

## **Discussion paper for STEPS (Rotterdam meeting)**

### **Strengthening our interpretative understanding of the issues and the actions we may need to take at local (national) and European (project) levels through the experiences of service users**

**Paul Cambridge**, Senior Lecturer in Learning Disability, Tizard Centre, University of Kent at Canterbury

#### **Some introductory thoughts**

I think our developing discussion amongst the group is a most interesting and productive way of working through some of the complex issues that the agenda set by the STEPS project has raised. It represents a valuable emerging discourse with the potential to provide a framework for monitoring the work and issues relevant to each of the different national partnerships and for informing comparative analysis by the project co-ordinators through common analytic strands and dimensions, relevant to overall European systems and interests.

I believe these next steps will be quite challenging. Firstly, we need to reflect on the myriad of issue the papers have collectively raised and identify common ground, a shared language and mutual themes. Secondly, we need to do this in ways which cut across and expose to scrutiny the hierarchies of power and power imbalance inherent in the organisation of services, related professional structures and resources allocation and rationing process. Thirdly we need to effect change.

Our language is varied and diverse - inclusion, equality, rights, emancipation, empowerment, equity, participation, citizenship, involvement/ discrimination, segregation, exclusion, marginalisation, stigmatisation, alienation, subjugation, injustice.

Yet these words represent, in their various ways, locations, places and scale the polarisation of power between the services we have constructed and the institutionalised dependency relations they perpetuate and service users themselves. We can conceptualise for example, a series of power continuums between service users and service organisations, professionals, care workers, managers, administrators and bureaucrats. We certainly need to analyse our policies, systems, structures and processes, but we need to retain our interpretative understanding of individual experience, both of those who work in services and those who use them, in order to be able to effect a shift in power along these continuums towards service users. This work will be incremental, not revolutionary, but it will by example demonstrate what needs to be done and can be done and this is inherently what we can achieve within the various national and local partnerships across STEPS.

I would not argue that the injustices which can be generated between service and individual user interests are deliberately cruel or brutal, as they cannot be compared to the abuse, neglect and mistreatment which for so long went unchallenged in our old long-stay institutions and which eventually led to their decline and closure. However, I would hypothesise the emergence of a new and hidden tyranny which we need to guard against. The new devices of care management, direct payments, business management and contractualism bring their own hegemonies. Nor are the new policies and procedures and regulatory and quality mechanisms we are seeing bad in themselves, but they also bring a new hegemony. It is perhaps simply that the newer service institutions we have constructed in the community mirror in different ways, our need to control and our incapacity to share power. Perhaps what I am also saying is that they distract energy, resources and attention from more fundamental concerns.

### **Reflecting on individual experience of oppression**

I am worried about going out on a limb at this point and am finding it difficult to articulate exactly what I am thinking, so you will need to excuse my ramblings. I think at the centre of what I am saying is that I believe we need to ensure that our work in STEPS and the various national partnerships remains grounded in the experience of oppression of

service users themselves, particularly as we are grappling with so many abstract concepts in difficult intellectual and political territory. Maybe a worked example would help illustrate what I mean.

One of the starkest themes I have identified in my work with people with learning disabilities in relation to oppression is sexuality and the contradictions and injustices which arise from the conflict between the rights of individual and the responsibilities of services themselves – key-worker, managers, care managers, administrators and business managers. In England service have a duty of care and protection, evident in the growth of risk assessment and risk management policies and protocols and associated individual guidelines. These are perhaps most visible in the domain of sexuality, particularly in relation to the research evidence on sexual abuse and the various practice and organisational responses to this actual and perceived risk. It is also visible in recent national government policy on the protection of vulnerable adults from abuse, requiring local government social services departments and other agencies such as the police and NHS related public sector organisations to work together.

The ordinary risks in sexuality such as consent, negotiation, power, mutuality and so on which are exacerbated by intellectual disability are magnified hugely when sexual health is introduced. Managing HIV risk for example, is one of the most difficult areas and highlights conflicts between individual rights and service responsibilities. Take John's case.

John is a young man with learning disabilities who tested positive for HIV as a part of a general health screening by a private health provider. A collection of serious concerns arose in relation to his rights and interests and those of his service in relation to informed consent, confidentiality, disclosure and the wider consequences of HIV testing. The events and outcomes summarised in his case experience illustrate how easy it is for services to become distracted from fundamental issues of rights while seemingly pursuing more vital agendas such as risk management and protection, and to develop defensive practices which exclude service users themselves.

I received a call from John's service asking for help after he had tested positive for HIV. A number of key considerations are evident for considering informed consent to HIV testing, and these are particularly important for people with learning disabilities, drawing on wider experience with HIV testing, the relative advantages and disadvantages of knowing an HIV status and the legal considerations regarding informed consent. The latter particularly relate to the consequences which might flow from having a test and possible carer liability. Critical questions concern in whose interest the test is being conducted and who the testing agent is, as both can affect the issues of competence and pre and post test counselling.

