

Ethics and Intellectual Disability

Embedded in Professional Practice: Ethics at the 12th World Congress of IASSID

Herman P. Meininger

For a long time ethics has not been a subject of interest within the International Association for the Scientific Study of Intellectual Disability (IASSID). However, a modest pre-conference workshop on ethics held in connection with IASSID's 10th World Congress in Helsinki in 1996 led to the start of a Special Interest Research Group (SIRG) on Ethics. It was and still is the smallest SIRG, but it has succeeded in putting a distinctive stamp on many activities within the IASSID membership. At the 12th World Congress, held in June 2004 in Montpellier, France, 11 symposia sessions and 2 roundtable session were organized by members of the SIRG on Ethics.¹ More importantly, many papers presented by experts in almost all the disciplines involved in the field showed a growing consciousness of the necessity and the benefits of embedding ethical reflection in professional practices of care, support, research and policy.

Session Themes

Some of the sessions on ethics had already been prepared at the SIRG's own workshop in November 2003 in Brisbane, Australia. For some of the Montpellier sessions other researchers were invited to contribute to the sessions.

In two sessions on 'professional development and ethics' the nature of professional ethics was explored. Though policies of regulating professional and moral behaviour by means of protocols and procedures fit well into the business-like service organisations, many papers showed an increase in conflicts between clients and service organisations that altogether cause great uncertainty about the moral commitment of professionals. Managerial control of professional behaviour and conformity to technological goals seem to hinder rather than to promote the moral and relational responsiveness and creativity that is demanded from professionals working in the field of intellectual disability.

In two sessions on 'life story work' narratives practices in care were demonstrated. These practices were evaluated as motivated by a morally inspired resistance against one-sided rational and social-technological ways of acquiring knowledge and providing care. Narrative practices are specimens of a hermeneutic approach in ethics and care and are mainly focused at a better and more integral knowledge of the identity of

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clients. At the same time, however, they promote the kind of reflection on the professional's own 'story of moral values' that is required in acquiring and exercising the virtues inherent to practices of care and support.

In this issue of the newsletter readers will find summaries of papers that have been presented in the aforementioned sessions. Other session themes touched on important questions concerning the use of the constructs of 'burden' or 'quality of life' within bioethics regarding intellectual disability. It will be clear that such notions heavily influence debates about the future of newborn screening for intellectual disability, also one of the session themes.

A continuing question in many sessions - and also in one of the keynote lectures - concerned the possibilities and limitations of informed consent of persons with intellectual disabilities. There were reports of practices of informed consent in research and in treatment with psychotropic drugs, and reflections on the nature of the decisionmaking process and the capacities involved in that process. It seems that in many cases the decisionmaking capacity of people with intellectual disability is grossly underestimated. Also, thoughtful approaches were presented about how to define 'good care' in situations where informed consent cannot be obtained, for instance when the use of

freedom from restrictive measures is considered. For a number of persons with intellectual disability, the acquire-

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ment of greater freedom and autonomy has implied a choice of starting a family of their own and becoming a parent. This has not only opened a new field of support and care and its concomitant research, it has also led to a number of moral questions that were explored in one of the sessions on 'parents with intellectual disability'. These questions concern the social responsibility implied in parenting, they concern questions of how to deal with wishes to become parents by support workers and service providers, and how to manage the incommensurate discourses of services that support the parents and services that safeguard the well-being of the children.

Roundtables

A new and widely acclaimed phenomenon at this World Congress were the roundtables organised by the SIRG on Ethics. Short statements of SIRG members opened lively and well moderated debates of about one hour. A first roundtable was about a paradigm that

plays a fundamental but often overlooked role at the background of many debates within the field of intellectual disability: social constructivism. Social constructivism involves the thesis that the notion of intellectual disability is a social and cultural construct rather than a 'natural' given. But does social constructivism go all the way down, in the sense that the difficulties and hardships persons with intellectual disability experience in their lives are entirely dependent on attitudes, habits, and beliefs such that when these are changed there will be no difficulties or hardships? The debate showed that there are weak and strong forms of both social constructivism and essentialism and a various arguments for and against all positions were exchanged. The argument that social constructivism always means social construction of 'something', evoked the question whether the 'something' of intellectual disability, i.e. intelligence, is an object or rather a status term like 'honour' or 'grace'. A provisional conclusion of the debate would be that strong forms of social constructivism and essentialism may lead astray.

