

Independence or Protection - does it have to be a choice? Reflections on the abuse people with learning disabilities in Cornwall

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Brief biographical details

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Deborah Kitson is the Director of the Ann Craft Trust, a UK based organisation working with staff in the statutory, independent and voluntary sectors to protect people with learning disabilities who may be at risk from abuse through providing training and consultancy, undertaking and publishing original research, and developing training materials. She is author and editor of a number of publications including 'Facing the Possibility', 'Equipped to Cope' and 'Training to Protect'. She was a member of the Steering Group of which produced the 'No Secrets' guidance and is the external representative on a number of Adult Protection Committees.

Key words: Learning disability; abuse; adult protection; choice; independence

Abstract

This commentary will use recent events in Cornwall to highlight the ongoing abuse of adults with learning disabilities in England. It will critically explore how two parallel policy agendas – namely, the promotion of choice and independence for adults with learning disabilities and the development of adult protection policies – have failed to connect, thus allowing abuse to continue to flourish. It will be argued that the abuse of people with learning disabilities can only be minimised by policies which reflect an understanding that choice and independence must necessarily be mediated by effective adult protection measures. Such protection needs to include not only an appropriate regulatory framework, access to justice and well-qualified staff, but also a more critical and reflective approach to the current orthodoxy which promotes choice and independence as the only acceptable goals for any person with a learning disability.

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Introduction

On 5th July 2006 the abuse of people with learning disabilities made news headlines across the UK. The trigger for this sudden wave of interest was the publication of an investigative report (Commission for Social Care Inspection & Healthcare Commission, 2006) into the multiple abuses suffered by people with learning disabilities living in the care of Cornwall Partnership NHS Trust. A day later, however, the mainstream media had again lost interest in the issue and by the weekend the story did not even merit a mention in the Sunday papers' news roundups.

Of course, it is nothing new for journalists to occasionally, on a slow news day, headline stories which at other times struggle for attention. Such attention, fleeting as it may be, has its value. Indeed, it has been argued (Fyson, Kitson & Corbett, 2004) that change within learning disability services in the UK has historically been driven by abuse, scandal and the ensuing inquiries. For example, the initial drive to close long-stay hospitals was triggered by reports in 1967, in the *News of the World* newspaper, of the institutional abuse which was occurring in Ely hospital, Cardiff. More recently, the physical and sexual abuse of people with learning disabilities living in homes run by Longcare (Buckinghamshire County Council, 1998) was one of the driving forces behind the passing of the Care Standards Act 2000. This Act led to the creation of the National Care Standards Commission (now replaced by the Commission for Social Care Inspection) – which, for the first time, provided a consistent national framework for the regulation and inspection of care services.

The investigation into standards of care in Cornwall Partnership NHS Trust identified numerous acts of abuse, which were described as amounting to 'institutional abuse'. The report recorded that:

"incidents included staff hitting, pushing, shoving, dragging, kicking, secluding, belittling, mocking and goading people who used the trust's services, withholding food, giving cold showers, over zealous or premature use of restraint, poor attitude towards people who used services, poor atmosphere, roughness, care not being provided, a lack of dignity and respect, and no privacy." (Commission for Social Care Inspection & Healthcare Commission, 2006, p.31)

Such abuse occurred in both hospital and community-based care settings, including 46 supported living homes. During the course of the investigation, the cases of 40 people with learning disabilities were referred to social services for investigation under adult protection procedures.

The report blamed a number of factors for the abuse, including ineffective management within the health trust; poor employment practices, such as a lack of training for staff; a breakdown of communication between health and social services; the failure of social services to provide needs assessments; and the non-implementation of adult protection policies by all agencies. It said that services described as assessment and treatment centres had slipped into being long-stay hospitals, and described supported living services as "being run as unregistered care homes, which did not meet accepted standards" (ibid, p.6). Amongst other things, the report recommended that 'effective action' be taken in Cornwall to prevent further abuse occurring; that social services should undertake community care assessments for all individuals who required social care; and that the supported living services should seek registration as care homes, so bringing

them under the regulatory framework and inspection regime of CSCI. It also recommended that, at a national level, all services for people with learning disabilities should review their joint working arrangements and the Department of Health should strengthen existing procedures for the protection of vulnerable adults.

