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Recording human rights abuses against disabled people: practical issues revealed by the Disability Awareness in Action *Human Rights Project*

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Introduction

I have been asked to provide a brief summary of practical issues that have been revealed by the Human Rights Project[1] that Disability Awareness in Action [DAA] has operated for the past 18-months. The Human Rights Project [HRP] currently comprises 1,200 separate reports of abuse against 2,000,000 disabled people. Perhaps the most sobering fact revealed by the HRP is that abuse was 1½ times more likely to end as a result of the victim's death, than as a result of legal intervention.

The DAA Human Rights project is a pragmatic, if modest, attempt to ensure that disabled people's organisations, human rights agencies, national and supranational governmental organisations have access to authoritative data concerning abuse of disabled people's human rights.

The finite resources available, in combination with the significant methodological issues thrown up, have conspired to delay the wide scale dissemination of Project data. However, it is our fervent hope that this meeting will serve to increase awareness of the Project and our need to build active partnerships with sister organisations, precisely because the HRP is intended to be a resource available to all agencies engaged in the promotion of our human rights.

Background to DPI Europe's Human Rights Network Project

In 1992, Disabled Peoples' International World Conference resolved to institute a centralised compilation of evidence demonstrating the human rights violations experienced by disabled people. A feasibility study, to examine implications for member organisations and individuals, was undertaken and,

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[1] The Human Rights Project has been made possible with the generous support of Comic Relief.

in 1997, DPI Europe obtained funding from the European Union for a 3-year project to include the participation of DPI organisations in 5 member states.

The DPI Europe project formulated guidance on the Universal Declaration of Human Rights – with particular regard to disability – and proposed strategies for the collection of information concerning violations. Most of those involved in establishing the project were lawyers, whose work formed the basis for formal training of a network of volunteer co-ordinators, in each of the participating states, regarding the collection of evidence from both individuals and material in the public domain. Following the *Amnesty International* model, the volunteers are independent of, though accountable to, representative organisations of disabled people and work under strict guidelines of confidentiality and anonymity. The evidence collected is submitted to the centralised database, maintained and managed by Disability Awareness in Action [DAA].

Methodological barriers

Defining abuse

The circumstances that will, or will not, comprise human rights abuse is often both contested and technically complex. Complexity *can* be compounded by the fallibility of the forensic process of evidence collection, particularly from a victim who has paid a high emotional cost for the abuse.

Despite these complexities and practical difficulties, few if any NGOs could afford to allocate day-to-day data collection and administration of a human rights project to legally qualified staff, experienced in obtaining and weighing evidence. It is, therefore, unavoidable that the reliability of data obtained could be questioned requiring, in my opinion, that the NGO takes all reasonable steps to ensure that project staff are both adequately trained and supervised.

State as 'principal'

No attempt has been [nor can be] made in the DAA HRP to establish state culpability for reported abuses, except where such responsibility is evident from the circumstances of the case. This has important implications for recording abuses of international legal duties that tend to be *addressed to nation states*.

DAA endorse an approach that acknowledges responsibility for omission as well as commission. We certainly see little ethical difference between committing human rights abuse as a principal or accessory or, indeed, closing one's eyes to evidence of ongoing or systemic abuse.

The numbers game

Any attempt to report international human rights abuse is subject to an inescapable paradox - evidence of abuse is hardest to uncover in the most repressive states, with the inevitable result that the highest frequency of abuse is recorded against liberal states.

In those states where gross violations of human rights (GVHR) are endemic, abuse that is confined to disabled people, rather than the wider population, may not be highly prioritised. Put simply, if the entire population lives with the risk of state-sponsored genocide, violations that threaten disabled people's right to education or to found a family may seem unworthy of comment.

Sources of evidence

The source of reports utilised to obtain 'evidence' of human rights abuse have fundamental implications on the reliability – and therefore credibility – of the project. Some of the implications associated with various sources of evidence are mentioned below:

Media

Where media reports comprise a significant source of data, one has to rely:

on the abuse being recognised in the first instance
on the issue being judged of general, rather than merely specialist or minority appeal
on the media having sufficient independence to report incidents objectively or at all
on reliably and systematically accessing published reports, particularly those published in foreign languages.

Individual reports

The ability to obtain primary evidence of abuse from individual complainants offers unparalleled opportunities; it also carries the greatest responsibility.

