

*Deafblind & neglected or deafblindness neglected? Revisiting the Beverley Lewis*

*Case*

Peter Simcock and Jill Manthorpe

**Abstract**

Deafblindness is a particularly complex impairment and deafblind people are considered to be some of the most vulnerable members of society; this includes vulnerability to abuse and harm. This paper explores this unique impairment in the illustrative case of Beverley Lewis, by reviewing archived published and audio material about the life and circumstances of the death of this young woman, including media reports, parliamentary debates and commentaries. Whilst it appears that the implications of Beverley's deafblindness may have been 'overshadowed' in media reports and inquiries, the paper suggests that further lessons for practice can be learned from the case by focusing on this condition. Drawing on contemporary research by specialist charitable organisations (*Sense* and *Deafblind UK*), the authors identify research highlighting deficiencies in support for many deafblind adults, which have implications for safeguarding policy and practice. It is concluded that attention is needed in three areas: increased awareness amongst social care and health practitioners of the particular vulnerability to abuse of deafblind adults; improved access to specialist assessment and specialist social care support, including one-to-one human support; and improved communication between

social care and health agencies, alongside more tangible signs of acceptance of shared responsibility for supporting deafblind adults.

## **Introduction**

The area of South Gloucestershire has recently been at the forefront of adult protection attention in England following the serious case review into abusive practices at Winterbourne View, a privately owned hospital for adults with learning disabilities and autism (Flynn, 2012). This paper revisits an earlier Gloucestershire case: that concerning the death of Beverley Lewis. Beverley was a black, deafblind woman with learning disabilities, who died in 1989 aged 23. Since her death and the subsequent inquiries, there have been numerous changes in adult safeguarding law and policy (Brammer, 2009). These include, *inter alia*, the policy guidance *No Secrets* (Department of Health (DH), 2000), the *Domestic Violence, Crime and Victims Act 2004* and the *Mental Capacity Act 2005*. The DH also issued policy guidance outlining local authorities' social care responsibilities in relation to deafblind people (DH, 2001; 2009). Reviewing media reports and publications spanning 1989-1990, it appears that Beverley's deafblindness received less attention than her mother's mental ill-health, statutory agencies' involvement, and perceived legal omissions at the time (Deer, 1989; Dettmer, 1989; Fennell, 1989; Anon, 1989c; Sapsted, 1989a, 1989b; Symonds, 1993). Reflecting on issues arising from this case and examining contemporary literature on deafblindness, the authors suggest that the specialist needs of deafblind people continue to warrant attention in policy and social

work practice, if deafblind people are to be safeguarded from harm or neglect and experience optimal quality of life. This may require: greater awareness of deafblind people's specific vulnerability to abuse; funding of specialist assessment and support; and greater co-ordination and shared responsibility amongst agencies working with deafblind people. Further themes, at the time of proposed legislative change in England (Spring 2013), are the potential role of social workers in accessing private households without invitation, the requirement for inter-agency co-operation, and a statutory basis for serious case reviews (DH 2012b).

This paper draws on published and audio material covering the Beverley Lewis case. Sources accessed include media reports (eg Sapsted, 1989a,b; *LBC/IRN* 1989; Deer 1989; Souster, 1989), Parliamentary debates, and commentaries (eg Fennell 1990; Matthews, 1990; Lamb 2000). We were unable to draw directly on Gloucestershire Social Services' internal inquiry. A *Freedom of Information Act 2000* request to review the inquiry report was denied, as it was considered exempt from disclosure on the basis of Section 44: as being information covered by Schedule 12a *Local Government Act 1972*.

### **The Beverley Lewis 'Case'**

Beverley Lewis was born deafblind owing to *congenital rubella syndrome* (then known as German measles), which, prior to UK national vaccination programmes, was a common cause of congenital deafblindness (Carvill, 2001; Dalby et al., 2009). Congenital rubella syndrome may also result in heart problems and learning disabilities (Robertson *et al.*, 2003); as deafblindness is

present from birth, difficulties with language development are common (Hart, 2008). Jervis (1989) and Linnett (2001) are amongst the few commentators to also report that Beverley was 'a 'black' girl'.

Beverley was known to local services as having learning disabilities. However, as the chronology (Box 1) illustrates, her formal education was reported to have ended when she was about ten years old (Shackleton, 1989a; Matthews, 1990). She subsequently stayed at home with her mother, Thelma Lewis, and is portrayed as having limited contact with the outside world. Nonetheless and intriguingly, Beverley was 'well known' to health and social services (Linnett, 2001, p29); she had an allocated social worker and named community nurse, and in 1985 was removed from home under section 135 *Mental Health Act 1983* and admitted to hospital - for one day (Morgan, 1989). However, the press also reported that Thelma repeatedly refused intervention from welfare services and denied professionals access to Beverley (MacDermid, 1989; Sapsted, 1989b; Lamb, 2000). On February 17<sup>th</sup> 1989, Beverley, aged 23, was found dead in squalid conditions, lying on a sofa, wrapped in newspaper, and weighing under four stone. Discussing Beverley's death on national radio, the day after the inquest, her sister, stated:

I strongly believe that Beverley's death was caused by starvation, at the time my mother was suffering from a mental illness.....so she was unable to give Beverley the full care that she needed. (LBC/IRN Radio, 1989)

Thelma, who was generally reported to have long-standing mental health difficulties or illness, was admitted to hospital on the day Beverley was found (Anon, 1989a; Shackleton, 1989b); being later reported as diagnosed with schizophrenia (Jervis, 1989; Symonds, 1993).