A policy problem

Following the report's publication, Health Secretary Patricia Hewitt announced a quality audit of all care services for people with learning disabilities in England. At the time of writing the terms of reference for this audit have yet to be made public. This is not surprising, since there are no readily available existing standards by which to measure the success or failure of services for people with learning disabilities. The report itself described services for people with learning disabilities in Cornwall Partnership NHS Trust as having failed to meet the 'general standards' required. At the same time, however, it noted that "there are no specific performance indicators for learning disability services" (CSCI & HC, 2006, p. 4). In lieu of statutory benchmarking, the report suggests that services should have referred to "a number of key documents, which describe best practice" (ibid) – namely the *Valuing People* white paper on services for people with learning disabilities (Department of Health, 2001); the *Reach Standards* for supported living (Paradigm, 2002); the *Mansell Report* (Department of Health, 1992), which provides guidance on the provision of services for people with learning disabilities and challenging behaviour; and *No Secrets* (Department of Health, 2000), which contains guidance aimed at protecting vulnerable adults from abuse.

We would suggest that the lack of clear and coherent standards applicable to services for people with learning disabilities is indicative of a wider policy malaise in this field, namely the failure of policy makers at all levels to make the necessary connections between two parallel agendas: one the one hand the desire to promote choice and independence for people with learning disabilities, and on the other the need to protect them from abuse. This difficulty is not explicitly identified by the authors of the CSCI/Healthcare Commission report, but its existence is implicit in the citation of such diverse policy documents in place of more considered benchmarks.

The choice & independence policy agenda

Since 2001, services for people with learning disabilities in England have been driven forward by the agenda set out in the *Valuing People* White Paper (Department of Health, 2001). This document outlines a vision for the development of services based on the four key principles of ensuring legal and civil **rights**, giving people **choice** in relation to key life decisions, promoting **independence** and supporting **inclusion** within mainstream services and local communities. In practice, creating change in services for people with learning disabilities has not proved easy (Fyson & Ward, 2004). Much of the progress to date has focussed on supporting the active involvement of people with learning disabilities in policy-making at local and national level (Fyson et al, 2004) and moving towards person-centred planning as the lynchpin of individual change (Institute for Health Research, 2005). In relation to service developments, the emphasis has been on promoting models of service provision which prize independence – in particular a move away from residential care homes and towards supported living as the preferred option for providing housing and support. Supported living (sometimes also known as 'independent living') may result in people living alone or in small groups, but differs from residential care in that it is premised upon legal tenancies and individuals with learning disabilities being in control of choices about where, how and with whom they live (Paradigm, 2002).

The emphasis on choice and independence does not emanate solely from policy developments which are specific to learning disability services: both are also emphasised in a range of recent Government policy developments – including the *Supporting People* programme (Office of the Deputy Prime Minister, 2004) of financing housing-related support for vulnerable adults; the ongoing promotion of direct payments in lieu of care services; the Green and White papers in adult social care (Department of Health, 2004 & 2005, respectively) and the position statement on the rights of people with disabilities *Improving the Life Chances of Disabled People* (Prime Minister's Strategy Unit, 2005). As well as sharing an emphasis on choice and independence, these pieces of policy and guidance share another trait: they all almost completely ignore the need for vulnerable adults to be protected from abuse. For example, the delivery plan, 2001 – 2006, for *Valuing People* (Department of Health, 2001, p.116-119) makes no mention of anything connected with protection from abuse; likewise the Green and White papers on adult social care fail to include any references to adult protection guidelines.