The second roundtable was an attempt to reconsider the moral tradition of paternalism. Professionals in the field of intellectual disability are not supposed to impose their own judgments upon their clients about their best interests. Where professionals continue

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to exercise paternalistic judgment, they are often criticized for being 'institutionalised'. Consequently, judgment on the clients' best interest is taken to be at home in the world of institutionalised care, a world that to a large extent has lost its credibility. People coming from practices of working with persons who have profound multiple intellectual

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disabilities or with criminal offenders with intellectual disability argued for a rehabilitation of best interest judgments as a moral tradition that human services cannot do without. In professional practice they are a moral necessity. Others, however, rejected paternalism as a principle or even an element of professional ethics. Professionals should never be put in the position of a proxy. On the other hand, proxies often themselves do not know what to decide, and ask for help and support from others, mostly professionals.

Future

Of course, some of the themes I mentioned will remain important in further ethical reflection. Parenting of people with intellectual disability was a rather new theme at this congress.

The questions that were raised need elaboration in the years to come.

The moral implications of care and support practices inspired by a market or business model for professional development and for relationships between professionals and clients were discussed only incidentally, but may in the future open new areas of ethical research and reflection.

From the perspective of moral theory a slow shift could be observed from principle guided theories to an ethics of care and a narrative ethics. The ideological battle between 'community care' and 'institutional care' seems to have been decided definitively in favour of the first. Now questions arise as to what kind of persons citizens (including professionals) have to be in order to let people with intellectual disabilities be an integral part of our lives and what kind of stories inspire us to become such citizens.

References

1 Abstracts of all presentations are included in 'Towards Mutual Understanding: Person, Environment, Community', special issue of the *Journal of Intellectual Disability Research*. Vol. 48, Part 4 & 5.

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Court Clarifies Role of Guardians in Foregoing Life-Support

Susan Poland

Baby Boy W was born by emergency cesarean section when the mother died from a seizure. The newborn was severely mentally retarded due to encephalopathy; he required a feeding tube and ventilator; and he showed pain. His irreversible and terminal condition was termed "dismal". Because no father appeared before the Broome County, New York, Surrogate's Court, the court appointed the maternal grandmother, a nurse with experience in ob-gyn and pediatrics, as temporary guardian. Under 2002 amended state law, the health care decisionmaking authority of the guardian of a mentally retarded ward was expanded to include withholding or withdrawing life-sustaining treatment. This court opinion clarifies that authority. Baby Boy W died after the hearing and order.

The court found that the amendments satisfy the constitutional requirements of due process and equal protection for all mentally retarded persons. Its written decision details the procedures. The guardian decides about foregoing life-support based on a best interests analysis concerning dignity, health, pain, the effect of artificial nutrition and hydration, and the general medical condition of the patient. No decision can be based on the presumption that the mentally retarded are not entitled to equal

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Professional Supports for Persons with Intellectual Disability: Products or Relationships?

Wil H.E. Buntinx

In their mission statements, support organizations for persons with intellectual disabilities are firmly committed to individualized care, customer driven service, client autonomy and choices. However, at the level of the daily life interface with their clients, support organizations must constantly meet the conflicting interests of the individual and the organization. The management of this situation often resorts to standardization and centralization of processes that eventually risk restricting the necessary 'degrees of freedom' of direct service staff (DSS) to the client's needs.

These restrictions emerge from external limitations in resources such as funding, regulations and labor market conditions as well as from internal limitations. Internal limitations can be identified as efficiency measures (e.g., cost reduction) resulting in recruiting DSS with low levels of training and pay, process standardization as in Individual Support Programs (ISP), accountability measures and compliance with self-inflicted rules and quality assurance requirements that usually are borrowed from product-oriented industries (such as the Deming cycle). The service interface – especially in 24-hour residential care – quite often shows a climate of high DSS turnover (figures up to 75% are no exception) and of control as reflected in a multitude of rules and regulations that are expected to direct the 'product' of DSS support as agreed upon in the ISP.

The output of human service organizations however is not products but services. In contrast with products,

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services are (1) intangible (e.g., 'quality of life', experiences, confidence, opportunities), (2) interactive (the client is both consumer and co-producer of the service), (3) instantaneous (no second chance to do it right) and (4) heterogeneous (no two customers are alike and no situation is ever the same). Delivering quality support services means meeting the needs of every client every time and under various circumstances (Bebko, 2000; Grönroos, 1995; Hall & Hall, 2002).