Insert Box 1 about here

Beverley's death triggered internal inquiries by the Health Authority and Gloucestershire County Council Social Services. These inquiries made joint recommendations, identifying three areas for improvement: (1) the development of an 'at risk' procedure for disabled adults and adults with mental illness; (2) stronger management of Community Mental Health Teams; and (3) individual programme plans for adults with learning disabilities (referred then as mental handicap) (Hansard, 1990c). These recommendations were forwarded to the Coroner. At the inquest, the Coroner identified weaknesses in the law, particularly the *Mental Health Act (MHA) 1983*. Although issuing a verdict of death by natural causes (Douglas and Philpot 2005, p121), he criticised services for failing to apply for *guardianship* under the MHA (Symonds, 1993). As Matthews noted (1990) the provisions of the *Disabled Persons (Services, Consultation and Representation) Act 1986* were also limited in this case, owing to Thelma's reported refusal of support and denial of access to Beverley. Tom Clarke MP (Hansard, 1991) later expressed concern about unimplemented sections of the 1986 Act and referred to a BBC documentary, which concluded that implementation of the Act's advocacy provisions may have prevented Beverley's situation.

In addition, limited inter-agency communication was highlighted as relevant by the adult protection co-ordinator in Gloucestershire (Linnett, 2001). However, despite a request from the family's lawyer to include 'lack of care by the welfare agencies' within the verdict, the Coroner apportioned no specific blame to those agencies or individuals working for them (Lamb, 2000; Linnett, 2001). While there were calls for a public inquiry into Beverley's death from her family (Matthews, 1990), the Disablement Group Chairman Jack Ashley MP (Hansard, 1990a), and *Sense* (a deafblind charity) (Jervis, 1989; Clark & Matthews, 1999), the Health minister announced that no such inquiry would take place (Hansard, 1990c). Commentators such as Dalrymple and Burke (2006) later cast this as a situation where professionals, although possessing the power to intervene, did not regard themselves as having the duty to do so.

In response to the case and inquiries, Gloucestershire Social Services developed new adult protection procedures and formed an 'Adults at Risk Unit' (Gloucestershire County Council, 2006). The Royal National Institute for the Deaf (RNID) (now Action on Hearing Loss) and the Royal National Institute for the Blind (RNIB) helped develop these procedures (Linnett, 2001). As noted, the charity *Sense* had also made representations around this case. However, the fact that Beverley was *deafblind*, and the implications of this, do not appear to have featured explicitly in the outcomes and recommendations of the inquiries or inquest. Some reports of the case do not observe this disability. Douglas and Philpot (2005, p121), for example, note that she had 'cerebral palsy, visual and hearing impairments and severe learning difficulties'; Slater (2004, p652)

describes her as ‘a multiply disabled young woman’. Emphasis on the need for review of mental health legislation subsequent to this case, is reflected in media reporting of the inquiries and inquest (Dettmer, 1989; Anon, 1989b; Morgan, 1989; Sapsted, 1989b) and, interestingly, the supported housing service named after Beverley, focuses on supporting women with learning disabilities and not deafblind women (McCarthy, 2000; East Living, 2010).

At national policy level, Tom Clarke MP (Hansard, 1990b) queried the actions that the DH intended to take in relation to community care services for deafblind people and training for professionals working with them. Matthews (1990) was one of the few to more decisively conclude that:

[L]ack of knowledge of deafblindness and its implications [was].... evident in Beverley’s life and cause of death (Matthews, 1990, p12)

This paper explores the unique impairment of deafblindness, to investigate if it was ‘overshadowed’ in Beverley’s case. We provide evidence of deafblind adults’ vulnerability and argue that social workers need to consider the implications of this complex impairment in safeguarding practice.

### **Deafblindness and vulnerability to abuse**

Lamb (2000) suggests that professionals may have acted earlier had Beverley been recognised as an adult vulnerable to abuse and neglect. Indeed, an understanding of vulnerability and the causes and consequences of being

vulnerable is now described as essential in safeguarding practice (Schroder-Butterfill & Marianti, 2006; Martin, 2007). Deafblind people have been described as ‘some of the most vulnerable members of our community’ (John Hutton MP; cited in Lewin-Leigh, 2000, p3) and this includes vulnerability to abuse (Kiekopf, 2007b). Deafblind participants in a recent survey by *Sense* (2012b) reported feeling vulnerable both in and outside their homes; including feeling unsafe in the context of receiving care and support.

Deafblindness is a severe and complex impairment (Bodsworth *et al.*, 2011), leading to difficulties with mobility, accessing information and communication (DH, 2009). Whilst many deafblind people attain high levels of independence (Alley & Keeler, 2009), these difficulties increase deafblind people’s dependence on others (Mar, 1993; Bodsworth *et al.*, 2011); such dependence has been linked to increased vulnerability to abuse (Calderbank, 2000; ADASS, 2005; Hague *et al.*, 2011). Furthermore, these difficulties often result in profound social isolation (Smith, 1993; Bodsworth *et al.*, 2011) and many deafblind people have small social networks (Mar, 1993). Other studies suggest that isolation may also be a risk factor for vulnerability to abuse (Gill, 2006; Garre-Olmo *et al.*, 2009; Johnson *et al.*, 2010).