To give informed consent, without which an HIV test amounts to assault, John would have needed to know what the test entailed, understand what might happen as a result of testing positive or negative and consider the wider implications for themselves, as well as agreeing to the test without pressure or bribery. For someone with a learning disability, considerations of confidentiality, disclosure, future sexual behaviour, possible treatment and illness would all need to be included. For these reasons, most of the few HIV and learning disability policies that have been articulated make testing without informed consent dependent on a High Court decision.

John was recently placed out of area into a private provider service, of which the staffed group home where he lived was a component. He had previously been placed with another out of area provider in another part of the country. His parents and placing authority social worker/ care managers were fully involved. He had moderate learning disabilities, with Klienefelter's syndrome. When John first joined the service, concerns were raised about his physical health, with general health screening arranged from a local private hospital. It was reported that the hospital subsequently telephoned the house manager to ask if he was able to give consent to an HIV test, with an affirmative answer. Consequently, an HIV test was included in the general health screening.

It was reported that a positive HIV test result was related to the service over the telephone. Following this disclosure, a case conference was arranged, which included John's parents, who had been told the test result, myself and his social worker, as well as the service and operations manager of the provider organisation. I provided background information on HIV transmission, risk and testing at the meeting, with the importance of re-testing acknowledged (false positives are very rare with proper testing procedures. False negatives can also occur if the person has recently been infected with HIV). Discussion understandably revolved around the possible routes of HIV transmission, including via sexual contact or medical procedures. There were reported to have been 'sexual issues' at his previous placement but these were unclear. John was also reported to have regularly absconded, which might fit the hypothesis of sexual contact outside the service as a receptive partner.

John's social worker agreed to make background enquiries regarding his previous placement. I agreed to talk with John about his HIV positive status following re-testing, particularly about safer sex and also to talk with the staff group about HIV and HIV risk management. At this point the service also expressed concern about their ability to continue to support him and his parents wanted greater clarity about how he might have contracted HIV.

The service was subsequently notified by telephone of a positive re-test result and I arranged to meet him.

The day before I planned to see him the service telephoned to say that a second re-test from the sample had been sent to the public health laboratory and had tested negative. A negative HIV status was confirmed through a third re-test via the public health laboratory. Although I met with John later, the basis of this work had changed to general sex education, consent, safer sex education, assertiveness work and personal safety. Yet within minutes of undertaking some basic sex education work with John using line drawings and identifying John social contacts, he disclosed serious sexual abuse. I was obliged through policies to notify the police and initiate an adult protection alert through the local adult protection procedures.

The explanation provided by the private consultant in relation to the false positive test is relevant in relation to ascertaining informed consent to an HIV test. It was related that consent for the HIV test from John was ascertained (judged) in relation to the possible effect on his care of a positive result. As an 'inadequate' blood sample was reported on the first test, due to discomfort for him, the opportunity to repeat the test at a reference laboratory was said not to have arisen.

The following observations summarise the conflict between individual rights and service responsibilities:

1. It could be argued that informed consent to an HIV test in John's case was not properly obtained (see outline discussion above). This might apply in relation to the potential personal implications for him, the checking out of capacity to consent over the telephone and the consequences for his support in the service. Adequate pre- and post-test counselling was also clearly arguably lacking. John was excluded from all such decisions.
2. The poor management of confidentiality in relation to a service users known or suspected HIV status. This relates to the absence of 'need to know' criteria and ad hoc disclosure to staff and third parties. In particular, a lack of rationale for informing the service user himself and his parents in relation to the initial test, the re-test and the relay of information on HIV status over the telephone. User and their interests should be put at the centre of information management and exchange
3. The failure to reference and engage guidelines on HIV and HIV testing and the inadequacy of the guidelines themselves. In times of stress or crisis, policies and guidelines can be inaccessible or not give the guidance on the detailed decisions and processes needed. Guidelines need to reference action, line management, accountability and responsibilities in services for people with learning disabilities, with due respect of individual rights and the wishes of the person or their advocate.

4. HIV testing and HIV risk assessment and risk management activities conducted in the absence of wider work on sexuality. Personal relationships and sexuality policies and guidelines need to be integrated with those on HIV and implemented through sex education work with service users and staff training. John received no such work prior to HIV testing and was unaware of his sexual as well as wider rights.
5. Inter-agency co-ordination for HIV testing in services for people with learning disabilities. Learning disability services do not have the detailed knowledge about HIV testing needed, and specialist health services, be they private or public, do not have the detailed skills needed to work with people with learning disabilities. New specialist advocates may be needed to support people like John make informed choices and help them navigate complex agency, organisational and professional systems and interests.

Research suggests that services have a variety of motives for wanting to support HIV testing for people with learning disabilities, without necessarily thinking through the consequences for the person or the service itself. In particular, the consequences of knowing about an HIV positive or negative status and how this will effect support and HIV risk management. Usually, services and staff really just want to know whether someone is HIV positive as they believe this will help in their support and in managing HIV risk. However, best practice service responses to someone assessed as high HIV risk should be technically the same as someone known to be HIV positive.