Moreover, those who promote this agenda of choice and independence often do so in a manner which assumes that there is no difference between a learning disability and a physical or sensory impairment (Gillinson et al, 2005; Prime Minister's Strategy Unit, 2005). This not only overlooks compelling evidence of the extent to which people with learning disabilities are known to be victims of abuse (Emerson et al, 2005), but may also increase their vulnerability by failing to take the possibility of abuse into account when planning services (McCartney & Thompson, 1996).

The adult protection policy agenda

At the same time as the social care agenda was promoting choice and independence as the guiding principles for services for adults with learning disabilities, a quite separate movement was developing which recognised the extent to which vulnerable adults needed protection from abuse. Campaigning charities including Action on Elder Abuse, the Ann Craft Trust, Practitioner Alliance Against Abuse of Vulnerable Adults (PAVA) and Respond sought to highlight the fact that, as with child abuse in the 1960s and 1970s, the abuse of vulnerable adults was an unseen epidemic of Titanic proportions. Despite their best efforts, and some significant developments at a local level in a handful of authorities, policy makers in the social care field appeared reluctant to acknowledge the scale of the problem.

It was therefore left to the legal profession, headed by the Lord Chancellor's Department, to make the first moves towards recognising the particular needs of vulnerable adults. Prior to this point in time there had been a feeling of hopelessness about reporting criminal offences – physical and sexual abuse included – where the person was vulnerable either by age or disability: few cases involving people with learning disabilities reached court and, of those which did, many were dismissed as unreliable witnesses (Carmody, 1991). It seemed that the court system not only excluded people from accessing justice but also gave a message to abusers that people with learning disabilities could be abused with impunity, hence increasing their vulnerability. This had repercussions for those working with people with learning disabilities, who became increasingly frustrated at being encouraged to report concerns and then finding that there was little further action taken. If the legal professions were not going to take the abuse of people with learning disabilities seriously then there was little point in raising the concern in the first place. This discouraged the reporting of concerns and allowed poor practice to continue, and on many occasions to become the accepted norm – just as was evident in Cornwall.

However, in 1998 the Interdepartmental Working Group on the Treatment of Vulnerable or Intimidated Witnesses in the Criminal Justice System published *Speaking Up For Justice* (Home Office, 1998). The aim of this report was to suggest ways in which access to criminal justice could be improved for anyone who had been the victim of abuse or who, for whatever reason, might have difficulties in giving evidence in court. To this end it made 78 recommendations for creating a system of justice that would be more accessible to both children and vulnerable adults. All of the recommendations which required legislative change were incorporated into the Youth Justice and Criminal Evidence Act 1999, and a set of detailed policy guidelines known as *Achieving Best Evidence* were also published (Home Office, 2002). It appeared that finally there was a real commitment by all agencies to create a legal framework that would accommodate vulnerable adults and create fairer access to justice for all.

In reality it was never going to be easy to fully implement the necessary changes, which required both a culture shift within the legal professions and a move towards more effective partnership between agencies working with and for people with learning disabilities. Furthermore, there was also a need for greater consistency on the part of social care agencies in their reporting of suspected incidents of abuse. To this end, in 2000, the Department of Health made its first foray into the realm of adult protection by publishing *No Secrets* - guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse. This document finally put adult protection onto the social care policy agenda and by doing so sent out a clear message that the vulnerability of some adults had to be recognised by social care agencies.

Since this time there have been further developments in adult protection, most notably the introduction in July 2004 of the PoVA list (Protection of Vulnerable Adults) which, for the first time, creates a national database of people considered unsuitable to work with vulnerable adults. Prior to this criminal records bureau (CRB) checks for those seeking to work in adult social care had relied purely on records of criminal convictions and - with so few abusers being prosecuted - the CRB often failed to identify abusers. The PoVA list has now given employers the opportunity to apply to list an unsuitable person, whether or not there has been a successful prosecution; if the application to list on PoVA is successful then that person is permanently barred from working with vulnerable adults.