For congenitally deafblind adults, the opportunities for learning available to them as children may have been greatly reduced compared to those available to hearing-sighted children (Kiekopf, 2007a). Kiekopf (2007a, 2007b) considers the implications of this in the context of safeguarding, highlighting that congenitally deafblind people may have a limited awareness of what is and is not



acceptable behaviour towards them. The combination of this limited awareness with social isolation and the further likelihood that deafblind people will have learned to accept touch as a way of relating to the world (Kiekopf, 2007b), are thought to increase their vulnerability to abuse. Neglectful behaviour may be perceived as the norm (Calderbank, 2000) and physical and sexual abuse as stimulating tactual experiences (Kiekopf, 2007b).

Where abuse is recognised as such by the deafblind adult, alerting others can be difficult. Communication poses challenges for all deafblind people, but can prove uniquely so for congenitally deafblind people, who may experience difficulty understanding the very concept of language (Hart, 2008). The impact this has on the disclosure of abuse is reflected in a review of five year's data taken from the *Sense Abuse Database*, which holds information on abuse allegations related to deafblind people using *Sense* services (Kiekopf, 2002); this reports that abuse was disclosed by the victim in only 9.5 percent of cases (n=94) (Kiekopf, 2007b). Deafblind people may be seen as 'safe victims' by those intent on abuse because they are 'unable to tell' (Kiekopf, 2007a, p1).

Whilst these factors may account for heightened vulnerability amongst deafblind people, they are not inherently vulnerable owing to their impairment alone. Rather, vulnerability to abuse arises from the complex interplay between the impairment, situational and structural factors, other characteristics such as race, gender and age, and, in a societal context that often devalues disabled people (Kiekopf, 2007b; O'Keefe *et al.*, 2007; Hague *et al.*, 2011). Joule and Levenson (2008) and Deafblind UK (2006b) highlight the further disadvantages faced by

deafblind people from Black and Minority Ethnic communities and the devaluing of disabled people was evident in some media reports of the Beverley Lewis case, in which Beverley was described as difficult to cope with (Souster, 1989) and as someone who, as a result of impairment, was 'not the most endearing person with whom to relate' (Deer, 1989).

Adequately assessing vulnerability to abuse and also resilience and protective factors amongst deafblind people requires an understanding of the complexity of vulnerability and awareness of the particular risks, their likelihood and severity for individual deafblind adults. Social workers with specialist deafblind competence and knowledge may therefore be well placed to conduct investigations, complete assessments, and construct support plans. Beverley apparently had no contact with any sensory impairment practitioners (such as social workers with D/deaf people or rehabilitation workers for the visually impaired) and therefore no such specialist assessment ensued (Barry, 1989; Matthews, 1990). Near a quarter of a century later, access to such specialist assessment and support services remains inconsistent, a proposition considered next.

### **Deafblindness and access to specialist support**

The absence of specialist sensory impairment worker contact with Beverley reflected what Matthews (1990, p11) described as 'serious shortcomings' in social services provision for sensory impaired people. The year before

Beverley's death had seen the publication of '*Breaking Through: Developing Services for Deafblind People*' (Deafblind Services Liaison Group, 1988). Produced by several agencies seeking to raise awareness of deafblind people's needs, this report highlighted the prevalence of deafblindness and suggested the range of services required (ibid). In the decade following Beverley's death, specific concerns about statutory agencies' response to deafblind people were raised by charitable organisations (Wood & Leece, 2003). Following the DH's (1997) good practice guidelines and a failed Private Members' bill presented by Lord (Jack) Ashley in 2000 that sought to require local authorities to assess the needs of deafblind people (Valios, 2001), the first statutory guidance outlining local authority social services' obligations towards deafblind people was published in 2001. This guidance, re-issued in 2009, requires local authorities *inter alia* to identify and make contact with deafblind people in their area, and, to undertake specialist assessment of their needs (DH, 2001; 2009). This assessment should be completed by a specially trained worker (ibid).

*Sense* judges this guidance as fundamental to improvements in social care for deafblind people (*Sense*, 2012a). However, their surveys of local authority implementation of the guidance highlight inconsistencies across England and Wales (*Sense*, 2005; 2007; 2010). The 2009-2010 survey, responded to by 53 local authorities (about a third of those in England and Wales), found that less than half of people identified as deafblind had received a specialist assessment (*Sense*, 2010). *Sense's* (2012b) survey of 89 deafblind people (54 % of responses were completed by deafblind people and 46 % completed by proxies), found over 30 percent reporting no specialist assessment; of those who had received

specialist assessment, half reported it difficult to access. Furthermore, some reported that the worker completing their social care assessment had no specialist qualification (*Sense, 2012b*). Whilst the data are drawn from small numbers of deafblind people from only one third (35 percent) of local authorities in England and Wales, they indicate failings in policy implementation. Limited funding, complexities in defining and recognising deafblindness, and lack of clarity in how to apply the guidance have all emerged as reasons for this inconsistency (*Valios, 2001; Roberts et al., 2007; Alley & Keeler, 2009*). Furthermore, the meaning of 'specifically trained' to conduct assessments is unclear (*Sense, 2012a*); assumptions that those with experience of working with single sensory impaired people can do so may be inadequate, because deafblindness is a distinct condition, recognized as a third separate impairment alongside deafness and blindness (*Lewin-Leigh, 2000; Alley & Keeler, 2009*).

