, irrespective of differences in capability and functioning’. (Vorhaus, 2015: 10)

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