Therefore, good support services should start with good understanding of the dynamics of the client's needs as well as of his context. This requires a high level of staff responsiveness. Responsiveness is at the very heart of care and support and should be understood as a mutual endeavor of care-giver and care-receiver, based on openness and

dialogue (Widdershoven, 1999). DSS responsiveness is a function of DSS skills and abilities (empathy to a person's need in an actual context and the ability to offer congruent responses) but also of the organizational context and conditions. One of the major context factors is continuity of the DSS presence in the lives of the clients. Providing standardized tools (such as rules, ISP and Deming cycle-based procedures) are no alternative and not sufficient conditions for creating a climate for contingency between staff responses and clients needs. High turnover and standardized support techniques risk freezing the client's needs into controllable and well manageable program frameworks, and missing the real needs of the person.

It is essential that the support organization creates conditions for interpersonal dialogue and offers space for heterogeneous and unpredictable outcomes of this dialogue. This means that DSS need to be assigned sufficient 'degrees of freedom' in their dialogue with the clients in order to be able to responding to their needs. Creating conditions for DSS autonomy, trustworthiness and spontaneity implies offering stability in DSS-client relationships so mutual responsiveness can grow. It also requires sufficiently trained and responsible staff engaging in the daily service encounters. The dialogue between client and DSS flows in the very daily and minute-to-minute

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Products or Relationships

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activities and requires reasonable 'degrees of freedom', meaning: sufficient opportunities for understanding and appropriately as well as creatively responding to the client's needs and wants. The outcomes of this dialogue are only predictable to a limited degree. Considering the degrees of freedom of DSS should be part of business ethics in support service for persons with intellectual disability.

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Abstract of a presentation at the 12th IASSID World Congress in Montpellier (France) on June 16, 2004; Symposium 'Professional development and ethics' (Moderator: H. Reinders).

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Professionals' Experiences of Addressing Ethical Issues in Services for People with Intellectual Disabilities: A Brief Report

Naomi Wilson

Ethical issues have been argued as ubiquitous for professionals in intellectual disability services for the following reason. Within the current political and social climate that broadly aligns with a moral framework of liberal individualism, professionals are obliged to guide the care of their clients in a way that fosters autonomy and independence. However, when these principles are applied to individuals with severe and complex intellectual disabilities they are liable to break down. This is because respect for autonomy entails acknowledging the right of the other to choose and act in accordance with his or her wishes or beliefs. However, this client group has a restricted capacity to make 'informed decisions' and, sometimes, severely impaired communication skills. This makes ascertaining their wishes a difficult task and, as a consequence, enhancing their choices and autonomy challenging.

It is conceivable that it is because of this proposed dichotomy that there is little research around ethical issues in intellectual disability services. Certainly, the literature that does exist is limited to theoretical debate challenging the premises of the moral frameworks and codes of conduct that professionals are accountable to in their practice. However, it is important to understand how ethical practice is

enacted in intellectual disability services as any mismatch between the philosophy of liberal individualism and the reality of clients' lives is likely to result in less than optimal services for this group. If the ethical framework that

The Premise of this research was to explore the psychological, emotional and relational experience of professionals who had taken responsibility for an ethical issue around a client with intellectual disabilities.

informs services does not fit with the experience of clients or professionals, then there is a risk that ethical issues become relegated, or deemed irrelevant to this group, as they are too difficult for staff and carers to realize.

One of the clinical responses to the complexities of ethical issues in intellectual disability services has been the establishment of Ethical Advisory Groups (EAGs) in some NHS Trusts in the UK. These are consultative rather than decisionmaking bodies that are internal to services and aim to support professionals in their consideration of ethical issues. The premise of this

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research was to explore the psychological, emotional and relational experience of professionals who had taken responsibility for an ethical issue around a client with intellectual disabilities. The role of the EAGs was considered from the professionals' perspectives, how resolution was achieved and the moral frameworks that professionals' used to inform their work.

Nine professionals in intellectual disability services were interviewed who came from a variety of disciplines, including; nursing, physiotherapy, psychiatry and clinical psychology. All of them had referred an ethical 'case' to a local internal EAG for consultation. The interviews were transcribed and analysed using a narrative methodology. This involved identifying themes between and across participants.

The first theme was the number of **different sources of conflict and complexity of ethical issues** that professionals faced. Professionals talked about experiencing conflict between different professional or political ideologies when trying to respond to ethical issues. They also highlighted a perceived conflict or mismatch between professional and public values and differences of thought between those who worked in intellectual disability services and those who did not.