Lack of access to specialist assessment has possible implications for safeguarding deafblind adults. Personalised care and support in complex cases may be easier to fund following comprehensive assessment, which can help provide the 'complete picture' necessary to better understand risk (*Manthorpe & Martineau, 2011, p233*). Speculatively, lack of specialist deafblind assessment of Beverley may have contributed to what Gloucestershire County Council (2006) later portrayed as professionals' limited awareness of the seriousness of her situation and its risks. This is not to suggest that specialist deafblind assessment or worker involvement is sufficient. Indeed, *Cambridge and Parkes (2006)* identify the advantages of specialist *safeguarding* practitioner involvement. What specialist deafblind assessment potentially offers is the opportunity to

commission tailored support to deafblind adults, including intervention in a person's best interests if the requirements of the *Mental Capacity Act 2005* are met, thereby possibly reducing the risks of abuse (Matthews, 1990; ADASS, 2005; Kiekopf, 2007a). Furthermore, a thorough assessment of deafblind adults' specialist needs, particularly those linked to communication, potentially maximises the usefulness of other safeguarding mechanisms. For example, local authorities may instruct an Independent Mental Capacity Advocate (IMCA) where an adult lacks capacity (Mental Capacity Act 2005), should there be concern that the family member may be implicated in abuse or unable to advocate for the adult lacking mental capacity. IMCAs have been reported as potentially having an important role in safeguarding, particularly in complex cases involving adults with no formal language (Brammer, 2009; Lee-Foster, 2010). However, Lee-Foster (2010) considers that IMCAs are unlikely to possess the skills to meet the communication needs of deafblind people. There seems a greater chance of meeting these needs if they are assessed and recorded on IMCA referrals, as specialist communication professionals may then be contacted and involved.

In addition to specialist assessment, the deafblind policy guidance (DH, 2009) asks local authorities to ensure that deafblind people have access to specialist services, including one-to-one support from specially trained staff. In Beverley's case, there appeared to be a perception that social services were concerned with meeting only personal care and/or other physical needs (Matthews, 1990). Indeed, at the inquest the local authority representative was said to have referred to Beverley's personal cleanliness, warmth and skin condition when

depicting *good care* (ibid). Many deafblind people do not require assistance with personal care (*Sense, 2012b*) but would nevertheless welcome more support (*Bodsworth et al, 2011; Sense, 2012b*). However, 19 percent of deafblind people (n=89) in *Sense's (2012b)* survey received no social care while 25 percent of those receiving social care reported having insufficient hours.

Deafblind people need assistance with mobilising, accessing information, and communication, including the teaching of new communication methods (*Kiekopf, 2007b; Sense, 2012b*). In order for such support to be effective and meaningful, they need accessible places to go to and people with whom to communicate (*Smith, 1993*). This necessitates a broad view of social care, beyond personal care. Whilst the *Draft Care and Support Bill 2012* acknowledges a broad scope of social care, with its focus on *well-being (Draft Care and Support Bill, 2012: First Clause)*, and the UK Coalition Government recommends a focus on wide-ranging outcomes in adult social care (*DH, 2012a*) the reality of increasing eligibility thresholds for publicly funded social care (*ADASS, 2011; Clements, 2011*) results in a focus on the most immediate of personal care and/or safety needs. It is therefore unsurprising that the social care needs remain unmet (*Clark, 1994; Valios, 2001; Sense, 2012a*); indeed, former ADASS sensory impairment sub-committee chair David Behan, currently head of the Care Quality Commission, stated that:

services to .....people who have a dual sensory loss, have traditionally been marginalized and removed from the mainstream of social care provision (*Behan; cited in Lewin-Leigh, 2000, p3*)

*No Secrets* (DH, 2000) called for a primary focus on the prevention of abuse and some serious case reviews have highlighted the plight of those who are below local authority eligibility thresholds (Thomas, 2011). As such, inadequate support packages or the absence of specialist social care have significant implications for the safeguarding of deafblind adults.

The needs of deafblind people related to communication, access to information and social inclusion may be deemed low-level and therefore ineligible for publicly funded support. However, failure to provide support to the individual or their family may result in lack of attention to cultural needs (Joule & Levenson, 2008) and increased isolation and stress, factors associated with deafblindness and heightened vulnerability. Additionally, lack of communication abilities increases vulnerability to abuse and many deafblind people need specialist support staff to teach and maintain communication strategies (Kiekopf, 2007b). Faulkner (2012) notes the importance of adults having clear information about the nature of abuse and how they can protect themselves from harm. Indeed, Standard Six in the *National Framework of Standards for Good Practice and Outcomes in Adult Protection Work* (ADASS 2005) states that everyone should have access to such information; therefore, it should be accessible to deafblind adults and for those using tactual communication methods, generally necessitating one-to-one support. Meeting such needs is therefore essential, not only to enhance deafblind people's quality of life but also to protect them from harm. In contemporary adult social care in England, this will require 'Resource Allocation Systems' to address such areas when funding is calculated and agreed

(Alley & Keeler, 2009). Owing to the complexity of deafblindness, people will also need a co-ordinated multi-agency response; this was implicitly judged as absent in Beverley's case and remains problematic, as highlighted next.

### **Co-ordinated multi-agency responses and deafblindness**

Failure to share information, lack of inter-agency communication and unclear leadership, responsibility and co-ordination were all implicitly criticized, by Beverley's family (*LBC/IRN Radio*, 1989) and the inquiry reports, as contributing factors to her neglect and death (Shackleton, 1989a; Lamb, 2000; Gloucestershire County Council, 2006). Whilst *No Secrets* (DH, 2000) explicitly referred to multi-agency and partnership working, failures in information sharing and poor inter-agency communication remain common themes in safeguarding practice, as noted in many serious case reviews (Brammer, 2009; Manthorpe & Martineau, 2011). This is of particular concern for deafblind adults: as a complex impairment, deafblindness invariably requires a multi-agency response (Mar, 1993; Hutton, 2000, cited in Lewin-Leigh, 2000), yet current policy (DH, 2009) places lead responsibility on local authorities (Wood & Leece, 2003). Whilst other public sector bodies have responsibilities arising from the *Equality Act 2010*, Wood and Leece (2003) suggest that the focus of the deafblind policy guidance (DH, 2001; 2009) demanding responses from local authorities diminishes other agencies' responsibility (such as the NHS) and impedes incentives for partnership and co-ordination.