Where individuals are provided with the opportunity to report abuse, we consider it *vital* that the agency concerned has prearranged and clearly understood procedures for:

verifying the accuracy of allegations made
offering support and counselling services for traumatised complainants that request or require it
referring cases to the appropriate investigative or prosecutorial agencies, where the complainant freely consents to this (it might also be considered appropriate to retain a 'watching brief' on subsequent treatment of the complainant)
making alternative accommodation and/or personal assistance available, where this would prevent further abuse
ensuring that there are staff available to just 'listen' to the victim when they need to talk.

Precisely because of the modest resources available to DAA and the responsibilities outlined above, we have deliberately avoided *encouraging* direct complaints from individual victims.

Other publications

Desk-based research of existing material, including biographies, academic research, crime statistics and reports by other disability NGOs offers another potentially valuable source of data. There are obvious ethical and methodological issues flowing from such secondary research methods, but these are well known to professionals in the relevant disciplines and do not need repetition here.

Should there be a time-limit on the inclusion of historical evidence?

At present, the DAA HRP includes a number of cases that occurred decades ago - including the holocaust and sterilisation programmes - but about which reliable evidence has only recently been available. This issue is a matter of some concern to the DAA Project team, not least because of the central dichotomy that results: despite the historic nature of these cases, the details of them are often not generally known; equally, reporting ‘old’ cases may serve to diminish the Project’s credibility for the wider community.

DAA responded to this difficulty by excluding all reports that related to incidents committed prior to 1990, except where the report concerns:

gross human rights violations
those that affect ‘substantial numbers’, and
those that have been demonstrably state-sponsored and endemic.

Cases falling into one or more of these categories are classified as ‘historic’ and are only used to provide background discussion in Project reports.

Confidentiality

I am sure that little needs to be said about protecting the privacy of informants and victims. It should also be noted that in many states, including the UK, personal data and the uses to which it can be put are strictly controlled.

The DAA HRP is registered with the appropriate UK-authorities and operates a strict confidentiality policy. Briefly, we have ensured that:

individuals (whether informants or victims) cannot be identified from the database
hard-copy information which could identify individuals is retained within a secure environment
restricted access to the HRP information amongst employees.

Which variables are relevant and/or appropriate?

In view of the sometimes negative reactions to medical perspectives, any question that seeks to elicit information concerning the victim's impairment may prompt extremely negative responses from disabled people. Indeed, previous (and unconnected) research projects have been significantly hampered when subjects believed that researchers had adopted a medically-based approach.

The risk of offending victims by seeking information concerning impairment-type must be weighed against the value of identifying relevant trends. For example, the DAA HRP offers some evidence for the 'common-sense' view that people with learning difficulties are at particular risk from enforced sterilisation and medical experimentation, whilst people diagnosed with mental illness risk controversial invasive medical 'treatment'.

Disability-specific issues

In addition to the widely identified constraints on accurate data collection and verification of human rights abuses, projects focusing on the abuse of *disabled people's* human rights are subject to a number of additional barriers:

where abuse is inflicted by people in a 'caring' relationship with the victim, the abuse may be seen as 'normal' or less damaging than the withdrawal of personal care that may result from complaining

even where the victim is willing to report the abuse, when it occurs in a 'closed' institution there may be little opportunity to do so, either as a result of the victims social exclusion, or the deliberate efforts of staff to suppress such allegations

the person abused may not self-identify as a 'disabled person', thereby preventing their reporting an abuse 'relating to' disability

the nature of the impairment itself may make it difficult or impossible for the victim to complain

the nature of the impairment may lead to any complaint being dismissed as unfounded and simply prompted by the impairment *i.e.* 'mischief associated with interference in the cognitive process'

in view of the common reliance on family members, rather than state-funded personal assistants, there are likely to be strong disincentives to making public an abuse that might have disastrous effects on the family – a price that they may be unwilling to pay.

In conclusion

A paper of such modest proportions cannot hope to do justice to the numerous practical issues revealed by the DAA Human Rights Project, but it is my hope that it offers a glimpse of the risks and opportunities provided by investigating this still neglected area.

Perhaps the single most important issue upon which we should conclude is to emphasise the emotional cost for staff-members engaged in this sort of work. It is comforting to assume, in our ignorance, that it is only ‘minor’ abuses that are inflicted on disabled people in the third millennium. The frequently graphic accounts and lurid photographs to which investigators are subjected, day in and day out, demand that agencies engaged in the recording of human rights abuse owe a particular and generous duty of care to their staff.