Despite recent successes in introducing laws and policies which seek to protect vulnerable adults from abuse and to ensure access to justice when abuse has occurred, the current system still contains many loopholes. In particular, there is a pressing need to ensure that the Safeguarding Vulnerable Groups Bill - which is expected to receive Royal Assent in late 2006 - considers the needs of *all* vulnerable people, whether they be children or adults. It was hoped that a single list could be introduced to replace both PoVA and the two lists currently used to bar people from working with children, List '99 (which lists barred teaching staff) and PoCA (Protection of Vulnerable Children which lists those considered unsuitable to work with children), so that if anyone barred from working with children would have also been barred from working with vulnerable adults. However, a decision was reached to maintain two lists - one relating to children and a second to adults, with a system of cross-referencing between them. A further issue of concern had been that people in receipt of direct payments do not have to request CRB checks or refer to either list when recruiting personal support staff. This decision was made with consideration to the right of individuals to make their own choices about whom to employ, but it clearly creates a loophole which could be exploited by those seeking to abuse. It is testament to the power of those who argued in favour of choice and

independence, as opposed to those who advocated for increased protective measures, that the outcome of debates during the passage of the Safeguarding Vulnerable Groups Bill went in their favour.

Discussion/Conclusion

Recent years have seen significant changes to legislation and policy guidance in relation to both services for adults with learning disabilities and the protection of vulnerable adults. Despite the considerable progress which has been made in both fields, there is a pressing need for better links to be made between the two. At present, many in learning disability services appear to remain convinced that the promotion of choice and independence are, in and of themselves, sufficient to protect people with learning disabilities from abuse. They seem loath to acknowledge the extent to which the promotion of 'choice' and 'independence' are intimately associated with 'risk', and immune to the possibility that choice and independence are not the only indicators of quality of life.

Promotion of independence and choice for people with learning disabilities is an admirable aim, and an understandable reaction against decades of provision which have demeaned and dehumanised this group of people. Admirable they may seem at first glance, independence and choice now run the risk of being fetishized to the point where they become the *sine qua non* of learning disability services: concepts beyond questioning.

We believe that, in order to better protect vulnerable adults from abuse, these beliefs can and should be challenged. That is *not* to say that we would wish a return to services in which people with learning disabilities are locked away from the rest of society and have no choice or independence, but rather a plea for a recognition of the obvious (if unspoken) reality that *if these people were able to be fully independent and to make important life choices without support then they would not be receiving state-funded services in the first place.*

There should be nothing wrong with acknowledging that, like most of us, people with learning disabilities can hope only to be interdependent rather than independent; that they need the support of others to make choices and to maintain an optimum level of independence. The danger is that, where organisations insist that people with learning disabilities are wholly responsible for their own, independent, choices they ignore the control exerted over them by others. In most cases control (or 'support') is proffered by caring family or staff members and is in the best interests of the person with a learning disability. But the pretence that such support does not also include an element of control leaves a dangerous gap in which abusers may find an all too comfortable niche. The fact that much of the abuse in Cornwall occurred in supported living services – which are supposedly the most emancipated form of provision – demonstrate to us that it is not safe to presume that any service can afford to ignore the need for effective adult protection systems. This includes all services, including those which are built on the premise of people with learning disabilities being in control, making choices about their daily lives and achieving significant levels of independence.

On a more positive note, and despite the fact that we do not believe the abysmal standards of care in Cornwall to be an isolated case, glimmers of hope can be drawn from the CSCI/Healthcare Commission report. The fact that it has highlighted poor working practices as constituting abuse, and as requiring the same intervention as more dramatic events such as a death or systematic sexual abuse, has to be welcomed as progress. It sends a clear message to all those who work with people with learning disabilities that such practices will not be tolerated. Furthermore, the national audit offers a real possibility that other

pockets of poor practice may be identified and eliminated. We hope that it will remind all those working with and for people with learning disabilities that they must never allow themselves to become complacent or to believe that abuse could not happen in their services.

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