Healthcare practitioners have a key role in safeguarding deafblind adults but lack of NHS involvement in adult safeguarding has been criticised (Faulkner, 2011). According to media reports, Beverley had not been seen by a General Practitioner (GP) for several years (Anon, 1989a; Sapsted, 1989b), and it appears that deafblind adults' access to health services remains problematic. Deafblind UK's (2006a) survey of 486 deafblind people and Bodsworth *et al.*'s (2011) study of 539 health surveys completed by deafblind people identified several factors adversely impacting on access to health services: inaccessible correspondence, lack of deafblind awareness and specialist skills amongst healthcare staff, and failure to provide communication support, resulting in reliance on family and friends. In Bodsworth *et al.*'s (2011) study, only 33 percent of participants reported regular support from healthcare professionals. For many older deafblind people, their dual sensory impairment may be dismissed as an inevitable part of ageing (Roberts *et al.*, 2007).

As noted, Beverley's mother reportedly denied welfare professionals access to her daughter. Such denial of access to a vulnerable adult who may be experiencing neglect or abuse continues to present dilemmas for safeguarding practitioners in England. Whether local authorities should have the legal power to enter premises and talk to that adult alone has recently been subject to consultation (DH, 2012b); there is some evidence that such a power is widely supported by social workers (The College of Social Work, 2012) although others fear this would shift attention away from an emphasis on professional skills in engaging with families (Samuel, 2012). Indeed, the Beverley Lewis case reveals that mere entry is insufficient if practitioners cannot communicate with

deafblind adults or observe the risks of neglect and act accordingly (a social worker reportedly saw her four days before she died). Currently, in a similar case, practitioners would be required to consider their powers under the *Mental Capacity Act 2005* (England and Wales), such as best interests assessments and IMCA involvement. Other current knowledge available to practitioners includes greater understanding of the risks of abuse and neglect in community settings.

### **Conclusion and Implications for Social Work**

Beverley Lewis' death was untimely and tragic. Reactions in the public and professional domains highlighted several problems in her care and support and the findings of the subsequent inquiries may have contributed to some positive changes, both locally and nationally. It appears that the realisation of Beverley's deafblindness and the implications of this were overshadowed in media reports of the case and, importantly, in the inquiries. However, in Gloucestershire, Beverley's death has been recalled and rewritten as part of the history of local safeguarding policy; she has subsequently been referred to as a woman (rather than a 'girl') who was 'deaf and blind due to congenital rubella syndrome' (Gloucestershire County Council, 2006, p6).

Revisiting the case accounts with a focus on deafblindness nearly a quarter of a century later has highlighted some key issues for social work practice: how to foster awareness of deafblind adults' vulnerability to abuse, how to convince commissioners of the need to fund access to specialist assessment and support, and how to address poorly co-ordinated multi-agency responses to dual sensory

impairment, for example by case management, joint commissioning and enhanced statutory duties to co-operate. Research by specialist campaigning organisations confirms that support remains deficient for many deafblind adults. There are clear implications for the safeguarding of such adults, who are potentially vulnerable individuals. Based on the issues raised in this paper, social workers' attention could focus on three areas.

First, efforts could be made to increase awareness of deafblind adults' vulnerability to abuse, as highlighted in national and international conferences (Mar, 1993; Kiekopf, 2007b) and by the *Sense Protection Committee* (Kiekopf, 2002) a decade ago.. In relation to personal budgets (cash for care), social workers will need to consider how to monitor and review actual support and in doing so may need to be proactive in ensuring that there is agreement about access to the service-user; that details of all care and support providers are known; and that they have access to and undertake communication and guiding skills training. Liaison with advocates or proxy decision-makers on behalf of deafblind people who also lack capacity is necessary, building on the recommendations of Williams *et al.*'s (2012) study about practice in supporting best interests decision-making. Commissioning requirements could also encourage advocates to access deafblind communication skills training (Lee-Foster 2010).

Second, deafblind people need improved access to specialist assessment and social care support, including one-to-one support. The importance of specialist assessment for deafblind people was recognised (2012a) in the DH's response to

the Law Commission's recommendations for adult social care law reform. Whilst *Sense* (2010) note increasing numbers of deafblind adults receiving one-to-one support, many still report only limited amounts to meet their needs (*Sense*, 2012b). Local Health and Well-being Boards may wish to hear of local service arrangements, including partnerships with specialist voluntary organisations, and public health practitioners, newly moving back to local authorities, may help focus on health promotion and prevention for those vulnerable to poor health outcomes. Improved access to carers' assessments may be warranted, since carer stress when supporting a deafblind person can be high (Wolf, 2005).