A further key theme was that of **professional vulnerability**. The ambiguity of ethical scenarios meant profession-

als felt vulnerable to 'getting it wrong' or making the 'wrong' decision for their clients. There was also a tendency for professionals to project themselves into 'worst case scenarios' and try to find solutions that minimised the potential

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for this happening. This sense of vulnerability meant that the narratives featured considerable anxiety and professionals talked about having to tolerate living with significant uncertainty.

A third theme was **seeking validation**. In relation to the vulnerability felt by professionals, they sought to share the responsibility of decisionmaking with other professional groups who were deemed to have more 'expertise'. One of the means of doing this was to use the EAG as a decisionmaking body despite professionals acknowledging that this was not its intended role.

The significance of relationships with clients and families was a further theme. Professionals talked about their close and intimate relationships with their clients and that the depth of these relationships meant they felt a moral responsibility to act as advocates for them. Where professionals had relation-

ships with clients' families they were depicted as important and significant, although they also found these relationships challenging. Professionals said they spent a lot of energy maintaining these relationships while addressing the difficult ethical issue and that they were frequently a source of rich ideas around how to resolve the issues faced.

The fifth theme was one of **fragility of resolutions and reflexivity**. Professionals felt that the nature of the situations they were dealing with were inherently difficult to resolve. For many, they had residual doubts about the best way forward, even after the issue had been 'resolved'. For some they felt that the issue was still 'live' or had the potential to recur in the future and that they were continuing to manage the dynamics of the situation. The fact that professionals had limited power to enact solutions for their clients and that, despite their efforts, many clients led deeply impoverished lives, was something that professionals discussed as a particularly challenging aspect of their role. This was also a part of their clinical work that was rarely articulated.

The final theme was **maintaining a sense of moral integrity**. Professionals 'stories' showed significant coherence in terms of the ethical principles they valued, how they described the ethical difficulties they faced in their clinical work and what they hoped would happen for their clients in the future. Professionals drew on a range of moral resources that were 'external' or differ-

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Professionals' Experiences

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ent to the ethical frameworks explicitly endorsed by services. For example professionals challenged the notion of evidence-based practice in intellectual disability services and drew on other moral, spiritual and political frameworks to inform their work. Overall they argued that having some sort of existential framework for creating meaning within their work was essential in order to work with people with intellectual disabilities.

The results suggested that the relationships professionals have with their clients with intellectual disabilities are often enduring and intimate due to the nature of people's difficulties, their resulting dependency and their need for advocacy. The close relationships professionals had with clients appeared to be the most valuable source of information when addressing a difficult ethical issue. In particular, emotional sensitivity rather than 'abstract' guidelines were emphasised as important. Overall, relationships with clients not only oriented professionals to ethical issues that could not be ignored but were also the means by which they could inform and enact changes.

Professionals' discomfort about not always being able to ascertain clients' preferences meant that even sensitive and intuitive care could not guarantee they had made the 'right' decision. Overall this uncertainty meant that the primary focus of concern for professionals was the pressure they felt to enact a robust solution that was professionally watertight, versus the reality that this was often an impossible task. This resulted in professionals oscillating between two

positions. One was to go to extreme lengths to find solutions and the other was to accept the inevitable limitations of their capacity to help clients. This re-

... staff should be helped to acknowledge their competencies, as well as the limits of care they can provide.

search suggests that the experiences of fear, vulnerability and retribution evoked by ethical issues need to become legitimate topics of discussion for all staff. In addition, help to recognise the limits of their ability to change clients' lives seems pertinent. A further proposal is that staff should be helped to acknowledge their competencies, as well as the limits of care they can provide. A role for EAGs might be to review how they support professionals with ethical issues. Specifically, how they could help professionals reduce the impact of systemic pressures that increase their anxieties and felt vulnerability to 'getting it wrong'. Potentially, by helping to acknowledge that clients' intellectual disabilities are not 'repairable', professionals might be freed to work more realistically and effectively.

Note: This work is in the process of being submitted for publication, therefore, it is hoped that a more comprehensive paper will be available shortly.

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Role for Guardians

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rights, protection, respect, or dignity. The attending physician and a consulting physician must concur that the mentally retarded person is terminal, is permanently unconscious, or has an irreversible medical condition. The attending physician must then agree that the life-sustaining treatment is an "extraordinary burden" in light of the medical condition and the expected outcome of such treatment. Finally, if the decision is to withdraw artificial nutrition and hydration, then there must be either no reasonable hope of maintaining life or such sustenance must be an "extraordinary burden."

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