In John's case the consequences for HIV risk management had clearly not been considered. Previous research reported a variety of service responses to HIV risk management including escorting someone when out and keeping someone at home in the service, although less aversive responses such as safer sex education and counselling were also mentioned and best practice examples illustrate a valued service response to a man assessed as high HIV risk, including assertiveness and safer sex education work with

the man himself and a variety of work and support for the staff group, such as through supervision, exploring the boundaries between the law and individual rights and staff training.

However, a recent case in New Zealand starkly illustrates how things can go badly wrong if information is mis-managed and considerations of confidentiality, 'need to know' and disclosure not properly thought through. Christopher Truscott, a man with learning disabilities living in Christchurch, was kept in confinement by his service, with one to one support. News of his HIV positive status had been released and his name repeatedly appeared in local and national newspapers. It was alleged that health care workers had tried to keep his HIV status secret, but that the Ministry of Health were tipped off that he was having unprotected sex with a large number of partners (Otago Daily Times, 28 April and 12 May, 1999; Sunday Star Times, 16 May, 1999).

He was arrested on a charge of criminal nuisance after admitting having unprotected sex without disclosing he had HIV following a complaint to the police from one of the men he had had sex with. He was given a suspended sentence and a supervision order was issued, with name suppression refused (Otago Daily Times, 28 April 1999). Truscott repeatedly absconded from his care and the police repeatedly checked out his 'old haunts', including 'public toilets' and other 'Gay rendezvous' (The Press, 10 and 11 October, 2000).

The Truscott case highlights complex issues regarding individual rights and responsibilities of people with learning disabilities and others and the responsibilities of the public service and law enforcement agencies. Fortunately, Truscott is receiving advocacy from the Justice Action Group (personal correspondence, October 2000) which seeks to change laws, lives and attitudes for people with disabilities (PO Box 9407, Newmarket, Auckland).

Another service recently spoke with me about their terrible worry and anxiety about a young man with mild learning disabilities they support who identifies as Gay and who

meets other Gay men. So much so they employ a curfew on his movements from mid evening which has resulted in the use of constraint when he has attempted to leave his group home. This resulted in him absconding for three days, fearful of returning as he was accused of assaulting a staff member when he resisted physical intervention. He was reported to be naïve and vulnerable in his sexual encounters and in his responses to HIV risk. He has a mobile phone on which he keeps the numbers of the men he knows and keeps the details of his sexual life very secret. Yet having a number of sexual partners would certainly not be an uncommon experience for many young men or young Gay men, nor would some unsafe sex. Nor would secrecy within a predominantly heterosexual social environment. However, a special challenge exists for supporting men with learning disabilities who have sex with men in relation to their personal safety and to safer sex, as well as safeguarding their individual rights.

One of the potentially most powerful models but one which is little explored or evaluated, would be to have a positive and assertive Gay role model in the man's life, in whom he could confide and who could give regular support and advice. This might be a Gay identified key worker or citizen advocate, with boundaries, accountability and responsibilities carefully defined and good support and advice provided for the person themselves.

What we need to strive for is not to impose impossible restrictions on the man's life, as happened in the Truscott case. Here, the man's name became well known throughout New Zealand and his private and personal life became public property, as well as that of health agencies, the police and his secure service. As a consequence, labels like 'male prostitute', 'HIV carrier', 'escape' and 'irresponsible' were given more prominence than his welfare and valued support as an individual person who happens to have a learning disability and depend on formal services for his support.

### **A possible way forward**

Rarely do so many competing forces come together in management and practice, but when they do, they starkly illustrate the risks of not centring action and support on

individuals and their wishes and interests. Where conflicts with service responsibilities emerge, then these need to be resolved with the persona and not for them. When they cannot be resolved independent scrutiny may be required. I have for example, been most impressed with the role of ethics committees in the Netherlands, where they involve themselves in helping resolve such conflicts, unlike their English equivalents which, developed from medical models, are primarily concerned with the ethics of research. Perhaps part of our work in STEPS is therefore to see how we can further develop, refine and transfer intermediate solutions and actions which can be deployed and employed before we learn effective ways to safely and more meaningfully transfer power to those who use services. Ethical devices and user self-organisation through advocacy are clearly those we are most familiar with but our work might help us find or define others.

John's experience is just one of many which remain hidden and one issue and area of rights out of many which we will all have seen or heard about in our work in services for people with learning disabilities. Perhaps we should double our efforts to ensure that each of the national partnerships uses case studies, user stories and user voices to illustrate the general analysis and provide a vital level of interpretative understanding for our work. Perhaps also we should all accept the task of developing an intermediate local outcome in the form of a support system or model to help safeguard and promote service user rights, building on any local initiatives such as advocacy projects or the work of ethics committees. We can then hopefully exchange or transfer productive local innovation and experience between partners.