Third, improved inter-agency communication is needed, alongside more tangible signs of acceptance of shared responsibility for supporting deafblind adults, whose needs are inevitably complex and cross disciplines and services. A decade ago, Wood and Leece (2003) suggested widening application of the deafblind policy guidance to the NHS and Education. Shared responsibility could also enhance the safeguarding of deafblind people who may be living outside the local authority that is funding their care, possibly with NHS contributions to this cost. There seems a need for closer working between adults' and children's services around the transition of deafblind young people to adult services (this organizational divide was not present during Beverley's life). This will involve attention to quality indicators of what makes for 'good transition' (DH Partnerships for Children, Families and Maternity/CNO Directorate, 2008) as for any young disabled person, but requires social workers to pay close attention to communication support, contact with specialists, and support in developing social networks.

As the numbers of deafblind people in the UK may increase significantly over the next 20 years, to 806 people per 100,000 (Robertson & Emerson, 2010), social workers will need the skills and confidence to work with members of this community to ensure that deafblindness is no longer neglected or marginalised in safeguarding policy and practice.

### References

Alley, R. and Keeler, G. (2009) *Kent Deafblind Development Project*, Maidstone, Kent Adult Social Services.

Anon. (1989a) Blind Spastic 'died in squalor'. *The Glasgow Herald*. 26<sup>th</sup> October.

Anon. (1989b) Coroner calls for help for handicapped. *The Glasgow Herald*. 2<sup>nd</sup> November.

Anon. (1989c) Tragic last visit, *The Evening Times*, Glasgow, 27<sup>th</sup> October.

Association of Directors of Adult Social Services (2005) *Safeguarding Adults. A National Framework of Standards for good practice and outcomes in adult protection work*, London, Association of Directors of Social Services.

Association of Directors of Adult Social Services (2011) *ADASS Budget Survey 2011*, available online at

[http://www.adass.org.uk/index.php?option=com\\_content&view=article&id=314&Itemid=252](http://www.adass.org.uk/index.php?option=com_content&view=article&id=314&Itemid=252) (accessed 29/09/12).

Barry, N. (1989) 'The cost of caring', *Social Work Today*. 2 November, pp. 7.

Bodsworth, S., Clare, I. C. H. and Simblett, S.K. (2011) 'Deafblindness and mental health: psychological distress and unmet need among adults with dual sensory impairment', *British Journal of Visual Impairment*, **29**(1), pp. 6-26.

Brammer, A. (2009) 'Legal Developments since 'No Secrets'', *Journal of Adult Protection*, **11** (4), pp. 43-52.

Calderbank, R. (2000) 'Abuse and Disabled People: Vulnerability or social indifference?', *Disability & Society*, **15** (3), pp. 521-534.

Cambridge, P and Parkes, T. (2006) 'The Tension between Mainstream Competence and Specialization in Adult Protection: An Evaluation of the Role of the Adult Protection Co-ordinator', *British Journal of Social Work*, **36**: pp. 299-321.

Carvill, S. (2001) 'Sensory impairments, intellectual disability and psychiatry', *Journal of Intellectual Disability Research*, **45** (6), pp. 467-483.

Clark, R. (1994) 'Community care for deafblind people. What is it? Where is it?', *British Journal of Visual Impairment*, **12**(1): pp. 3-6.

Clark, R. and Matthews, M. (1999) 'Creating and maintaining a support system: An analysis based on experiences at Sense', in McInnes, J. (ed), *A Guide to Planning and Support for Individuals who are Deafblind*. Buffalo: University of Toronto Press.

Clements, L. (2011) 'Social Care Law Developments: a sideways look at personalization and tightening eligibility criteria' *Elder Law Journal*. **1**, pp. 47-52.

Dalby, D., Hirdes, J.P., Stolee, P., Strong, J.G., Poss, J. Tjam, E., Bowman, L. and Ashworth, M. (2009) 'Characteristics of Individuals with Congenital and Acquired Deaf-blindness' *Journal of Visual Impairment & Blindness*, **103** (2), pp. 93-102.

Dalrymple, J. and Burke, B. (2006) *Anti-oppressive practice: social care and the law*, Maidenhead, Open University Press.

Deafblind Services Liaison Group (1988) *Breaking Through: Developing Services for Deafblind People*, Peterborough, Royal National Institute for the Deaf.

Deafblind UK (2006a) *Cause and Cure: Deafblind people's experience of the NHS*, Peterborough, Deafblind UK.

Deafblind UK (2006b) *Good Practice Guide: Supporting deafblind people from BME communities*. Peterborough: Deafblind UK.

Deer, B. (1989) A tragedy that should be left to rest in peace – Beverley Lewis.  
*The Sunday Times*. 5<sup>th</sup> November.

Department of Health (1997) *Think dual sensory: Good practice guidelines for older people with dual sensory loss*, London, The Stationery Office.

Department of Health (2000) *No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*, London, Department of Health.

Department of Health (2001) *Social Care for Deafblind Children and Adults*. LAC (2001)8 London, Department of Health.

Department of Health, Partnerships for Children, Families and Maternity/CNO Directorate (2008) *Transition: moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*, London, Department of Health.

Department of Health (2009) *Social Care for Deafblind Children and Adults*. LAC (2009)6 London, Department of Health.

Department of Health (2012a) *Reforming the law for adult care and support. The Government's response to Law Commission report 326 on adult social care*, London, The Stationery Office.



Department of Health (2012b) *Consultation on New Safeguarding Power*, London, Department of Health.

Dettmer, J. (1989) Social workers 'told of woman's squalor' – Beverley Lewis. *The Times*. 27<sup>th</sup> October.

Douglas, A. and Philpot, T. (2005) *Caring and Coping: A Guide to Social Services*, Abingdon, Routledge.

*Draft Care and Support Bill 2012*. HC Bill. 2012.

East Living (2010) *Beverley Lewis House*, London, East Thames Group.

Faulkner, A. (2012) *The Right to Take Risks: Service-users' views of risk in adult social care*. JRF Programme Paper, available online at [www.jrf.org.uk/sites/files/jrf/right-to-take-risks-faulkner.pdf](http://www.jrf.org.uk/sites/files/jrf/right-to-take-risks-faulkner.pdf) (accessed 25/07/2012)

Fennell, P. (1989) 'The Beverley Lewis Case: Was the law to blame', *New Law Journal*, **139**, pp. 1557 – 1558.

Flynn, M. (2012) *Winterbourne View Hospital. A serious Case Review*, South Gloucestershire, South Gloucestershire Safeguarding Adults Board.

Garre-Olmo, J., Planas-Pujol, X., Lopez-Pousa, S. Juvinya, D., Vila, A. and Vilalta-Franch, J. (2009) 'Prevalence and risk factors of suspected elder abuse subtypes in people aged 75 and older', *Journal of the American Geriatrics Society*, **57**, pp. 815-822.

Gill, C. (2006) 'Disability, Constructed Vulnerability and Socially Conscious Palliative Care' *Journal of Palliative Care*, **22** (3), pp. 183- 191.

Gloucestershire County Council (2006) *Gloucestershire Adults At Risk - Annual Report 2005/2006*, available online at [http://www.gloucestershire.gov.uk/media/adobe\\_acrobat/l/p/annreportAAr0506\\_1.pdf](http://www.gloucestershire.gov.uk/media/adobe_acrobat/l/p/annreportAAr0506_1.pdf) (accessed 30/09/12).

Hague, G., Thiara, R. and Mullender, A. (2011) 'Disabled women, domestic violence and social care: the risk of isolation, vulnerability and neglect', *British Journal of Social Work*, **41**, pp. 148-165.

Hansard (1990a) *Early Day Motion 461 Death of Beverley Lewis* Session 1989-1990 Ashley, J. Date Tabled: 06/02/1990, available online at <http://www.parliament.uk/edm/1989-90/461> (accessed 27/10/2012).

Hansard (1990b) Written question, Clarke, T. HC Deb 07 March 1990 cc646-648, available online at <http://www.publications.parliament.uk/pa/cm198990/cmhansrd/1990-03-07/Writtens-2.html> (accessed: 27/10/12)

Hansard (1990c) Written answer, Dorrell, S., *HC Deb 26 July 1990 vol 177 cc431-2W*, available online at [http://hansard.millbanksystems.com/written\\_answers/1990/jul/26/beverley-lewis](http://hansard.millbanksystems.com/written_answers/1990/jul/26/beverley-lewis) (accessed 01/11/12)

Hansard (1991) Commons Sitting , Clarke, T., *HC Deb 07 February 1991 vol 185 cc442-8*, available online at <http://hansard.millbanksystems.com/commons/1991/feb/07/authorised-representative> (accessed: 23/10/12)

Hart, P. (2008) 'Sharing Communicative Landscapes with Congenitally Deafblind People: It's a Walk in the Park!', in Zeedyk, M.S. (ed) *Promoting Social Interaction for Individuals with communicative impairments*. London: Jessica Kingsley Publishers.

ITN (1989) *Beverley Lewis Inquest Verdict: Natural Causes*, available online at <http://www.itnsource.com/shotlist//ITN/1989/11/01/T01118901/?s=thirkettle> (accessed 01/11/12).

Jervis, M. (1989) 'The dilemma of intervention', *Social Work Today*. 7 December, pp. 22.

Johnson, F., Hogg, J. and Daniel, B. (2010) 'Abuse and Protection Issues across the Lifespan: Reviewing the Literature', *Social Policy and Society*. **9** (2), pp. 291-304.

Joule, N. & Levenson, R. (2008) *People from Black and Minority Ethnic Communities and Vision Services: A Good Practice Guide*. London: Thomas Pocklington Trust.

Kiekopf, S. (2002) 'Establishing a protection committee in a campaigning organization for deafblind people', *Journal of Adult Protection*, **4** (1), pp. 40-43.

Kiekopf, S. (2007a) 'Protect and thrive', *Talking Sense*, available online at <http://www.sense.org.uk/content/talking-sense-article-protect-and-thrive> (accessed 14/08/12)

Kiekopf, S. (2007b) Reasons why deafblind individuals are vulnerable to abuse. In *World Wide Connections Breaking the Isolation 14<sup>th</sup> Deafblind International World Conference*. 25-30 September 2007. Perth, Australia

Lamb, L. (2000) 'Would 'No Secrets' have saved Beverley?', *Talking Sense*. 46 (3) Autumn/Winter 2000.

Lee-Foster, A. (2010) 'Capacity to communicate: Sense's three-year project training independent mental capacity advocates in communication skills', *Journal of Adult Protection*, **12** (1), pp. 32 – 42.

Lewin-Leigh, B. (2000) *Standards for Services for Adults who are Deafblind or have a Dual Sensory Impairment*. London: Sense.

Linnett, M. (2001) 'Hard Care: the role of an Adult Protection Unit and Co-ordinator', in Pritchard, J. (ed) *Good Practice with Vulnerable Adults*. London: Jessica Kingsley Publishers.

*LBC/IRN (1989) Inquest into death of disabled woman in squalid conditions.*

LBC/IRN Radio. Thursday 2<sup>nd</sup> November, available online at

<http://bufvc.ac.uk/tvandrado/lbc/index.php/segment/0012000483006>

(accessed 13/08/2012)

MacDermid, A. (1989) Social worker saw Beverley Lewis only eight times. *The Glasgow Herald*. 28<sup>th</sup> October.

Manthorpe, J. and Martineau, S. (2011) 'Serious Case Reviews in Adult Safeguarding in England: An Analysis of a Sample of Reports', *British Journal of Social Work*, **41**, pp. 224-241.

Mar, H.H. (1993) 'Psychosocial Services: Presentation', in Reiman, J.W. and Johnson, P.A. (eds) *Proceedings from the National Symposium on Children and youth Who are Deaf-Blind*, 1-19, Monmouth, OR, Teaching Research Publications.

Martin, J. (2007) *Safeguarding adults*, Lyme Regis, Russell House.

Matthews, M. (1990) 'Beverley Lewis: the outcome', *British Journal of Visual Impairment*, **8** (11), pp. 11-13.

McCarthy, M. (2000) 'An evaluative research study of a specialist women's refuge', *The Journal of Adult Protection*, **2**(2), pp. 29-40.

Morgan, D. (1989) 'Beverley Lewis: Able to intervene', *Community Care*, 30 November, pp. 18-19.

O'Keefe, M., Hills, A., Doyle, M., McCreadie, C., Scholes, S., Constantine, R., Tinker, A., Manthorpe, J., Biggs, S. and Erens, B. (2007) *UK study of the abuse and neglect of older people: Prevalence survey report*, London, Comic Relief and Department of Health.

Roberts, D., Scharf, T., Bernard, M. and Crome, P. (2007) *Identification of deafblind/ dual sensory impairment in older people*, London, Social Care Institute for Excellence.

Robertson, J. and Emerson, E. (2010) *Estimating the Number of People with co-occurring Vision and Hearing Impairments in the UK*, Lancaster, Centre for Disability Research.

Robertson, S., Featherstone, D.A., Gacic-Dobo, M. and Hersh, B.S. (2003) 'Rubella and congenital rubella syndrome: global update', *Pan American Journal of Public Health*, **14** (5), pp. 306 – 315.

Samuel, M. (2012) 'Most social workers want powers of entry in safeguarding cases', available online at <http://www.communitycare.co.uk/Articles/15/10/2012/118598/most-social-workers-want-powers-of-entry-in-safeguarding-cases.htm> (accessed 29/10/2012)

Sapsted, D. (1989a) Beverley: 'natural death' – Inquest on Beverley Lewis. *The Times*. 2<sup>nd</sup> November.

Sapsted, D. (1989b) Coroner calls for review of 'limited' mental health Act – Beverley Lewis verdict. *The Times*. 2<sup>nd</sup> November.

Schroder-Butterfill, E. and Marianti, R. (2006) 'A framework for understanding old-age vulnerabilities', *Ageing & Society*, **26**, pp. 9-35.

Sense (2005) *Deafblind Guidance: Five Years On. Sense Local Authority Survey Report Adult Services 2005*, London, Sense.

Sense (2007) *Sense Local Authority Adult Survey*, London, Sense.

Sense (2010) *Deafblind Guidance: Eight Years On. Sense Local Authority Survey Report Adult Services 2009-2010*, London, Sense.

Sense (2012a) *Draft Care and Support Bill. A response from Sense*, available online at <http://www.sense.org.uk/publications/draft-care-and-support-bill-response-sense> (accessed 29/10/12)

Sense (2012b) *Fair care for the future. Why social care matters for deafblind people*, London, Sense.

Shackleton, J. (1989a) 'Legislating for love', *Local Government Review*, **153**, 16 December, pp. 982-983.

Shackleton, J. (1989b) 'The inconvenient handicapped', *Local Government Review*, **153**, 23/30 December, pp. 1006-1008.

Slater, P. (2004) 'Reforming professional training and protecting vulnerable adults from abuse: A thematic analysis of the new social work degree's prescribed curriculum', *British Journal of Social Work*, **34**, pp. 649-661.

Souster, M. (1989) Spastic woman starved in squalor – Beverley Lewis. *The Times*. 26<sup>th</sup> October.

Smith, T.B. (1993) 'Psychosocial Services: Reaction', in Reiman, J.W. and Johnson, P.A. (eds) *Proceedings from the National Symposium on Children and youth Who are Deaf-Blind*, 21-40, Monmouth, OR, Teaching Research Publications.



Symonds, R.L. (1993) 'Guardianship – a case for wider use', *Psychiatric Bulletin*, **17**, pp. 276-278.

The College of Social Work (2012) 'Survey reveals social worker support for power of entry to private households', available online at

<http://www.collegeofsocialwork.org/pressrelease.aspx?id=6442477478>

(accessed 29/10/12).

Thomas, P. (2011) 'Mate Crime': ridicule, hostility and targeted attacks against Disabled people', *Disability & Society*, **26**(1), pp. 107-111.

Valios, N. (2001) 'In from the cold?', *Community Care*. No. 1387 pp. 20-21

Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T. and Heslop, P. (2012) *Making Best Interests Decisions: People and Processes*, Bristol, Norah Fry Research Centre.

Wolf, F. (2005) "Come together, right now" *Talking Sense*, available online at

<http://www.sense.org.uk/content/talking-sense-come-together-right-now>

[\(Accessed 21/02/13\).](#)

Wood, M. & Leece, J. (2003) 'Developing Integrated Support for Deafblind People: Social Services Going it Alone?', *Journal of Integrated Care*, **11** (5), pp. 39-45.